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Michael Ronald Smith
The End of the End: A Qualitative
Exploration of Barriers that Impact
Social Workers'
Capacity to Provide End-of-Life
Care to Inmates

ABSTRACT

The purpose of this qualitative, exploratory study was to identify and examine barriers that impact social workers' capacity to provide end-of-life care to biopsychosocially, spiritually vulnerable inmates. The study was guided by the research question, *What barriers impact social workers' capacity to provide end-of-life care to inmates?*

A sample of 12 master's-level social workers was recruited and interviewed. The sample consisted of ten women, two men, and one person of color. Participants in the sample worked in seven correctional institutions, in seven states, at the federal, state and county level. The study's findings indicate that at each of these levels, the correctional institution's environment, staff, and policies presented participants with the most substantial and entrenched barriers to their provision of end-of-life care to inmates. Participants also reported that their personal characteristics as well as those of their inmate patients negatively impacted their capacity to provide end-of-life care.

Implications for social work research, practice, and education as well as social welfare policy in this specialty are discussed. The urgency to reduce and mitigate the negative impact correctional institutions have on social workers' capacity to provide end-of-life care to biopsychosocially, spiritually oppressed and vulnerable inmates is underscored.

THE END OF THE END: A QUALITATIVE EXPLORATION OF BARRIERS THAT

IMPACT SOCIAL WORKERS' CAPACITY TO PROVIDE END-OF-LIFE CARE TO

INMATES

An project based upon independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2010

ACKNOWLEDGEMENTS

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Chapter I

Introduction

An alarming and steadily increasing number of inmates are serving life sentences and growing old in U.S. prisons. Solomon (2009, July 22) reports that 140,610 inmates— approximately 10% of the total prisoner population in the U.S.—are serving life sentences as of 2009, compared to 34,000 inmates serving similar sentences in 1984. Leland (2009, October 17) notes, "American prisons are home to a growing geriatric population, with one-third of all inmates expected to be over 50 by next year." Temporini (2010) attributes this increase to "transinstitutionalization (transferring individuals with mental illness from hospitals to correctional institutions), the criminalization of substance abuse, and the use of mandatory minimum sentences" (p. 119). A logical consequence of the increase in the number of inmates serving life sentences is an increase in the number of inmates dying in prison, which they do, by the thousands, each year (Mumola, 2007).

Like most other inmates, those who die in prison, are disproportionately poor, under-educated, physically ill, people of color (Sexton, 2007; Temporini, 2010). In addition to having experienced considerable trauma -- often untreated and resulting from exposures occurring prior to and during incarceration -- the majority of these inmates have experienced socioeconomic, cultural and spiritual oppression both prior to and throughout incarceration, and guilt, shame and loss associated with crimes they might have perpetrated or witnessed. In addition, they have lived a significant span of their lives in a socially stigmatized institution, often away from family and friends (Dubler &

Heyman, 1998). As Dubler and Heyman (1998) note, "Dying alone, in pain, without social, familial, and spiritual supports is the terrifying end that many prisoners and, indeed, most people fear. Unfortunately, it is too often the reality they experience"(p. 355).

The original intent of this study was to interview dying inmates to learn more about this reality in hopes of improving it. This author also hoped to provide voice and visibility to a very small fraction of those who die behind bars, hidden away and silenced. However, it was pragmatically untenable to obtain a sample of dying inmates in the time period allotted for the completion of this study. Therefore this author chose to talk with social workers providing end-of-life care to this population to gain a more comprehensive, if removed, understanding of the physical, mental, emotional and spiritual conditions under which inmates die in prison and the nature of end-of-life care provided by professionals in correctional settings: Were dying inmates alone? If not, who was there? What services did they receive? What could be made better?

The available literature on the provision of end-of-life care for inmates focused largely on the macro- and mezzo-level components of such care. For example, there is a literature describing the programming and staffing structure of prison hospice programs and examining staff challenges associated with integrating hospice programs into correctional settings. This author found minimal research discussing the micro-level practice of providing end-of-life care to inmates, particularly by social workers, and no research that asks social workers to describe the composition, strengths and challenges of their practice with dying inmates.

The paucity of literature on this topic reinforced this author's sense of urgency to conduct research that contributes to a theoretical and practice-based discussion on how to best meet the end-of-life care needs of this highly marginalized, vulnerable and rapidly growing inmate population. Therefore, in an effort to further define social work practice is this area, foster corrective a dialogue among providers, administrators, advocates and policy makers, and bring additional awareness and visibility to this much-needed area of practice, a study was conceived involving in-depth interviews with social workers currently providing end-of-life care in correctional institutional settings, and asking the following question: *What are the barriers impacting social workers' capacity to provide end-of-life care to inmates?*

Chapter II of this study will provide a review of the literature, through which this study was conceptualized. Chapter III will describe the methodology used to recruit and interview the study's participants and analyze their responses. The major findings of this study will be presented in Chapter IV and discussed in Chapter V. Chapter V will also discuss the strengths and limitations of this study as well as the implications of the findings for social work research, practice, education and social welfare policy.

Chapter II

Literature Review

Given the steadily increasing number of biopsychosocially, spiritually vulnerable and oppressed inmates, dying in prisons within the United States, one might hypothesize that providing end-of-life services to this population represents a significant opportunity for theory development and innovation in social work practice and research (Leland, 2009, October 17; Linder and Meyers, 2009; Solomon, 2009, July 22; Temporini, 2010). Indeed, social workers have demonstrated considerable investment and influence in ensuring that more and more inmates receive a "good-death" (Dubler, 1998, p. 151). The literature well documents the role social workers have played in advocating for, implementing, and evaluating new programs in this arena. The literature is also replete with descriptions and analyses of the macro and mezzo (middle) level practice components necessary for providing compassionate end-of-life services in decidedly uncompassionate correctional settings. It further describes both staffing composition and systems-level interventions needed to integrate disparate practices and values, represented in hospice and correctional programs, in the effective delivery of end-of-life care to inmates.

However, limited literature exists regarding the micro-level practice components of end-of-life care in prison hospice programs or in prisons, in general. These practice components include the personal and professional identity development of the helping professional providing end-of-life care to inmates and the impact of this development on

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practice; the attitudes of professionals toward their work environment and service population; and the training, philosophy, ethics, and policy that guide/influence social work practice. This author is interested in investigating the barriers these components might pose for social workers providing end-of-life care to inmates. As little literature exists that describes the influence of these components on social work practice with dying inmates, this review will identify related literary themes in the closely affiliated fields of end-of-life care to non-incarcerated patients and services to inmates.

Also lacking in the literary discussion is a robust examination of the theoretical base informing social work practice with dying inmates. Given the combination of intrapsychic distress and injury, isolation and dehumanizing interpersonal interactions exacted upon inmates as a condition of incarceration—Kupers (2009) considers these equivalent to psychological torture—the prospect of an inmate dying in relationship only to him or herself has been described as "the antithesis to good end-of-life care" (Dawes & Dawes, 2003, p. 782). Therefore, this review will conclude with an explication of relational theory and its impact on the delivery of end-of-life care, with a specific focus on such care provided to inmates.

In summary, this review will begin with an overview of the history of end-of-life care to inmates and social work's role in program development, including the GRACE Project. An examination of the impact of program structure and organization on social work services to incarcerated and non-incarcerated individuals at the end-of-life will follow. It will then examine themes that emerge in the literature related to the delivery of end-of-life care to non-incarcerated patients including sub-sections related to the micro-practice domains of professional and personal identity; education and training; and

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philosophy, ethics and policy. From there, the review will examine factors influencing non-end-of-life social work practice correctional settings and, lastly, briefly explicate relational theory and its potential role in the social workers' provision of end-of-life care to inmates.

History of End-of-Life Care to Inmates

This section will review the chronology and major developments in the provision of end-of-life care to inmates. Included in this review will be a specific discussion of the GRACE Project as a pioneering effort to research, standardize, innovate and advocate for prison hospice programs.

Chronology of major developments in end-of-life care for inmates.

Ratcliff and Cohn (2000) explain that prior to the early to mid-1980's correctional institutions had not developed sophisticated approaches to working with dying inmates. These authors attribute the advent of such services to the sense of urgency to address the health care needs of dying prisoners accompanying the rapid influx of inmates with HIV/AIDS and the increase in the length of prison sentences in the early 1980's (Ratcliff & Cohn, 2000). This sense of urgency was also fueled by two landmark Federal Court rulings: *Estelle v. Gamble* (429 US 97 [1976]), which established '"the government's obligation to provide medical care for those whom it is punishing by incarceration . . .'" (Linder et al., 2002, p. 550); and *Wellman v. Faulkner* (715 F.2d at 271 [7th Cir. 1983]), which concluded that "a prison or jail must provide 'a medical care system that meets minimal standards of adequacy'" (Linder et al., 2002, p. 551).

 Linder et al. (2002) note that prior to these two rulings, prisons were guilty of "deliberate indifference to serious medical needs of prisoners [which] constitutes the

'unnecessary and wanton infliction of pain' . . . proscribed by the Eighth Amendment (p. 550)." Following both an increase in need and newly established legal precedent, some correctional institutions began looking to community hospice models as a means of meeting the end-of-life care needs of dying inmates (Linder et al., 2002; National Hospice and Palliative Care Organization, 2007; & Boyle, 2002).

Levine (2005) notes:

Many of the psychological and social issues surrounding death are likely quite different in the prison population. Prisoner patients are often isolated and have no say in the choice of health care provider. Prisoners may fear abuse from the health care staff, and traditional support systems including family and friends are often lacking (Maull, 1991a). It is likely, therefore, that a successful approach to delivering quality end-of-life care in this population will need to be quite different. Toward that end, several states…have developed inmate-cooperative hospice programs. (Levine, 2005, p. 319)

Ratcliff (2000), Taylor (2002), Wright and Bronstein (2007) briefly chronicle the prison hospice movement and associated research, from the first two programs beginning in 1987 in Vacaville, California and in the 1990's in Springfield, Missouri. Maull (1991a, 1991b, 1998a, 1998b), a former inmate, then prison hospice worker, examined the attitudes of prison hospice workers at the newly established Springfield, Missouri prison hospice program. This work constituted the literary and advocacy base for the development of end-of-life programs for inmates. Currently, there are approximately 75 prison hospice programs in the U.S (C. McAdoo, personal communication, January 20, 2010).

The GRACE project.

The scope of Guiding Responsive Actions for Corrections at End-of-Life

(GRACE) Project represents a significant development in the field of end-of-life care for

inmates, by bringing visibility to the specials needs of this population. The GRACE

Project was funded between 1998-2001, through the Robert Wood Johnson Foundation's

Promoting Excellence in End-of-Life Care grant (Byock, Twohig, Merriman, & Collins,

2006). Staffed through Volunteers for America (Volunteers for America, 2001), it

represented the first national effort to inventory and standardize end-of-life practices at

the federal and state jurisdictional level.

A considerable focus of the GRACE Project was to evaluate and address the

structural and systemic barriers that impede the development and provision of quality

end-of-life care services for inmates. These barriers include: prisons promoting

conformity rather than individual preference; prison over-crowding and diminishing

opportunities for correctional and health care staff to treat inmates as individuals;

concerns about drug abuse restraining efforts to provide state-of-the-art pain

management; concerns about liability and litigation creating pressure to use aggressive

treatment when a patient does not elect it; difficulties involved in reconciling the security

and institutional efficiency emphases of correctional personnel with the service and

communication requirements of end-of-life care; and treatment planning being frustrated

by crowding and inmate classification (Ratcliff & Cohn, 2000; Ratcliff & Craig, 2004).

The Structural and Organizational Context of Social Work End-of-Life Care

The following discussion begins with an examination of the literature dealing

with the impact of organizational structure on social work end-of-life practice in prison

and non-prison settings. It then reviews the literature on program development and staff, volunteer, and patient attitudes and perceptions on prison hospice programs.

Integration of prison hospice programs within a correctional setting.

Correctional institutions and hospice programs operate under disparate, oft-conflicting philosophies of justice and compassion. The discussion of challenges involved in integrating these philosophies and programs emerges as a considerable theme in several descriptive studies (Boyle, 2002; Evans, Herzog & Tillman, 2002; Bauersmith & Gent, 2002; & Linder, Knauf, Enders & Meyers, 2002). Although this integration was, for the most part, successfully achieved, Boyle's (2002) descriptive study of prison hospice programs within the Maryland Division of Corrections notes, "….This program has not been seen as an institutional or system priority. Thus, requests for construction and maintenance, special dietary needs, and equipment purchases take a long time to resolve. No special funds have been allotted for this program…" (p. 676).

In an effort to better understand the integration difficulties noted by Boyle (2002), Wright and Bronstein (2007) carried out a qualitative study, interviewing 14 prison hospice program coordinators, across the country, regarding the nature of the staff and the environment in which they provide, develop, and administer end-of-life programs for inmates. The authors found that the coordinators, who might feel responsible for putting the best face of their program forward, each noted that they felt as though they had successfully integrated their hospice program within the prison, although differences in personal and professional philosophies, attitudes, and job description caused challenges for integration between hospice staff and correctional staff. The authors concluded that successful integration of hospice programs within a correctional environment requires

careful organizational planning, administrative support, correctional staff investment, and interdisciplinary composition and involvement among the hospice staff.

Differences in programming and end-of-life care between prison and jail hospice programs have been noted in the literature. Several studies have examined staffing, use of volunteers, training, and facility capacity issues at large, maximum-security prisons (Linder et al, 2002; Boyle, 2002; Evans et al, 2002). One of these studies was carried out at the Louisiana State Penitentiary at Angola, which is the largest maximum-security prison in the country, with 5108 inmates, 82% of whom are serving sentences in excess of 20 years (Evans et al., 2002, p. 553). Because dying inmates in these correctional institutions will spend the remainder of their lives incarcerated, hospice programs in these institutions attempt to provide on-site end-of-life care, which Boyle (2002) notes is not always successful.

Through their descriptive analysis of the Broward County jail hospice program, Bauersmith and Gent (2002) present a useful distinction between jail and prison hospice programs. The authors note that because jail stays are typically less than a year, compared with prison stays, which tend to be much longer, fewer inmates will actually die in jail. The authors explain that community hospice programs are regularly accessed by the social work staff at the Broward County jail as a less costly alternative to developing on-site hospice care at the jail.

Johnson-Swagerty (2008) provides a case example of one inmate to illustrate the unique partnership that developed between Winnebago County Jail, in Rockford, Illinois and Hospice Care for America, a community hospice program. Through this case example, the author reinforces the contention in Bauersmith and Gent (2002) that end-of-

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life care for inmates can be modified to meet the needs of the dying inmate, while negotiating the complex structural and organizational barriers posed by correctional institutions. The following quote from the Nurse Practitioner at the Winnebago County Jail makes salient this point:

> We worked together to provide a solution in an environment that is not conducive to exceptions. It was truly one of those amazing accomplishments in that we were able to give him [the inmate focused on in the case example] a good death. That was always our focus…(Johnson-Swagerty, 2008, p. 26)

Staff, volunteer, and patient attitudes and perspectives on prison hospice programs.

Given the lack of concordance between prison and hospice care philosophies, the study of differing staff, volunteer and patient attitudes and perceptions on hospice and end-of-life care have received the interest of several researchers in this field. Maull (1991b) conducted a study of the attitudes of correctional staff, volunteers and patients toward end-of-life care at the Federal Medical Center at Springfield, Missouri. Patients and volunteers reported having positive attitudes toward the program, with volunteers reporting that it provided them with life enrichment, growth, and an opportunity to come to terms with their own mortality. Patients reported that the program helped them out of states of depression associated with dying alone, isolated, and incarcerated. The study found that most correctional expressed favorable attitudes toward the program, 10% reported negative attitudes. In their findings on prison hospice integration, Wright and Bronstein (2007) discuss the possibility that prison hospice programs themselves might be able to counteract the negative attitudes of correctional staff. Specifically, the authors

include the finding that their study participants believed the hospice program had a positive, "compassionate" (Wright & Bronstein, 2007, p. 402) impact on the greater correctional environment.

In an article published in the *New York Times,* Leland (2009) provides visibility and reinforcement to the work of Maull (1991b) and Wright and Bronstein (2007). Leland (2009) agrees with these authors regarding the disparity between correctional staff and inmate volunteer attitudes and the positive impact prison hospice programming can have on the perspectives of both groups:

> …the hospice program here [Coxsackie Correctional Facility, Coxsackie, NY] initially met with resistance from prison guards. 'They were very resentful about people in prison for horrendous crimes getting better medical care than their families,' including round-the-clock companionship in their final days.…The guards have come to accept the program.…But still there are challenges unique to the prison setting.…But…the inmate volunteers bond with the patients in a way that staff members cannot, taking on 'the touchy-feely thing' that may be inappropriate between inmates and prison workers. (Leland, 2009, para. 8)

Leland (2009) also quotes an inmate volunteer, who might represent the feelings of the volunteer participants in Maull (1991b):

> I was just thinking about why I'm in here and the person's life that I took… sitting with this person for the first time and actually seeing death firsthand, being right there, my hand in his hand, watching him take his last breath, just caused me to say, 'Wow, who the hell are you?...' (Maull, 1991b, para. 20)

Social Work and End-of-Life Care Practice in Non-Prison Settings

Emerging within prison hospice program literature, as well as in literature on end-of-life care in other settings, is the theme of interdisciplinary collaboration in relation to program structure and social work practice. Wright and Bronstein (2006) conducted a qualitative study to determine the effect of interdisciplinary collaboration on the quality of care provided to dying inmates. Their study found that interdisciplinary collaboration with those outside prison hospice was critical, that collaboration through prison hospice has a positive impact on dying prisoners, that collaboration through prison hospice has a positive impact on prisoner volunteers, and that collaboration through prison hospice has a positive impact on the culture of the prison.

Specific focus has been given to the role of the social worker on the interdisciplinary palliative care team. Using post-modern and social construction theories as a lens through which to examine the impact of interdisciplinary collaboration on social work identity development, and ultimately practice, in a variety of end-of-life care settings, Payne (2006) argues:

> The example of palliative care social work shows us that social work in specialist settings defines its identity in relation to its specialist community of practice in a multi-professional team, negotiating the role of its specialist knowledge, rather than seeking to establish a defined professional role. (Payne, 2006, p. 149)

Oliver and Peck (2006) carried out a qualitative study, exploring the strengths and challenges hospice social workers experienced as members of an interdisciplinary team. The researchers conducted 23 phone interviews with such social workers and asked them two questions: "What do social workers perceive as the strengths of interdisciplinary

collaboration?" and "What are the challenges for social workers on interdisciplinary hospice teams?" (Oliver & Peck, 2006, p. 7). The authors reported the following findings:

> Participants identified issues related to team process, administrative processes, and barriers to effective team collaboration. Collaboration was fostered by good communication, trust, roles, joint visitation, respect, team building activities, and administrative interest and support. Challenges to collaboration included large caseloads, a focus on the medical model, limited visits, personality and team conflict. (Oliver & Peck, 2006, p. 7)

Reese and Sontag (2001) explored barriers to effective utilization of each discipline represented on the hospice care team, with a central focus on social work. The authors describe the professional competition that may arise between social workers, nurses, and chaplains as rising health care costs create pressures to streamline the team composition. The authors outline 13 barriers to effective use of the disciplines including the view of social workers as ancillary, less clinically relevant, misunderstood, and perhaps even competitive providers by other team members and some clients. The authors then provide solutions for each barrier, focusing on how social workers can reduce their perception by others as ancillary and increase their effectiveness as team members.

Professional identity and the social work role on the palliative care team.

Professional identity and the social work role on the palliative care team have also received much attention in the literature. Considerable literature exists regarding the historic challenges the field of social work has faced developing a robust professional identity (Abbott, 1995; Abramovitz, 1998; Flexner, 1915; Hopps, 2000; Shoemaker,

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1998.), and the following section explicates this theme, further. Much of the latter part of this section will examine issues of role ambiguity and confusion highlighted in studies of interdisciplinary collaboration.

Rusnack, Schaefer, and Moxley (1998) endeavor to provide a clear delineation of the roles and functions of palliative care social workers. They note that "social work is a discipline within hospice which serves an ecological function: It seeks to integrate care within hospice by bringing together the self-care of patients with the caring functions of family, other hospice disciplines and the service network" (p. 5). Using tables, the authors attempt to provide what is essentially a job description for social workers engaged in hospice care.

Where Rusnack et al. (1998) provide a clear, concrete description of social workers' role in providing hospice care, several authors conclude that considerable ambiguity and confusion pervade social work end-of-life practice, as a function of professional identity (Altilio, Gardia & Otis-Green, 2007; Black, 2006; Clark, 2004; Kulys & Davis, 1986; MacDonald, 1991; Munn & Adorno, 2008; Payne, 2006; Reese & Brown, 1997; Reese & Sontag, 2001).

At the behest of the National Association of Social Workers (NASW), Kuyls and Davis (1986) inventoried all social service duties performed in 34 hospices, defining each of the activities as typically performed by social workers, and surveyed the nursing, social work, and volunteer staff regarding which of these activities they performed most frequently. Findings indicated a lack of clarity regarding the social work role based on the frequency with which other disciplines reported carrying out traditional social work practices. Notably, the survey found that nurses were as likely as social workers to report

providing crisis intervention and more likely than social workers to report providing

counseling – both tasks typically associated with the social work function.

Altilio et al. (2007) used meta-analysis to determine the extent to which palliative

and end-of-life care standards, as provided the National Consensus Project's Clinical

Guidelines for Quality Palliative Care, are aligned with social work values and

perspectives (Altilio et al., 2006). They conclude:

> In fact, social workers might have written the definition of 'quality palliative
>
> care,' as evidenced by the amount of concordance between the documents
>
> reviewed and the… National Consensus Project's Clinical Guidelines for Quality
>
> Palliative Care. Yet in many ways our profession is playing 'catch-up' and
>
> chasing opportunities to collaborate, lead and enrich both the care and the
>
> literature emerging in this field of practice…(Altilio et al., 2006, p. 83)

Earlier, MacDonald (1991) had explored the "lack of unique social work role" (p.

275) in hospice care. He noted that despite the considerable influence of social work in

the field of hospice care, and the value placed on its contribution in the literature, the

professional functions of hospice social workers are performed by many members of the

interdisciplinary team, creating blurring of boundaries and a reduction of a clearly

identifiable need for social workers on hospice teams. He notes:

> The basic affinity between hospice and social work is illuminated by Specht and
>
> Craig's (1982) definition of social work as a 'profession with a dual purpose: to
>
> assist individuals and groups whose needs are not adequately met and to help
>
> change institutions so that they are more responsive to individual and group
>
> needs' (p. 11). This definition applies equally to the mission of hospice, in which

the individuals and groups in question are terminally ill patients and their

families, and the institution in need of change is traditional medicine.

(MacDonald, 1991, p. 275)

MacDonald (1991) hypothesizes that social workers are "victims of their own

success" (276)—because other fields have adopted and adapted so much of social work's

professional identity and philosophy for their own use in hospice care—and suggests a

focus on field-specific interventions and research designed to explicate further the unique

contribution of social work in hospice care.

Additional studies of interdisciplinary collaboration in hospice and end-of-life

care have highlighted similar issues related to ambiguity in role definition and social

work identity on the team (Reese & Sontag, 2001; Payne, 2006). As above, Payne (2006)

discusses the relativist, ultimately inconsistent nature of social work roles within

interdisciplinary palliative care teams, while Reese and Sontag (2001) conclude that

social workers should focus on reducing their ancillary roles on interdisciplinary teams to

increase their effectiveness as providers on hospice care teams.

Where Payne (2006) and Reese and Sontag (2001) use the mezzo-level practice

component of interdisciplinary teams to contextualize social work identity development

in end-of-life care, Clark (2004) examines social work identity development from a

macro or systems-level perspective. The author states, "the role of social work is still

being defined within modern health care, and specifically with regard to facing advanced

illness and end of life" (p. 838) and describes four future opportunities and challenges

that might shape social worker's role in delivering end-of-life care including, the aging of

the population, managed health care, disparities in health care, and building cultural

competency to reduce disparities in access to quality end-of-life care for socially oppressed populations. The author notes that the field of social work currently lacks "a high level of self-awareness, professionalism, and knowledge" (Clark, 2004, p. 841) and encourages the field to continue to recruit diverse social workers "not simply for the delivery of social services, but also to increase avenues for acquisition of culturally competent skills by all social workers" (p. 842).

Several authors (Altilio et al, 2007; Clark, 2004; MacDonald, 1991; Payne, 2006; Reese & Sontag, 2001; & Rusnack et al., 1998) offer useful descriptive studies of the role of social work in end-of-life practice. Others (Reese & Raymer, 2004; Munn & Adorno, 2008; Black, 2006; Reese & Brown, 1997) recognize this theme and attempt to measure and address it through empirical research.

A study by Munn and Adorno (2008) yielded findings consistent with those of the studies discussed above. The authors examined the views of long-term care social workers regarding professional roles at the end of life and barriers to fulfilling those roles. Findings indicate that study participants could not and/or did not describe a consistent social work role at the end of life. The authors conclude that social work must develop a more articulate description of its role in end-of-life care, particularly in long-term care settings, through increased presence of end-of-life curricula in social work education programs and increased research on social work roles at the end of life (Munn & Adorno, 2008, p. 353).

Black (2006) performed interdisciplinary research and examined how nurses and social workers perceived their roles in the areas of advanced care planning and advance directive communication with dying patients. Using two focus groups to collect data, the

author notes the social workers and nurses seem to have clear understanding of each others roles in advanced care planning and advance directive communication with dying patients. However, the author also notes that the roles of both professions seem interchangeable in this area and recommends that additional research is needed to enhance understanding of the unique attributes each profession brings to this area of end-of-life care.

Similarly to Black (2006), Reese and Brown (1997) conducted interdisciplinary research to study the difference between clergy, social workers and nurses in their delivery of psychosocial and spiritual care. The authors note that 35 of the 37 charts indicated that patients had received such care, with spirituality and death anxiety being the two most frequent areas of concerns for the patients. Clergy were found to provide more spiritual support than social workers and nurses, while social workers addressed more psychosocial concerns than clergy and nurses. The article then addresses the need for all hospice staff, particularly clergy, social workers and nurses, to receive additional training and education around the spiritual and psychosocial needs of hospice patients.

Through descriptive and empirical analysis, the above articles demonstrate areas of greater or lesser clarity among social workers and other disciplines regarding the social work role. This literature review will now examine themes that emerge from the literature related to the impact that personal identity has on social work end-of-life practice.

Personal identity.

Having examined the literary themes related to the micro-level practice domain, professional identity, and its impact on social work practice with dying inmates, this

review will now examine literary themes related to how social workers' personal identity and use of self might influence their work with dying patients.

Post-modern theory of relational therapy makes clear that a clinician's self-perception (sense of self) cannot be divorced from their sense of their clients, i.e. the development of the self in relation to others, as noted in the above section (Greenberg & Mitchell, 1983; Mitchell, 1988; Katz & Johnson, 2006). Payne (2006) offers the following examination of personal identity development as it relates to social work as a field and, specifically, the specialty of end-of-life care:

> Personal identity comprising a continuous sense of self, interacting with responses to others' perceptions, leads to two different sorts of social interactions. People become part of collective interests, and also carry out social roles. The roles are molded by both the personal identity and the collective interests….People have a stake in their collectivities and their collectivities have a stake in both the personal identity and the social roles that their stakeholders carry out. Thus, a social worker acquires a personal identity as a social worker that affects their general and professional behavior and attitudes, and this identity is created through the social processes that create the professional group. The personal identities of social workers contribute to the social construction of the social identity of the professional group. Thus, a palliative care social worker gains an identity in this particular social work specialism, and the special meaning of social work that emerges for them, through what their specialist practice contributes to the emergence of social work in general. (Payne, 2006, p. 140)

Berzoff and Silverman (2004) begin by noting:

Palliative-care social workers must…possess the values and attitudes that allow

them to engage therapeutically with those experiencing loss, death, and suffering

without rushing to fix problems or eventually burning out.…Indeed, social

workers experienced in end-of-life care must examine their own values regarding

end-of-life issues.…Such insight is important to assure that the starting point for

services is defined by the dying person and the family, and not by the professional

or cultural, religious and spiritual beliefs of the social worker.…The personal

assessment and clarification of boundaries that accompanies work in palliative

care should be on-going…inasmuch as numerous ethical dilemmas concerning

self-determination, access barriers for services, advance directives and issues of

mental competence arise in home care settings. (Berzoff & Silverman, 2004,

Forward xxv-xxvi)

These authors make clear that social workers must endeavor to examine, and

bring into alignment with NASW Code of Ethics, their personal attitudes, values, and

perspectives toward end-life-care. The following section will examine perspectives

toward difference and attitudes toward death that might impact social workers' capacity

to provide end-of-life care to inmates.

Cultural differences between the social worker and the patient.

Lopez (2006) discusses the potential challenges that difference related to culture

and ethnicity might pose for clinicians working with dying clients. Specifically, the

author indentifies four defensive dynamics common in end-of-life care practice,

including "color blindness, cultural transference, cultural countertransference, and over-

identification" (Lopez, 2006, pp. 98-98). The author then presents steps for reducing the

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impact of cultural countertransference in end-of-life care practice. She notes that first, clinicians must examine their own attitudes, beliefs, and issues related to death and dying. Next, the author advocates for practitioners to develop a continued sense of their cultural identity through examination. She then encourages practitioners to examine their culture's attitudes and beliefs around death and dying. Lastly, the author stresses the importance of on-going supervision and sharing with colleagues around such aspects of identity (Lopez, 2006, pp. 99-101).

Factors associated with worker attitudes toward death and end-of-life practice.

Black (2005) examined the relationship of social workers' personal attitudes towards and experiences with death and their behavior regarding communication information of advanced directives with dying patients. Her findings suggested that practitioners' death attitudes and experiences influenced social workers' advance directive communication with their patients. For, she notes, "Practitioners' behavior was found to differ by fear of death or death avoidant attitudes and recent personal experiences with a terminal diagnosis. Thus, social workers' personal death attitudes and experiences may pose serious implications for advance directive communication practice" (Black, 2005, p. 30).

Heyman's (2008) study of the factors influencing health care professionals' attitudes toward the health care proxy found that participants had a generally positive attitude toward the health care proxy, with prior professional and training experience having the greatest positive influence on the participants' attitudes toward the health care proxy.

Sanders and Swails (2009) examined attitudes and beliefs of hospice social workers providing care to end-stage dementia patients and found a range of factors (lack of education, patient discharge, and late referral) that negatively impacted participants' capacity to deliver end-of-life care to this population.

Education and training.

In a review of the literature, incomplete education and training emerged as the most salient theme related to social workers' feeling of preparedness in the provision of end-of-life care. Works by Christ and Sormanti (1999) and Walsh and Csikai (2005) broadly examine the inadequacies in social work education and training related to end-of-life care and the barriers these pose to social work practice in this field.

Christ and Sormanti (1999) begin by noting:

Insufficient training of health professionals has often been cited as a major barrier to improving the system of care for dying patients and for the bereaved. Although specific problems have been identified for physicians and nurses, the problems of social work in this substantive area have only recently been explored. (Christ & Sormanti, 1999, p. 81)

Most germane to the proposed study is authors Christ and Sormanti's (1999) examination of the following questions in their study: "In the current clinical environment, what barriers, both within and beyond your agencies, impede your efforts to carry out these roles and responsibilities and participate in these programs?", "How well were you prepared by your MSW program for this work?" and " How adequate is your continuing education in this area?" (Christ & Sormanti, 1999, pp. 86-87). Findings indicated a lack of access among participants to information, opportunities for continuing

education and training, and advocacy (for social workers and their patients). Participants

also noted that some other health care professionals lacked the adequate skills and

training required to provide quality end-of-life care for patients. Regarding participant

responses, the Christ and Sormanti (1999) note:

> These workers did not adequately recognize the high level of their own
>
> knowledge and skills. Preoccupied with their own specific service dilemmas, they
>
> failed to identify ways they could help other agencies to solve interdisciplinary
>
> problems. For example, they underestimated how other professionals' lack of
>
> knowledge about how to tell a denying or unaware patient about his or her
>
> impending death in an acute-care hospital might prevent a timely referral to a
>
> hospice. This lack of appreciation of their potential contribution led to frustrating
>
> struggles with other disciplines rather than to creative compromises. (Christ &
>
> Sormanti, 1999, p. 93)

Supporting these findings is Walsh and Csikai's (2005) presentation and review

of the end-of-life program developed through the Project on Death in America, Social

Work Leadership Development Awards initiative. The authors note that despite the fact

that vast numbers of social workers are confronted daily with end-of-life experiences,

social work education and training programs (BSW, MSW and continuing education) are

"missing vital content about end-of-life care, palliative care, and bereavement" (Walsh &

Csikai, 2005, p. 11).

Wesley, Tunney, and Duncan (2004); Csikai and Bass (2000); and Crunkilton and

Rubins (2009) examined social work education and training inadequacies as they relate to

specific areas of micro-practice. Wesley et al. (2004) examined the educational needs of

hospice social workers to address the spiritual needs of diverse clients through assessment and intervention and found participants lacking and requesting greater training in this area. The authors note:

> Increasingly, social workers find themselves serving culturally diverse patients from different religious and spiritual backgrounds. However, poor understanding of cultural variables related to death and dying among predominantly white, middle-class hospice staff often leads to barriers to hospice access by minorities. (Wesley et al., 2004, p. 41)

The authors conclude that education and training programs should assist social workers to "see themselves as learners when confronted with unfamiliar spiritual traditions can improve their cultural competence for work with diverse populations social work a joy and a challenge" (Wesley et al., 2004, p. 46) and that hospice organizations should provide more thorough, in-house training materials and opportunities for social workers.

Csikai and Bass (2000) note that, "end-of-life care decision making is perhaps the most difficult practice situation faced by health care social workers" (Csikai & Bass, 2000, p. 1). To better understand the difficulty in this decision-making process, the authors surveyed 63 social workers regarding their experience with end-of-life decision making, their knowledge of the National Association of Social Worker's policy document, "Client Self-Determination in End-of-Life Decisions" (National Association of Social Workers, 1996), and their feelings of preparedness to participate in and assist clients with end-of-life decision making. Participants reported the most significant ethical challenge as conflict and confusion (among other providers and family members)

caused by patients' lack of an advanced directive, particularly in situations in which their competency in making end-of-life care choices was questioned (Csikai & Bass, 2000). Participants called for comprehensive education and training on "end-of-life issues and ethical decision-making practices" (Csikai & Bass, 2000, p. 20).

Crunkilton and Rubins (2009) discuss medical social work and other medical professional assessment and intervention with patients experiencing psychosocial distress at the end of life. The authors describe the reasons why the DSM IV-TR and the medicalization of psychosocial distress is insufficient to "describe the dying patient's experience" (Crunkilton & Rubins, 2009, p. 75), and encourage social work education programs to teach comprehensive skills in meeting the psychosocial needs of dying patients.

As noted in the foregoing discussion, social workers in end-of-life practice settings might approach their work with educational and training deficits and therefore limited capacity for intervening to support specific areas of identity and distress experienced by their dying patients.

Philosophy, ethics, and policy.

This section examines emergent literary themes related to the impact of philosophy, ethics and national policy on the delivery of end-of-life care to inmates and social workers' capacity to provide end-of-life care to non-incarcerated patients.

When reviewing the extant literature related to the impact of philosophy, ethics and policy on the delivery of end-of-life care to inmates, three themes emerge most prominently: the challenge of reconciling the disparate values/philosophies of hospice programs with those of correctional institutions; the ethical imperative to provide inmates

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with a good death; and the lack of standardized policies, at the national level, for providing end-of-life care to inmates. As Wright and Bronstein (2007) and Boyle (2002) have noted, integrating hospice programs within correctional settings is a challenging endeavor that requires skilled, intentional planning and staff investment from both institutions. Mahon's (1999) report from the conference "Death and Dying in Prisons and Jails: Caring for Prisoners, Families and Caregivers" (Mahon, 1999, p. 213), highlights the programming and policy imperatives necessary to improve the public perception of end-of-life care needs among inmates and to legislate funding for quality medical care, compassionate release and discharge planning.

Dubler (1998) and Cohn (1999) relate ethical and just governance with the delivery of end-of-life care to inmates. Dubler (1998) notes the presence of a growing inmate population that might be in need of end-of-life care, laments this population's absence of the "good death" (Dubler, 1998, p. 151), and discusses how "compassionate release" (p. 153) for dying inmates is politically and structurally challenging for correctional institutions, but potentially necessary to manage the increasing need for treating dying inmates. Dubler (1998) concludes by arguing for an increase in the standards of care, systemic resources, and political will necessary to provide dying inmates with a decent environment and medical care.

Cohn (1999) elaborates on Dubler's (1998) appraisal of the current lack of oversight of the biopsychosocial, emotional and spiritual care provided to inmates. Through an historical analysis of the concepts of "Value of persons, Social contract theory, Justice, Just desserts and Utilitarian calculus" (Cohn, 1999, pp. 252-257), seeming to echo the themes in Mahon (1999), notes that our justice system, along with

society as a whole, has misinterpreted the original meanings of these concepts. According to Cohn (1999), this has resulted in denying prisoners adequate health care, especially at the end of their lives; a mistake, the author argues, that will lessen our moral and ethical composition as a society. That having been stated, the author concludes with the following passage:

> ….If we can learn to take care for what is arguably one of the least valued
> populations in our society, then we certainly can provide care for others
> population groups. Our society should not have to rely on the courts, as it has in
> the past, to serve as its moral conscience. (Cohn, 1999, p. 258.)

Griffin and Rohrer (1994) and Mahon (1999) address the lack of national standards for delivering end-of-life care to inmates. Griffin and Rohrer (1994) conducted a descriptive study of the end-of-life health care options available for terminally ill inmates in the United States. Specifically, the authors were interested in examining whether states in which terminally ill inmates received end-of-life care had policies or laws regarding living wills and do not resuscitate orders, and the measures state correctional facilities employed in the provision of end-of-life care for their inmates. The study demonstrated that while the majority of states provide either community or correctional institution-based end-of-life care for inmates, polices detailing the manner and quality of this care were inconsistent or non-existent. Included in Mahon's (1999) report are recommendations for policy development in the following areas: equal quality in end-of-life care in prisons and the community; up-to-date education on the delivery of end-of-life services for correctional health care staff; national criteria for compassionate

release; improved informed consent standards regarding prisoner's refusal of end-of-life; and appropriate discharge planning for inmates who receive compassionate release.

> ### *Philosophy, ethics and policy related to social workers capacity to provide end-of-life care to inmates.*

Two themes emerge from the literature related to the impact of philosophy, ethics and policy on social workers' capacity to provide end-of-life care to non-incarcerated patients: social workers' involvement in end-of-life care policy development and review—particularly as these policies relate to disenfranchised populations and health disparities—and social workers' role in developing and ensuring ethical end-of-life care practices, particularly as they relate to client self-determination.

> *Social workers' involvement in end-of-life care policy development and review.*

Roff (2001) and Stein and Sherman (2005) address the limited and often unsophisticated manner in which conversations about death and dying in the United States shape end-of-life care policy. Roff (2001) notes:

> Discussions about death, dying and end-of-life preferences remain one of the last
> communication taboos left in American society. As a nation, we are mired in
> controversy over physician-assisted suicide, euthanasia and effective pain
> management for those facing end-of-life" (Roff, 2001, p. 52).

Roff (2001) and Stein and Sherman (2005) then position and encourage social workers to be leaders in developing more humane end-of-life care policies in this country.

Stein and Sherman (2005) then note:

Social workers…must be leaders in advocating for changes in policy to improve

> the delivery of palliative and end-of-life care services. Policy developments—

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whether through legislation, administrative regulations, or judicial case law—

have a strong impact on the delivery of hospice and palliative care and the

specific roles of all health care providers…because social workers are excellent

case advocates and clinical practitioners, we must expand our horizons and

actively use our skills to influence legislators, administrators, and organizations,

to have an effective impact on public policy, and to infuse palliative care into the

entire health care system. (Stein & Sherman, 2005, p. 1271)

Specifically, Stein and Sherman (2005) address the role social workers can play in

reducing access barriers for disenfranchised populations in need of end-of-life services.

They note:

Although social work has done an excellent job of educating its own students

about cultural issues, it has not taken a leadership role in educating those outside

the profession. With their knowledge of human nature and their solid grounding

in activism and community organization, they should be in the vanguard of health

care workers designing comprehensive, equitable programs to eliminate health

care disparities and to ensure that currently disenfranchised populations receive

proper care.

NASW's standards for palliative and end-of-life care state the following:

[Social workers should] identify barriers to effective palliative and end of life care

at the macro level by addressing issues of financial inequities, lack of culturally

competent services, and other access issues and to address those barriers so that

individuals experience the highest quality of life possible to the end of life. (Stein

& Sherman, 2005, p. 1279)

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Roff (2001) agrees that social workers should be more active in developing policies to meet the end-of-life care needs of all patients, including the most vulnerable. As a social worker, the author analyzes, critiques, and suggests alterations to three spotlight pieces of federal end-of-life care legislation (the Pain Relief Promotion Act, the Conquering Pain Act, and Advance Planning and Compassionate Care Act), concluding by encouraging social workers to "position themselves as leaders of the cultural and political changes, ensuring that quality of life includes quality of death" (Roff, 2001, p. 66).

Social workers' role in developing and ensuring ethical end-of-life care practices.

Csikai and Bass (2000), Csikai (2004), Csikai and Sales (1998), and Stein and Sherman (2005) all address the impact of ethics in social work end-of-life care practice and the greater role social workers might play in resolving ethical dilemmas in such practice. Csikai and Bass (2000) found that many social workers were unaware of the National Association of Social Worker's policy document, "Client Self-Determination in End-of-Life Decisions" (National Association of Social Workers, 1996), designed to help resolve ethical dilemmas in end-of-life care practices. These authors call for greater education regarding the availability of this resource. Csikai (2004) reports on a survey of 120 hospice social workers regarding, "ethical issues in hospice care, how the issues were managed, and the extent to which social workers participated in the resolution of ethical dilemmas" (Csikai, 2004, p. 67). The author found medical condition (pain management) and family involvement in the end-of-life care to be the most frequent type of ethical issues to arise in the study. Social workers most often addressed these issues in

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interdisciplinary team meetings and would have liked greater access to and participation on ethical committees for the resolution of such issues.

Csikai (2002) and Csikai and Sales (1998) examined social workers' participation on hospice ethics committees and the expectation that committee chairs had for social work participation. Both studies recognized the invaluable role that social workers play in interdisciplinary teams and lament the limited participation of social workers on hospice ethics committees. The authors note the study findings suggest that, "…both groups [social workers and committee chairs] viewed that social workers were important contributors and expected higher participation in the three main activity areas case consultation, policy, and education than currently took place" (Csikai, 2002, p. 261).

Stein and Sherman (2005) note that recent, high profile cases related to end-of-life care provision, like the Terri Shiavo case, have changed the political landscape and made more confusing the once clear and firm ethical ideas of self-determination. Such confusion, they continue to note, has created ethical dilemmas for social workers related to patient self-determination in a variety of end-of-life care settings. In the following passage, the authors then provide the NASW's response to such developing confusion: "A policy statement of the National Association of Social Workers…(2003) states that the social work profession is committed to, 'the right of the individual to determine the level of his or her care…and make informed choices'" (Stein & Sherman, 2005, p. 1272).

As noted above, the field of social work has pioneered several macro-level aspects of end-of-life care in correctional settings over the past ten years including, research and program development. This author is curious to examine the current role

social workers might be playing in developing and advocating for policies that shape end-of-life care for this inmates.

Factors Influencing Social Work Practice in Correctional Settings

Social work practice within prisons is a complex, multi-disciplinary endeavor in which the professional identity of corrections staff and the institutional philosophy of correctional systems are often at direct odds with the professional identity of social workers as individuals and as a field. The literature on this topic encourages the field of social work to negotiate these complexities and hostilities in a manner that continues to benefit care to the vulnerable populations incarcerated in U.S. prisons, including those populations that will die while incarcerated (Granse, 2003; Linder & Meyers, 2009).

Two primary themes emerge from the literature this area, including conflicts experienced in the integration of social work professional identity in correctional settings, and the training and education necessary for social workers to better integrate and provide care in correctional settings.

Conflict integrating social work professional identity into correctional settings.

Davis (1978) and Gumz (2004) provide descriptive, historical studies of social work practice in correctional settings. Davis's (1978) dissertation provides a meta-analysis of social work's historical views and roles in corrections settings. The author describes the major trends spanning social work's 100-year relationship with correctional settings, including the period from 1878-90, which introduced social work to correctional settings. This was followed by the professionalization of social work in the early 20th Century, providing the field credibility and momentum to develop specific roles in the

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correctional settings in the mid-twentieth Century, almost entirely abdicated by the late-Twentieth Century (Davis, 1978).

Gumz (2004) echoes Davis (1978) and notes that a marked decrease occurred in the profession's engagement in corrections, beginning in the mid-70s. The author posits that the punitive philosophy and nature of these institutions may conflict with social workers' professional identity, presenting political and ethical barriers that negatively impact their capacity to deliver care to inmates.

Mazza (2008) provides a specific context to the sentiments of Davis (1978) and Gumz (2004) by describing the successes and challenges of practicing social work in a prison setting with groups of fathers. The author outlines the challenging environment created by prison administrators and correctional officers, as well as the physically oppressive nature of the institution in which social workers must assist inmates in developing interpersonal and self-respect and dignity.

Following the theme of historical conflict integrating and reconciling the philosophies and practice of social work and correctional institutions is the call for social work to renew its investment in corrections work. Higgins and Severson (2009) describe the need for social work to redefine itself to address the needs of the older inmates reentering to and reintegrating in their communities after incarceration. The authors lament the lack of literature related to social work and gerontological offenders and provide best practices from social work with elderly non-offenders as a partial model for work with this increasingly marginalized population. Higgins and Severson (2009) echo MacDonald (1991) by noting the role challenges—limited field-specific interventions and

research—that social work might experience in supporting new service populations, specifically older inmates returning to their communities.

Dawes and Dawes (2004) explicate the role of social workers in the dehumanization of inmates. They note that this has been done through social workers' use of the medical model to describe inmates' problems, locating the problems internally, as inherent to the inmate and not as related to their environment. The authors support the use of an ecological framework as an alternative model for guiding social work practice in prison. They describe how this model is more consistent with current social work theory and values, encouraging greater appreciation of the biopsychosocial stressors resulting from inmates' relationship to their environment and promoting interventions aimed at mitigating these stressors. The authors acknowledge the challenges of social work practice in prisons, and, like Mazza (2008), are encouraged by the possibilities of such practice, particularly as it relates to empowering vulnerable populations within correctional facilities.

Reamer (2004) agrees with Dawes and Dawes (2004) in advocating for an ecological lens through which to deliver social work interventions to inmates. However he argues that while this fundamental value of social work is still very much a part of the juvenile justice system, it is largely missing from the field of criminal justice as a whole. In response, the author advocates for improved leadership in the field (Reamer, 2004).

Training and educational needs of social workers in correctional settings.

Included in the call for invigorating social work involvement in corrections is an emphasis on curriculum required to prepare social workers to meet the needs of the growing inmate population (Ivanoff, Smyth & Finnegan, 1993; Severson, 1999; Lowe &

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Bohon, 2008; Church, Baldwin, Brannen, & Clements, 2009). Ivanoff et al. (1993) point out that social work's participation in correctional work has never been more necessary, even though, "social work has largely abdicated its historical role in the field of corrections" (Ivanoff et al., 1993, p. 137). These authors describe the limitations of social work course and fieldwork curriculum in the area of correctional systems and institutional settings. They conclude by advocating for an increased "information and procedural knowledge base useful in preparing students for fieldwork in correctional institutions" (p. 137).

Severson (1999) explores and describes the several components of social work education programs that must be innovated and adapted to increase social workers' capacity to work with the growing numbers of persons with serious and persistent mental illnesses, overworked and underappreciated detention personnel, and an often tedious and impersonal judicial processes involved in modern jail systems (Severson, 1999, p. 53). The author then describes the academic opportunity jails represent for social work education, by providing students, and the field of social work in general, with avenues to increase capacity in skills-set areas already included in the curriculum, such as cultural competency in work with diverse population, coordination with social service and criminal justice agencies, policy and planning, advocacy and research:

> …the knowledge and skills needed to effectively address inmates' problems are the same as are already taught within social work educational curricula. This point cannot be underemphasized: inmates experience the same mental illnesses, the same types of stresses, the same interpersonal disruptions and systemic barriers as clients served in community mental health centers and hospitals. Human behavior

and individual, group, and community practice courses are as germane to the

corrections environment as they are in any other social work setting. (Severson,

1999, p. 66.)

Lowe and Bohon's (2008) study represents the lone empirical study in the

literature related to education, training and social workers in correctional settings. The

authors note the limited exposure to content on inmates and correctional settings provided

to social work students and conclude that there is a need for social work education

programs to add this curricular focus. The work of Church et al.'s (2009) concludes that

increased education might reduce attitudinal barriers to social workers' (MSW and BSW)

interest in working with this population.

Relational Theory and Social Work End-of-Life Care Practice with Inmates

As noted in the Introduction, the literature contains little explication or

examination of the theoretical base(s) that informs social workers' practice with dying

inmates. Therefore, this section will review relational theory and its possible contribution

to end-of-life care practice in correctional settings. In particular it will consider how this

system of thought may inform professional practice in the areas of reducing dying

inmates' sense of isolation and increasing their capacity for a nurturing psychosocial,

emotional and spiritual connectedness at the time of their death.

Hadley (2008) provides historical context for the emergence of the relational

theory and notes that during the mid-to-late 1980's, clinicians and theorists began

deconstructing and re-examining the foundation of psychoanalytic/psychodynamic

thinking. The author then outlines the key issues in the deconstruction of the foundations

of psychoanalytic/psychodynamic thought, which include considering the context,

culture, race, gender, relationships, class and experiences of both the patient and the

therapist as they influence each other and the interpersonal field between them. Included

in the consideration of the experience of the clinician and the patient is how they can co-

construct experiences together that can be reflected upon in order to further

understanding and growth. Hadley (2008) follows this by noting that from this

deconstruction of psychoanalytic/psychodynamic thought, "a self and other," or

"relational turn" occurred in psychodynamic thinking, which led to the development of a

relational theory (Hadley, 2008, p. 208).

Relational theory largely dismisses the "classical," one-person psychologies that

locate the motivation for human behavior in biology and instinct. It evolved from a base

in two-person psychologies, such Object-Relations Theory and later Self Psychology

(Miller and Greenberg, 1983; Miller, 1988; 1997, 1998) to suggest "the socially

constructed nature of human reality…recognizing the therapists' as well as the members'

irreducible individuality and initiative taking, and toward therapy as about meaning-

making rather than scientific discovery of The Truth (Rubenfield, 2007, p. 115)."

Hadley (2008) describes how relational theory shapes clinical practice:

In a practice setting, a relational perspective, or 'two-person' model, focuses on

the subjectivities of both the therapist and the patient, becoming embedded in a

complex, rich dynamic. They construct this dynamic together, influenced by what

each one brings to the dyad, including the influences of their experiences in the

contexts in which each has lived. Whereas other psychodynamic approaches to

practice tend to focus on the client's feelings, behaviors, and mind—delineating

countertransference as the aspect of the therapist's experience of the client that is

relevant to the work—a relational approach includes the mutually influential subjectivities of both participants, conscious and unconscious, in social context. (Hadley, 2008, p. 211)

This description of relational theory in practice might lead one to question the clinical or pragmatic value of engaging in what is a necessarily time and energy (psychic, emotional, spiritual) intensive process of co-creating an intersubjective, therapeutic space with a dying inmate patient, whose history and social context is almost certainly quite different from that of the clinician's. Hadley (2008) addresses this question (not specifically to dying inmates, but toward oppressed, marginalized populations more generally) and discusses the unique opportunity and clinical value relational therapy represents for oppressed populations, by noting that relational theory has 1) created a framework and impetus for clinicians to recognize the "inevitability of race, class and culture entering the therapeutic situation" (Hadley, 2008, p. 214) and 2) invited and encouraged clinicians to gain a better understanding of their biases toward diverse, oppressed, and marginalized populations (p. 214). This echoes the thinking of Berzoff and Silverman (2004) and Lopez (2006), previously discussed in the *Attitudes Toward End-of-Life Care for Inmates and Associated Barriers* section of this literature review.

In this author's opinion, a relational approach can help social workers and dying inmates in co-creating an external reality, where the patient's biopsychosocial and spiritual needs and vulnerabilities are acknowledged, held, re-authored, and honored in partnership with trusted and caring person (Granse, 2003).

Conclusion

In the service of gaining a better understanding of what barriers might impact social workers' capacity to provide end-of-life care to inmates, this review yielded four overall themes. The first theme recognizes social workers have played a significant role in advocating for, researching and designing end-of-life care programs in correctional settings; however, very little information exists regarding their micro-level practices in these settings. The second theme relates to the historical ambiguity and confusion social workers have experienced in their roles as end-of-life care providers, and this study hopes to gain a better understanding if such ambiguity and confusion exist in correctional settings, and if they create barriers to social workers' capacity to provide end-of-life care to inmates. The third theme relates to very limited information that exists, regarding the impact of personal identity (specifically that of cultural difference) on social workers' end-of-life care practice. Given what might be considerable cultural differences between social workers providing end-of-life care to inmates and the population with whom they work, this study aims to collect such data for further analysis. The final theme relates to what the literature describes as the limited preparation end-of-life care social workers receive, prior to, and during, their tenure in this field. This study aims to examine the extent to which social workers working in purposefully restrictive correctional environments felt prepared to provide services to an incredibly vulnerable population, deprived population.

This study's interview instrument was developed by synthesizing the emergent literary themes related to the micro-level practice barriers experienced by social workers providing end-of-life to non-incarcerated patients as well as those barriers

experienced by social workers, providing non-end-of-life care to inmates. The following

chapter will now provide the methodology used to identify and recruit participants and

gather and analyze the data collected in service to investigating the research question,

What barriers impact social workers' capacity to provide end-of-life care to inmates?

Chapter III

Methodology

Study Purpose

The purpose of this qualitative study was to gain a deep, rich understanding of what social workers consider to be the barriers associated with providing quality end-of-life care for inmates. This study was guided by the research question, *What barriers impact social workers' capacity to provide quality end-of-life care to inmates?* "Barriers" in this study were defined as objective, subjective and intersubjective elements that impede the capacity of social workers to provide what they believed to be quality end-of-life care to inmates.

Study Design and Sampling

This exploratory study used interviews with a non-random purposive sample of 12 social workers to gather qualitative data related to the above research question. The inclusion criteria required participants possess a master's and/or doctoral level degree in social work and be providers of, or have provided, end-of-life care for inmates in the United States. Participants must also have been able to converse in English.

Participants were recruited using a combination of snowball methods and direct outreach to end-of life programs affiliated with correctional facilities as described below.

Initial recruitment efforts included e-mailing six individuals who had published literary articles regarding the provision of end-of-life care to inmates and requesting their participation in the study (see Appendix D: Letter for Direct and Snowball Recruitment

of Study Participants). Of these, five agreed to participate in the study and were asked to provide their mailing address for the purpose of receiving the Letter of Informed Consent (see Appendix B: Letter of Informed Consent). Following receipt of their signed consent form, an interview was scheduled. Of these five, only one actually met the inclusion criteria and completed the interview; the other four informed the researcher at the start of the interview that they did not and had not provided end-of-life services to inmates, but rather had trained staff and inmate volunteers to provide such services, and thus did not meet the inclusion criteria. Therefore, they were not interviewed.

One of the initial group of six authors contacted, who did not meet the study's inclusion - the principal investigator of the GRACE Project - offered to share her general expertise on the study topic area via telephone. In addition, she provided the researcher with a contact at the National Hospice and Palliative Care Organization (NHPCO) tasked with maintaining an inventory of the correctional institutions providing end-of-life services in the country as a possible means of furthering recruitment.

The NHPCO contact then provided the researcher with contact information for five social workers who met the study's inclusion criteria, as well as the names of six correctional institutions where she knew such social workers practiced.

Of the five social workers whose names and phone numbers had been provided by the NHPCO contact, three responded positively to the researcher's recruitment request and became participants in the study. One of these three participants provided contact information for an additional individual who responded positively to the researcher's recruitment request and also became a participant in the study.

The researcher called the general number of one of the correctional institutions provided by the NHPCO and was transferred to the social worker who practiced in the area of end-of-life care. This social worker also became a study participant and provided the researcher with the names and telephone numbers of the social workers at the remaining five sites. This resulted in four additional participants.

Two additional participants were recruited by contacting the state and county correctional departments that were noted in the literature as providing end-of-life care to inmates. The researcher was provided direct access to two social work staff who met the study criteria at two of the programs. These staff responded positively to the researcher's request and became study participants.

In an attempt to broaden the scope of recruitment efforts the researcher had also posted the recruitment plea on the online listservs of two organizations - the Social Work Hospice and Palliative Care Network and the National Association of Social Workers (NASW) - in which the researcher had membership. (see Appendix F: Posting for Listserv and Website Recruitment). The program directors at these organizations as well as the National Prison Hospice Association and the National Organization of Forensic Social Work, were also e-mailed regarding the study and recruitment needs (see Appendix E: Letter for Organization Assistance in Recruitment). This approach, however, yielded no participants.

Data Collection

Data was gathered by audio-recorded telephone interview lasting no more than one hour, with the mean interview time being 49 minutes. The instrument (Appendix C: Interview Instrument) used to gather the data included demographic questions (related to

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the social workers and the inmates with whom they work) and open-ended questions structured under the following domains: Professional Identity, Personal Identity, Background and Training, Philosophy on Providing End-of-Life Care to Inmates, Attitudes Toward Work in Prisons and with Inmates, and Practice.

Probing techniques and clarifying questions were used to gather additional information, when the interviewer thought it necessary. At the close of the interview, participants were asked if they had any additional comments for the researcher.

Sample Characteristics

This study's sample included 12 master's level social workers, who provided end-of-life care to inmates in county, state or federal correctional institutions. The sample was composed of 10 females and two males; their ages ranged from 34 to 62. Eleven of the participants identified as Caucasian and one of the two males identified as Hispanic. All of participants identified their socioeconomic status as middle-class, and they all identified as being spiritual, and their spiritual practices varied. Participants' experience providing end-of-life care to inmates ranged from 2 to 30 years.

Data Analysis

Interviews were recorded using a digital audio recorder; transferred to MP3 files; and transcribed, using software that allowed this researcher to adjust (slow) the playback speed of the original recording. After each interview was transcribed, this researcher analyzed the data through two methods.

In the first method each transcription was read multiple times and coded, using highlights, in the text of the transcriptions. Memos were created to augment these codes and included code notes, theoretical notes, and operational notes. These notes assisted

this researcher's process of identifying and describing codes, recording emergent themes and analyzing their relationships. Quotes and their origin in the data were captured using operational notes. Memos were drafted in either the margins of the transcriptions next to the highlighted code and/or in a separate document that mapped the memo to its location in the transcription; for example, "Code note: transcription title, page, line; note."

The memos were then read multiple times to identify categories of themes, and new documents were created, titled by these categories (for example, "Integration of Social Work and Corrections Philosophy"), and corresponding memos were cut and pasted into each document. The documents were then organized in subcategories: for example, "Integration of Hospice and Corrections: Environmental." or "Integration of Hospice and Corrections: Personal." The final product for this method was a series of documents that were organized by theme category; theme; and then augmented with corresponding code, theory and operational notes.

The second method involved creating separate documents titled with a different domain from the Interview Instrument (for example, "Personal Identity"); these documents contained the instrument's questions for each domain and the responses from the 12 participants for each question. In this way, the data were reorganized by domain and sub-organized by question. Each document was read multiple times and coded, using highlights, in the text of the transcriptions. A similar approach to that of the first method was used for developing codes and memos for the data therein.

In the first method, themes were identified, categorized, and analyzed as they organically arose from the original transcriptions; however, the second method artificially grouped data - and subsequently themes - into categories that matched the domains in the

Interview Instrument. The final product for the second method was a series of documents, organized by domain; corresponding theme; and augmented with code, theoretical and operational notes. The final products of both methods were then compared and additional memos were created regarding this comparative process.

Chapter IV will provide further, more comprehensive description of the sample characteristics and a summary of the findings, including a summary of codes and themes emerging from the data.

Chapter IV

Findings

The purpose of this qualitative study was to gain a deep, rich understanding of what social workers consider to be the barriers associated with providing quality end-of-life care for inmates. This study was guided by the research question, *What barriers impact social workers' capacity to provide quality end-of-life care to inmates?* "Barriers" in this study is defined as objective, subjective and intersubjective elements that impede the capacity of social workers to provide what they believed to be quality end-of-life care to inmates.

This chapter will present a detailed description of the sample characteristics, including gender, age, religion/spirituality, race/ethnicity, and experience and training. Demographic characteristics of the inmate population served, as reported by study participants, will follow. Descriptive data will be followed by a presentation of study findings which emerged in a qualitative analysis of participant responses to questions regarding their perceptions of barriers in the areas of social work professional identity, the structure and ideology of correctional institutions, inmate and participant characteristics and experiences, and community attitudes.

Sample Characteristics

The sample included 12 master's level social workers who provide some aspect of end-of-life care to inmates in county, state or federal correctional institutions, whether through direct practice, training of other staff and volunteers, or supervision. The 12

participants were recruited from a total of seven states: four mid-western states, two northeastern states, and one southern state.

The sample was composed of 10 females and two males. Eleven of the participants identified as Caucasian and one of the participants identified as Hispanic. One participant declined to answer the question, *How old are you?* The age range of the remaining 11 participants was 34 to 62 years; the mean age was 45 years old, and the mode and median age was 41.

All participants identified their socioeconomic status as middle-class. All identified as being spiritual and their spiritual practices varied. Three participants identified as having been raised to practice some form of organized Judeo-Christian religion; two of these stated that they now have spiritual practices that differ from those with which they were raised, while the other stated that they no longer practice any organized form of spirituality. Three participants did not indicate the spiritual practices with which they were raised, but identified as currently practicing some form of organized Judeo-Christian religion. The remaining three participants did not indicate the spiritual practices with which they were raised and identified as practicing a form of personalized, non-organized spirituality, broadly defined. For example, one such participant identified her spiritual practice as volunteering at a community hospice program in the area, where she lives.

Participants' experience in the area of end-of-life care with inmates ranged from 2 to 30 years. One participant had professional hospice experience prior to providing end-of-life care to inmates. Three participants had had some level of formal hospice or end-of-life care training either prior to, or immediately after their assignment in end-of-life

care to inmates. The remaining nine participants received relevant training at some point

during their tenure as end-of-life providers, whether immediately following their new

assignment, or intermittently, throughout this tenure.

Ten of the twelve participants had no prior professional experience working in

correctional institutions and no prior formal training in correctional institution settings at

the time of accepting assignments as end-of-life care providers to inmates.

Characteristics of Participants' Patients

In an effort to learn about whether, or in what way, differences or similarities

between practitioners' and inmates' demographic characteristics were perceived by

participants as barriers to the provision of quality care, participants were asked to

describe the general ethnicity/race, gender, age, socioeconomic status, and

religious/spiritual characteristics of the inmates to whom they provided end-of-life care.

Three of the participants noted that the majority of their inmate patients were Black, with

Caucasian being the next most represented group, followed by Asian, Latino, and Native

American. Two of the participants noted that the majority of their inmate patients were

Caucasian, with Blacks being the next most represented group, followed by Asians,

Latinos, and Native Americans. Two of the participants noted that the majority of their

inmate patients were equally split between Blacks and Caucasians, followed by Asians,

Latinos, and Native Americans. The remaining five participants did not indicate any

racial or ethnic group as being in the majority and described them as Black, Caucasian,

Asian, Latino, and/or Native American.

The reported overall inmate patient age ranged from 22 to 93 years old. Four

participants indicated that the majority of their inmate patients were middle-aged to

elderly. The remaining eight participants did not indicate the majority age range of their inmate patients, but rather provided the overall age range of the population with which they worked.

The majority of participants reported that their inmate patients practiced some type of spirituality or organized religion, mostly Judeo-Christian or Islam.

All of the participants reported that the majority of their inmate patient population was of lower socioeconomic status; however, three participants also noted that their inmate patients' socioeconomic status ranged from lower to middle to affluent. Socioeconomic status of patients was reported to vary by the type of correctional institution in which they were being held, with the majority of affluent inmate patients being held in federal institutes of corrections.

Eight of the 12 participants worked in correctional institutions that housed only male inmates; one participant worked in a correctional institution that housed only female inmates; and three participants worked in correctional institutions that held both male and female inmates, but worked with primarily male inmates.

Barriers in the Provision of Quality End-of-Life Care to Inmates: Findings

The following section will provide a detailed summary of the findings and subsequent themes and sub-themes identified through qualitative analysis of participant responses to the study question, *What barriers impact social workers' capacity to provide quality end-of-life care to inmates?*

The professional identity of medical social workers in correctional

institutions as barriers.

Responses regarding the manner in which participants' professional identity as

medical social workers in correctional institutions impacted their capacity to provide end-

of-life care to inmates included several components. Specifically, these components

included: the number of duties the participants were asked to perform; the size of their

caseloads; the perception of their roles by others in the organization/institutional setting

and by the participants themselves; and the nature of the training and/or prior

professional experience to which they had access. Each of these components and what the

participants believed to be their associated barriers will now be explicated, separately.

Participants' duties and caseloads as barriers.

In response to the question, *What is your title and what are your duties?,* the

majority, or ten of the twelve participants, described themselves as either "medical social

workers" or social workers performing medically related duties. Each of these

participants described being either the only medical social worker in their institution or

one of two such social workers. They described having multiple duties and large

caseloads. For example, one participant responded to the above question, with the

following:

> I'm a medical social worker, I'm licensed clinical social worker in the state of….
>
> My duties here, include working with our hospital inpatient population, we have
>
> about 40 bed hospital unit, I'm on the hospice committee; I'm not the chairperson,
>
> but I do a lot with them, assigning inmates, doing training. I work with all the
>
> medical inmates at our facility, we have about 2000 inmates, not all of which are

medical problems, but I'm the only social worker in our facility. So I see a lot of inmates. I help with discharge planning, setting up social security…when they have questions about anything and everything, I work with the hospital...I'm the chairperson of the bioethics committee at our facility…and any inmate that wants to be considered for compassionate release, early release from prison, if they're terminally ill…I do the background for that, hold the meetings, do the minutes, inform the inmates. If the inmate is considered for that program, there is a specific packet of information that has to go forward, I do that. We do all the bone marrow transplants in the bureau of prisons in our facility, I do that, not the transplant, obviously, but I do the paperwork that the central office reviews to make a decision. I do orientation every week for new inmates, take care of advance directives for our hospital population, deal with families...a little bit of everything.

Participants were not asked specifically if the number of duties they were asked to perform or size of their caseloads presented barriers to their capacity to provide end-of-life care to inmates; however, two participants provided the following responses to the question, *What changes (environmental, political, personal, professional, etc.) would improve your work with dying inmates?*:

> I guess just more time to spend on it. Working with the dying patients is only a portion of my job, it's small portion of my job. I'm still responsible for all the other medical patients, 300 hundred other medical patients, so time is a big factor; it's the one thing I wish I had more of…
>
> More time designated for the program, so for example, like I said, everyone has other duties, so everyone's pulled in a thousand different directions, so it would

be nice to have a team that more specifically had this as their job assignment.…When you look at it right now, we're the size of any small community of 2,200, so at any given time…there's not of us to support an entirely different type of people, people have to share jobs, but that would be ideal if that could be changed.

The remaining two participants, who did not identify as medical social workers, identified as "clinical social workers."

Lastly, one participant described the loneliness she experienced in her role as a medical social worker as a challenge to her work, noting the following in response to the question, *What changes (environmental, political, personal, professional, etc.) would improve your work with dying inmates?*:

> …the one thing that I struggle with…working in a medical model, is that I'm the only social worker. And there are other master's-level social workers, but it's in an entirely different area, and they don't do the work I do; it's more clinical. And it gets lonely sometimes, being the only social worker. So I look for meetings to go to, and just doing this interview helps. I think that's a challenge is being all alone.

While not a barrier, six participants described the unique role inmate volunteers played in mitigating the impact of their over-burdened caseloads had on their patients, by providing these dying patients with an on-going, vigilant relationship at the end of life. For example, as part of her response to the question, *Are you part of a team that provides end-of-life care to inmates? If so, how is the role of the social worker defined - by you? By others on the team? Please explain/describe any practice challenges or benefits you may experience as a member of a team.,* one participant noted: "….We have three trained

volunteers, most important inmate companions, who are inmates, who are trained and are

the ones who do most of the legwork with the dying inmates."

As part of her response to the same question, a separate inmate noted:

…if we get word from a physician that someone is imminently dying and we

expect them to die in the next two or three days, we'll round up the troops [inmate

volunteers] and assign 24-hour coverage. And I've gone to these volunteers,

walked out to their work places and said, 'I need somebody tonight, to stay all

night,' and they'll say, 'put me down.' And they work all day at their job, and then

they'll take a nap, and then they'll stay with someone all night long, someone

who's dying, all night long. And on no sleep they'll go to their job the next

morning and they'll say, 'put me down, I'll do it again tonight'….They will come

through in a pinch, when we need them.

The perception of participant roles as a barrier.

The manner in which participants believed their colleagues on interdisciplinary

care teams perceived their role as a social worker in the correctional institution also

emerged as a potential barrier to their capacity to provide end-of-life care to inmates. For

example, four of the 12 participants noted some level of role ambiguity or confusion in

response to the questions, *Are you part of a team that provides end-of-life care to*

inmates? If so, how is the role of the social worker defined - by you? By others on the

team? Please explain/describe any practice challenges or benefits you may experience as

a member of a team. The participant that did identify role ambiguity or confusion as a

barrier to end-of-life care provision responded in the following manner to the above

question and subsequent probing:

…federal prison social workers are few and far between, there're only about 35 of

us and there're 110 institutions, and they basically don't know what to do with

us…I'm not custody; I'm kind of in the middle. I get lumped into medical mostly,

and then custody...so I've been there for three years, so I look at every moment as

a teaching moment. Like, 'ok, no, no, no, this is what social workers

do'…[correctional or medical staff] that have had exposure to social workers

before kind of get that [the organization structure and the role of social workers],

but then they don't, and the ones who don't, don't have any clue, are like, 'what

are you supposed to be doing? What do you do?'…[and] I do feel pulled to do

things that aren't really in my scope, sometimes, but I try to be very rigid, because

there's only two of us, and, my federal caseload is like 400, and not everyone's

leaving and not everyone's terminal or not everyone needs additional support, but

that's a lot of guys, I'm juggling.

The same participant provided this response to the following probe, *Are there any*

barriers that come up for you in terms of this challenge of how people see you and your

ability to provide care to inmates?:

That's actually an excellent question. Yes, there are lots of barriers, believe it or

not, some of them we put in place ourselves, because we have to be pretty rigid

with how we practice. And again the lack of education the lack of understanding

of what social workers do is a huge barrier…

Participant training/professional experience as barriers.

The final component of the participants' professional identity that arose as a

barrier to their capacity to provide end-of-life care to inmates was the level of training

and professional experience they had providing such care before they entered the field, as well as their on-going access to continuing education and training in their current roles as providers of end-of-life care to inmates. Regarding the training and professional education of participants prior to entering the field, three out of twelve participants responded that they felt that more such training or experience would have better prepared them for their current roles. Expression of this barrier arose most frequently in response to the question, *What limited you from feeling more prepared to begin this work?* The following responses to this question, from this group of three participants, are illustrative of this finding:

…pretty much my lack of experience working in the medical field, that was the biggest thing; I didn't really have that much experience, I worked with little kids. Thankfully, I didn't have that much experience with death and dying…

…it's hard to say; I guess if I'd worked at a hospice, community hospice, I would feel more prepared. I've dealt with hospice in my life, with my grandmother, things like that, but the way it is on the outside, when I say outside I mean if you had hospice for your parent, it's a lot different than inside a prison setting…

Regarding access to continuing education and training, an additional two participants responded they felt that more access to such resources would improve their capacity to provide end-of-life care to inmates. One of those participants provided the following response to the questions, *What skills do you believe are required for providing quality end-of-life care to inmate?* and *How are these skills acquired?*:

.…I think that piece of the practice is continuing education, being on top of medical practices, even though I'm not medical, medical…I'd like to say I was taught them in my master's-level program, but I don't think so. I'd say these skills are acquired just by constantly being on the lookout for continuing education classes, or being vigilant about growing in your profession, rather than just sitting there and not doing anything, but growing in your profession. Taking advantage of teaching programs, or continuing education, social work meetings. It's very important…I think it's hard to get medical continuing education classes for a social worker, that's a barrier. They have to trainings for physicians and nurses, so I try to go to those. Of course, I do dialysis, so I'm constantly in the medical field that way, and I got to nephrology social workers meetings. But I think a barrier is...I would have liked to have had more medical training to do what I do. I would like there to be medical social work training. Pure medical social work training is not there.

The correctional institution as a barrier to social work practice: Environment, staff education and attitudes, and policies and practices.

This finding relates to how participants viewed components of the correctional institution as preventing or inhibiting them from delivering quality end-of-life care. Specifically, these components related to the correctional institution environment as a practice setting; the education and attitudes of institutional staff; and institutional policies, practices, and philosophies. The identification of these institutional-related barriers arose in response to range of interview questions, but most frequently to questions regarding attitudes (of participants, other staff, and community) toward work in

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prisons and with inmates. Further explication of the three components of institutionally-related barriers, along with illustrative examples of each, is provided below.

The correctional environment or setting as a barrier.

The first component of the institutional setting as a barrier relates to the overall environment of the correctional setting. This component was discussed most frequently in participants' responses to the question, *What feelings do you associate with the environment in which you practice?* Of the ten participants to whom this question was posed, one participant described having positive feelings toward the environment; four participants described negative feelings toward the environment; and five participants described having ambivalent or "mixed" feelings. The participant that described having positive feelings toward the environment noted having worked in what she considered a more challenging environment prior to working in the correctional institution, specifically child protective services. Of the remaining nine participants, those that expressed negative feelings toward the environment were more likely to describe these feelings as a barrier. For example, one participant noted:

> …well, it's a very stressful and high-pressure environment. Everybody's locked up in a cage, and if you're locked in cage, you want to get out. So everybody's focused on getting out...either getting out of the health center and into a G.P. [general population]-type situation, or getting out of prison and getting home. So...people don't want to...are less able to accept the fact that they're terminally ill, and what's happening to them, than if they were in the community, even though I'm sure it happens in the community. It's just a high-pressure environment, lots of rules; everybody's on edge. You screw up and you can get fired pretty easily.

You say the wrong thing, or you ventilate your feelings in the wrong set of ears...whew, oh, boy. So those are the kind of things. It's a kind of tense and uptight and uptight kind of atmosphere.

In response to a question asking whether the stressful nature of this environment ever gets in the way of his practice, this participant stated:

Sometimes…that goes along with practice in the correctional environment…I'm a person that has too much to do, and [I'm] covering two jobs right now…and it's like, 'ok, I'm going to see Mr. so and so in such a type of room;' and [then] it's like, 'oh crap, I got to walk by so and so's room, who will see me, who will beat on the door and holler to talk to me, and I don't really have time to talk to him, I don't want to talk to him, so what do I do? Do I stop and talk to him, and then maybe relate to him in a way I don't want to relate to him and wouldn't want to be related in, if was the offender?' But I really don't have the time to listen to this guy go on and on about something that I can't help him with, when there are things that I can help people with. Those are the kind of things that I run into.

Another participant's response to the question, *How long do you think you will continue to work with dying inmates?*, further highlights the stressful nature of the environment and its perceived impact on practice:

That is a good question. I'm not sure...probably not very long… because...oh gosh...the sadness of it all…I find that it's a sad process. It's more so sad in this environment than anything else. I truly feel…I think I could probably work hospice, with people dying in general, terminal patients. [Working with] dying inmates is a very, very heart-wrenching process.

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The education and attitudes of correctional institution staff as barriers.

Participants described how the attitudes of correctional staff (including, correctional officers, case managers, counselors, and nurses) negatively impacted both their own, as well as inmate volunteers' (under their supervision) capacity to provide quality end-of-life care. Most participants attributed these attitudes to limited education, including: a lack of higher education in the case of correctional staff; a lack of education regarding specific facets of end-of-life care in the case of multiple types of staff; and/or a perceived lack of education among these staff regarding the role of inmate volunteers as end-of-life care service providers - specifically in the case of nursing staff. Discussion of this component arose in response to several questions throughout the interview, examples of which are presented below.

In the case of correctional officers' lack of higher education fostering attitudes that resulted in barriers to care, one participant provided the following in response to the question, *What feelings do you associate with the environment in which you work?*:

> The barrier is [related to the prison environment], and I can't emphasize this enough, the mentality of a lot of the [correctional] staff I work with. And I think it's directly attributed to their low education, their lack of being able to be promoted anywhere. They have a sense of authority they don't really have…that's the main barrier: not really the institution, the locked gates, everything you have to do just to into the prison, or the potential for violence; for me, it's the staff I work with…it makes it really hard. It took me…a year and a half to be accepted at this institution…and I would be trying to get information…keep being stonewalled.

Two participants discussed what they perceived as the limited education of some correctional staff, regarding different facets of end-of-life care, and how that limited education resulted in such staff having attitudes that might present barriers to their capacity to provide end-of-life to inmates. In response to the question, *What influences and/or experiences challenged your development of your philosophy on providing end-of-life care to inmates?,* one participant noted:

Barrier comes, when other people think they don't deserve it. The correctional staff or other staff here say, 'why do they get to watch TV, or why do they get to...the shouldn't'…[then I say] 'Well, we discussed the benefits of that.' I've had that argument with a counselor here, a case manager here...'why should they be able to watch TV?' 'Well, the fact is, this person is in and out of consciousness. It reduces their agitation; it brings normalcy to their end of life, to just lay there and pass the time.' So I mean, whereas one person [might say], 'well, they don't deserve it; they're lying in bed'…[then I say], 'well, they can't participate in general activities, and this...reduces their need for staff services, by allowing them to watch some movies, and it's so simple, and it doesn't interfere with security of the facility.' And so once I find I have a dialogue with someone like that, and we start to understand each other...they're usually like, 'oh, I get it.'

Another participant provided the following in response to the question, *What changes (environmental, political, personal, professional, etc.) would improve your work with dying inmates?*:

…I think with ours…and it's huge and will be on going…is education. The value of education, and when I'm talking about education, I'm talking more about staff

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than offenders [inmate volunteers], offenders are always there on Thursdays for
education and knowledge about how to care for other people; they are grateful,
when there's an in-service. It's educating the staff, that have been around along
time, that are the [type of people, who think of things as being] black and
white...and encouraging them to see the value of it…

One participant described, with vigor, the negative impact that attitudes of
nursing staff had on her own as well as inmate volunteers' capacity to provide end-of-life
care to inmates. The participant was not asked and did not describe what might have
fostered these attitudes within the nursing staff, but did add that education was
recommended by others, specifically the nursing director, as a strategy to improve such
attitudes; however, the participant did not believe that education had been or would be a
successful strategy to improve such attitudes. This participant added the following in
response to the questions, *Are you part of a team that provides end-of-life care to
inmates? If so, how is the role of the social worker defined - by you? By others on the
team? Please explain/describe any practice challenges or benefits you may experience as
a member of a team.*:

Well our biggest struggle comes from people outside of our committee, other staff
members, who don't, or won't understand what it is we do. And specifically, I'm
talking about our nurses. And being a hospital unit, we have a lot of nurses. We
have a 40-bed inpatient hospital unit, which is fully staffed by nurses. And so we
invite them to our meetings, we try to encourage them to be involved, so they
have a better understanding and they basically ignore us…sometimes it feels like
we're beating our head against the wall. We invite the nurses, we invite other staff

to our meetings so they can understand what's going on, but nobody comes, nobody attends, nobody wants to be involved. But they want to complain. We try to educate the nurses and the staff, and we are sort of stymied in that, because you have three shifts worth of people, who are busy taking care of their patients, so it's hard to do things, so it's kind of tricky to educate them without stepping on toes, without trying to make people feel defensive. So a lot of times, we'll go through our director of nursing and reach out to her and say, 'Look we're having these issues,' and try to follow a chain of command, basically. And I'm not sure how much she follows up them; usually her reaction is, 'ok, well we need to do education,' and then that falls to the wayside.

The same participant provided the following in response to the question, *What changes (environmental, political, personal, professional, etc.) would improve your work with dying inmates?*: "just more education within our facility, within our staff population, probably…the nursing staff. Top choice." However, this participant also believed that, while she would also recommend educational efforts as a strategy to improving nursing attitudes, the institution and its staff would continue to inhibit, even thwart such efforts.

Four participants discussed neither the impact of education on the correctional staff attitudes nor what they felt to be the derivation of such attitudes, but rather only the challenges such attitudes presented for them in their work. These participants described feeling that their desire to provide what they believed to be quality care to dying inmates was ridiculed and/or viewed by other staff (mainly correctional officers) as evidence of weakness or as being "out of place" in the correctional facility. One of these participants

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provided the following response to the question, *What feelings do you associate with the environment in which you practice? Do these feelings pose a barrier your practice?*:

> …we're in a correctional setting. These are inmates; they have broken the law. This is their punishment…to serve whatever amount of time the judge feels is appropriate for them to serve. So we have some [correctional] staff…that look at it like, 'they're thugs; they ain't got nothing coming.' That's what you hear, 'they ain't got nothing coming'…[and] they call me a 'thug-hugger,' if I'm too nice…we're often called 'thug-huggers,' and it makes it hard for me for other staff to view me like that.

The policies, practices and philosophies of correctional institutions as barriers.

The third and final component of this finding relates to the challenges that participants experienced as they attempted to learn the policies and practices of the correctional institution, reconcile their social worker values and philosophies with those of the correctional institution, and negotiate the quality and quantity of end-of-life care they were able provide in what they perceived as the "restrictive" environment of the correctional setting. Each of these challenges will now be presented and summarized as separate sub-themes; the manner in which participants struggled to create more opportunities for families of dying inmates to visit these inmates will be presented as a specific example of the third sub-theme.

The first sub-theme relates to the challenges participants experienced as they attempted to learn the policies and practices of the correctional institution. Of the 11 participants who were asked the question, *Did you feel prepared to provide end-of-life care to inmates, when you began this work? What limited you from feeling more*

prepared to begin this work?, four reported that they did not feel prepared, because they

had not previously worked in a correctional institutions. They reported finding learning

the "ins and outs" of the institutional setting to be a barrier to their capacity to perform

their duties over all, and specifically to their capacity to provide end-of-life care to

inmates. In response to the above question, one participant noted the following:

> It's a very difficult setting. I think it's really hard to describe to anyone who
>
> doesn't work in corrections. When I first started, I described it as beating your
>
> head against walls. And you have to find out, which is not on paper, 'who gets
>
> things done, who can you got to for this issue that it'll get done?', and it's not
>
> always on the organization chart. You have to learn all the rules and tiptoe; one of
>
> the things that's been hardest for me in terms of advocacy for the patients…there's
>
> a constant assessment of which person will do what for you, how far you can go
>
> with that person, when to push, when not to push. That's the most difficult part of
>
> working in the correctional setting.

Another participant provided the following response to the same question:

> I felt prepared on the dying part of it… But the correctional, yes, that was a
>
> barrier, because I did not come from a corrections background, and I'm still
>
> learning that. There's so many ins and outs and things that you have to do, and
>
> steps that you have to take, and people that have to be notified. So I...not knowing
>
> the correctional, that was a barrier, because basically, I had to say, 'Wait, you
>
> need to stop and learn the corrections piece, before you can do the hospice piece.'
>
> The second sub-theme relates to the challenge participants experienced,

reconciling their social work values and philosophies with those of the correctional

institution. Eleven of the 12 participants described experiencing some level of challenge related to being social workers in the "restrictive" or "domineering" correctional environment described above. One participant described the social work profession as being "more liberal" than other professions represented in her correctional institution. These participants reported on-going struggles to do what they believed professional (social work) ethics and values required of them in a setting that was perceived as fostering a set of values prohibitive of the delivery of services based in social work values and ethics. Three of these participants also expressed the challenge of being, what one participant termed, "[a] corrections officer first, and social worker second." One participant provided the following response to the question, *Is there anything else that you'd like to add about professional identity, who in you are in your role that might make it challenging?*:

> …sure, yeah, if you're going to be a social worker, who…works in a prison, you are definitely...going to experience some role confusion, because in a prison…you are all considered correctional workers first. So what that means, regardless of my title, or what I feel my code of ethics are, if there is a custody issue that occurs, my very first responsibility is as a custody worker. So for example, if there was a fight right now, and I should say this too, if I have to hang up the phone very quickly, for example there could be a fight that happens right now, I need to respond to that fight. If I see an inmate assaulting a staff person, I have to take that inmate down; I have to do, physically, whatever I have to do to ensure the safety of that staff person. So, that's not typically a social worker…there is some role ambiguity in that sense.

In response to the question, *Do your feelings toward the environment in which you work present barriers to your practice?,* one participant stated:

> You realize in this setting, that you are not all always achieving the social work ideal or ethics to whatever. It's a very imperfect world; you do the best you can. The way I cope is in several ways, and one way, I also come back to myself and say, 'what would they have if we weren't here?' it may not be perfect, but it's better than whatever it would be if we were not involved.

The third sub-theme relates to the challenges participants experienced negotiating the quality and quantity of end-of-life care they were able provide in the "restrictive" correctional environment or setting. Under this sub-theme, the example of advocating for family visitation of dying inmates was frequently noted as an area of practice in which participants felt most challenged, yet diligent in providing. Five participants referred to the importance and/or need for family visitation in their responses the question, *Please provide your personal philosophy on what it means to provide end-of-life care to inmates,* and four participants included it in their responses to the question, *What do you consider to be quality end-of-life care for inmates?*. However, in response to the question, *What changes (environmental, political, personal, professional, etc.) would improve your work with dying inmates?,* one participant noted the challenges they perceived to its implementation:

> I would like to change, that would be almost impossible to implement, would be to provide the inmate with more time with their relatives on the last months that they will be here on the hospice program, because I believe that they can benefit and also the family from sharing time with them. But because of our certain

scenario on the correctional setting, it would take a lot of logistic…it would take a lot of coordination with correctional staff and clearance with those people who are trying to come out to the institution.

Another participant reinforces the salience of this sub-theme in the following response to the question, *Does the criminal justice system in this country and in the state and county in which you work support and/or pose a barrier to your capacity to provide end-of-life care to inmates?*:

It provides some barriers to provision of the psychosocial aspects of care…That family to me...if we have somebody actively dying, we can get family in....With our current warden, I haven't really had this situation, but we can usually get family in to see them. But family has to come and go in an hour; only two persons can be in a room at a time. In the past, we've been able to get maybe two or three or four days in a row...get a one-hour visit, but for a family that really wants to sit there and hold their loved one's hand, that's inadequate.

The following response to the question, *Is there anything that you'd like to add about the work you do with dying inmates, any barrier you face, any successes you've had, or anything else you like to add that wasn't brought up in these questions.,* while not necessarily addressing the challenges associated with family visitation, serves to highlight the value one participant placed on family involvement in the end-of-life process for inmates:

I think part of my motivation…is the families that are on the outside, that are suffering the [effects of the] terminal illness of their one...trying to provide some sort of service to them, even though they're long distance….I mean most of our

guys are from nowhere near here, they come from all over the country. The sense

of satisfaction...their [the family's] expression of thankfulness that…they feel that

this person [the inmate, their family member] is getting good, quality end-of-life

care, so even if they have to die in prison…that they're [they family] comfortable

with them dying, here, with us.

Inmate and participant characteristics and life experiences as barriers.

This finding relates to participants' perceptions of inmate and study participant

characteristics and life experiences as barriers to the provision of quality end-of-life care

to inmates. The perception of each (i.e., inmate characteristics, and participant

characteristics and life experiences) as barriers will be presented separately and further

explicated, below.

Inmate characteristics as barriers.

Seven participants discussed three characteristics of inmates that presented

barriers to their capacity to provide them with end-of-life care. These inmate

characteristics included: suspicion (as noted by two participants), personalities (as noted

by four participants, and denial (as noted by four participants).

Inmate "suspicion" was noted by two participants when describing what they

considered significant barriers to participation of eligible inmates in end-life care

services: in some cases, participants described inmates as being eligible to receive end-

of-life services, but as feeling suspicious of such services or untrusting of medical

professionals. One participant provided the following response to the question, *Can you*

describe any characteristics of the population, with which you work, that challenge your

capacity to provide them with quality end-of-life care as you described it?: "They're [the

70

inmate patients] very suspicious of everyone, so that makes it hard. The doctor may be providing the best care they can, but they're very suspicious of anyone in charge, most of them have problems with authority."

In response to a question regarding how correctional institutions might adapt to better deliver end-of-life services to inmates, another participant noted the following:

…because there's a lot of distrust around the medical care, around the medical staff, and around other people. So, what happens if you start building these programs, then there's a lot less distrust, which makes it a lot less problematic to manage people, who are in that condition in the institution. Because I know that a lot of times...not in ours, but in prisons, they have dedicated areas, and sometimes, people are afraid to go to those dedicated areas, because they're afraid that someone's going to kill them once they're there. Or make them die faster. So that means that means that they end up staying in general population, which can be a lot more problematic for the management of the facility…

Overall, participants provided no specific explanation as to why inmates might feel suspicious of end-of-life services. One participant, however, provided the following response to the question, *Can you describe any characteristics of the population, with which you work, that challenge your capacity to provide them with quality end-of-life care as you described it?*:

You have other inmates telling them, 'You need to do this...' for example, if it's end-of-life, and they still have the mental capacity, we like for them to make a do not resuscitate order, a DNR. But other inmates will talk to them and tell them, 'they'll just sit and let you die.' It just this mentality that they're not going to be

taken care of, and that's a challenge, because we are taking care of them as best we can. And I guess that's mainly it.

Four of the 12 participants described the personality types of some of their dying inmate patients as constituting a barrier to their capacity to provide end-of-life care. Participants raised this as barrier most specifically when responding to the question, *Please describe any characteristics of the population, with which you work, that challenge your capacity to provide them with quality end-of-life care as you've described it.* Two of these four participants used the phrase "antisocial personality" to describe the personalities of their inmate patients, as illustrated in the following two responses to the above question:

> …some of them are extremely tough to talk or get through to, like someone with an antisocial personality disorder, things like that that are extremely...they can be volatile, they can…push you away, or the push/pull. They can be argumentative or different things…And sometimes that's very difficult for people to do: that despite a very difficult...to be yelled for something and maintain your cool about it, and to come back and address it, when everybody's able to address it is a good...is something not everybody can do, and that's certainly a barrier for people ….So I'd say that's one of the bigger things: just some of the personalities are very difficult.

> They're inmates, they're antisocial-personality-disordered inmates, who likely will stay antisocially-personality-disordered inmates until they reach that age, where they burn out; but for many of them, at that point, what are their options, they

don't have any others options besides going to back to what they know. I mean

that's the majority...you're talking about Axis II guys, who if they're in the federal

system, have probably been at what they've been doing for a long time or they

were pretty big time out there, or else they would have ended up in a state system.

So you're talking about working with some significantly pathological, Axis II

guys.

Denial was another inmate characteristic that participants reported as presenting

participants and, by report, their inmate volunteer-supervisees, with barriers to providing

end-of-life care to inmates. Four participants described how inmates' denial might

negatively impact [participants'] capacity to provide care throughout the end-of-life care

process. Participants were not asked why they believed inmates experienced such denial,

nor did they acknowledge denial as a typical reaction for someone facing the end-of-life.

Two participants offered the following responses to the question, *Please describe any*

characteristics of the population, with which you work, that challenge your capacity to

provide them with quality end-of-life care as you've described it.:

> …there's a real stigma in their opinion about dying in prison, so we have some
>
> difficulty with…I guess you can call it, higher levels of denial: the inmates have a
>
> harder time accepting that they are going to die. And they're going to be in prison.
>
> And that's something that's very difficult for the volunteers; they always mention
>
> that as one of their chief areas of concern…so that when they [inmate volunteer]
>
> are working with patients with the denial…[it is] difficult for them…

Sometimes, they're reluctant...especially if they're not what you would call terminally ill. We've had some cancer patients, that we've assigned hospice for, and a couple of the younger guys get all wigged out, 'what do you mean hospice? I'm not dying. No, no way. I'm not having them come talk to me, because I know what happens, when those hospice guys come up, because the last guy, he died. So no, I'm not talking to anybody'…they just know the word hospice means dying. So some guys just won't accept it, (and then say) 'I'm not that sick. I'm not that sick, yet.'

Participant characteristics and lack of life experiences as barriers.

In addition to the characteristics of inmates, some participants described the manner in which their own characteristics and the lack of life experiences presented barriers or challenges to the provision of end-of-life care. In response to the question, *Please describe any characteristics of the population, with which you work, that challenge your capacity to provide them with quality end-of-life care as you've described it,* the characteristics participants noted specifically were "fear", and whether they felt valued in the work they did. In regard to the lack of life experiences, participants did not describe their own lack of such experiences, but rather discussed how a social worker entering this field without certain life experiences might face barriers to their capacity to provide end-of-life care to inmates.

Personal identity.

In response to the question, *Do you believe your identity, or any of its components, has had an impact on, or is a barrier to, your ability to provide end-of-life services to inmates? Why or why not?*, nine participants, believed that their personal

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identity (race/ethnicity, gender, age, socioeconomic status, and/or spirituality) had some

impact on their capacity to provide end-of-life care to inmates. Five of these believed that

their personal identity had a negative impact (although they were reluctant to speak on

behalf of their inmate patients, and therefore were not entirely sure of such an impact was

truly negative) and the remaining four participants believed that their personal identity

had a positive effect on their capacity to provide such care. Four the five participants who

believed that their identity had a negative impact on their work, provided

religious/spiritual beliefs most frequently (three times) as the reason for such an impact;

race/ethnicity and gender was raised twice, and socioeconomic status and age was raised

once. Four participants provided the following responses to the question, *Do you believe*

your identity, or any of its components, has had an impact on, or is a barrier to, your

ability to provide end-of-life services to inmates? Why or why not?, illustrating

participants' perceptions regarding the potential for religious/spiritual beliefs,

race/ethnicity, gender and/or socioeconomic status to negatively impact their capacity to

provide end-of-life care to inmates:

> I think sometimes there are different religious beliefs, so it's making sure that I
>
> attend to those or whatever the belief is about end-of-life care, because everybody
>
> has their own belief about end-of-life, so it's making sure that I'm not putting
>
> mine onto someone else.

> …It can be a barrier...just being female, just being white, I'm not the same. It just
>
> puts us apart, [their] feeling like I might not understand what they're going
>
> through. I come from a different back, come from a different place. They know

I've had a different life than they do. And those things they see, and can be

barriers…

I think my age and gender has had some negative impact, when I first started,

because I work in an all male prison, so that's taken some time. They always try

the new people, so it's taken some time to establish who I was there. So my race,

not really a big deal. But my age and gender were the biggest deal.

It does, and I try to be aware of than at any given time so it won't interfere with

my perceptions and expectations of the work, whenever I have to deal with the

release. It's pretty difficult for anybody, especially social workers, to understand

the perceptions of the client's world if you have not ever been poor.

Attitudes and perceptions.

Attitudes and perceptions toward their work was the second set of participant

characteristics that participants believed created or might create challenges or barriers to

their capacity to provide end-of-life care to inmates. These challenges or barriers arose

most frequently in their responses to the questions, *Did you experience any barriers in*

making the decision and/or gaining employment in this field?, Did you feel prepared to

provide end-of-life care to inmates, when you began this work? What limited you from

feeling more prepared to begin this work?, and *Do you feel valued in the work you do?*

Does how you feel about how you are valued pose a barrier to your practice with dying

inmates? Please explain. Expressions of fear regarding exposure to inmates dying and

not feeling valued in their work were the two most frequently raised attitudes or

perceptions that participants believed negatively impacted their capacity to provide end-

of-life care to inmates. Two participants raised expressions of fear regarding exposure to inmates in response to the question, *Did you experience any barriers in making the decision and/or gaining employment in this field?,* including:

I was worried about how I'd feel when one of my inmates died, how would I take that personally...you know, what kind of contact would I have with the family, that kind of thing. So that was the biggest thing, how would I feel emotionally about that. Would I appropriately be able to have appropriate boundaries, to feel like, 'ok, I'm very sad that you died, but I can still go on?'

Yes. And I think I on-goingly wrestled with how to do it well, and how to it at all. I'd never seen anyone pass away; I'd never been with dying people. I didn't know what the process looked like. So I had to seek out people, who knew and who could explain to me, help me understand this process both medically, and spiritually, and physically, and all those things. So there were some barriers. Initially, when I got here…wanted to stay out of those rooms and, 'I don't want to go there.'

One participant expressed such fear in response to the question, *Did you feel prepared to provide end-of-life care to inmates, when you began this work? What limited you from feeling more prepared to begin this work?*: "….knowledge, I think knowledge, and fear, too…that I wasn't doing the right thing or saying the right thing.

In response to the question, *Do you feel valued in the work you do? Does how you feel about how you are valued pose a barrier to your practice with dying inmates? Please explain.,* seven participants described not always feeling valued in their work, and two of

these described such feelings as presenting barriers to their capacity to provide end-of-life care, as illustrated in their responses to the above question:

"Yeah, sure they [the feelings of not being valued] absolutely do. Yeah, if you feel like you're not appreciated, you feel like, 'what's the point? What am I working hard for, if there's no appreciation or rewarding for that?' and "…absolutely. It [the feeling of not being valued] makes it hard to go in some days…"

Participants were not asked why they did not feel valued, and most did not provide explanations in this regard; however, some participants did allude to feeling part of a bureaucracy that did not value the individual efforts of any of its staff. To this effect, one participant provided the following response to the question, *Do you feel valued in the work you do? Does how you feel about how you are valued pose a barrier to your practice with dying inmates? Please explain.*:

Sometimes…[but]… it doesn't hinder me from doing my job, it's just a frustration sometimes, so I get...and, again, I'm the only social worker here right now, and I have been since June, when the other guy retired. And I'm doing double the work; so sometimes I feel…'ahhhhhh [overwhelmed, panicked sound].' So if somebody would just say thank you, and I don't mean an inmate, but like if my supervisor could recognize...'you've really working hard!' it would just be nice. But that's a pipedream. Any job you work at, you're not going to get thanks.

Lack of life experience.

The third and final participant characteristic related to the report of some participants regarding the value they placed on life experience in preparing them to provide end-of-life care to inmates, and the consequent negative impact that a lack of

such experience might have on the preparation of social workers entering this field. Specifically, when discussing life experience that helped prepare them, these participants were referring to the quantity and quality of their (or other social workers, providing end-of-life care to inmates) exposure to personal loss and/or moments of being vulnerable and powerless, and how such exposure allowed them to better empathize with their dying inmate patients. When they discussed the impact on preparation of a lack of life experience, they were referring to how lacking such exposure might pose a barrier to being able to empathize with such patients.

The following four quotes highlight why participants thought their life experience was helpful in their work. Each quote is in response to the question, *Is there anything else around personal identity and how who you are impacts the work you do?*:

…well, you know I have had a lot of different life experiences, I have been a single parent; and I am resident alien, so...my outlook on different things, it could be different from other people…[I have an] understanding that bad things do happen to good people. And circumstances don't always dictate that the character of that person is bad just because they're incarcerated. And also that their nationality or their ethnicity doesn't have much to do with it, either. I just look at everybody as individuals and just base [my approach to my work] that on...the circumstances that they're in. And because of being an immigrant, I have a different perspective of discrimination in this society, the American society. So I think it does exist, if you want to know that, I do think it has an impact on different access to services.

I think life experiences greatly influenced my ability to work with the prison population. I mean, I've never had anybody in prison, I've never been in prison, but I went through a series of major losses, about seven years ago, when I realized just how fragile life is, and I'm just reluctant to hold standards on people that I really don't understand or know who they are. So I think that's helped me and my work… my husband died, he was a dentist, he died; we lost his practice; we lost our house; and the IRS was after us; and then my dog died.

I think with every instance, that I'm able to work with an inmate who is dying, I'm able to utilize experiences or things that I've learned in the past, either from previous hospice experience, before I came here, or hospice experience here, with other inmate, or personal, life situations that I experienced before I ever got [into] hospice…I was present when my mother died, and that was when I was in graduate school. And I was present...actually I was not present at my brother-in-law's death, but I was present up to within hours of him dying, and saw the different struggles that members of the family had and the denial. But the time that they could have...the members could have, hugely...and he himself...but he was never to the point that he accepted it, and he died, I truly think, believing that he was not going to die. So that was to me, very, very sad. But the family really struggled, and I think they could have benefited from having that support.

…well, sometimes, I think it's better that I'm not coming from the background that these guys are coming from, because I don't have any baggage about it. And I

see that in social work in general, a lot, and if someone's gone into the field that they have interest in, because of some history or baggage that they had, then that interferes with their work. For me, I don't have that. I don't come from where they come, I haven't been dying myself, so I don't have that barrier...so I think my identity of who I am, sometimes helps, because I don't get into...it doesn't interfere with my ability to take a look, from the outside as an outsider, someone more objectively saying, 'what might this person at the end of life need that I might be able to assist with?'

The next two quotes examine whether the participants thought a lack of life experience was a barrier to providing end-of-life care to inmates. The first quote follows the participant's description of the skill necessary to provide quality end-of-life care to inmates and is in response to the question, *How are these skills acquired?*:

I think through living life. I know I couldn't have come here straight out of school and had the same beliefs and philosophy and strength that I had [to do this work]. I had to go through what I went through on the streets in my previous practice; I had to see what else was there. I notice that people, who come to work here [at the correctional facility, where this participants worked], if they're very young, with less life experience, they are more unhappy, more cynical, more critical, more unwilling to take a look at the broader picture. So I think one is experiencing a broader variety of things in life to get to the point to understand more of the grey area's of life and not the black and white...that everybody starts out believing in…

The second quote, from a different participant, is in response to the same question as above:

> I need to say this, but with hospice, a lot of it is experience. I think that person...when I worked in [name and location removed]…I was obviously one of the older social workers, and there would be social workers that were 24, 25, and people...the person that's 80 years old or 70 years old…trying to talk to a 24 year old about dying?...even though the 24 year old may be the most compassionate and understanding person there is, I have to say end-of-life care is, where, sometimes age is actually on your side, as you have had those life experiences and practice in listening…

Community stigma and attitudes as barriers.

This finding is based on the responses of two participants and relates to challenges or barriers they experienced when attempting to connect their dying inmate patients to services in the community. In one instance, a participant experienced barriers while trying to refer her patients to health services outside of the institution. Specifically, this participant experienced these barriers as part of her work on an interdisciplinary team in the setting of a correctional institution. The participant provided this response:

> The barriers I face in the community are huge.… A lot of it is the prejudice against someone who is an inmate. I have guys who are leaving in the middle of their chemotherapy cycle; they're terminal, but they can't stay with us. So trying to find those resources, and how they're going to pay for it. We apply for social security for them to get SSI, Medicaid. But when I try call to make appointments with an oncology doc, or any type of resource, I always have to leave out that I'm

calling from a prison until the absolute end, otherwise they tell me they can't help me and disconnect.

In the second instance, in response to the question: *What influenced your philosophy on providing end-of-life care to inmates?,* the participant alluded to community stigma and attitudes in the context of participant efforts to place dying, former inmates in community nursing homes or hospice programs, although it was not explicitly described as a barrier:

> …when I'm releasing these patients, the ones that are being compassionately released, or the ones, or coming to their release date, and I'm dealing with nursing homes and hospice on the outside, and they, 'but, they're an inmate.' And I say, 'yes, until the day they're released from here, they're a citizen, like you and I. And the thing is you know there history, coming from me, and you may have other guys in there [community nursing homes and hospices], who served time, but you don't know it, because they're not incarcerated any longer'…

In *Chapter V,* these findings will be discussed through the lens of relational theory. Additionally, the strengths and limitations of the study and the implications of these findings for the field of social work and future social work research will also be discussed.

Chapter V

Discussion

The purpose of this qualitative study was to gain a deep, rich understanding of what social workers consider to be the barriers associated with providing quality end-of-life care for inmates. This author believes his study succeeded in gaining such an understanding of these barriers, which emerged within the following finding areas: the correctional institution and medical social workers' professional identity in such institutions, inmate and participant characteristics, and community stigma and attitudes. An additional salient finding, while not a barrier, relates to the manner with which many participants employed the services of inmate volunteers, in a relational manner, to provide end-of-life care to inmates; this finding will be viewed and discussed in greater depth through lens of relational theory, described below.

The following section will discuss the relationship between study findings and the extant literature. Following this discussion, the lens of relational theory will be applied to examine the implications of study findings for relationships between social workers and the inmates to whom they are providing end-of-life care. The study's strengths and limitations will be then explicated, followed by a discussion of implications of study findings for social work research, practice, education and social welfare policy.

The Correctional Institution and Medical Social Workers' Professional Identity in such Institutions as Barriers

Study participants identified the correctional institution milieu in which they practiced as the most prevalent and significant barrier to the provision of end-of-life care to inmates. Such a barrier developed as participants struggled to overcome the steep learning curve associated with practicing in a correctional environment, integrate their philosophy toward end-of-life care with that of the correctional institution, and negotiate these institution's policies and practices in a manner that allowed them to provide the least compromised end-of-life care to inmates.

One third (N=4), participants directly attributed their lack of education about and experience in correctional settings to the barriers they experienced, throughout their tenure as end-of-life care providers for inmates. Several participants noted instances, where a lack of understanding of the correctional system "ins and outs" created difficulty for them in their work. The overall sentiment from these participants was that formal and continuing education might have alleviated some of their confusion, regarding the specific mechanics and policies of their work environment, but nothing would have eliminated their "trial by fire" experience of being professionally initiated into the "demoralizing," "territorial," and "frustrating" correctional setting. Such an initiation process considerably hindered how and when they felt prepared to provide end-of-life care to their patients, and most of these participants noted that it was their "personality" that allowed them to successfully push through this process.

The difficulty many participants experienced as they familiarized themselves with the correctional institution was compounded by their struggle to integrate their social

work values, ethics and philosophies with those of such institutions. Nearly all of

participants discussed that who they were, and what they were able to do for their patients

as social workers in a correctional institution, was far-removed from typical

conceptualizations of social workers and social work practice with patients at the end of

life. Some participants noted that while their values, ethics, philosophies might be

somewhat compromised in this setting, they were at least glad that they were there to

provide some level of social work service and advocacy for inmates. While four

participants expressed a feeling of obligation to conform to the demands of the

institution, by being "correctional officers first and social workers second", other

participants noted that they did not make many "friends" in their work, because they

pushed back against the values, ethics, and philosophies of the correctional system. It was

these participants for whom the above-mentioned integration created barriers to their

capacity to provide care, as they (or the inmate volunteers they supervised) faced

retaliation to such push back from other staff, most notably through a lack of cooperation

from these staff.

Whether or not participants challenged the philosophies of their correctional

institution, many of them faced barriers resulting from the pervasive, sometimes

intractable negative attitudes possessed by some correctional staff also described in Maull

(1991b), Wright and Bronstein (2007), and Leland (2009). Through his study, this author

learned of the seemingly heroic extent to which some participants struggled daily to

educate and/or otherwise mitigate the negative impact of correctional staff views of

inmates as not worthy of holding vigil over their dying peers or being cared for as they

died.

Most participants, who attempted such mitigation, did so through diligent education, perennially informing correctional staff of inmates' need for and right to end-of-life care. For example, one participant recounted the process of having to constantly educate nursing staff, who seemingly did not want or need such education and preferred to restrict the movements and activities and generally disrespect the inmate volunteers, who were attempting to care for their dying peers. This participant described education as a kind of red herring that obfuscated some other source of these nurses' negative attitudes. Other participants believed their efforts to educate correctional staff (often officers) were more effective. One participant believed that the correctional staff, whose negative attitudes posed barriers to her work, were envious of her higher education, and mitigating the impact of such attitudes was done less through education, than through assertion of her authority.

Participants also experienced barriers posed by correctional institution policies. Eleven participants believed correctional institutions' restrictive policies created a significant disparity between the quality of end-of-life care they would liked to have provided, and the quality their patients received. For example, several participants decried the limited access dying inmates had to their families, stating this was a primary component of what they believed constituted quality end-of-life care. Some participants even alluded to creating surrogate family experiences for their patients, so that these patients and their families would know that not all inmates die alone, without support.

Ivanoff et al. (1993), Severson (1999), Lowe & Bohon (2008), and Church et al. (2009) call for more comprehensive education focused on the mechanics of correctional institutions, and the needs of inmates, to increase social work interest, activity, and

efficacy in these institutions. However, this study's findings regarding participants' perceptions of the challenges to social work practice posed by institutional policies provided this author with greater sympathy for and understanding of the historic decrease in social work engagement in correctional settings described in Dawes (1978), Gum (2004) and Mazza (2008).

In keeping with Oliver and Peck (2006), some participants noted that the provision of quality end-of-life care was hindered by the size of their caseloads and the number of duties they were asked to perform. In contrast to other studies describing role ambiguity among social workers on end-of-life care interdisciplinary teams (Kulys & Davis, 1986; MacDonald, 1991; Payne, 2006; Reese & Sontag, 2001; Munn & Adorno, 2008; Black, 2006; Reese & Brown, 1997) all participants in this study offered very clear descriptions and understandings of their roles. When ambiguity and confusion did occur, they did so because team members misperceived participants' roles, or were unsure of how to use/work with them on the team. Participants noted that barriers to care arose when they were forced to spend time educating team members about their roles, rather than providing end-of-life care.

Additionally, Kulys and Davis (1986), MacDonald (1991), Payne (2006), Reese and Sontag (2001), Munn & Adorno, 2008, and Black (2006) note that social workers often are not active enough in defining their roles, taking ancillary positions on the team; and that other professions on an interdisciplinary teams expropriate components what have traditionally been considered social workers' domain, reducing the perceived and actual need for social workers on such teams. This study's findings contradict these authors, in that several participants noted they had to be very active in defining and

executing their roles, which sometimes meant being prohibitively "rigid" in their practice, as described by one participant. Some participants reported that rather than being constricted, their roles were expanded to include the work of others on the team, thus taxing their capacity to treat their patients. Overall, participants suggested that both the demands as well as the "domineering" nature of their practice environment forced them to be very definitive in how they carved out and executed their roles.

Inmate and Participant Characteristics as Barriers

The impact personal characteristics had (or did not have) on participants' capacity to provide end-of-life care to inmates rather intrigued this author. Some participants reported that the manner with which inmates presented themselves as they died negatively impacted their capacity to work with them. These participants referred specifically to the challenges that some inmates' suspicion, fear, and personality traits created for the participants. A small handful of participants understood this presentation as reflective of the confluence of the correctional environment and the life histories of such inmates, which fostered a lack of trust within these inmates and a seeming aversion to care. Severson (1999) notes, "…the knowledge and skills needed to effectively address inmates' problems are the same as are already taught within social work educational curricula (p. 66);" however, this finding suggests that inmates, approaching the end of their lives, might experience increasingly more complicated biopsychosocial, spiritual stressors for which social workers' training and education programs have not adequately prepared them.

It noteworthy that despite the demographic differences found between the participants and their inmate patients, none of the participants reported the race, age, or

socioeconomic status of their patients as constituting a barrier to their provision of quality care. However, one female participant noted difficulty in working with an all-female caseload, because of the inherent sadness of watching women die in prison. Another participant noted that the seeming disparity between some of her patients' spirituality and the crimes they committed made it hard for her to express tolerance toward them. Both of these participants noted that they had to continually monitor these reactions to ensure they did not overly impede their work. Highlighted in this finding is a disparity between the inmate characteristics that trigger an inhibitory countertransferential response from participants worthy of on-going monitoring and those that do not trigger such a response.

The finding that only five of the 12 participants reported that their race, ethnicity, age, gender and socioeconomic status could negatively impact their capacity to work with their patients is of particular interest in terms of its implications for the cultural competency training needs of such workers who are likely to be providing care to patient/inmates with demographic characteristics different from their own. One potential explanation for this disparity involves racism and classism that pervades the criminal justice system and normalizes the presence of poor, under-educated individuals as inmates. In this instance, working through cross-cultural difference is not seen as valued, because race and class are mapped onto inmates as elemental, defining qualities. Although this was an exploratory study, this author hoped a majority of participants might discuss the potential for their identity to be a barrier to their capacity to provide end-of-life care; such a finding might have suggested greater ability to provide culturally competent care to a very diverse, vulnerable population. However this finding was not bourn out in the data. Furthermore, this author was quite surprised that four participants

reported their identity had a positive impact on their ability to provide end-of-life care to inmates. Berzoff and Silverman (2004) and Lopez (2006) suggest that social workers' personal identity cannot be divorced from their work with their patients; and relational theory, as explicated by Hadley (2008) reinforces this suggestion. Therefore this author remains curious to further investigate, what, if any, impact personal identity difference has on the relationship between social workers and dying inmates. Additionally, this finding, and that of the previous one, related to the potential disparity in countertransferential responses, suggests a potential need for increased cultural competency training/supervision for social workers, providing end-of-life care to inmates, as noted in Lopez (2006).

Lastly, related to personal characteristics, three of this study's participants described their fear of exposure to an inmate's death as a barrier to their desire and capacity to provide these inmates with end-of-life care; it kept them from feeling prepared enough, ready enough, to provide the type of care they wanted to. They did not directly attribute the etiology of this fear to personal experiences with death; however, elsewhere in the study, they noted that such experiences informed their practice. This finding is in keeping with those of previous studies exploring the impact of personal death experiences and attitudes on social workers' ability to communicate with non-incarcerated patients about advance directives (Sanders & Swails, 2009; Hayman, 2004; Black, 2005). Several other participants expressed that personal death experiences, and life experiences in general, made them feel more prepared to provide end-of-life care to their patients; these participants were emphatic that a lack of life experiences, including exposure to death and dying and instances of personal vulnerability and loss could be a

barrier to social workers' capacity to provide empathic end-of-life care to inmates—a population whose majority has experienced considerable loss, vulnerability, death, and dying. Additional research is required to test the hypothesis inherent in this finding: social workers with such life experiences have an affinity for end-of-life care provision.

Community Stigma and Attitudes as Barriers

The final salient finding concerns the community stigma and attitudes that four participants noted as posing significant barriers to their capacity to provide end-of-life care to inmates, particularly those who were either being compassionately released or had served their sentences and were returning home. These participants noted they met with extreme prejudice, trying to find community-based hospice, nursing home, or other end-of-life care services for their patients. Participants reported great frustration with this prejudice and described various attempts to secure community-based services for their patients, some of which were more successful than others.

Importantly, this finding is not reflected in the extant literature. Such a finding suggests that although many of this study's participants, along with authors Dubler (1998), Cohn (1999) and Mahon (1999), have called for a more liberal use compassionate release, social workers and their exiting patients might experience significant community-based barriers to care.

Relational Theory and Barriers to Social Work Practice with Dying Inmates

Given the physical and intrapsychic injury, isolation, loneliness as well as the dehumanizing interpersonal interactions exacted upon inmates as a condition of incarceration, this author chose to theoretically examine this study's findings through the lens of relational theory. A psychotherapeutic approach informed by relational theory

posits that a therapist and patient might co-create an external reality, where the patient's biopsychosocial and spiritual needs and vulnerabilities are acknowledged, held, re-authored, and honored in partnership with a trusted and caring person (Granse, 2003; Hadley, 2008). Viewed through the lens of relational theory, this study's finding's suggests that correctional institutions either do, or have the capacity to, significantly hinder participants' capacity to co-create holding, nurturing, corrective relationships with their dying patients.

As stated by the majority of participants, their caseloads, duties, and roles did not allow them the time or resources to provide psychotherapy informed by a relational approach. Nearly, all participants were still invested in assuring that their patients did not die alone. They were often not able to be consistently present as their patients died. Therefore, the value these participants placed on the end-of-life care that inmate volunteers are able to provide patients heartened this author. More than half of the participants discussed the unique role that volunteers play in co-creating, with the patient, an intersubjective relationship, in which the patients are held physically as well as psychosocially and spiritually, during the last hours of their life to ensure that inmate "no dies alone." While perhaps not identifying it as such, these participants were employing a relational approach through their on-going development and use of volunteer inmates as end-of-life care providers. The use of inmate volunteers to provide end-of-life care, to do the emotional heavy lifting and form significant, holding relationships with dying inmates, offered this author a new perspective on the possibly applications of relational theory in correctional settings, where social workers are few and over-burdened.

In addition to the manner with which their caseloads, duties, and roles inhibited their capacity to provide relationally-derived psychotherapy, this author is curious if the negative qualities of the correctional institution impact the relationship between participants and their inmate patients. Hadley (2008) notes that in a relational approach the subjective experiences of the therapist and patient become complexly intertwined and "embedded" in what becomes a co-created, rich dynamic" (p. 211). It seems plausible to this author that this study's participants—who expressed that the correctional environment in which they worked and its staff often left them frustrated and sad—might bring such feelings into their relationships with their inmate patients, through a parallel process. In fact, two participants endorsed they did just that, with one of them specifically noting that inmates were easier to take out frustrations on than patients in the community. This participant noted that taking out her frustrations on inmates was facilitated, because inmates were both seen as intrinsically less worthy of patience and the prison environment endorsed this behavior. A relational approach might help social workers, facing similar environmental and occupational stressors to mitigate the impact of those stressors on the relationships they have with inmate patients. For example, a relational approach might allow the two participants mentioned above to gain a more sophisticated empathic understanding of the impact their frustration, sadness, and anger has on their vulnerable patients.

Hadley (2008) also notes that relational theory is uniquely suited for working with oppressed populations, because it encourages the intersubjective examination of cultural difference between the therapist and patient as a corrective experience. Through his study, this author did not gain any definitive understanding of how cultural or

demographic difference factors into the relationship between participants and their patients. However, as discussed earlier, the majority of participants did not offer this difference as a component of the set of barriers they perceived impacting their provision of quality care, which leaves this author with a lingering curiosity about how patients viewed the impact of such difference on these relationships. The use of a relational approach in this instance might allow social workers from dominant groups to understand the capacity of their identity to negatively impact their patients, many of who have experienced considerable oppression, because of their cultural, demographic identities.

Through his research, this author gained significant, yet still nascent, insight into the complex relationships between participants and their patients. He still believes approaches derived from relational theory might positively impact those relationships, yet he understands that executing such approaches might be very challenging in correctional environments designed to limit peoples' capacity to form meaningful, nurturing, and corrective relationships. Implications for how social workers' relationships with dying inmates might be improved, through the use of relational theory, will be discussed later in this chapter.

Study Strengths

As far as this author knows, this study is the first qualitative exploration of the perceptions of social workers regarding the barriers they experience in their efforts to provide end-of-life care to inmates. Therefore, this study's primary strengths reside in two domains. The first is information, in that this is the first study to gather data on the perceptions of social workers regarding the micro-level practice barriers practitioners might experience when they provide end-of-life care to inmates. Participants

overwhelmingly portray correctional institutions as the largest of source of such barriers. The second domain is communication, as this is the only study known to this author that offers social workers a collective voice with which to directly address the field, and provide it with the above description, in an effort to improve the quality of end-of-life practice with inmates. Additionally, the comprehensive nature of the data collected and analyzed in this study offers several opportunities for future social work research on this topic, as will be described in more depth, below. Finally, this qualitative study's sample size of 12 participants provides a solid basis for a trustworthy and confirmable data analysis.

Study Limitations

This study's small sample size of 12 participants precludes findings from being generalized across a larger population. Further, the sample was not gathered using a randomized approach, also diminishing the capacity for generalization of findings across a large population.

Data collection methods also constitute a study limitation. Not all participants were asked the same set of questions; additional questions, regarding the personal identity (demographic characteristics) of participants' patient/inmate population, were added after the study was already underway. Certain questions were omitted if the researcher believed that responses to those questions were already embedded in previous responses to different questions, if he forgot to do so, and/or because of time constraints.

Given time constraints in carrying out the research, the researcher was unable to pilot the instrument prior to its utilization with study participants. Some questions were confusing to participants, possibly affecting their response. Several participants indicated

that they found the Interview Instrument's terminology confusing. The word "barrier" confused several participants, and this author was asked to clarify what was meant by that term. It was this author's opinion, that they felt the term to be an inaccurate way to describe any difficulties they experienced providing end-of-life care to inmates; and they often used the word "challenge" to describe such difficulties. Some participants had difficulty understanding what was being asked of them in the questions, *What feelings do you associate with the environment in which you practice? Do these feelings pose a barrier your practice? Please explain.* and *What feelings do you associate with the population you serve? Do these feelings pose a barrier your practice? Please explain.* Additionally, the following questions confused participants: *Are you part of a team that provides end-of-life care to inmates? If so, how is the role of the social worker defined - by you? By others on the team? Please explain/describe any practice challenges or benefits you may experience as a member of a team.* and *How does being a social worker influence your practice with dying inmates? If this influence poses a barrier to your practice, please explain how.* Some participants expressed difficulty understanding the question regarding their perceptions of their professional role on the team, or their profession, as a "barrier" to practice.

This author does not want to underestimate the potential for researcher bias in these interpretations: as a man of color, this researcher entered the field of social work to help mitigate the affects of oppression his clients might experience in response to their racial, gender, socioeconomic and spiritual identities. And as a Black man, he also approached this study from a philosophical, ethical position of being fiercely anti-prison, anti-incarceration. In small handful of instances, this author lead participants in their

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answers to questions and interpreted their responses, rather than probing for additional

clarification. He remains unsure if this leading and interpreting was due to his bias, but

they ultimately, negatively impacted this study's reliability and validity.

While successful in obtaining a unique sample of practitioners in this field of

practice the lack of diversity in this study's sample (only one of the twelve participants

identified as being of color and only two participants identified as being male) poses an

additional and significant limitation to the generalizablity of study findings.

Study Implications

The following section will explicate the implications of study findings for social

work research, practice, education, and policy.

Implications for social work research.

Study findings have provided the basis for the development of several questions

deserving of further research. This study only scratched the surface of describing the day-

to-day practice routines for social workers providing end-of-life care in correctional

institutional settings. Research exploring the nature of such work in greater depth –

including, but not limited to: the nature and number of the duties and caseloads of such

social workers; the types of services provided; patterns of referral to other disciplines;

and factors associated with the inability to provide certain services - would add

considerably to our knowledge in this important area of practice. Finally, future research

should involve a larger national sample including bachelors-level social workers who

represent a portion of those who provide this care. Such study may yield findings leading

to a more sophisticated understanding of how the duties and caseloads of medical social

workers in correctional settings impact their capacity to provide end-of-life care to inmates.

Findings indicating participant difficulty with exposure to death and inmate response to death and dying provide the basis for further study of the experience of the helping relationship among social workers as well as dying inmates. Specifically, there is a need to investigate the following questions: *How do such inmates experience the relationship with the social worker, who provides them with end-of-life care? How do they experience the demographic disparity between themselves and social worker, who provides them with end-of-life care? How do they experience the relationship with the inmate volunteers, who provide them with end-of-life care? Does the inmate experience differences between their relationships with these two different providers? If so, what differences? And do these differences impact their psychosocial, spiritual well-being at the end-of-life their lives? If so, how?* This author was disheartened to learn that seven of this study's participants (all of whom were well-educated, middle-class, Caucasian women did not believe that their personal identity had the capacity to negatively impact their work with under-educated, poor, men of color, who were dying in prison. In this author's opinion, research, including the above questions, is key to improving the manner with which social workers conceptualize the relationship between their identity and their practice with oppressed and marginalized dying inmates.

Many participants described significant disparities between the how the institutions' executive staff and their employees (specifically, correctional officers, nursing staff, and case managers) perceived the need and value of end-of-life care for inmates. These participants noted that the vast majority of executive staff endorsed and

supported the needed for such care; however, as noted in the above discussion, other correctional staff did not. This author is curious to further explore the origin and maintenance of this disparity as the findings of such research hold the promise of fostering more consistent, reliable assistance and encouragement to social workers providing end-of-life care to inmates.

Lastly, the findings indicating participants' perception of the negative impact of community stigma and attitudes on social workers' capacity to provide end-of-life care to inmates, particularly, raises questions about the specific nature of such stigma and its impact on care, deserving of further research. As one participant noted, "…as our populations grows, and you're having older and older inmates, you're going to find more need…for quality end-of-life care."

Implications for social work practice.

This study has multiple implications for macro, mezzo, and micro-level social work practice. Beginning at implications for macro-level practice, this study's participants practiced in a variety of different correctional settings, from "hospital-like" medical facilities in federal prisons, to small county jails, where end-of-life care was out-sourced to community agencies. While each of these settings/facilities presented participants with unique, often frustrating barriers, this study also highlighted the variety of practice options and opportunities for social workers interested in providing end-of-life care to inmates. For example, all federal medical centers have ready-made hospice environments for social workers to enter and practice such care. This author hopes social workers providing end-of-life in community-based settings will take note of the potential to build relationships with local county correctional facilities if they are interested in

increasing dying inmates' much-needed access to appropriate services. This study also introduced the need and opportunity for social workers and community-based agencies, providing end-of-life care, to develop stigma-reducing initiatives that will improve the quality of and access to appropriate services for dying inmates, exiting the criminal justice system and returning to community settings.

This study's primary implication for mezzo-level social work practice with dying inmates relates to work on interdisciplinary teams. Having reinforced the extant literature's conclusion that work on such teams can create barriers, this author hopes his study will provide social workers with an opportunity to have an increased dialogue around such barriers, share lessons learned, and build advocacy momentum to reduce such barriers across a variety of end-of-life care practice theaters.

Three major implications for micro-level practice emerged from this study. Related to the first implication, it seems quite clear to this author that culturally competent practice is not reinforced for or seen as urgent by social workers, providing end-of-life care to inmates. It is this author's hope that his study's findings will provide an opportunity for such social workers and the correctional institutions that employ them to further assess the need for and better deliver culturally competent care to dying inmates as well as all inmates within their care.

The second implication relates to the sheer complexity and size of several participants' caseloads and duties. Some participants in this study expressed they simply had too much on their plates to provide their patients with the quantity and quality of end-of-life care they would have liked. Such findings imply the need for conversations and activities in the field of social work and corrections aimed at the goal of reducing the size

and complexity of such caseloads and duties. There is a need for the field of social work to re-examine its limited participation in correctional work and focus on developing visibility and recruitment initiatives to increase practitioner engagement in this specialty. Likewise, social workers already practicing in this field should work with their host institutions to re-evaluate and bolster their commitment and capacity to provide care that is equal to that provided in the community.

Lastly, findings indicate the need for an emphasis on relationally-based practices to be employed by social workers in their provision of end-of-life care to inmates. Correctional institutions often staunch the capacity of social workers and their inmate patients to develop the kind of relationships that facilitate the complex, intersubjective work traditionally espoused by relational theory. Yet, this author believes relationally derived techniques might be developed and used that increase social workers' understanding of the unique vulnerabilities their dying inmate patients' experience as a result of the psychosocial, spiritual, cultural oppression they face - before and during incarceration - in combination with their compromised physical health and their experience with death and dying. An increased understanding of such vulnerabilities might allow these social workers to employ a more-sophisticated use of empathy and compassion in their already-valiant efforts to provide their patients with a "good death." This author also believes that relational theory would offer social workers more comprehensive and intentional opportunities to integrate their life experience, experience many of this study's participants saw as essential for providing this "good death." As noted earlier, the infusion of resources allowing in-depth work and increased staffing is a

necessary first step in the successful integration of this theoretical perspective in daily practice.

Implications for social work education.

The findings of this study echo the extant literature's call for education and training programs to increase social workers' capacity to provide end-of-life care to diverse populations as well as provide social workers with more skills, information and experience to practice in correctional institutions. These findings also suggest specific practice and theory areas such programs might bolster to improve social workers' capacity to improve work with dying inmates.

The finding that some participants experienced inmates' suspicion, personalities and denial as barriers to care suggests that social work training and education programs might increase the availability of courses explicating and normalizing the process of death and dying, particularly for populations with an historic lack of trust in the health care system, and those who are dying in restrictive environments. These findings also echo the call of Wesley et al. (2004) and Lopez (2006) for social work training and education programs to increase the capacity of their graduates to provide end-of-life care to culturally diverse populations.

This study also suggests that continuing education programs need to be made more available and accessible to social workers providing end-of-life care to inmates.

Lastly, these findings suggest that social work education and training programs might be deficient in recruiting demographically diverse students. The population of aging and dying inmates continues to increase, and the majority of such inmates will be disproportionately from diverse and oppressed populations. More research is needed to

examine any impact the demographic disparity between social workers and inmates might have on the provision of end-of-life care to diverse inmates. However one might hypothesize that the field of social work - specifically its education and training institutions - it should invest, considerably, in diversifying its workforce, if it is serious about improving the quality of life and death of such inmates. To this end, the field might refine its methods of recruitment aimed at attracting and supporting a diverse student body, which includes the development of traineeships and programs encouraging interest among students in this field of practice. Additionally, the field of social work might increase its advocacy for resources for scholarship, traineeship, and curricular development in this field of practice.

Implications for social welfare policy.

Study findings regarding the impact of high caseloads on quality of end-of-life care imply a need for advocacy and policy development in a number of areas effecting social workers capacity to provide end-of-life care, including the creation of new social work positions in local, state, and federal correctional institutions. Findings also point to the need for legislation regarding compassionate release for inmates to allow for the more ready release of dying inmates into community or family care setting.

Findings regarding the impact of the host environment on practice have implications for the modification of administrative policies in correctional institutions, including increasing the quality and quantity of education for all correctional staff receive, regarding the value of quality end-of-life care for inmates. Further needs for modification implied by findings include: reducing the security restrictions to that prohibit visitation from dying inmates' families; decreasing the size of the caseloads and

streamlining the duties the create barriers for social workers in their provision of end-of-life care; and creating greater opportunities for inmate involvement in the development of their end-of-life care plans.

Conclusion

This study was conceived to explore the capacity of social workers to meet the end-of-life care needs of an inmate population that is diverse, vulnerable and rapidly growing. The study was then conceptualized, and its value was reinforced, through an examination of the literature related to social workers' capacity to provide end-of-life care to this population. The 12 participants in this study revealed an unusually deliberate dedication to provide end-of-life care to their patients to the best of their ability. Impeding their ability to provide such care were significant barriers imposed by the environment, policies and attitudes of correctional institutions and their staff. Far too many patients and duties as well as a lack of prior education about correctional institutions also presented participants with barriers. Other important barriers emerged through the analysis of this study's findings; however, the correctional institutional environment was most widely endorsed by participants as having the greatest impact on their ability to provide such care. Also emerging in the data was the strength, courage and ingenuity that social workers exhibit in the face of the daunting ethical, philosophical, environmental, and attitudinal barriers inherent in the integration of social work and correctional practice.

While a body of literature does exist describing the challenges social workers have historically experienced as service providers in correctional institutions, the findings yielded through successful recruitment of a unique sample, as well as the use of

qualitative data collection and analysis, provide important opportunities for future

research. This author hopes his study offers a new point of departure for improving

macro, mezzo, and micro-level social work practice with diverse, vulnerable, and dying

inmates.

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Appendix A

Human Subjects Review Committee Approval Letter

SMITH COLLEGE
School for
Social Work

Smith College
Northampton, Massachusetts 01063
T (413) 585-7950
F (413) 585-7994

January 21, 2010

Michael Smith

Dear Michael,

Your revised materials have been reviewed and all of the changes have been carefully made. You did an excellent job of focusing your interview guide so that you will explore your major questions. We are happy to give final approval to this very interesting study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Beth Lewis, Research Advisor

Appendix B

Letter of Informed Consent for Participation in Student Research

Dear Participant,

My name is Michael Smith, and I am a student at the Smith College School for Social Work, Class of 2010. I am writing to ask your participation in the research study I am conducting for the purposes of my MSW Thesis, presentation, and publication. This focus of this study is explore and describe the nature of social work practice with dying inmates and will be guided by the research question, *What barriers impact social workers' capacity to provide end-of-life care to inmates?*

Participation in this study will include your being interviewed over the phone for no more than one hour and will be asked to answer questions related to your practice of providing end-of-life care to inmates. Participation in this study requires that you 1) are a prison hospice social worker, who provides end-of-life and palliative care to inmates; 2) are conversant in English and; 3) practice in the United State of America. The interview will be audio-recorded and transcribed by me. You are being asked to participate in this study on behalf of yourself, only, and not your employing agency/institution, your clients or the institution in which you practice.

Potential risks associated with your involvement include, 1) comprising your clients confidentiality, and 2) censure from your employing agency/institution, if they view your participation in this study, negatively. Benefits you might experience through your participation in this study include, 1) knowing that you are contributing to the knowledge-base of hospice social work and specifically such work with inmates, 2)

assisting in the development of research that improves the quality of end-of-life care provided to inmates, and 3) providing an opportunity for professional and personal reflection on the specific topic of end-of-life care for inmates, who have spent a considerable amount of time in prison. No monetary compensation will be provided for your participation in this study.

Your participation in this study will be confidential. All persons viewing the information collected from your interview, besides the me, will be required to sign a confidentiality agreement, and my advisor will have access to the data after all identifying information has been removed. All information collected through this study will be presented as a whole, should it study be used in publications and/or presentations; brief illustrative quotes or vignettes will be carefully disguised in publications and/or presentations. All information obtained through your interview will be kept in a locked manner for three years, in accordance with federal guidelines, and will have all its identifying information removed. If your information is still needed after three years, it will continue to be kept in a locked manner and will be destroyed immediately, once it is no longer needed. If you choose to withdraw from the study after three weeks, I will use my discretion whether or not to include your contribution in the final data analysis.

Your participation in this study is voluntary, and you may refuse to answer any questions during the course of the interview. If you wish to withdraw from the study, you may do so at any point during the interview and up until three weeks following the date of the interview. If you withdraw within that time, all materials related to your participation will be immediately destroyed. If you wish to withdraw from the study, following the interview, you may contact me through the information provided below.

Should you have any concerns about your rights or any aspects of the study, you are

encouraged to contact me, or the Chair of the Smith College School for Social Work

Human Subjects Review Committee at 413.585.7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

_____

Participant Signature   Date

_____

Researcher Signature   Date

Thank you very much for your time and participation.

Sincerely,

Michael Smith

PLEASE KEEP A COPY OF THIS FORM THAT HAS BEEN PROVIDED FOR

YOUR RECORDS.

Appendix C

Interview Instrument

Professional Identity

- What is your title and what are your duties?

- Are you part of a team that provides end-of-life care to inmates? If so, how is the
  role of the social worker defined - by you? By others on the team? Please
  explain/describe any practice challenges or benefits you may experience as a
  member of a team.

Personal Identity

- How do you identify yourself, ethnically?

- How do you identify yourself in terms of gender?

- How old are you?

- How do indentify yourself in terms of socioeconomic status?

- Do you indentify as being spiritual? If so, in what ways do you consider yourself
  to be spiritual?

- Please describe the broad range of the ethnicities/races, genders, ages, and
  socioeconomic statuses of the inmates with whom you work.

- Do you believe your identity, or any of its components, has had an impact on, or
  is a barrier to, your ability to provide end-of-life services to inmates? Why or why
  not?

Background and Training

- How long have you worked with dying inmates?

- What experiences informed and/or provided motivation for your decision to provide end-of-life care to inmates?

- Did you experience any barriers in making this decision and/or gaining employment in this field?

- Did you feel prepared to provide end-of-life care to inmates, when you began this work? What limited you from feeling more prepared to begin this work?

Philosophy on Providing End-of-Life Care to Inmates

- Please provide your personal philosophy on what it means to provide end-of-life care to inmates.

- What and/or who influenced this philosophy?

- What influences and/or experiences challenged your development of this philosophy?

Attitudes toward Work in Prisons and Inmates

- Does the criminal justice system in this country and in the state and county in which you work support and/or pose a barrier to your capacity to provide end-of-life care to inmates? Please explain.

- What feelings do you associate with the environment in which you practice? Do these feelings pose a barrier your practice? Please explain.

- What feelings do you associate with the population you serve? Do these feelings pose a barrier your practice? Please explain.

- Do you feel valued in the work you do? Does how you feel about how you are valued pose a barrier to your practice with dying inmates? Please explain.

Practice

- What do you consider to be quality end-of-life care for inmates?

- What skills do you believe are required for providing quality end-of-life care to inmates?

- How are these skills acquired?

- What barriers have you experienced in acquiring these skills or have you observed others experience?

- Please describe any characteristics of the population, with which you work, that challenge your capacity to provide them with quality end-of-life care as you've described it.

- How does being a social worker influence your practice with dying inmates? If this influence poses a barrier to your practice, please explain how.

- How long do you think you will continue to work with dying inmates? Please explain.

- Would you recommend this type of practice to your social work peers? Please explain.

- What changes (environmental, political, personal, professional, etc.) would improve your work with dying inmates?

Appendix D

Letter for Direct and Snowball Recruitment of Study Participants

Dear Participant,

For a Smith School for Social Work MSW thesis project, I am interested in exploring barriers that impact social workers' capacity to provide end-of-life care to inmates. This study requires that participants possess a master's and/or doctoral level degree in a social work and be providers of, or have provided, end-of-life care for inmates. Participation in this study would include a telephone interview lasting approximately one hour, consisting of open-ended questions.

I am writing to inquire if you would be available to participate in this study and/or if you would be able to provide me with contact information for additional social workers, who meet the above criteria. If this were a possibility, I would send a description of the study design and methods, along with the interview questions approved by the Smith College School for Social Work Human Subjects Review Committee, for your review. I would be seeking participants beginning no later than February and ending no later than early April 2010.

Please don't hesitate to contact me through either the phone number or email listed below with any questions.

Thank you in advance for your time and consideration. I greatly appreciate any assistance you can provide.

Sincerely,

Michael Smith

Appendix E

Letter for Organization Assistance in Recruitment

Dear (Organization Name),

For a Smith School for Social Worker MSW thesis project, I am interested in exploring barriers that impact social workers' capacity to provide end-of-life care to inmates. This would be a telephone interview lasting approximately one hour, consisting of open-ended questions.

I am writing to inquire if your organization would be able to provide me with any of the following: 1) contact information for social workers, who provide end-of-life care to inmates; 2) access to databases, that I could query to obtain contact information for this type of social worker; and 3) access to any listserv, websites, etc, where I could post electronic recruitment materials. I would be happy to provide in advance any materials related to the study design and purpose, as well as the study instrument approved by the Smith College School for Social Work.

Please let me know if you are able to assist me. If there is someone else within the organization in addition to yourself to whom this letter should be forwarded, please feel free to do so. And Please do not hesitate to contact me through either the phone number or email listed below with any questions.

Thank you in advance for your time and consideration. I greatly appreciate any assistance you can provide.

Sincerely,

Michael Smith

Appendix F

Posting for Listserv and Website Recruitment

Dear Prospective Participants,

I am recruiting for a study exploring barriers that impact social workers' capacity to provide end-of-life care to inmates. This study requires that participants possess a master's and/or doctoral level degree in a social work and be providers of, or have provided, end-of-life care for inmates. Participation in this study would include a telephone interview lasting approximately one hour, consisting of open-ended questions.

If you are interested in participating, please contact me through email.

Thank you very much.