

“I’m Not Much One to be Invisible”: End-of-Life Spiritual Care for Lesbian, Gay, Bisexual,
Transgender, and Queer Elders

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General Honors

University of Colorado Boulder

Defended on April 9, 2018

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IRB Protocol #17-0641

Acknowledgements

To the LGBTQ elders who did not receive inclusive end-of-life spiritual care, whose stories were not heard.

To the recovering addict.

To all those who live in the margins and the footnotes.

To the “outsiders within.”

To Danny, for sticking around throughout this project and listening to my complaints, rants, theories and impassioned brainstorming sessions.

To my friends and family—especially those who helped me edit this monster.

To the team at Kaiser Permanente Colorado’s Palliative Care Team and the Undergraduate Pre-Health Program—thank you for helping me find and clarify my passion for end-of-life care and health equity.

To CU Boulder’s Professional and Academic Conference Endowment (PACE) program for funding to attend conferences and share this research.

To my committee and mentors—for your lessons, patience, encouragement and guidance.

To my participants, for your vulnerability and authenticity.

“To the light.”

Abstract

People that experience the “intersectionality” of multiple forms of oppression feel the collective results of these discriminations in distinct ways. One perfect example of this is Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) elders: LGBTQ elders experience ageism differently than other elders and trans/homophobia in ways distinct from younger LGBTQ people.

The literature by and for end-of-life chaplains have not explored the experiences of LGBTQ *elders*. This gap in knowledge is particularly precarious given the large population of LGBTQ Baby Boomers entering and soon to enter into elder-oriented care like EOL care. In order to better understand the complex relationship between end-of-life (EOL) chaplains and LGBTQ elders (Baby Boomers and older), in-depth semi-structured qualitative interviews were conducted with seven EOL chaplains and fifteen LGBTQ elders in the Colorado Front Range area. The resulting data gives EOL chaplains info to help them “see” spiritually as LGBTQ elders see.

Interviews with LGBTQ elders revealed important LGBTQ elder-specific life experiences, how LGBTQ elders view spiritually and religion, how several LGBTQ elders viewed addiction as an important component of their spiritual journey, and the connection for LGBTQ elders between gender/sexuality and spirituality. While Christianity may have labeled LGBTQ individuals “sinners” throughout their life, LGBTQ individuals in this sample were quite spiritual. LGBTQ elders found their spirituality in places dominant society and Christianity do not often look: in the feminine, in their sexuality, in recovering from addiction, in supporting their LGBTQ siblings through difficult times, and in living out their authentic lives as LGBTQ individuals. These stories hold important lessons for both EOL and society in general.

Contents

Chapters

1. Introduction.....	1-20
2. Standpoint Theory, Queer Spiritual Epistemologies and the “Outsider Within”.....	21-34
3. Research Methods.....	35-46
4. Role of an End-of-Life Chaplain.....	48-63
5. The LGBTQ Patient, LGBTQ Health and Intersectional Histories.....	64-96
6. The Spiritual, The Religious, and Everything Beyond and Between...	97-126
7. LGBTQ Addiction, Recovery as a Spiritual Journey.....	127-135
8. Gender, Sexuality and Spirituality.....	136-158
9. Conclusion, Being Expanded.....	159-163
Works Cited	164-174
Appendix A	
A. Semi-Structured Interview Guide.....	175-177

Figures

1. The “Taboo Milieu.....	3
2. EOL Care Relationship.....	5
3. Halkitis’ Definition of Spirituality.....	100
4. Halkitis’ Definitions of Religion.....	101

Tables

1. EOL Chaplain Demographics.....	39
2. LGBTQ Elders Demographics.....	40
3. LGBTQ Elders’ Definitions of Religion.....	103
4. LGBTQ Elders’ Experiences with Religion, Religious People.....	105-107
5. LGBTQ Elders’ Definition of Spirituality.....	115
6. LGBTQ Elders’ Spiritual Beliefs, Experiences, and Practices.....	118-120
7. LGBTQ Elders’ Connection Between Sexuality and Spirituality.....	146
8. LGBTQ Elders, Connection Between Gender and Spirituality.....	154

Chapter 1: Introduction

‘In the rising of the sun and in its going down, we remember her
In the blowing of the wind and in the chill of winter, we remember her
In the opening of buds and in the warmth of summer, we remember her
In the wrestling of leaves and in the beauty of autumn, we remember her
In the beginning of the year and when it ends, we remember her
When we are weary and in need of strength, we remember her
When we are lost and sick at heart, we remember her
When we have joys we yearn to share, we remember her
For as long as we live, she too shall live, for she is now a part of us.
We remember her.’

- Poem shared with me by LGBTQ
Elder 15¹

Introduction: “We Remember Her”

One of my first in-depth interviews for this project was conducted with Elder 14.² She is an 82-year-old, a Quaker with a “direct line to God,” and an all-around hilarious woman. I got to be with her as she reflected on many of the same concerns other people her age might. She showed me around her house, pointing out where a hot tub used to be before she got worried about falls. She talked to me about the people she loved—reading me letters and showing me pictures. She reflected on the friends that had been with her to celebrate her 80th birthday, even allowing herself to get excited about the possibility of an 85th. She introduced me to her dog—who Elder 14 informed me was the one who really runs their home. Together we vulnerably explored topics of death, love, loss, joy. I listened to her find meaning in her career and I was there to be witness to her heart for service and social justice; passions which she told me stemmed from her life-mission to introduce the children of God to each other and from her belief

¹ LGBTQ Elder 15 told me that she read this piece at the funeral of a lesbian friend.

² LGBTQ Elder participants are typically referred to as “Elder” then their number. Their number was decided based on the order in which their interview was analyzed. EOL chaplains are referred to as “Chaplain” then their number. Again, the number is based on the order of analysis.

that “the nature of human relationships is that of God in me connecting with that of God in you.” There was just one thing: Elder 14 is a lesbian.

Being LGBTQ, for Elder 14, is an important part of who she is. But the question must be asked, would all people see it that way? Would all providers caring for her see this like Elder 14 does? Towards the end of our time together, she told me about getting angry about a young woman who cut her in line at the supermarket, a sign of disrespect that infuriated her. “I’m not much one to be invisible,” Elder 14 told me. She is not much one to be left unseen, unrecognized. However, becoming invisible is a legitimate risk when it comes to her recognition as an LGBTQ person in elder services and end-of-life (EOL) care. Invisibility is a reasonable fear when it comes to addressing her spirituality during her final days—a spirituality which is central to who she was. A spirituality, which she told me, is inseparable from her feminism and journey as a lesbian.

Providing Elder 14, and all LGBTQ elders with inclusive spiritual care during EOL is the aim of this thesis. In order to do so, I must explore places that society tells us are “taboo”: spirituality, death and sex. Rather than run away, I aim straight at the intersection between all three—the “taboo milieu” (see Figure 1). In doing so, I hope to bridge the gap between EOL chaplains (primary providers of EOL spiritual care) and LGBTQ elders. In doing so, I hope to capture these stories, the unrecognized strengths that LGBTQ members have to share with the world. I hope to help bring to light that which multiple systems of oppression would prefer be left in the dark, to hear these voices that society decided to silence. In addressing this “taboo milieu,” I fulfill the “radical inclusion of the other” mandated by the history of hospice. I

recognize spirituality in the last places science, cisgender³- heterosexual-dominated society and Christianity ever thought to look. In doing so, “we remember her”: the queer, the feminine, the elder, the sexual.

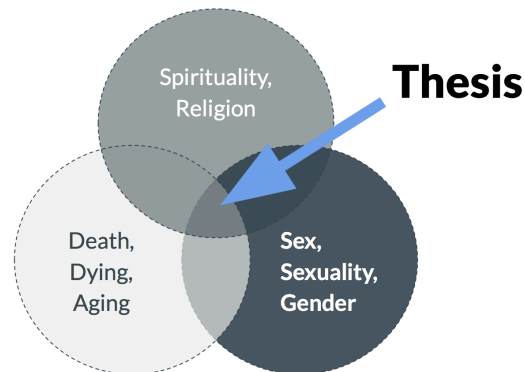


Figure 1: The “Taboo Milieu” – What happens when you put spirituality, sexuality, and death into one project—a convergence of topics society says are too inappropriate, too unprofessional, too divisive to talk about? Don’t worry, I will find a way to add another taboo topic or two before the project is done.

The Problem

Elder care and the way we treat our elders in the United States is entirely unprepared for the complexity, nuance and humility required to make the shift to inclusive care for LGBTQ elders. Often this appears to be a result of willful ignorance. For example, some institutions of elder care have demonstrated a resistance to recognizing the distinctive issues for LGBTQ elder in their care (Hughes et al.). If elder care does not approach these unique and important differences and identities in the nuanced ways they deserve, LGBTQ elders are at extreme risk for being silenced during the final days of their lives.

³ Cisgender means a person assigned male at birth and identifies as a man, assigned female at birth and identifies as a woman. This is the “opposite” of transgender individuals who do not identify with the gender they were assigned at birth.

These generations of LGBTQ elders are the individuals who were at the forefront of Stonewall, the protest that marked the start of the gay rights era. These individuals were those who experienced the grief of HIV/AIDS, who watched sodomy laws repealed state by state, who made marriage equality possible, who brought the transgender identity to the forefront of the LGBTQ movement (Faderman). When they are placed in a non-inclusive space where their caregivers, providers or neighbors are not accepting, LGBTQ elders are forced back into the closet, unable to express their fullest selves (Hughes et al.). This is an issue of justice that must be addressed.

Older LGBTQ adults have experienced significant discrimination during their lives because of their identities. They also have experienced dramatic social shifts regarding how the majority of U.S. society views matters of gender and sexuality (Faderman; Swartz and Fruhauf). The Baby Boomer generation, specifically, was at the forefront of LGBTQ-oriented activism ranging from all-out protest to legislative changes (Bowland et al.). This history will be explored later; however, the social movement that is a trademark of these generations is a good sign that activism can be expected to continue as LGBTQ elders demand more from the care they will be receiving (Haber). LGBTQ elders—defined here as born prior to 1964—are already entering into the care arenas described above. Outside of their activism, the LGBTQ Baby Boomers also represent, like the Boomer generation as a whole, a much larger population than what previously has encountered elder or EOL care. This is true not only because there are increasingly more LGBTQ people who are open and “out” about their gender and/or sexuality but also because the Baby Boomer generation is huge in comparison to other age generations (Swartz and Fruhauf). For context, data from a 2010 report by the National Gay and Lesbian Task Force estimated that by 2030 there will be between 3.6 and 7.2 million LGBTQ adults over the age of 65 (Swartz and

Fruhauf). LGBTQ-inclusive care is no longer a luxury. The large population of LGBTQ Baby Boomers will see to that. This thesis adds to the literature to make inclusive spiritual practices for LGBTQ elders a reality in palliative care and hospice (which are referred here together as EOL care).

Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (“WHO | WHO Definition of Palliative Care”). Palliative care and hospice, while similar, are not the same. Hospice specifically is considered a form of palliative care that takes place in the final 6 months of life and is exclusively comfort-oriented, not curative (Lutz). Figure 2 demonstrates the relationship between hospice and palliative care.

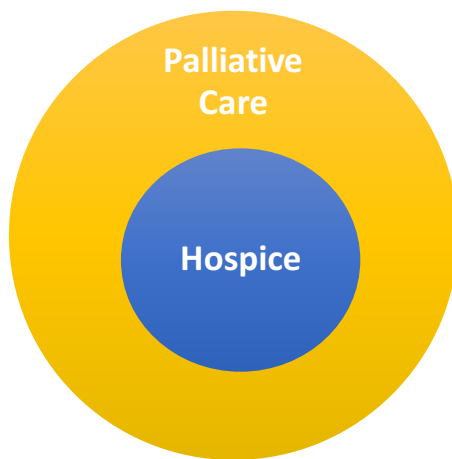


Figure 2: EOL Care Relationship – These two circles describe the relationship between the two primary forms of end-of-life (EOL) care. Hospice, represented inside palliative care, is a form of palliative care. Not all palliative care, however, is hospice care.

Palliative care, which is increasingly being called supportive care (Fadul et al.), and hospice care are especially difficult physiologically—with respect to complex pain and symptom management involved with serious illness and the dying process. Furthermore, EOL care is also

immensely complicated socially, psychologically and spiritually (Rome et al). Spirituality in EOL care is the focus of this project. EOL care, perhaps for obvious reasons, is tied to elder-oriented fields like gerontology as well as specialties such as oncology, pulmonology, neurology, cardiology and nephrology (Chando). Because of this, it is important that EOL care be at the forefront of the conversation around inclusion in medical treatment for LGBTQ elders.

It is important to clarify at the start of this project a few definitions that are relevant. The meaning of “EOL care” should be clarified and narrowed. “EOL care” as a general term could be much more expansive than just palliative care and hospice; for the purposes of this project, EOL care will be limited to these two specialties. Religion in this project is defined as “a personal or group search for the sacred that unfolds within a traditional sacred context”(VandeCreek 3). This is different than spirituality.

[Spirituality] is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices” (Puchalski et al.)

While religion is important for some individual’s spirituality, that is not the case for everyone. Spirituality is the primary focus of this project, however religion will be addressed as well.

Spirituality is recognized as an integral component in EOL care⁴. A 2005 National Institute of Health study found that spiritual well-being is an important goal to address during EOL. That study, among other suggestions, recommended “that families and patients benefit from programs that support dignity, purpose, and meaning” (Kastenbaum 141). “Dignity, purpose, and meaning,” as Puchalski et al. definition indicates, belong to the domain of spirituality.

Nevertheless, spirituality in EOL care remains poorly researched.

⁴ I’d argue that spiritual care is at the core of hospice after pain and symptom management has been addressed.

This scarcity of research on the spiritual component of EOL care is especially true for marginalized group like LGBTQ populations. While the National Consensus Project for Quality Palliative Care emphasizes spiritual, religious and existential dimensions of care as well as the *cultural aspects of care*—which is how gender identity and sexual orientation is often coded in health care—relatively little research has directly addressed the spiritual needs of LGBTQ individuals in EOL (*Clinical Practice Guidelines for Quality Palliative Care*). This spiritual, also called “existential,” care is most often placed in the scope of a chaplain’s practice (Acquaviva 62–65). When spirituality *is* explored, even in resources explicitly addressing LGBTQ inclusion, it is consistently done in such a way that avoids the complexity and the pain that has been inflicted on LGBTQ people by many practitioners of religious institutions. It side-steps the estrangement that happens during EOL as a direct result of some others’ interpretations of religion.

EOL Chaplains are expected to be the primary individuals providing EOL spiritual support, however the literature available to that profession is behind when it comes to LGBTQ-inclusion. The literature for some specialties—specifically gerontology, psychology and social work—are having more nuanced conversations around the intersections LGBTQ elders and EOL for LGBT(Q) people (Bowland et al.; Clarke et al.; Duffy and Healy; Foster et al.; Fredriksen-Goldsen; Haber; Hughes et al.; Kimmel; McFarland and Sanders; Orel; Perrson; Ramirez-Valles; Schope; Siverskog; Swartz and Fruhauf). In contrast, journals for pastoral care, pastoral counseling and health care chaplaincy are still debating theology that views homosexuality as sinful and almost entirely neglects transgender people in their conversations.

Pastoral care provider Joretta Marshall summarizes the diversity opinions existing in Christian theologies which range from “believing that all people are created and intended for

heterosexuality [and that] any behavior that is outside that norm represents something sinful” to the view that “one can understand and experience same-gender-loving relationships as a blessing in the larger realm of God’s created diversity, not simply to be tolerated or affirmed, but as witness to the richness of God’s creation.” Marshall goes on to explain that other perspectives can be found between these two extremes—reflecting the theological diversity found in the greater Christian faiths (Marshall 61–62). This diversity has certainly been seen in the pastoral care and chaplain literature found for this project. For example, some pastoral care and chaplaincy literature is still exploring topics like celibacy (Yarhouse et al.) and trying to support patients who wish not to identify with the same-sex attraction they experience (Yarhouse). In stark contrast, other authors and theologians join Marshall in emphasizing more welcoming theological approaches (Anderson and Fukuyama; Graham; Jelinek; Marshall; Zahniser and Boyd). One particularly inclusive stance comes from Lorna Hochstein’s article “What Pastoral Psychotherapists Need to Know About Lesbians and Gay Men in the 1990s,” in which Hochstein shares her own progressive assumptions and beliefs on pastoral care:

I practice [as a psychologist and pastoral counselor] from the belief that being gay or lesbian is a healthy variant of human sexuality. I believe that being gay or lesbian is not incompatible with Christian values and ethics. I believe that pastoral counselors and other psychotherapists who do not hold these values should not and cannot ethically treat gay and lesbian clients and should refer such clients to appropriate therapists. . . . In order to follow the overarching ethical command to do no harm, we must do more than simply be ‘open.’ . . . [W]e therapists are obliged to know it if we are to work within our area of competence. Not everyone can do this or do it well. If you can’t, learn to refer well (74).

This stance raises challenging theological questions. What should a chaplain do if their personal beliefs do not align with those of Hochstein? Can one still support an LGBTQ person even if one does not agree with their identities? Is openness, tolerance or respect enough? How practical are theological debates—or queer theory for that matter—when it comes to the pluralistic world? What do chaplains in the Colorado Front-Range actually believe in 2017? These are questions

that are hard to find in existing literature and will be explored through in-depth interviews with EOL care providers.

In an interview, the founder of the modern hospice movement, Dame Cicely Saunders, shared what can only be described as a foundational goal of this thesis. “I don’t think you help people in anguish by coming in with easy answers. What you do is come in to listen. And in listening you very often hear: What is the strength already in that family?” (*Dame Cicely Saunders - Interview - Thames Television 1983*, 1983). The LGBTQ community, the LGBTQ “family”—particularly elders—have gone through much anguish and yet, perhaps because of this, have also cultivated significant strength and resilience. It is time to listen to those stories, learn from them and share those lessons. It is time to add to the beautifully rich history of EOL care—to see views that have been neglected and silenced. Building on the truly interdisciplinary nature and tradition of inclusion in end-of-life care and viewing the issue through an intersectional lens, it is time to embrace nuance and paradox in order to humbly explore this “taboo milieu” (Figure 1).

History of End-of-Life Care, Implications on this Project

“I think the truth is if you really care about the quality of somebody else’s life as much as you care about the quality of your own, you’ve made it.”

- Edith Windsor, Plaintiff in Windsor vs. United States⁵

It is impractical to do a full exploration of the history of Hospice and Palliative Care. Nevertheless, a brief review of this history is important for several reasons. First, it gives a helpful overview of EOL care for those readers who are unfamiliar with these specialties.

⁵This was the case that made defining spouse as exclusively between opposite-sex partners unconstitutional. This quote was shared with me by LGBTQ Elder 6.

Second, this history, at least in the West, is undeniably tied to Christianity. Religion and by association, spirituality, can be seen in every historical stage of EOL care—albeit in a shifting capacity. This makes this history important in order to better understand how LGBTQ elders interact with EOL care—especially its spiritual dimensions. Lastly, this topic must be explored because the history of EOL care—through its foundational traditions of caring for the outsider, “other,” sick and suffering—sets a precedent, even a mandate, for LGBTQ inclusion.

While compassionate care for the dying was most likely happening prior, 4th century infirmaries known as *nosocomeia* were established in Christian lands. In the 5th Century, a form of Christian hospice became well established—this included care of the dying homeless, especially those trekking to the Holy Land (Kastenbaum 151). In his article, “The History of Hospice and Palliative Care,” Dr. Stephen Lutz shares that the root word of ‘hospice’ (as well as hospital and hospitality) is the Latin word *hospes* which is a term for a traveler or a traveler’s host. This relates to the fact that these posts served as shelters for the ill and dying Crusader (Lutz 304). This highlights an interesting connection between the history of hospice and hospitals.

Ostensibly hospital and hospices were one and the same for a significant portion of their history. Both were closely tied to religion, were associated with service by and for the poor and were seen as death houses (Cockerham 336). These institutions diverged, however, as hospice became the “innocent casualty,” during the Protestant Reformation. During this period, religious-oriented hospices faded as bureaucratic and technology-oriented medicine took over (Kastenbaum 152). While hospitals had been home for the poor and dying, this changed around the end of the 19th century as scientific and technological innovations made it more likely for patients to be cured and survive their disorders (Cockerham 337). While the numbers of hospitals

exploded, became oriented to curing illness, and became more secular, the ideals of hospice survived—due in no small part to the leadership of remarkable women. In fact, women “have been the prime movers in attempting to improve the care of dying people” (Kastenbaum 154).

One of those women was Dr. Cicely Saunders, a devout Anglican, who played a dominant role in forming the tenets used in hospices worldwide. Her interdisciplinary view stemmed from having served in various roles in her careers as a social worker, nurse and eventually medical doctor. The foundational elements that she established in the 1960s with her modern conception of hospice are still dominant today. These foundations include the utilization of an interdisciplinary team; the concept of ‘total pain’ which is the combined physical, spiritual, and psychological discomfort; the use of opioids; and support of loved ones of the dying (Kastenbaum 152-155).

After establishing the modern hospice movement in the U.K., Saunders gave a lecture at Yale in 1963 that sparked the movement in the United States. In the U.S., hospice was championed by equally impressive women such as Elisabeth Kubler-Ross—famous for her model of the stages of grief (Lutz 305). By the 1970s, hospice had come a long way from its shared roots with hospitals and the rest of the medical institution. It had become a legitimate alternative to the “‘never-say-die,’ high-tech, impersonal approach increasingly dominant in Western medicine” (Kastenbaum 154). Hospice’s return to “Western medicine” began to take place in 1978 when a federal government task force found that hospice could not only improve EOL but also had the potential to decrease Medicare expenses. This federal support led to an explosion of hospice programs. The numbers grew from a single program in 1974 to over 5,000 in just 35 years (Lutz 305-306). While this history belongs to hospice, palliative care was conceived separately.

As mentioned, hospice is a form of palliative care but not all palliative care is hospice care. While hospice is exclusively comfort care-oriented, palliative care outside of hospice can be given at the same time as curative treatments (e.g., patient with cancer in palliative care can receive chemotherapy in palliative care but typically not in hospice). The history of palliative care, as we know it today, is much shorter than that of hospice. A Canadian physician named Balfour Mound is credited with first using the term “palliative care” in 1974. Palliate, the verb, comes from the Latin word *palliare*, which means “to cloak.” This points to the symptom management associated with palliative care—specifically pain care. Today, there are palliative care teams in most major hospitals (Lutz 307).

This exploration of the history of EOL care, especially hospice, highlights two integral themes in end-of-life care that are relevant for this thesis. First, there has consistently been hospitality in healing the homeless, poor, traveler, suffering, marginalized. This is a theme that I call “radical inclusion of the other.” Dame Cicely Saunders shared her reflection on palliative care and hospice using the term “unlike.” She believed that the diverse perspectives from “unlike” or different backgrounds strengthened the discipline (*Dame Cicely Saunders - Interview - Thames Television 1983*). This undeniable love for diversity mandates LGBTQ-inclusion. It calls for providers to hear the stories, to sit with the ‘total pain,’ to love and be witness to the healing of lesbian, gay, bisexual, transgender and queer elders during and until the end. Indeed, it demands that providers change their way of seeing, to shift their worldviews. This thesis aims to assist in fulfilling that mandate.

Second, there is a strong theme of religion and spirituality present throughout the course of EOL care’s history. In an interview, Dr. Saunders gave a striking description of “the spiritual” dimensions she finds in EOL care—not only for patients and their loved ones but also providers.

I think the [EOL provider] has to look at his own sense of meaning of life and that has to be an involvement at the real depth of what it means to be human. What we're looking at, I think, is the whole area of spirituality which is *much wider than the purely religious practice*. It is, I think, the search for *meaning*, the look at one's own most important *values*, the feeling of looking beyond yourself and somehow *belonging to something more than you are*... [T]here is something about knowing who you are and looking back on your life and coming to terms with it and being able to lay it down with some degree of quietness which I think is much deeper than just psychological and it's something I would give the title spirit to (*EPEC-India: Plenary Three - Elements and Models of Palliative Care*, emphasis added).

This view of spirituality is central to the modern concept of EOL care. In fact, the dimensions of spirituality clarified by Saunders here—namely, as a source of “meaning,” “wider than purely religious” and “deeper than just psychological,” that connects someone to “something more than [themselves]”—are reflected closely in the EOL spiritual care that chaplains and other EOL providers emphasize today. While hospice leaders have historically been religious, there is notably an emphasis on giving freedom to the patient to explore whatever gives them meaning, whatever gives them strength (Kastenbaum 154). The central focus of spirituality with regards to health and healing is one that was modeled by EOL care, historically.

In the modern, hyper-technical context of health care, this focus on the spiritual needs of patients is rare—especially outside of EOL care. However, that is starting to change. For example, major medical journals such as the *Lancet* in the U.K. and the *Journal of the American Medical Association (JAMA)* have recently issued articles and issues that recognize and explore the important connections between health and spirituality/religion (Karam et al.; VanderWeele et al.). Chaplains are considered primary providers for spiritual and “existential” care (Acquaviva 183). However, in these articles published in well-regarded journals, mention of chaplains was nearly nonexistent: they are mentioned once in *JAMA* (VanderWeele et al.) and completely missing in the *Lancet* article (Timmins et al.). This foreboding lack of chaplains' voices in this conversation will be countered throughout this thesis.

Intersectionality: A View of Compounding Oppression

Kimberlé Crenshaw is a well-known civil rights advocate and critical race theorist who proposed a framework that will be central to the analysis in this thesis: intersectionality. In a talk entitled *The Urgency of Intersectionality*, she reveals the hidden experiences of police violence against black women. In this talk she also describes the circumstances that originally necessitated formation of this new frame of viewing the effects of multiple systems of oppression and power. Crenshaw describes the story of Emma DeGraffenreid, an African-American woman who worked at a car manufacturing plant. When DeGraffenreid attempted to find a better job, she experienced difficulty getting hired—difficulty which DeGraffenreid attributed to being both black and a woman. Upon taking her case to court, the judge in Emma’s case was not willing to recognize the nuance of her case—namely the African Americans hired for labor jobs were all men and that all the women hired for secretarial roles were women. As a black woman Emma didn’t fit either of those groups; she was excluded by both of those hiring practices. This double discrimination, or “injustice squared” was the product of a legal system that could not see Emma’s story as unique from the experiences of white women as well as those of African American men. As Crenshaw puts it, “If you’re standing in the path of multiple forms of exclusion, you’re likely to get hit by both”(Crenshaw). Understanding where this model came from is useful for a nuanced view of LGBTQ elders.⁶

Just as Crenshaw uses “intersectionality” to describes why the experiences of black women are often missed, this model is crucial to understanding the experiences of LGBTQ elders. LGBTQ elders are hit by ageism and trans/homophobia. This intersectional oppression is

⁶ It is also important to understand that intersectionality is a radical critique of power, not simply a buzz word thrown around in social justice communities.

nuanced: LGBTQ elders are often excluded not only within the LGBTQ communities but also are unable to participate comfortably in care and programs for elders. For example, the needs of LGBT(Q) older adults have been ignored in health care, policy and mental health research (Robinson-Wood and Weber). Elsewhere this is referred to using phrases like ‘double discrimination’ and ‘double jeopardy’ (Clarke et al. 219). Intersectionality provides an immensely useful model to recognize these lives made invisible by systems of power and structures of oppression.

One of the structures of oppression relevant to this thesis is ageism. It is conceivable that many elders experience ageism. Clarke et al., shares Butler’s definition of ageism as “‘a process of systematic stereotyping of, and discrimination against, people just because they are old.’” Stereotypes of older people include that they are “slow, forgetful, living in the past, [and that] they smell” as well as that they are conservative or old-fashioned (Clarke et al. 219). It is also imagined that they are uninterested in sex or are sexually inactive (Davis and Soka). A perfect example of this is a study conducted in Australia that demonstrated that one reason that providers do not talk about sex with their older patients in an oncology context is they assume these patients are “way past all of that” (Hordern and Street). This assumption of asexuality results in expression of sexuality being viewed as a problem. Sex is the territory of the young. Notably, this asexual assumption is worse for older women than older men—think about all the Viagra commercials you’ve watched (Clarke et al. 219). Lastly, all elders are at significant risk for abuse and neglect. This is a problem of huge magnitude. For example, Soka and Teaster share results from a study by Acierno et al, conducted in 2010 that found that one in nine older adults reports experiencing mistreatment. This is a particularly pressing given the fact older adults will comprise 20% of the population in less than fifteen years (Soka and Teaster). While these are

legitimate problems for all older adults, LGBTQ people experience these same rejections, stereotypes and abuses in nuanced ways.

The experiences and struggles of black women are often described as being made invisible or silenced (see discussion in Dillard, 2006 for a great example). This same language is consistently used to describe LGBTQ elders. In fact “invisible” is one of the most common description of LGBTQ elders in the existing literature (Duffy and Healy; Fredriksen-Goldsen; Haber; Smolinski and Colón). Clarke et al. puts it well. “Popular images of LGBTQ people tend to be of younger people dancing the night away in a ‘gay club’ or marching in feather boas and hot pants in a Mardi Gras parade! Beyond middle age, it would seem that LGBTQ people simply disappear” (Clarke et al. 216). Robinson-Wood and Weber made similar statements. “People who are young, attractive, white, wealthy, promiscuous, dramatic, gender conforming, and physically fit are iconic” (Robinson-Wood and Weber). This, however, leaves a lot of people out of the picture. This hegemonic assumption of the young, partying, middle-class, white LGBTQ person is rather sexy and easy to market, sell and consume. While undeniably these images stereotype young LGBTQ people, perhaps worse, they render entirely absent LGBTQ elders who are missing in these representations (Robinson-Wood and Weber).

I had a funny experience of this in my own life. A friend and classmate who is also LGBTQ recently invited me to his house for a game night. In his invitation he mentioned the other attendees would be “LGBTQ elders lol.” When I got there, the oldest person in the room was 40. The average, around 27. While this was clearly a joke, I believe this story is telling: there is severe discrimination against elders happening *within* the queer community that make them invisible. If 30 and 40-year-old LGBTQ people are elders, where does that leave the 60, 70 and 80 year olds?

While LGBTQ elders overall are poorly affected by ageism, research indicates that older gay men are particularly impacted.

Sociologists Brian Heaphy, Andrew Yip, and Debbie Thomson (2004) have conducted the first major British study of ageing and old age within non-heterosexual communities using focus groups, interviews and a postal survey (with a total of 316 lesbian, gay and bisexual participants aged between 50 and 70+). They found that 35.3 per cent of women and 69.5 per cent of men felt there was a lot of ageism in non-heterosexual communities (Clarke et al. 219–20)

In a community where all are supposed to be welcome—a community they fought to make feeling welcome possible—LGBTQ elders indicate that they feel discriminated against because of their age. In the “youthist” gay culture, older gay men are seen as lonely, isolated, sexless, poorly functioning and depressed. Worse yet, they are believed to prey upon younger gay men. This stereotype within the gay community is built upon a long-time notion that links gay men with promiscuity and pedophilia, which is entirely unfounded given research that demonstrates older gay men rarely interact with younger gay men (Clarke et al. 217).⁷ History and perceptions like these do not take place in a vacuum, so it is crucial to recognize these stereotypes for what they really are: relics of the same myths that lead to witch hunts of gay and lesbian teachers on accusations of supposedly trying to recruit and seduce students (Faderman 333). These stereotypes, when unchallenged, can be damaging. It has been suggested that this could be a result of hyper-masculinity and sexual focus in the gay community which are traits that do not age well (Haber). This elucidates the reality of a potentially painful dichotomy for gay older men. They are entirely unseen by the non-LGBTQ community while being viewed as unwanted and predatory within the LGBTQ community.

⁷ Given this stereotype, researching the sexuality of older LGBTQ adults becomes difficult. At no point is my analysis of these elders meant to contribute to wrongful assumptions that LGBTQ older adults are hypersexual—a problematic view of LGBTQ people in general, but especially gay men.

While the literature on gay older men seems particularly painful, lesbian and bisexual older women seem not to experience ageism in the same way as their gay counterparts. Some have suggested this could be because lesbians are more relationship-focused (seen in Haber). Others believe this is connected to the feminist traditions on which many lesbian and bisexual women communities are founded. In fact, a feminist lens would explain why lesbians are less likely to be viewed as unattractive with age and are not tormented to the same degree by the sexist body image ideals of straight women (Robinson-Wood and Weber).

The invisibility of LGBTQ elders perpetuates problems in health care and social service settings. Since only young people are ever represented as being LGBTQ, heterosexist and genderist assumptions run amok for LGBTQ elders. Heterosexist assumptions are particularly common when the elder has dementia (Fredriksen-Goldsen). These assumptions often create a severe discomfort for LGBTQ elders when interacting with health and social care (Clarke et al.; Duffy and Healy). Some of the existing literature as well as news stories describe LGBTQ people who fear for their safety and end up returning to the 'closet' while receiving care for elderly (Gross). This can happen because they may be forced to live with roommates or neighbors who come from a generation where discrimination towards LGBTQ people was allowed (Duffy and Healy). Outside of neighbors, however, stories about discrimination by caregivers are also alarming. Clarke et al. shares several sad examples: one gay man had a caregiver threaten to 'out' him, a lesbian woman had a caregiver refuse to bathe her because she was LGBTQ and another woman who was paralyzed and needed help changing the channel of her TV but was afraid to ask to switch to lesbian-oriented programming because of a homophobic comment made by her caregiver (228).

It might be easy to discount these narratives as anecdotal and extreme, but survey data indicate otherwise. Duffy & Healy share a study by Hughes that analyzed data from 372 aging lesbian and gay participants; 46% of whom indicated they experienced discrimination in aged care as a result of their sexual orientation (2014). Soka and Teaster highlighted investigations that show LGBT(Q) elders experience “victimization in the form of verbal abuse, threat of violence, physical assault, sexual assault, threat of orientation disclosure, discrimination, and physical attack.” Furthermore, LGBTQ elders are often at greater risk for victimization than non-LGBTQ older adults: they are less likely to report or seek help after abuse and are more likely to be isolated than heterosexual or cis-gender counterparts—making them more likely to become victims of abuse, neglect and exploitation (Soka and Teaster).

In the lives of LGBTQ elders, these abuses and forms of discrimination are not isolated incidents but build upon long histories. For example, until 1973 when homosexuality was no longer considered a personality disorder in the Diagnostic and Statistical Manual, treatments including lobotomy and castration were performed on LGBTQ people (Fredriksen-Goldsen et al.). During the HIV/AIDS crisis of the 80s and 90s, people with AIDS formed activist communities to be heard during a time when the federal government was letting them die. Government-run health organizations like the Center for Disease Control and Federal Drug Association under the leadership of conservative presidential administrations refused to take action despite the death of thousands of men with AIDS (France). Furthermore, to this day, experiences with health care for transgender people are widely recognized as a disaster (“Health Care System Fails Many Transgender Americans”).

In contrast to LGBTQ elders who indicate a distrust and discomfort with health care, providers appear to be woefully ignorant. Robinson-Wood and Weber share misconceptions

often heard from healthcare providers collected by The National Resource Center on LGBT Aging in 2013. These themes included the following: “(1) we do not have any LGBT older adult clients; (2) I can identify the LGBT individuals within my service population; (3) I treat everyone as equal; (4) there is not a distinction between gender and sexual identity; and (5) it is illegal to ask about a person’s sexual orientation or gender identity” (Robinson-Wood and Weber). Several of these came up in the interviews with EOL chaplains.

As this section has revealed, LGBTQ elders have been forgotten in more than one way. This thesis aims to fill that gap, the missing voices of LGBTQ elders. This section on intersectionality gave a crucial lens with which to view the struggle of LGBTQ elders. With this introduction in mind, we move into the theoretical underpinnings of this project. Specifically, how does this intersectional experience of LGBTQ elders shape their worldviews? How is spirituality integrated into those worldviews?

Chapter 2: Standpoint Theory, Queer Spiritual Epistemologies and the “Outsider Within”

When you’re speaking to someone as a chaplain, try to tap into your own vulnerabilities, your own wounded places. That’s where you totally meet people in a sacred place is through your own woundedness. They’re talking about their woundedness and you’re not just there as a sounding board. Really engage with them through your own woundedness—whatever in your life that may be.

- LGBTQ Elder 9

In this section I will first lay out my hypotheses through two fundamental claims with this project. I will then summarize the historical roots of Standpoint Theory which helps ground those claims. Following that, I will explore how intersectional lesbian feminism and critical race theory help voice support for a queer spiritual worldview. And finally, I will use feminist-based reflexivity to lay out part of my own story, part of my own “woundedness,” in an attempt to clarify my connection to this project.

Claim 1: Chaplains working in the EOL setting are simultaneously the best and the worst people to capture stories of LGBTQ elders and be witness to these queer spiritual epistemologies of death. They are the worst individuals because they are representatives of not only the very religious institutions that historically excluded and ostracized LGBTQ-identified individuals, but also because they are representatives of a medical system that historically abused LGBTQ people. Nevertheless, the way EOL chaplains engage their patients—humbly listening, learning, attempting to take on the worldviews of their patients—situates them well to not only witness but hopefully be expanded by the queer spiritual perspectives of LGBTQ elders during EOL.

Claim 2: LGBTQ elders grew up in a world run by a dominant group that historically believed, wrongly, that these individuals could not be religious, thereby also wrongly assuming they could not be spiritual. Actually, LGBTQ elders were not only able to find deep spirituality, but in the last places Christianity, science, and cisgender heterosexual society would look. I

predict that the discrimination LGBTQ individuals felt on a larger scale also helped form their relationship with death, especially spiritually. These spiritual strengths, like many counter-dominant worldviews, run the risk of being left unacknowledged by dominant society. When heard, these stories provide important lessons for EOL care.

An Introduction to Standpoint Theory, “Folk Philosophies”

Feminist-based Standpoint Theory contributes a theoretical model to support these claims. “Standpoint Theory emerged in the 1970s and 1980s as a feminist critical theory about relations between the production of knowledge and practice of power” (Harding 1). Standpoint Theory stems from a history of worldviews born out of oppression. Its roots come from Marxist thought which examined structures of class by studying those of the lower class instead of the elites of the time. Women took this principle and applied it to their own situations when engaging in research of the politics during the women’s movement (villanovauniversity). Sandra Harding, a feminist thinker, adds that Standpoint Theory can be thought of in a few ways. Historically, “it was presented ... as a philosophy of both natural and social science, an epistemology, a methodology (a prescriptive ‘method of research’ as several of its theorists phrased it), and a political strategy.” These various dimensions are traditionally supposed to be kept separate (Harding 1). As Harding puts it, Standpoint Theory is oppressed groups’ expression that “[t]he social order looks different from the perspective of our lives and our struggles.”⁸ Such standpoint themes emerge from groups that bear the brunt of society’s suffering and discrimination—women, non-white racial groups, people with disabilities, queer

⁸ Harding represented this by using a metaphor in one interview. Just like a biker, walker, busser and a driver would all have entirely different experiences of the same city, different populations have different views of the same society (villanovauniversity).

people, religious minorities, etc. These standpoints are often represented by ‘folk philosophy’ or ‘folk science’ which rarely fit into the framework of Western philosophies or scientific theory—and are thereby rejected by major social institutions (Harding 3). Rejections of non-dominant standpoints, Harding expresses, allow dominant portions of society to retain “systematic ignorance and error about not only the lives of the oppressed, but also the lives of their oppressors.” Support only goes to scientific approaches, epistemologies and methodologies that uphold existing social and power structures (Harding 5). Overall, Standpoint Theory holds that “the experiences of oppressed groups can become an important source of critical insight” (Harding 7). Harding is quick to point out that where there are different forms of intersecting oppressions (i.e., different intersectionality), different standpoints arise. The relevance to LGBTQ elders is obvious: at the intersection as both elders and LGBTQ individuals, their perspectives are valuable. It is now helpful to explore examples of these “folk philosophies.”

A good example of a standpoints comes from critical race theory. Geographer Clyde Woods exemplified this when he wrote about what he called “blues epistemology.” This phenomenon, which Woods emphasizes is also a site of geographic knowledge, is indigenous to the United States. It comes from the experience of working-class black individuals and was originally conceived out of the experiences of slaves on plantations in the Mississippi delta—the plantation block from which Woods argued modern neo-liberal industrial capitalism emerged. This epistemology is a complicated and expansive knowledge system with important lessons for global social justice, especially with respect to working against racial and economic disparities.

In addition to being a musical tradition, the blues is a knowledge system indigenous to the United States that is expressed through an ever-expanding variety of cultural, economic, political, and social traditions. Embedded within the blues tradition are highly developed and institutionalized forms of philosophy, political economy, social theory and practice, and geographic knowledge that are dedicated to the realization of global social justice (Woods 48–49).

Blues epistemology is another way of seeing the world that was born out of a racist, profit-driven, dehumanizing system. As a result, Woods argues it holds critical lessons for bringing about a more just society. Nevertheless, dominant society and intellectual traditions do not recognize blues epistemology for its important counter-oppressive lessons.

There is a spiritual dimension to this knowledge system which occupies an essential position.

The blues and spirituals are not simply mechanistic responses to oppression. They are the conscious recodification of African and African American knowledge systems, soundscapes, *spirituality*, and social research traditions (Woods 59-60, emphasis is mine).

The spiritual component of these “folk epistemologies” is the area to which I will now aim my focus.

‘Conocimiento’ and The Erotic: Towards Intersectional Queer Spiritual Epistemologies

In order to affirm the spiritual as an important component of some “folk” epistemologies, I draw from the work of intersectional feminists—specifically lesbian feminists of color.⁹ Demonstrating where this has been done before by well-respected academic leaders and activists allows me to propose that the spiritual stories of LGBTQ elders reveal their spiritual worldviews—which is exactly what EOL chaplains aim to understand.

Gloria Anzaldúa, a Chicana queer feminist writer, thinker and activist, outlined her relationship with her spiritual way of knowing, known as *conocimiento* (literally meaning “knowing” in Spanish). Anzaldúa expands on this concept in her book, *Light in the Dark/Luz en lo Oscuro* by clarifying the necessity to recognize organic spiritual epistemologies as well as

⁹ Just as intersectionality was utilized to recognize the experiences of women of color, Standpoint Theory allows us to recognize how that intersectionality informs their way of seeing the world.

clarifying from where *conocimiento*, arises. Note, Anzaldúa wrote this in the second person so throughout the remainder of the quotes from her piece she will speak to “you” while speaking of her own experience.

Many are witnessing a major cultural shift in their understanding of what knowledge consists of and how we come to know, a shift from the kinds of knowledge valued now to the kinds that will be desired in the twenty-first century, a shift away from knowledge contributing both to military and corporate technologies and to the colonization of our lives by television and the Internet, to the inner exploration of the meaning and purpose of life. You attribute this shift to the feminization of knowledge, one beyond the subject-object divide, a way of knowing and acting on *ese saber* you call ‘*conocimiento*.’ Skeptical of reason and rationality, *conocimiento* questions conventional knowledge’s current categories, classifications, and contents. Those who carry *conocimiento* refuse to accept spirituality as a devalued form of knowledge and instead elevate it to the same level occupied by science and rationality. A form of spiritual inquiry, *conocimiento* is reached via creative acts—writing, art-making, dancing, healing, teaching, meditation, and spiritual activism—both mental and somatic (the body, too, is a form as well as site of creativity) (Anzaldúa, “Now Let Us Shift . . . *Conocimiento* . . . Inner Work, Public Acts” 119).

As made obvious by this last quote, Anzaldúa believes that culturally prioritized ways of knowledge are no longer sufficient and that the spiritual, specifically the feminine spiritual, will emerge as a valued source of knowledge. Importantly, this source of knowledge is undeniably tied to the political: claiming *conocimiento* means taking a political stance against the structures of knowledge and power that seek to invalidate *conocimiento* and the lessons it holds. For Anzaldúa, an important component of this way of knowing comes from her relationship with spirits which for her includes nature, animals and “*tus muertos*” or one’s relatives who have passed away (119-120). Instead of relying on the secular ways of knowing celebrated in society or even those represented by dominant religious beliefs, Anzaldúa finds comfort in other spiritual forms of spiritual guidance.

Your reflective mind’s mirror throws back all your options, making you aware of your freedom to choose. You don’t need to obey the reigning gods’ laws (popular culture, commerce, science) and accept fate as decreed by church and culture. To further the self,

you choose to accept the guidance and information provided by symbology systems such as the Tarot, I Ching, dowsing (pendulum), astrology, and numerology (120).

For Anzaldúa, this is deeply grounded in her womanhood, her feminine way of seeing. But in another book, *Borderlands/La Frontera*, she also speaks to how being an outsider—especially as a woman and lesbian of color—influenced her ways of spiritually knowing through an ability she calls *la facultad* (the faculty).

La facultad is the capacity to see in surface phenomena the meaning of deeper realities, to see the deep structure below the surface. It is an instant ‘sensing,’ a quick perception arrived at without conscious reasoning... Those who are pounced on most have it the strongest—the females, the homosexuals of all races, the darkskinned, the outcasts, the persecuted, the marginalized, the foreign. When we’re up against the wall, when we have all sorts of oppressions coming at us, we are forced to develop this faculty so that we’ll know when the next person is going to slap us or lock us away... It’s a kind of survival tactic that people caught between the worlds, unknowingly cultivate. It is latent in all of us (Anzaldúa, *Borderlands/La Frontera: The New Mestiza* 60–61).

It is clear that being the outsider has impacted Anzaldúa’s spiritual ways of knowing and being in the world. Beyond the conscious and the logical, there is an undeniable spiritual dimension for her.

Another queer feminist writer, Audre Lorde also offers useful perspectives on queer feminist spiritual epistemologies. In her book *Sister Outsider*, she outlines what she calls “The Erotic as Power.” The erotic, which she argues is the dimorphic opposite of the pornographic, is a very spiritual and very feminine source of power. However, because this sexual and spiritual way of knowing does not align with dominant male, straight, scientific, or Christian frameworks, it is rejected and fiercely squashed—in order to prevent a change in the status quo or the social order.

The erotic is a resource within each of us that lies in a deeply female and spiritual plane, firmly rooted in the power of our unexpressed or unrecognized feeling. In order to perpetuate itself, every oppression must corrupt or distort those various sources of power within the culture of the oppressed that can provide energy for change. For women, this has meant a suppression of the erotic as a considered source of power and information within our lives (Lorde 54).

Lorde continues by explaining that women have been taught to distrust this source of power. Dominant, male society, she writes, trusts the erotic's depth of feeling only enough to "exercise it in the service of men"—like a parasitic relationship. At the root of this oppression, lies a terror, she claims. Dominant masculine culture "fears this same depth [of the erotic] too much to examine the possibility of it within themselves" (54-55). She describes, using a rather biblical metaphor, how the erotic was hard-fought to identify and claim, but how it now colors her whole way of seeing the world.

During World War II, we bought sealed plastic packets of white, uncolored margarine, with a tiny, intense pellet of yellow coloring perched like a topaz just inside the clear skin of the bag. We would leave the margarine out for a while to soften, and then we would pinch the little pellet to break it inside the bag, releasing the rich yellowness into the soft pale mass of margarine. Then taking it carefully between our fingers, we would knead it gently back and forth, over and over, until the color had spread throughout the whole pound bag of margarine, thoroughly coloring it. I find the erotic such a kernel within myself. When released from its intense and constrained pellet, it flows through and colors my life with a kind of energy that heightens and sensitizes and strengthens all my experience (58).

Despite all the oppressive systems that it takes to contain the erotic and keep it unrealized, despite all the barriers to recognizing its potential, once touched, the erotic lights up one's entire experience of the world.

Interestingly, there are similarities between Audre Lorde's description and those of Anzaldúa. Most notably, Lorde also mentioned a feeling that something was right, an intuition of sorts. Rather than rejecting that the spiritual experience of "this just feels right" has value, Lorde entirely trusts it. Just as Anzaldúa discussed creativity as a critical component of *conocimiento*, Lorde shares the relationship between her creativity and the erotic.

Another important way in which the erotic connection functions is the open and fearless underlining of my capacity for joy. In the way my body stretches to music and opens into response, hearkening to its deepest rhythms, so every level upon which I sense also opens

to the erotically satisfying experience, whether it is dancing, building a bookcase, writing a poem, examining an idea (57-58).

For both Lorde and Anzaldúa, the spiritual is highlighted and clarified by creative processes.

Lorde like Anzaldúa—as well as Clyde Woods for that matter—does not ignore the political implications of recognizing these spiritual sources of knowledge. Notably, Lorde points out the erotic is deeply feminine and that it is a woman's responsibility to claim/reclaim that source of strength—which is political in and of itself. However, she also goes on to critique another significant system of power: capitalism.

The principal horror of any system which defines the good in terms of profit rather than in terms of human need, or which defines human need to the exclusion of the psychic and emotional components of that need -- the principal horror of such a system is that it robs our work of its erotic value, its erotic power and life appeal and fulfillment. Such a system reduces work to a travesty of necessities, a duty by which we earn bread or oblivion for ourselves and those we love. But this is tantamount to blinding a painter and then telling her to improve her work, and to enjoy the act of painting. It is not only next to impossible, it is also profoundly cruel.

Lorde's statement here is a rejection of the foundational elements of a capitalist system which measures success by profit. Instead, she reclaims the joy that comes with following the erotic into its full potential. She reclaims the emotional, psychic, and spiritual satisfaction that comes with fulfilling work. Lastly, it is also clear that both Anzaldúa and Lorde state that, while these ways of knowing are entirely grounded in the feminine, both *conocimiento* and the erotic can be accessed by everyone—man, woman and everyone else.

Through the writing of these women, a queer spiritual epistemology begins to emerge. It is intuitive, guided in a way. It embraces the feminine and also sexual. It finds a spiritual joy in

the creative.¹⁰ And it is innately and inherently political.¹¹ It appears to reject the principle that dominant religious traditions are the only means of finding spiritual fulfillment—instead finding the spiritual in unexpected and nontraditional places. Because the EOL chaplain’s role entails listening to a patient’s story—learning how the patient sees and experiences their world spiritually—it is crucial that we recognize existing models of queer spiritual epistemologies upon which the stories of the elders in my sample can build. Throughout the following chapters of this project, I will examine how the responses of LGBTQ elders in interviews point to various other queer spiritual epistemologies.¹² Note, while work of feminists of color was used to establish the existence of queer spiritual epistemologies, the primary intersection explored in this thesis is that of LGBTQ elders. Other intersectional experiences should be researched in the future.

¹⁰ Participants often spoke of creativity being connected to their spirituality. They frequently referenced endeavors such as singing, painting, poetry, literature, gardening, etc. LGBTQ Elder 9, for example, told me that when she dies she wants the women’s singing group she is a part of to surround her, singing her through her transition. She also mentioned that growing up as a lesbian, she experienced alienation and depression. Her spirituality and music got her through that. EOL Chaplain 7, a gay man, shared how his creativity allows him to see his patients on multiple levels. He said he could theoretically approach EOL spiritual care theologically, psychologically, or emotionally “with those textbook structures in mind”. “But if you have the osmosis of music or literature or the fine arts or sculpting. If you have your hands in the clay of the soul of life, you’re going to see this differently. You’re going to work this differently.”

¹¹ “The best thing I do with my politics is be who I am. Which really speaks to my spirituality too—thank God! Can you imagine if I had to be personal and political, where would I find the time and energy?” A quote from LGBTQ Elder 5. This embodies what many of the LGBTQ elder participants expressed. Their spirituality was intertwined with their politics, their service, their activism. Many of them made meaning out of these endeavors. Chaplains should recognize this as important components of LGBTQ elders’ histories and finding meaning.

¹² Other examples of queer spiritual epistemologies that came up in my literature research: Joy Ladin, a transgender woman and Jewish poet is interviewed for the *On Being* podcast ; *Gay Theology Without Apology* by Gary Comstock; lastly, Judith Halberstam wrote *In a Queer Time and Place: Transgender Bodies, Subcultural Lives*.

Reflexivity: Processing as the “Outsider Within”

Whenever I came in contact with a participant who was particularly well situated to provide advice for the chaplains who someday will hopefully read this work, I would ask them to share with me what they would want EOL chaplains to know and do differently when working with LGBTQ patients. The quote shared at the beginning of this chapter was a piece of advice coming from LGBTQ Elder 9, who had previously done hospice chaplaincy. It feels particularly relevant here.

When you’re speaking to someone as a chaplain, try to tap into your own vulnerabilities, your own wounded places. That’s where you totally meet people in a sacred place is through your own woundedness. They’re talking about their woundedness and you’re not just there as a sounding board. Really engage with them through your own woundedness—whatever in your life that may be.

This quote speaks well to my place in this project, my positionality and personal goal. Rather than seeing my own “woundedness” as a flaw in my research methods that must be controlled out to limit biases, which my training as a neuroscientist would have me do, I have chosen to see it for what it is, a strength.¹³ My personal connection to the stories trusted to me was a powerful tool for connecting me personally with this project and participants but also in sustaining my passion throughout the year-long process. In order to stay true to my woundedness, I rely upon some well-supported feminist and intersectional feminist methodologies that allow me to do so. Specifically, I rely on the feminist research principle of Reflexivity. In doing this, I situate my own “woundedness” at the heart of this project, which allows me to creatively pull from places

¹³I see my own woundedness as that which holds this thesis together. Towards the end-stages of working on this project, a metaphor formed in my spirit and mind. This thesis, for me, has come to be like the AIDS quilt. Each of these stories must be told and represented in their uniqueness—an individual square in the quilt. Nevertheless, the themes and big picture must also be presented in order to help other LGBTQ elders with similar stories. My story holds it all together, the thread, even if unnoticed.

that many, perhaps most, cannot. Intersectional feminist thinkers, once again, encourage me in this endeavor, specifically, Patricia Hill Collins.

As a black feminist sociologist, Hill Collins puts forward her idea of the “outsider within” status—a position black women have occupied for generations. She writes that “Afro-American women have long been privy to some of the most intimate secrets of white society;” these women worked for white families, seeing from the inside while always remaining outsiders, always separate. This gave them unique and creative views of both the white dominant portion of society but also communities of color in relation to that privilege. Hill Collins points out this unique perspective should be celebrated instead of excluded from academic conversations (Hill Collins 103). She also points out that there are other outsiders within academic institutions.

[A] variety of individuals can learn from Black women’s experiences as outsiders within: Black men, working-class individuals, white women, other people of color, religious and sexual minorities, and all individuals who, while from social strata that provided them with the benefits of white male insiderism, have never felt comfortable with its taken-for-granted assumptions (121-122).

Hill Collins describes how this immensely important social position is often lost, either because 1) many outsiders within leave sociology entirely or 2) because those individuals “suppress their difference,” becoming “bonafide, ‘thinking as usual’ sociological insiders” (122). In both cases, she argues, her field of sociology ends up losing. She encourages people to conserve the creative tension of the outsider within status, specifically in sociology, telling individuals to “trust their own personal and cultural biographies as significant sources of knowledge” (122). She challenges the assumed neutrality of traditional sociological approaches as well as points out the unique strengths of the “outsider within” perspective.

In contrast to approaches that require submerging [outsider within] dimensions of self in the process of becoming an allegedly unbiased, objective social scientist, outsiders within

bring these ways of knowing back into the research process. At its best, outsiders within seem to offer its occupants a powerful balance between the strengths of their sociological training and their offerings of their personal and cultural experiences. Neither is subordinated to the other. Rather, experienced reality is used as a valid source of knowledge for critiquing sociological facts and theories, while sociological thought offers new ways of seeing that experienced reality (122).

The true critiques of sociology—and other fields—must come from outsiders within, individuals who vulnerably center their experiences of exclusion in order to provide a unique, and needed perspective

Reading these perspectives gave me strength to share my own “outsider within” statuses, to share my “woundedness.” Embracing my “outsider within” allows me to locate my positionality in this project. Rather than being some sort of footnote, my story allows me to do this research, to see this project on “multiple wavelengths” (as Chaplain 7 described his work).

I grew up going to a Community Bible Christian church. Overall, this was a lovely experience. There was just one thing, I’m also (mostly) gay. I grew up in a community, in a family, that loved me very much but also said horribly homophobic things. I grew up learning theologies and frameworks that did not reflect me, did not reflect my story. What I was told about homosexuals was not true about me—that part of me didn’t feel inherently sinful. Indeed, I was always an incredibly spiritual person. I still am. How could this be? Just as Patricia Hill Collins said, at this point I had three choices: 1) I could reject the church entirely; 2) I could deny being gay entirely;¹⁴ or 3) I could be both and neither, I could be the outsider within. In the church, I decide to look with new eyes. Rather than rejecting Christian teachings as outright

¹⁴ No judgement whatsoever is leveled for any LGBTQ person who had to choose these two options for their safety or wellbeing. I am incredibly lucky and grateful that I was born into and stumbled upon a situation that allowed me to choose the third way—many do not have the option.

inconceivable, propaganda, hateful, I was reminded of the flawed family community that loved me. I was reminded of the “glory bumps” that I would feel when I sang hymns or felt God moving in my life. I would not and could not reject that part of me. I could also not deny the fact that the exact same transcendent experience that I’d had in church time and time again is precisely what I felt watching the musical *Rent*, reading LGBTQ poetry, dancing for the first time at a gay bar. Being gay, just like everything else about me, is spiritual—it has to be!¹⁵ I decided to reframe how I looked at the Bible. I had to read it with different eyes. For me, God was all about love. The Bible had an undeniable message of humility and helping the “least of these.” This is me, the outsider within.

At the same time, I am also a scientist. For me, being a spiritual person in scientific spaces was just as difficult as being both gay and Christian. I have had to carve out a space for myself where I can approach neuroscience, biochemistry, physics in spiritual ways. To talk about my spirituality and or faith in a scientific setting remains very difficult for me.¹⁶ While I was able to find supportive communities where I could be both Christian and gay, being both a scientist and spiritual has proven far harder. Nevertheless, I have occupied the outsider within in those spaces in these fields as well—neuroscience, sociology, public health. I believe these parts of

¹⁵ People may not believe me when I say I’m gay; that may be so foreign to their experience they have no concept of what I mean. The same is true for my spirituality! Some may reject that I can know that I’m gay. “Just because that’s how he feels does not necessarily mean it’s true.” They may similarly reject that my spiritual experiences exist—if science can’t prove it, it’s a superstition or delusion. This doesn’t change the fact that I’m still gay and that my spiritual experiences are still very real for me. Let’s just agree, reader, for the duration of this project to trust people when they share their stories and identities.

¹⁶ Fortunately, this has changed a bit as neuroscience is starting to recognize the importance of mindfulness and meditation.

myself, together, positions me particularly well to do this project. I can see the issue at multiple levels, on multiple wavelengths, with multiple lenses that others might miss.

Beyond how I look at these issues, who I am was an important way to connect with my participants. In every interview I had to call forth important parts of myself as an integrated whole. I connected with each of my participant, often using entirely different pieces of who I am to do so. Talking with a Buddhist, I shared some of their language from listening to Buddhist retreat recordings. Talking to scientists, I pulled from my neuroscience background and training as a biologist. With chaplains, I pulled from my religious experiences and Christian background. With LGBTQ elders, I didn't hide my sexuality if they needed that to feel comfortable sharing their vulnerable selves and authentic stories. Having occupied the position of outsider within myself, I was ready to hear the intersectional, often painful experiences of my participants. I connected with them in ways most others likely couldn't. I asked questions at the right moment because I saw things others would not have. I was able to engage these individuals through my "woundedness." Rather than hindering my thesis, there is no doubt in my mind my story enriched it.

Chapter 3: Research Methods

*Recruitment*¹⁷

“My name is Harvey Milk and I’m here to recruit you!”

- Harvey Milk, Gay Rights Leader

For my thesis, I employed a qualitative approach to ethnographically explore the life experiences of lesbian, gay, bisexual, transgender and/or queer (LGBTQ) elders¹⁸ as well as the work and life experience of end-of-life (EOL) chaplains. I conducted a total of 22 interview—7 with EOL chaplains and 15 were with LGBTQ elders. To qualify as a LGBTQ elder, the individual had to personally identify as lesbian, gay, bisexual, transgender and/or queer. In addition to this, they needed to be born prior to 1964. To qualify as an EOL chaplain, the individual had to be a professional chaplain in palliative care, hospice, or both who was currently practicing or who had practiced for more than three years on the Colorado Front Range. It is important to note, however, that these categories were not mutually exclusive (i.e. there were chaplains who also fit the description of LGBTQ elders as well one LGBTQ elder participant who had previously served as an EOL chaplain in the Colorado Front Range area). This overlap was partially intentional and partially coincidental. Regardless, as will be discussed in the analysis section of this chapter, this was useful for cross-checking the reliability of coding

¹⁷ When I started talking about recruiting for my thesis with a mentor, they said something akin to “get it haha... LGBTQ... *recruiting*.” They continued to tell me about a LGBTQ friend of theirs who let them in on an inside joke: anytime an LGBTQ person recruits a straight person to become LGBTQ, the new recruit gets a blender (I have also heard toaster). For years, people have claimed that because queers can’t reproduce they have to recruit. I am happy to report to my readers that my recruitment efforts for this project went even better than expected.

¹⁸ Note, LGBTQ is how this population was described in this thesis—to be more inclusive of participants who identified as queer, pansexual, etc. When past research describes that population as “LGBT” I am consistent to that or include (Q) at the end of LGBT.

analysis for both populations.

Recruitment of LGBTQ participants took place primarily by contacting organizations—either via email or phone. For the LGBTQ elder group this meant contacting LGBTQ organizations in the Colorado Front Range. Many of these organizations had a specific representative or meetings for older adult LGBTQ members. I also contacted organizations that were formed exclusively by and for older LGBTQ people. Upon contacting these organizations, I gave them my email and phone number so potential participants could schedule meetings with me. Upon finishing a semi-structured interview with a participant, I would ask the participant to share my information with anyone they thought might fit my criteria and be interested in participating in the project—this recruitment style is known as “snowballing”.

Sometimes snowballing even happened spontaneously. On multiple occasions I arrived expecting to do one interview and then would be pleasantly surprised to also be allowed to interview the partner of the original participant as well. For example, one of the chaplains I met was LGBTQ and got me in contact with their partner whom I later interviewed. Additionally, I attended an EOL decision-making event held by one of the LGBTQ organizations in the Colorado Front Range where I announced my project and shared my information—I later interviewed several people as a direct or indirect result of that event.

I typically made first contact with the EOL chaplains by emailing or calling hospice and palliative care programs in the Colorado Front Range. This was the most successful method—giving me four of my seven EOL chaplain interviews. As with the elders, I would then request they pass on my information to colleagues so I could continue to recruit using the snowballing method. On only one occasion did another chaplain follow up after being referred to me from this process. I also contacted one chaplain personally via email and they agreed to an interview.

The last chaplain was recruited because one of the LGBTQ participants worked in a hospice and gave my information to their chaplain coworker.

Semi-Structured Interviews

Upon being connected with a participant, I would start by explaining more about the project to the participant. With LGBTQ participants, I was fairly open about my description. With the chaplains, I intentionally described my project using only the necessary information. Typically, I would say something like “I am researching end-of-life spiritual care for underrepresented populations.” I chose to do this for several reasons. First, if a participant did have a bias towards LGBTQ people, I did not want my explanation of the project to prevent the chaplain from participating. Secondly, I chose to use this description because, should an interview be scheduled, I did not want the chaplain to be able to study or review the literature on LGBTQ-inclusive care if they would not have done so otherwise. My hope was to have more authentic conversations.¹⁹

After giving a description, the participant and I would set up a location and time for our meeting. I encouraged them to pick somewhere where they would feel comfortable talking about taboo topics like death, dying and religion. I met twelve of the fifteen LGBTQ participants at their home, two at their place of work, and I met the last person at a coffee shop. I am particularly satisfied with where the interviews took place because I believe by talking to the clear majority of the interviewed LGBTQ elders in their homes, our conversations were much

¹⁹ Importantly, upon meeting with a chaplain, I would give them a more precise description of the project—both verbally and through the IRB-approved consent form they signed prior to beginning the interview. Therefore, should they have decided they no longer wanted to participate, they always had that choice.

less formal and more intimate. Moreover, the conversations were more representative of the setting where the majority of hospice care takes place: the home. For the chaplains, four of the seven interviews took place in a coffee shop, two others took place at the participants' places of work, and the last chaplain interview took place over Skype. For the Skype interview, both that chaplain and I were in our homes.

The interviews I conducted for both populations were semi-structured, giving flexibility for participants to share their stories and experiences freely. Furthermore, I attempted to keep my interruptions to a minimum. For nearly all of the interviews—both chaplains and elders—I would start by having them give a brief introduction of themselves, asking them to share anything they felt was particularly interesting or relevant to my project. Following that introduction, I would follow up with more rigid pre-established demographic questions. After those questions, I would have them tell me about their spiritual and/or faith background as a child and/or their earliest spiritual memory (if they had one). This question posed a wonderful introductory starting place.²⁰ According to Kvale, “such opening questions may yield spontaneous, rich descriptions where the subject themselves provide what they experience as the main aspects of the phenomenon investigated”—in this case, spirituality (Steinar Kvale). This was confirmed in my experience, as many of my participants independently addressed several of my research questions just by sharing those memories. After answering that question, I would build on what they had shared and continue with the interview (following the questions from Appendix A in a semi-structured manner).

²⁰ Also, on my all-time favorite podcast, *On Being*, the host Krista Tippett starts all her interviews with that question and I love that! I really tried to channel my inner Krista Tippett (and Brené Brown) during multiple parts of this project.

For both my populations, I collected demographic information on race/ethnicity, age, sexual orientation, marital status, gender, gender identity, the general geographic area where they grew up and where they lived now. For both populations, I also collected information on their current religious/spiritual background or belief system. For just the elders I also collected the religious/spiritual background growing up. The results of this demographic breakdowns are as follows:

Table 1: EOL Chaplain Demographics

<i>Race/Ethnicity</i>	
5 – White	
1 – South Asian	
1 – Mixed	
<i>Age:</i>	
Range: 1982 - 1946	
3 – Born between 1946 and 1964, “Baby Boomers”	
4 – Born between 1965 and 1985 “Generation X”	
<i>Current Religious/Spiritual Background (some listed twice)</i>	
4 – Christian	
1 – Episcopalian	
1 – American Baptist	
1 – Catholic	
1 – Presbyterian/Spiritual	
2 – Buddhist	
1 – Zen Buddhist	
1 – Tibetan	
2 – Spiritual	
1 – Presbyterian/Spiritual	
1 – Atheist/Spiritual	
	<i>Sexual Orientation</i>
	4 – Straight
	2 – Gay
	1 – Lesbian
	<i>Marital Status</i>
	4 – Married
	3 – Single
	<i>Childhood Geographic Communities</i>
	7 – United States of America
	2 – Midwest
	2 – Eastern Colorado/Front Range
	1 – East Coast
	1 – South
	1 – Mix
	<i>Current Geographic Communities</i>
	7 – United States of America
	6 – Colorado Front Range
	1 – Pacific Northwest
	<i>Gender Identity, Gender</i>
	7 – Cisgender
	5 – men
	2 – women

Table 2: LGBTQ Elders Demographics

<i>Race/Ethnicity</i>	<i>Current Religious/Spiritual Background</i> <i>(some listed twice)</i>
13 – White	12 –Spiritual Not Religious
1 – Latino	7 – General Spiritual, Not Religious
1 – Mixed	1 – Shamanic
<i>Age</i>	1 – Quaker/Spiritual Not Religious
Range: 1962 – 1934	1 – Atheist
12 – Born between 1946 and 1964, “Baby Boomers”	1 – Wiccan & Nature-based
3 – Born prior to 1946, “Silent Generation, Greatest Generation”	4 – Christian
1 – in their 80s	1 – Evangelical Lutheran Church of America
3 – in their 70s	1 – Episcopalian
8 – in their 60s	1 – Catholic/Buddhist
3 – in their 50s	1 – Quaker/Spiritual, Not Religious
<i>Marital Status</i>	2 – Buddhist
10 – Married	1 – Buddhist
5 – Single	1 – Catholic/Buddhist
<i>Original Religious/Spiritual Background</i>	<i>Current Geographic Communities</i>
14 – Christian	15 – United States of America
5 – Catholic	14 – Colorado Front Range
2 – Methodist	<i>Childhood Geographic Communities</i>
2 – Quaker	13 – United States of America
2 – Presbyterian	5 – Midwest
1 – Southern Baptist	3 – Eastern Colorado
1 – Lutheran	3 – East Coast
1 – Congregational Church	2 – South
1 – None	1 – Caribbean
<i>Sexual Orientations:</i>	1 - Canada
6 – Lesbian	<i>Gender Identity, Gender</i>
6 – Gay	13 Cisgender
1 – Bisexual/In Lesbian Relationship	7 – Women
1 – Pansexual	6 –Man
1 – Queer/Borderline Asexual	2 – Transgender
	1 –Woman
	1 –Gender Queer

The average chaplain interview lasted around an hour and a half whereas the average elder interview lasted around two hours. Each participant received a copy of my Internal Review Board (IRB)-approved consent form which outlined expectations of confidentiality and gave a general review of the project. Upon reading the consent form, they gave me the signed portion and kept the informational portion for their own records. This form emphasized that their participation was voluntary and that they did not need to answer every question during the interview. Despite the sensitivity of my topic and the often painful stories shared, there was only one situation in which a participant outright refused to answer a question.²¹ The majority of the participants truly enjoyed being given the time and space to share important parts of their lives to someone eager to listen. I take pride in this, given the often heavy nature of my topic.

Chaplains and elders were asked some questions that were shared and some questions were unique for their populations. In the cases where there was an overlaps—i.e., LGBTQ chaplains, LGBTQ elders who have done EOL chaplaincy—participants were asked questions from both of the question pools (see Appendix A).

Data Security and Analysis:

My interviews were audio recorded with participant's permission. I made the decision to not transcribe these interviews. Instead I chose to use audio analysis of the files (mentioned in Steinar Kvale). After each interview, I downloaded the recorder file from the recorder to my computer to have it stored in two locations. My computer is password-protected. Following finishing the analysis of the interviews, the files on the recorder were deleted entirely.

²¹ One of the male chaplains did not want to share his age, instead he eventually stated that he was born “directly post Baby Booming”.

After completing the 22 interviews over the course of seven weeks, I separated the participants' recordings into two separate folders—one folder for chaplains and another for elders. The next phase was the analysis portion of the project which took place over two and a half weeks. I analyzed the chaplain interviews first, followed by the LGBTQ elders. To start the process, I listened to the entirety of the respective group's interviews without taking notes. Following listening to the entire group at least once, I listened to the interviews again, this time taking detailed notes on what the participant was saying and at what time marker they were saying it so later I could pull out verbatim quotes. During this note-taking phase, I also removed any names or identifying markers to ensure confidentiality. After compiling these notes, I coded these note documents line-by-line. I highlighted an emerging theme in a specific color. These themes were then compiled in a separate document using short, descriptive memos to help me keep track of who said what. Upon compiling all the memos under respective themes, the memos for each theme were then explored again for sub-themes. Quotes were retrieved for the final write-up. The resultant themes, sub-themes and quotes comprise the content of following chapters.

As mentioned above, having overlap in my populations was very useful for my analysis. I was able to check the reliability of the themes with these intersecting individuals. In other words, after coding the results of both populations, I took the interviews with three chaplains who identified as LGBTQ to compare their stories to the elder themes. Similarly, the one LGBTQ elder participant who had done hospice chaplaincy previously was compared against the identified chaplain themes.

Limitations

As stated previously, most participants identified as white. Furthermore, while social class was not formally collected like other identities—a limitation in and of itself—most the participants in both populations shared they were college educated and/or middle class. For the chaplains, specifically, women were underrepresented in my sample (only two of the seven chaplains identified as female). And only two chaplains were people of color—with only one individual identifying as South Asian and another who identified as coming from mixed racial and ethnic background. With respect to the LGBTQ participants, only two of them identified as a race other than White—in those cases, Latina and mixed. This is likely representative of the larger population of EOL chaplains practicing in the Colorado Front Range.

In summary, my analysis includes the perspectives of those who are come from a lower socioeconomic background, are not college educated, and are from non-white racial or ethnic background; however, the majority of the findings in this thesis relate to older, middle class white individuals. Research conducted in the future should focus more on the intersections of class and race in their recruitment and analysis.²²

Other limitations of my research relate to recruitment methods. For example, as described above, I chose to keep the description of my project minimal when initially speaking with EOL chaplains and then give them details upon meeting in person. This was helpful for setting up an

²² Briefly, I want to point out the overarching disparities that exist for EOL care in the United States. Unfortunately, the racial demographics represented in my samples, specifically the LGBTQ elders, represent the population of patients that are most likely to utilize end-of-life care (i.e., there are huge disparities when it comes to non-white patients in EOL; for a particularly good example of this see (Smith et al.)). While researchers like me should continue to recruit more representative samples in the future, society and EOL care providers should also make necessary efforts to ensure that patients and families in the EOL care setting represent the larger population of their community as a whole—especially with respect to race and ethnicity.

honest and in-the-moment interview, but could have contributed to chaplains not participating in the project. On more than one occasion people with whom I spoke on the phone or emailed wanted to know more about my project. Several times I did not get called back after leaving messages. While this might have been a result of other number of factors, initially describing my study population as “underrepresented people” instead of “LGBTQ elders” likely was not enough initial information for some potential participants.

Similarly, my recruitment methods within the LGBTQ sample could have affected my subsequent analysis. To recruit, I contacted LGBTQ organizations or went to recruit at events held by these LGBTQ organizations. Thus, the people I recruited have LGBTQ groups and LGBTQ organizations as a potential support system. This might skew my analysis. For example, my participants shared passions for politics and community service—which was often spoken of in a spiritual context. Being recruited as a member of an LGBTQ organization may relate to this finding (i.e., several participants were involved in LGBTQ organizations as a part of their service; had I recruited in a different manner that may not have emerged as a theme).

Furthermore, I recruited participants through a snowballing method, meaning a participant would pass my information on to other interested parties. In my research, the participant often suggested I interview their partners. Because of this, my LGBTQ participants potentially reflect a disproportionate proportion of the LGBTQ community in the Colorado Front Range who are married. A recent Gallup poll shared that only 10.2% of LGBT Americans are married (Gallup Inc.). In my sample, over 60% of my LGBTQ participants were married. This should be kept in mind when thinking about LGBTQ elders generally—especially in the context of social support structures during EOL. Future studies should focus more on LGBTQ adults

who are less integrated in the LGBTQ community as well as LGBTQ elders who are not married.²³

The religious and spiritual backgrounds of my participants were further potential limitation. The majority of both LGBTQ and chaplain participants grew up in Christian homes—21 out of the 22. Three of the chaplains no longer identified with that background. For the other population, the elders, all but two of the fifteen no longer participated actively in Christian communities. There was representation of the Buddhist faith—both in the chaplain and elder population. Other than Christian, Buddhist and “Spiritual Not Religious” participants, however, there was no representation of other belief systems or religions. Therefore, future research should look to the issues examined here while being more inclusive of other faith backgrounds and beliefs—Muslim, Jewish, Sikh, Humanists, non-spiritual atheists, agnostics, etc. Nevertheless, Christians in the Colorado Front Range are the most common “spiritual” individuals so this sample is likely fairly representative.

Another obvious limitation of this research was that more conservative perspectives were lacking in both populations. All of the participants presented as fairly progressive when it came to LGBTQ inclusion. Furthermore, those who all shared political views all appeared to be quite liberal. This may be a reflection of the Colorado Front Range where this study took place, a reflection of populations that are willing to participate in my project might be more liberal, or may simply be a result these populations—specifically LGBTQ people—typically are more

²³ On the other hand, while the representation of married LGBTQ participants is certainly a limitation, it is also a potential strength. My project is one of the first to be conducted researching LGBTQ elders in EOL care after same-sex marriage became legalized on a federal level. Therefore, this allows a unique ability to examine how the legalization of same-sex marriage has impacted EOL and EOL spiritual care.

liberal. Regardless, in the future, studies done on this topic and on these populations should make a point of being more inclusive of different political backgrounds.

Regarding the gender and gender identity of the participants, there were no EOL chaplains who identified as transgender or gender non-conforming. Efforts should be made in the future to ensure those rare but important voices are not only heard but made central. Two of the fifteen LGBTQ elders identified as transgender—one a transgender woman and the other as gender queer. While their voices are represented, the overwhelming majority of the LGBTQ participants were cisgender. If I were to do this project again, I would potentially focus exclusively on recruiting transgender participants rather than try and include them with the lesbian, gay and bisexual participants. This is simply because trans-specific research is lacking and the unique dimensions of that worldview often get lumped into LGB experience when it is, indeed, quite different.

Another limitation presented by this research is the generalizability of results. In 10 years, people who fit the definition of “elder” used in this thesis will not have the same experiences as those who were collected in this sample. Similarly, this research reflects the Colorado Front Range. Other LGBTQ communities—even in Colorado—likely would provide different answers than those in this sample. Overall, findings with chaplains are likely more generalizable.

The last limitation I would like to discuss is potentially the most profound. None of my LGBTQ elders was utilizing EOL care services at the time of their interview. Most, in fact, appeared to be quite healthy. On multiple occasions people—especially the younger ones—told me something along the lines of “death isn’t coming for me anytime soon.” I hope they are right.

Nevertheless, this is telling.²⁴ This population gives an approximation of what the spiritual needs of LGBTQ elders in the EOL care setting would be. I imagine, as did my participants, their answers will be different when more face to face with death. Recognizing that, I still firmly believe the data collected here, despite these limitations, are still valuable and provide the best glimpse of the EOL spiritual needs of LGBTQ elders that research has captured to date.

²⁴ An obvious irony here is I (Tyler) was 23 years old at the time of researching and writing this thesis. Just as with the elders, my view of death is also impacted and stands as a limitation for this project due to my age. I'm sure my analysis would have been different if I were to have conducted this study in my 40s, 60s, or 80s. Inversely, I also imagine my passion for end-of-life and death issues will also impact my view of death when it comes.

Chapter 4: Role of an End-of-Life Chaplain

In listening to the stories of those to whom we seek to offer care, we are confronted with the new realities, embodied spiritual truths and deep and meaningful insights into the experiences of illness and the implications of this for genuinely person-centered care. In a techno-medical context that may well have forgotten what it means to be human and to live humanly, such a revelation is crucial. I want to propose that it is within the realm of narrative that chaplaincy can find a sure foundation for its theory and professional practice. Narrative offers a conduit through which chaplains can make a genuine and unique contribution to the development of healthcare practices and offer vital insights and new competencies to the healthcare team.

- John Swinton, Healthcare Chaplain
(Swinton 228)

Introduction

At various points researching and writing this thesis, I lost sight of why my project was truly important. I began settling into the worldviews being shared with me and these stories became familiar and normal. I forgot how special what I was witness to truly was, how surprising what I was learning might be to others. There were a few events in my life while working on the thesis that helped me to wake up, to realize my call to this project was critical and that the information I was collecting needed (and needs) to find its way to the public.

One of these events took place in my *Intro to LGBTQ Studies* course Fall of 2017. Having just read and discussed the relationship between LGBTQ identity and religion, our class had moved on to discussing the readings on LGBTQ aging. At one point, one of my classmate made a powerful statement—having had a lifetime of horrible experiences with religious people in their life, they was (this individual identified as gender non-binary) worried about LGBTQ elders. “I know many hospices have chaplains. What happens at the end-of-life when an older LGBTQ is dying, vulnerable, and a chaplain comes in and tries to convert them or offer them some kind of salvation?” This view is not uncommon! Several of the LGBTQ elder participants, when it came up, shared similar fears: “I don’t want to be converted,” “I don’t want them to

impose their beliefs on me,” “I don’t want things to be like the conservative town where I grew up.”

What the interviews with this sample of EOL chaplains revealed, however, is that these beliefs appear to represent misconceptions of what the role of an EOL chaplain actually is.²⁵ In response to these misconception, I wanted to share how EOL chaplains in the Colorado Front Range described their role. Overwhelmingly, they all explained what they do as the exact opposite of what my classmates and the LGBTQ elders who raised fears believed. These chaplains saw themselves as walking alongside and supporting the patient and families, not leading. They were extremely uncomfortable with imposing their beliefs and were quick to point out this EOL spiritual process is not about them. Before going into details of the EOL chaplain role, however, I feel it is fitting to first explore another common theme discussed by chaplains: rejection or patients who did not want chaplain support.

Jesus, Crock Sandals and ‘We’re Just Not Religious’: Chaplain Rejections

As will be discussed later in this project, the chaplains all remember working with relatively few LGBTQ patients. The chaplains in this sample often attributed this to their belief that LGBTQ patients and families probably would not want to see the chaplain—a person who often is wrongly stereotyped as a close-minded religious person. One participant, EOL Chaplain

²⁵ I want to validate people who might disagree with this statement. The fear is entirely reasonable! What I said is only true with certainty for the sample collected in this study. However, given the code of ethics and training processes for EOL chaplains, discussed later in the conclusion of this chapter, I feel it is reasonable to assume that most if not all chaplains serving the public through an interfaith, non-denominational hospices or palliative care setting would answer my questions similarly to how the chaplains in my sample did (i.e., not imposing their personal beliefs on patients).

4, who identified as both an atheist and a lesbian mentioned that she loves supporting LGBTQ patients—when they allow her to.

It's wonderful when I feel like I have the opportunity to support LGBT folks, [transgender] folks. To, um. And when they're open to me. Sometimes, you know, there's just so much crap from Christianity, if that's been their tradition. I mean they just, they never even let me walk through the door because they make a lot of assumptions. And I can't blame them for that. Um. But sometimes people are open and willing. But yeah there's that, it's kind of ironic. There's just all that stuff with Christianity that is so toxic—that often times that's a barrier to people being willing to let me in. So when I am allowed in, I just really try to navigate that so carefully—to gain their respect and their trust.

Unfortunately, this chaplain who is uniquely situated to support LGBTQ patients and families was often not wanted because patients and families had been hurt by religion and did not want to have anyone who they believed to be a religious person in the room or part of the EOL conversations. The irony, as she pointed out, is Chaplain 4 comes from the LGBTQ community as a lesbian. However, LGBTQ individuals often did not want to talk to her. Overall, chaplain participants shared that the reasons for these so called “rejections” were varied.

Outside of LGBTQ patients, the chaplains described diverse reasons for a patient not wanting their support. For many, the patient thought the chaplain was just for religious people. Therefore, patients who were atheists or individuals who had been hurt by religion often did not want the type of support they believed chaplains could provide. Chaplain 4 told me about one experience with a family of vegans. This family were all passionate about animal welfare and animal justice, which Chaplain 4 pointed out and recognized seemed to be on a spiritual level. Nevertheless, at the end of what turned out to be a lovely session, the family did not want that chaplain's services because they “weren't religious.” It would appear they missed the point: chaplains can “do” the religious side, indeed they often do, but that is not even close to all that chaplains do.

There were other reasons for rejection too. Chaplains also talked about how religious people from non-Christian traditions also rejected them, preferring their own religious community and religious leaders for support. Interestingly, almost all the chaplains also talked about some Christian patients who would request the chaplain not come back. Most of the chaplains described interactions with Christian patients who would conduct “litmus tests” on them—asking their beliefs on Jesus, the Virgin Mary, their understanding of scripture, the church they went to, etc. One of the male Buddhist chaplains even described how one patient requested that chaplain not come back because that specific chaplain had an earring and wore Croc sandals. Sometimes, several chaplains said the chaplain-patient relationship just did not click and for no apparent reason, it was not a good fit. While the reasons for patients not wanting the chaplains’ support were diverse, common themes arose regarding how the chaplains responded to these rejections.

Every single chaplain I spoke to had a very light-hearted response when a patient or family did not want their services. Never did they appear to take the “rejection” personally. All of them mentioned it was completely fine when someone decided they did not need or want the chaplain’s help. The chaplains recognized that the patients and the families wanted a person they could trust, who understood them. Each of the chaplains in my sample respected that. Sometimes, they simply are not the right person and that was fine. Chaplain 7 put it in a particularly funny way.

Interviewer: Have there been times when people outright rejected you?

Chaplain 7: Oh yeah! My philosophy is I’ve been kicked out of a lot of dumpier places than this. [Both laugh] I mean, it’s not personal.

Beyond taking the patient’s “rejection” in a receptive manner, the chaplains all fully recognized why people might have the response they did. As people who were seen as religious leaders, the

chaplains acknowledged how religion impacted different people in very different ways. Nevertheless, beyond accepting their place in this interaction, all the chaplains seemed to also recognize that many of these “rejections” were also result of a misunderstanding of the chaplain role—like the vegan family in Chaplain 4’s story. Because this type of misconception has become overwhelmingly apparent during this project, the remainder of this chapter will attempt to clarify how EOL chaplains actually described as what they do and do not do.

“It’s Not About Me”: What an EOL Chaplain Does Not Do

As I mentioned in the introduction to this chapter, there are definitely some misconceptions about the role of a chaplain.²⁶ In order to try and paint a better picture, I will first discuss what chaplains indicated they did not do—namely, they did not bring their own agenda into the interaction and they did not impose their views on their patients or their patients’ families.

During the interviews with the chaplains, an overwhelming pattern was they all constantly and continuously let me know that they try not to have an agenda with their patients. While some described it as “not having an agenda,” others would say something like “it is not about me.” Even in these interviews, during which I was directly asking them for their opinions on topics like sexuality, death, and dying, several said something akin to “that’s just what I think though, I would never force this on a patient.” It was clear almost immediately that the chaplains recognize that their beliefs did not really matter in these conversations and in EOL spiritual care. Two examples are particularly relevant for my project. Chaplain 5, who is a Zen Buddhist and is

²⁶ In fact, this is true outside of the general public: much of the research I encountered indicated that many health care providers do not even fully understand the diverse role of a health care chaplains (Taylor et al. 104; Jeuland, et al. 502; Lyndes et al. 89)

also gay talked about a homophobic remark made by a patient. During his training, a nearby city in another state passed a law legalizing same-sex marriage which at that time in history was rare. Chaplain 5 was in the room visiting a patient when this news came up on the television set. This patient launched into a tirade after hearing the news, ranting about “how disgusting homosexuals are and how wrong same-sex marriage is.” As a gay man, but also as a chaplain, Chaplain 5 shared how he had to navigate this very carefully.

I’m thinking oh my gosh, how could you be so narrow-minded. But the worst part is I’m in the role of chaplain so, *I’m not here for me. I’m not here for my story.*

Despite the emotional toll this patient’s words were taking on Chaplain 5, he made the decision to recognize that this situation was not about him. EOL Chaplain 4, who is a lesbian, shared a similar experience.

[A family] said derogatory things about gays and lesbians which is one of those things that I run into too. And it’s like, you know. I just tried just to let that wash over me. Because *it’s not about me.*

As both of these examples already demonstrate, for the chaplains in my sample—even when it comes to these chaplains’ identity as an LGBTQ individual—the patient matters more in that specific setting.

All of the chaplains I interviewed refused to impose their opinions or beliefs on their patients. They only shared or self-disclosed when they were asked the question directly, sometimes not even then. Several of the chaplains, interestingly enough, indicated that they chose chaplaincy over congregational pastoring because as chaplains they did not have to take on that evangelical, pastoral voice. Evangelizing or proselytizing was described as offensive to several chaplains in their specific role. Because of this, navigating the power dynamic of being recognized as a religious leader was difficult at times. For example, Chaplain 5, the gay man who

had to listen to his patient say homophobic comments about same-sex marriage, shared with me how he decided to navigate that situation.

When he asked me what I thought about it, I just said ‘well you know, I’m not really here for politics.’ And so I asked him, you know, about his illness and what was going on there and we were able to engage with that. And I was able to set my fuming aside until after I was able to leave the room and then I could go talk to someone and vent.

As the chaplains would put it, it is not their job to convince folks that one viewpoint is correct.²⁷

It is not their job to teach, or “enlighten” a patient. Overall, and importantly, the majority of chaplains in this sample indicated that they were hesitant to self-disclose much of anything about themselves. Outside of the chaplains’ religious backgrounds, which patients often wanted to know about, chaplains almost never would share their own identities or beliefs.²⁸

Navigating Different Beliefs and Disagreements as a Chaplain

Chaplains often had different beliefs than their patients. Interestingly, the approaches they utilized when they encountered those disagreements followed certain patterns. When the chaplains in my sample talked about navigating disagreement or difference of beliefs, they would do so by focusing in on the patient or family member and their needs. In addition to this, chaplains often engaged in these interactions by reframing or adapting to the issue or ritual at

²⁷ The relevant words of Hospice chaplain and author, Kerry Eagan:

[Hospice] chaplains are sort of the opposite of storytellers. We’re story holders. We listen to the stories that people believe have shaped their lives. We listen to the stories people choose to tell, and the meaning they make of those stories. While religion plays a central role in spiritual care for many patients, it doesn’t for many others. Spiritual care, faith, and religion are not the same thing. *Some chaplains might also be priests and pastors, but in their roles as chaplains, they don’t preach or teach. Instead, they create a space—a sacred time and place—in which people can look at the lives they’ve led and try to figure out what it all means to them.* (Eagan 17–18, emphasis is mine)

²⁸ I think this has made my project super interesting. I got to hear the thought, beliefs and opinions of chaplains who are always in the position of listening to those of others. It was my privilege to listen to the listeners.

hand while staying true to themselves (i.e., trying to find a place of common ground where they could be true to both their beliefs and the beliefs of the patients).

On several occasions chaplains explained how they made sure a patient or family member felt heard—even when a chaplain did not necessarily agree with what was being said. Several times, the chaplains described never arguing with the concerns that the individual was sharing but instead focusing in on the underlying needs of the patient. They described being patient, trying to stay curious and listen to the family/patient, trying to stay respectful of the person in that situation.²⁹ EOL Chaplain 7 provides a good example of these practices.

Interviewer: How do you engage people who have different spiritual beliefs than you, maybe even contradictory potentially?

Chaplain 7: Meeting on last... Tuesday. Just, you know. They were, ‘There’s only one way to God and that’s through Christ and the rest of you are burning in hell. And... those God-damned Democrats.’ It was just like, [the EOL team] was all just sitting there like, hmmm. Here we are—we’re in that meeting. You know? And what matters is that in addition to being a guy who needed to be on a soap box for a minute, he was a loving and devoted and attentive husband to a dying wife. And if that’s what he needed to do to vent for a minute, to express his anger towards his life situation, then so be it.

This was not the time nor the place to debate politics with this husband. Rather, the chaplain decided to focus in on the situation, the underlying suffering, the bigger picture. This allowed Chaplain 7 to be patient with views he did not necessarily agree with. Several of the EOL

²⁹Chaplain 2, in particular, shared his specific views regarding the traits he believed all EOL chaplains must have. A chaplain has to have tolerance, patience, and humility. Tolerance is not apathy but instead having respect for different worldviews and viewpoints. Patience meant not positing motives or intentions for another person too quickly, especially during a disagreement. And finally humility, which for him meant chaplains must recognize there are a limits to their knowledge and personal experiences; therefore, they should always be ready to listen and learn. He noted, and I agree, that not only chaplains would benefit from cultivating these approaches.

chaplains in my sample mentioned utilizing this technique when they disagreed with a viewpoint of their patients or a family member.

Chaplains explained that when a patient shared a strong belief, they would then sometimes ask the chaplain directly what the chaplain believed. Several of the chaplains described using these moments to avoid the question entirely— “I’m not here to talk about politics,” or even saying phrases like “well I’d prefer to keep this conversation about you.” Sometimes this worked. Chaplain 2 gave a story in which this type redirection didn’t work. One patient expressed a particularly strong theological stance which Chaplain 2 didn’t necessarily agree with. At first Chaplain 2 just listened carefully. But then, the patient asked him what his belief was. Chaplain 2 expressed to me that he evaluated the relationship with the patient— believing it was strong enough to share his stance. He then told me that he entered into things lightly, saying he didn’t see things exactly the same way. When the patient voiced his disagreement Chaplain 2 suggested they could just agree to disagree. Eventually, that patient just decided not to ask Chaplain 2 back. This example goes to show that these interactions don’t always go smoothly. However, it is important to point out the following: 1) Chaplain 2 only shared his perspective when asked directly; 2) he entered into the potential disagreement lightly, being deliberate with his words and phrasing; and 3) he opened up an opportunity to find common ground or at least agree to disagree; and 4) when the patient decided to not ask Chaplain 2 back, Chaplain 2 did not take that personally. Overall, however, this sort of situation appeared to be rather rare—Chaplain 2’s story was the only example of this type of disagreement shared in my interviews.

Overwhelmingly, all of chaplains discussed ways in which they would reframe their beliefs to better fit the situation or adapt to find common ground between their beliefs and their

patients'. For example, several chaplains spoke of the way they pray. One chaplain described this as "chameleon-like." Chaplain 6, a Buddhist, exemplified this well; when working with Christians, she doesn't necessarily believe "God" is an entity outside of the patients. As a result, when praying she would emphasize God is *with* us—which she points out is scriptural in the Christian tradition. Furthermore, rather than praying for "healing" or a miracle, she prayed for "wholeness." She even mentioned that she feels comfortable giving patients communion. Even though this ritual was not part of her tradition, she had reframed it for herself to better embody her beliefs—"it's a beautiful expression of non-duality." This felt authentic to her, no conflict.

Chaplain 5, another Buddhist, discussed how he negotiated his personal boundaries with his patients. When formerly serving as hospital chaplain, prior to his work in hospice, he would be asked to do infant baptisms. Because he didn't feel comfortable performing the baptism, himself, he would lead the parents or family members through that ritual because they could perform it as Christians. Similarly, Chaplain 4 talked about a family that was making her particularly uncomfortable because the daughter of a dying father was trying to get Chaplain 4 to convince the father to align with the daughter's fundamentalist Christian beliefs (e.g., to get baptized again in the daughter's church). Rather than take on that authoritative, pastoral voice that the daughter wanted, Chaplain 4 took a different approach.

The daughter at times would kind of try to set me up in the conversation to, you know, say... I don't know. It was uncomfortable but I was able to hold true to who I am and to my approach and, you know, I think I probably said, 'well I'm not sure I would articulate that the same way that you are' or something like that. It was kind of more a theological discomfort than anything. But I offered to them to sing some hymns because it was Christmas time. Sang some Christmas carols for them, had prayer. We were able to have kind of a private worship time which they really appreciated and loved and so that gave me a tool to provide common ground and to get away from the theological discussion and differences and just support them in the here and now. They probably were not, I hope that they weren't aware of any discomfort on my part.

Overall, examples like this were abundant—indeed, it is part of the expectation of chaplains to navigate spaces like these in this way.

This section embodies what is *not* part of the EOL chaplain role. They are not there to convince anyone of their beliefs, they are not there to impose their ideas, they are not there to self-disclose or share anything about themselves—unless asked. I love one story that further represents this. Chaplain 5 talked about how after a conversation with a Baptist Christian man, the man commented that after the conversation he had a stronger faith in Jesus Christ. Chaplain 5 told me that if he, a Buddhist, can help a strengthen a Baptist’s faith in Jesus then he’s done his job. I believe this sentiment is shared by the entirety of the EOL chaplain sample.

The past two sections described what chaplains do not do. This is important for anyone who may have been hurt by religion in the past—including LGBTQ elders. With the next section, I will attempt to highlight how chaplains engaged in spiritual support with their patients.

“Walking Alongside,” a Spiritual Companion: The EOL Chaplain’s Job³⁰

Given the misconceptions the majority of people have about what an EOL chaplain’s role is, and having clarified what EOL chaplains do not do, I will use the remainder of this section to highlight how EOL chaplains described their work. In this section I will highlight the “walking alongside the patient’s spiritual journey” which the chaplain participants consistently talked about.

³⁰ During Fall of 2017, I had the wonderful opportunity to attend the American Society for Bioethics and Humanities Conference held in Kansas City, Missouri. During one of the sessions, I overheard a chaplain speaking with another chaplain. He complained how often when social science researchers describe the role of a chaplain, the descriptions missed the mark—which I interpreted as missed the mark spiritually. I see this as an important warning of sorts and will make every possible effort to avoid such a description. As a result, I aim to utilize many voices—including, most importantly, EOL chaplains themselves.

Rather than leading, EOL chaplains explicitly clarified their role is to follow: What is important for the patient? What are their existing sources of strength? Rather than to force one viewpoint on their patient, they attempted to see as their patients see—how do they experience the world? How is that worldview informed by spirituality? What does spirituality mean to them?

For EOL Chaplain 7, it was about supporting his patients in dying authentically, staying true to who that patient was, who that family was. This empathetic supportive role was described in a few ways, for example, being witness to the patient's and/or family's stories.

I get to carry those stories, that's the gift. That's the beauty of what [chaplains] do is we are the holder[s] of story.

All chaplains shared this sentiment. In one way or another the chaplains were there to respect the unique path the patient and their family had taken: the pain, the victories, the grief, the love. The narrative that framed the life of a patient or that family's time together was where chaplains went. Chaplain 3 put that following in a unique way.

It's a matter of, um, kind of putting myself in a person's journey and experience that as they do.

Chaplain 3 aimed to see as his patients see, to join them wherever they were and walk with them. This "walking with" appeared to be a trademark of the EOL chaplain's description of their work. They attempted to be in this spiritual space for the patients however the patient needed them to be there. Several chaplain participants described this as following the metaphorical "trail of crumbs." They saw this as being fully present, to allow a sacred space to emerge. When they did this, the chaplains shared, the patient showed who they wanted and needed the chaplain to be in their EOL spiritual journey.

In addition to being witnesses to the story and strength that was already there, the chaplains shared that sometimes their job also meant enhancing the spiritual strength, reigniting that spirituality. Chaplain 5 summarized it well.

[Chaplains] enter into the process that a family is experiencing with their loved one in such a way that we can *help to sort of enliven that*, and just to be a part of that. Not to somehow intervene in it or lead it, or anything, but just to walk alongside that.

For some of the chaplains this “enlivening” appeared to mean ever so gently challenging their patients. In other words, once a relationship of trust had been established, digging beyond the surface-level answers the patient might originally give. Chaplain 5 described this as “getting through the smokescreen.”

You want to ask the right question that really is either something that they can’t simply answer or they have to really go deep... Being able to really listen and get through the ‘smokescreen.’ Because a lot of times when we’re challenged, we’re struggling... we say things that are kind of more of a ‘smokescreen.’ And the other person just typically goes, ‘oh, ok’ and moves on. Whereas chaplains, the training that we get is to see through that and—when it’s appropriate—to call it out or to ask a question that makes them have to get rid of that and go a little deeper. So, during the superficial, you know, I may let you get away with that for a little bit as we get to know each other, but at some point I’m going to go, ‘No, I’m not going there’ [laughs]... The ‘smokescreen’ is really, you know, more of a way of trying to get you, I’m answering your question but not giving you answers that are leaving me vulnerable or open... You know, like, for example, I’ve had people that are telling me how distraught they are over their spouse dying but then they say, ‘but, you know, I pray to the Lord Almighty and he gives me peace.’ Meanwhile, they burst into tears. And I’m like, ‘kay that’s not what I would call peace. For me, if you’re truly at peace, you’re not bawling because you’re at peace. That’s kind of contradictory, so. So I’m listening. That’s an example of a ‘smokescreen.’

In helping his patient to get vulnerable, not simply letting them give the “Sunday school answers,” Chaplain 5 was able to go deep with this patient and find their true sources of strength.

Sometimes, this process of “enlivening” also meant pointing out spirituality where the patients might not have otherwise noticed before. One perfect example of this again comes from Chaplain 5 who talked about being with a family who were huge hockey fans. At one point, he simply observed that hockey was like that family’s church. Their spirituality was different than

what might be expected, but hockey was how they came together and bonded as a family. He told me that this family immediately opened up to him after he helped them to see hockey in that way. He shared some of his role is helping families to realize that their spirituality is not “textbook,” but it is there. Chaplain 2 put it in terms of trying to help families see from different perspectives.

I don't think it's my job to convince folks, necessarily. It's my job to companion with them on their spiritual journey and give them some new things, perspective to think about... Engage those questions, offer different perspectives, and have some genuine, sincere, open dialogue about the issues that confront us all.

Chaplains tried to help their patients see their situation differently, if necessary. By pointing out things the patient or family might not have noticed by themselves, the chaplains assisted these people in finding spiritual gifts that the patient or family may have overlooked along the way.

In short, chaplains described their roles as being a present source of support and an empathetic ear that, when necessary, might reframe the patient or family's story to help identify sources of hope and/or strength. Upon building a relationship of trust, they described creating an environment where the patient or family could be vulnerable. This “source of strength” that was mentioned repeatedly was, for the chaplains, always spiritual and sometimes religious. In the next chapter we will explore the unique historical experiences of LGBTQ elders in order to better understand how that might inform their spiritual worldviews.

“Consciousness Raising Processes”: From Respect to Allies

While some people might believe that EOL chaplains are interested in proselytizing, that is in fact contrary to their code of ethics. The “Common Code of Ethics for Chaplains, Pastoral Counselors, Pastoral Educators and Students” was a document released in 2004 by a consortium of spiritual care professional organizations that laid out the ethical responsibilities of

chaplains—EOL and otherwise. In the preamble of this document, it states the fundamental ethics. Spiritual care professional like EOL chaplains must:

- affirm the dignity and value of each individual;
- respect the right of each faith group to hold to its values and traditions;
- advocate for professional accountability that protects the public and advances the profession; and
- respect the cultural, ethnic, gender, racial, sexual-orientation, and religious diversity of other professionals and those served and strive to eliminate discrimination (*Common Code of Ethics for Chaplains, Pastoral Counselors, Pastoral Educators and Students (2004) | Ethics Codes Collection*)

Other documents that outline the ethical expectations for chaplains confirm this. For example, to achieve accreditation, many chaplains are required to prove their ability to perform a number of competencies. The Board of Chaplaincy Certification Inc. (BCCI) released a document entitled “Common Qualifications and Competencies for Professional Chaplaincy.” Most notably, a chaplain must be able to “[p]rovide spiritual care that respects diversity and difference including, but not limited to culture, gender, sexual orientation and spiritual/religious practices” (*Association of Professional Chaplains*). At the most basic level, EOL chaplains cannot discriminate against LGBTQ individuals. If they do so, it is a flagrant violation of their code of ethics that is reportable. They must respect the individual dignity of each person—which includes the gender and sexual orientation of that person. Beyond simply respecting the views of LGBTQ elders, however, this projects calls for EOL chaplains to be expanded and to change their own spiritual worldviews in order to best “walk with” their LGBTQ patients. While this thesis will outline important information to help EOL chaplains achieve that goal, chaplain literature that currently exists is also helpful.

For example, Robert Anderson and Mary Fukuyama write in their book *Ministry in the Spiritual and Cultural Diversity of Health Care: Increasing Competency of Chaplains* about this

process of expanding one's spirituality. These authors rely on a life narrative, that is, the story someone uses to describe their life, to explore the topic of culture. They argue that several identities can be important in these narratives including "age, gender, race, ethnicity, family of origin, chosen family, generational realities, spiritual and religious beliefs and practices, life style, social abilities, economic resources, sexual preferences and physical and emotional gifts, limitations, and characteristics" (Anderson and Fukuyama 7). (Again, the focuses in this project is almost exclusively the intersection of age and LGBTQ identity). They state that the process of interacting with someone with a different background can clarify one's own culture (i.e., what one assumed to be true universally may be challenged by people with different beliefs). Leaning into this process can result in an **expansion** of one's own spiritual worldview.

A synergy takes place when one experiences cultural diversity. Consider a metaphor of a window that has reflective qualities to it. Looking through the window of diversity, one sees difference; new ways of doing things or of being in the world; one's worldview becomes expanded. This seems to meet a natural human impulse, to transcend oneself and one's situation... At the same time, cultural diversity provides a mirror in which one sees self (beliefs and customs). Through this self-reflective process a greater sense of self can emerge, a clearer understanding of one's beliefs, for example. We see this interaction effect as being like a spiral, an expansion of consciousness, connections with others and connections with self and community. Many persons who engage in this consciousness-raising process also become aware of social justice issues and incorporate social action into their learning process (30-31).

Together, this demonstrates that EOL chaplains have the responsibility to expand their spiritual way of seeing when it comes to navigating difference with their patients. In the follow chapters, I will provide the information to aid EOL chaplains in this process with LGBTQ elders.

Chapter 5: The LGBTQ Patient, LGBTQ Health and Intersectional Histories

The LGBTQ Patient: A Brief Introduction to LGBTQ-Inclusion

Overall, when the EOL chaplains in my sample spoke of their experiences with LGBTQ patients in EOL and in healthcare chaplaincy, there was a resounding theme: those experiences were very few. Chaplains more commonly encountered LGBTQ family members than LGBTQ patients, which they could count on one or two hands. Furthermore, chaplains—especially those who were not LGBTQ themselves—expressed that they experienced interactions with LGBTQ patients as relatively “normal.” In other words, the spiritual issues that came up for LGBTQ patients were the same as patients that were not LGBTQ.³¹

First off, I believe the EOL chaplains were telling the truth. The chaplains are likely seeing fewer LGBTQ patients (the generation of LGBTQ elders with which they interact is the least likely to be “out”). Furthermore, chaplains indicated that they did not ask about the sexuality or gender of their patients because they try not to have an agenda with their patients (see Chapter 4). In other words, if it was important for the patient to discuss, chaplains expected patients to bring it up themselves.

Historically speaking, this is impressive. As I will discuss later in this chapter, homosexuality was long seen as a mental illness in medicine. In a Christian context, homosexuality was a sin. Transgender folks share similar stories. Therefore, that chaplains are able to express that their LGBTQ patients are “normal,” is a good first step. These chaplains have obviously done some work to reach this first level of LGBTQ-inclusion. However, we have

³¹ Each of them was able to come up with examples of LGBTQ patients in the past. Two chaplains shared stories about transgender patients—one, interestingly, whose partner did not know he was trans. Other chaplains talked about LG patients.

to continue the progress. It is problematic to stop at “LGBTQ patients have exactly the same, normal human spiritual experiences” and call it a day or feel satisfied with that answer.

It is useful to briefly make a comparison to how this would sound if the chaplains were talking about race as opposed to gender and sexuality. If a patient of color were to come in to EOL care, they would, without a doubt, most likely have very similar, very “human” EOL spiritual issues. Nevertheless, to think that racism doesn’t impact their lives and their spiritual views is to deny an entire facet of their existence and life experiences. To say, “all patients are the same, I am colorblind” leaves the assumed neutrality of whiteness entirely unchallenged. Statements like this allow whiteness to continue being “normal,” and thereby privileged. It requires no shift in the spiritual worldview of the chaplain. Returning to our LGBTQ patients, I extend the argument—what exactly is a “normal” EOL spiritual experience? When this “normal” goes unexplored, heteronormative and cisgender-normative assumptions persist, which deepens discrimination. Chaplains may continue to use their straight, cisgender spiritual lenses instead of attempting with humility to understand how their LGBTQ patients see. Furthermore, what happens when someone does not have a partner supporting them or if they are not “out”? If this “normal” means every person in EOL care without a partner is automatically assumed to be straight, single LGBTQ people may never feel safe to explore their full stories or their sexual/intimacy needs. Similarly, given the medical and religious abuse that many LGBTQ elders have experienced and/or witnessed, is it hardly any wonder that they might try to avoid talking about the LGBTQ parts of themselves. Beyond that, we can also begin to see why they may not want to talk to a chaplain at all. Lastly, even if LGBTQ issues did not emerge as an identity issue, per se, in EOL spiritual care—which was something even some of the LGBTQ chaplains indicated—it will likely not always be this way. Indeed, given the responses of the

LGBTQ participants—especially the Baby Boomers—I can all but guarantee that chaplains will need to inform themselves on these issues between now and the next fifteen or so years because a large population of loud, proud and out LGBTQ patients are coming.

Admittedly, this creates a very difficult position for EOL chaplains.³² Overall, most of the chaplains were wonderful—without a doubt, I would trust my own EOL spiritual care to any of them. Some of them shared being moved by experiences with their LGBTQ patients—which demonstrated the spiritual and social justice work they had already done. However, there is still room for growth. I believe EOL chaplains who identify as LGBTQ have a lot to teach the EOL chaplaincy profession when it comes to this topic.

What the LGBTQ EOL chaplains said highlighted what the non-LGBTQ EOL chaplains did not say. For example, two of the LGBTQ EOL chaplains did not personally self-disclose their identity when working with LGBTQ patients; however, they did express that their experiences informed them as to what questions to ask and where they should go with their patients. Chaplain 5, who was gay, mentioned that he knew how to ask about family without assuming there was an opposite-gender partner or children. This chaplain mentioned that he knew what questions to ask about religion if and when it came up because of his own painful history with Christianity. Chaplains, whether LGBTQ or not, need to train themselves not to assume what a family structures for a patient looks like.³³ They should also understand the experience of LGBTQ individuals in and with religious communities.

³² I am not an EOL chaplain. Maybe someday I will be. In the meantime, I rely on the work of EOL experts who focus on LGBTQ-inclusion (see Acquaviva).

³³ The implications of this go far beyond just not assuming with the patient but also their family members. A teacher of mine who is a lesbian told me a story that relates. Teacher's father (Father) recently moved into an assisted living setting. The wife of my teacher (Wife) went to support her father-in-law. One of the nurses asked if Wife was Father's daughter. Wife said she

Chaplain 4, who was lesbian but mentioned she does not typically self-disclose that with patients, told me about having been introduced to women's theology as well as women and lesbian poetry. She also told me a story about another woman in her life who was also a lesbian—this friend had tried to be ordained but was rejected because she was LGBTQ and subsequently committed suicide.³⁴ Clearly, Chaplain 4's experiences gave her the information to support LGBTQ patients well. EOL chaplains should learn from this, becoming more comfortable with the work of feminism and the implications on their work and their theology. They should also recognize that when it comes to mental health, suicide and substance abuse, LGBTQ patients may or have painful histories or need additional support (discussed later).

While those two LGBTQ chaplains mentioned they almost never self-disclosed their identity, the third LGBTQ EOL chaplain in my sample, Chaplain 7, said that when he came out to one of the gay patients “it was like someone turned on the light.” For that patient, knowing that he was being cared for by someone from the LGBTQ family changed everything—he was able to talk about the support his partner would need, he opened up more, he allowed Chaplain 7 to be present with him during his final hours. For EOL chaplains who are LGBTQ themselves, this experience demonstrates that self-disclosure, if they are comfortable with it, may be helpful in relationship building with their LGBTQ patients. Furthermore, this demonstrates that having someone on the interdisciplinary team who is LGBTQ is important. Being LGBTQ helped EOL chaplains connect more deeply with their LGBTQ patients. LGBTQ chaplains were able to see

was not. Nurse responded by saying, “I didn't know [Father] had a son”—assuming Wife had to be married to a man. Do you think an LGBTQ patient would feel safe to “come out” to their providers if assumptions like these were being made?

³⁴ More than a third of the LGBTQ participants in my sample talked about experiences suicides, two of those had LGBTQ partners who committed suicide. Others talked about their own history with depression and suicidal ideation.

the challenges and anticipate the needs of their LGBTQ patients before those challenges even arose. They were able to see with similar spiritual worldviews as their patients, use similar standpoints. They could be on the same “wavelengths” as Chaplain 7 put it.

Obviously, not all EOL chaplains are LGBTQ. They shouldn’t be! LGBTQ is only one component of a diverse EOL chaplain population. Therefore, the question must be asked, what can straight and cisgender chaplains do to make sure they are creating the most inclusive and comfortable environment for all their patients? What should they do to see, spiritually, as their LGBTQ patients might experience their world?

First, avoid assumptions. Chaplains in this sample were all fairly good about this. For example, several of them said while they had not interacted with many LGBTQ patients, there were probably many who were not “out.” Ask questions—to everyone! Don’t skip over them ever. Questions such as “What words do you use to describe your sexuality? What words do you use to describe your gender? What pronouns do you use? What words would you use to discuss your race and/or ethnicity?”³⁵ (For a whole book on this and LGBT-inclusion in EOL care, see Acquaviva). Importantly, the idea that “if it’s important to a patient, they’ll bring it up” is based on the assumption that LGBTQ people will share a vulnerable piece of themselves to a chaplain who is not only a religious representative but also a representative of a medical system—two

³⁵ This can be hard, and sometimes uncomfortable. I asked all the participants in my study each of these questions. Sometimes they would give me a look, “what do you *think* my gender is?” However, for my transgender participants—especially Elder 5 who was gender-queer—asking that question made him more comfortable. I asked, rather than simply letting my idea of him be my reality. Similarly, I had wonderfully and interesting conversations when I did not make assumptions about sexuality. For example, upon visiting one lesbian couple’s home I was surprised that one of them identified as bisexual. In my experience as a researcher, giving these exceptional individuals a chance to share a piece most people don’t care to ask about was entirely worth all of the confused looks from participants who expected me to know their gender, race, sexuality, etc. simply by looking at them.

institutions that have both been sources of discrimination and abuse for LGBTQ people. Instead, asking questions like the examples above signals to the LGBTQ patient that the chaplain is actively trying to not make assumption about sexual orientations and gender identities. It signals to them that they are in a safe place and that the EOL chaplain can be trusted.

In addition to these changes, I suggest chaplains make changes at an organizational level as well. Institutionally, ensure the EOL care organization's anti-discrimination statements include sexuality and gender identity.³⁶ This is likely something LGBTQ patients will look for when researching EOL care programs. Similarly, ensure that EOL care entrance forms ask about gender identity and sexuality in a way that provides appropriately open choices for patients to fill out their identities.

Finally, I encourage EOL chaplains to learn about LGBTQ history, LGBTQ art, LGBTQ spirituality, feminist theology, queer theory.³⁷ For the remainder of this chapter (and thesis), I will assist in that educational process by providing information on LGBTQ-specific health disparities, sharing a little bit about LGBTQ history with a focus in Colorado, and finally sharing some of the life-experiences shared by LGBTQ elders in this sample.

³⁶ One of the EOL care organizations from which I recruited chaplain participants had an anti-discrimination and harassment statement posted online that included neither gender identity nor sexual orientation.

³⁷ In the lit review process of this project, I phone-interviewed a non-LGBTQ hospice chaplain from Los Angeles, California to get a sense for the types of questions I should ask chaplains during the interviewing stage of the project. He told me that he had studied some queer theory and queer theology. However, he told me "it just never came up" in his work. I found this pretty intriguing. As a result, I asked EOL chaplains during my interviews if gender/sexuality comes up in any ways outside of the LGBTQ context. Several of the participants said it did not. A few chaplains commented that some patients who were men sexually assaulted female EOL providers. A few chaplains who were men talked about how men grieve differently—often becoming angry instead of sad. All of these stories point to "toxic masculinity" as a theme. I will not comment much on that idea here but it certainly fits their descriptions well. Clearly, gender studies and feminism are relevant in the EOL care setting.

LGBTQ Health Disparities

For the past five years as an undergraduate I have been studying public health and health equity. I have come to the conclusion that EOL care is in a very precarious position to examine societal health disparities. I personally refer to this position using the term “EOL Goldilocks Canary Hypothesis.” The “EOL Goldilocks Canary Hypothesis” posits that EOL care patient populations, like the proverbial canary in a coalmine, can be a warning sign and reflection of much larger societal health disparities. However, this presents a challenge: marginalized communities should neither be overrepresented nor underrepresented in the EOL setting; the percentages should be a direct reflection of the larger population. Like Goldilocks, the population of underrepresented patients cannot be too high nor too low.

Let me explain with people of color as an example. If our healthcare systems and community public health systems were equitable for everyone, which they are not, the population of EOL patients would directly reflect the racial and ethnic breakdown of the larger population. If people of color were overrepresented amongst EOL patients, this would be cause for concern. This overrepresentation could likely point to the fact that communities of color were experiencing health disparities that resulted in them disproportionately developing the chronic illnesses that necessitate EOL care—cancer, COPD, etc. This could indicate that people of color are dying younger and are experiencing less healthy lives, which is of obvious concern. Similarly, if people of color were underrepresented in EOL care, this would also point to potential health disparities (i.e., if the percentage of EOL patients of color were significantly less than the percentage in the general population). This could mean there are barriers preventing people of color from accessing EOL service. Maybe they cannot afford it. Perhaps they cannot trust their EOL care or the EOL care of their family members to a healthcare system that has

consistently been a source of discrimination and abuse. Regardless, both overrepresentation and underrepresentation of people of color in the EOL setting could point to larger issues. The goal should be to have an EOL care population that is a direct reflection, percentage for percentage, of the larger community.³⁸

This idea extends nicely to the LGBTQ community. Survey estimates taken in 2012 place the percentage of the population that identifies as LGBT at around 3 percent (Gates and Newport). Given these numbers, which are very conservative, for every 33 patients with whom a palliative care clinician or hospice worker interacts, at least one of those patients is likely LGBT (and/or Q). Considering this fact, how could EOL chaplains—several of whom who had been doing EOL spiritual care for decades—indicate that they had very few patients who identified as LGBTQ? After a quick and very conservative calculation,³⁹ I estimate EOL chaplains would interact with at the very least 15 LGBTQ patients per year. However, EOL chaplains in my sample indicated LGBTQ patients who were “out” were rare, several chaplains saying that in their entire career they could count LGBTQ patients on a single hand.

Clearly, LGBTQ people, at least according to the chaplains in this sample, appear to be underrepresented in EOL spiritual care. This could be the result of several factors. LGBTQ patients may not want to see chaplains, a disparity because, as discussed previously, spirituality

³⁸ An additional goal would be everyone would be fairly old or at least dying at the same age (i.e., certain populations shouldn't have a significantly lower life expectancy than another).

³⁹ There are 52 weeks in the year and 5 days in each of those weeks are workdays: ($52 \times 5 = 260$ workdays in the year). Let's say a chaplain is extremely lucky and receives 30 days of vacation or paid-time-off each year ($260-30=230$); indicating the chaplain works 230 days out of the year. Now if a chaplain served only 2 patients per day, another extremely conservative estimate based off my personal experience shadowing EOL chaplains, that chaplain would interact with about 460 patients in a year ($230 \times 2=460$). 460 patients times the 3.4 percent LGBT estimate would estimate that this hypothetical chaplain would have interacted with about 15 LGBT patients ($460 \times 0.034=15.64$).

is widely recognized as a crucial dimension of EOL care. It could also be because LGBTQ patients are not open about their gender or sexuality with their providers, which is particularly common amongst older LGBTQ people. Finally, this could also be because LGBTQ people (especially older gay men due to HIV/AIDS) died young or avoided EOL care entirely for whatever reason. I suspect all of these factors play a part.

However, several trends in LGBTQ health indicate that LGBTQ individuals, while they may not be “out,” might actually be overrepresented in the EOL care population as a result of specific health risks. For example, several authors have commented on how riskier health behaviors exist amongst LGBT (Q not included in the article) individuals. Davis and Soka cite several studies that include amongst these risky behaviors higher rates of smoking, substance abuse and risky sexual activity. They also share that lesbian and bisexual women have a higher average BMI than heterosexual women, which is associated with chronic illnesses and poorer health outcomes (Davis and Soka). The literature further indicates that lesbians are at a higher risk for breast and endometrial cancer (Cartwright et al.). Similar risks were indicated for gay and bisexual men who have a greater likelihood to develop certain chronic illnesses that might put them in the EOL care setting. For example, Cartwright et al. shared results from a study done in 2006 by Smolinski & Colón which reveal that gay and bisexual men had a greater risk for Hodgkin’s disease, anal cancer, and non-Hodgkin’s lymphoma (Cartwright et al.). Studies cited in the same article also indicate that transgender individuals would likely be in EOL care setting as a result of higher likelihood for diabetes, liver abnormalities and heart disease which were connected to hormone treatment (Cartwright et al.). On a basic level, results like these indicate that the representation of LGBTQ elders might in fact be greater in the EOL care setting than in

the greater society. These health behaviors and chronic illnesses might actually make it more likely that LGBTQ elders would come into contact with EOL chaplains.

Beyond these health risks, other factors might make EOL cases with LGBTQ people more complicated. For example, a source I read on LGBTQ-specific EOL care shared a study from 2012 by Durso and Meyer showing LGBTQ individuals have a higher risk for mental health problems such as suicidal ideation, anxiety, mood disorders such as depression as well as substance abuse (Davis and Soka).—substance abuse and addiction, specifically, will be explored in Chapter 7. A study of LGBT elders conducted by Fredriksen-Goldsen et al. indicated that a sample of LGBT elders revealed that half of that population had been told by their doctor that they had depression, nearly 40% had considered suicide, and more than half felt isolated from others (Davis and Soka). With regards to substance abuse, a recent 2017 study conducted on LGBTQ-elders revealed that 20% of the LGB elders in their sample expressed behaviors of high-risk drinking (Bryan et al.). To explain this, several sources have pointed to the theory “Minority Stress” which posits that oppressed groups, like LGBTQ people, experience chronic stress and poor health outcome as a result of discrimination such as homophobia, transphobia and stigma (Everett; Davis and Soka). These psychosocial factors could conceivably complicate the EOL care for LGBTQ elders.

Specific spiritual care needs for LGBTQ individuals in the EOL care setting are also complicated (see Chapter 6). Previous authors who have written on spirituality during EOL for LGBT older adults have indicated that being more educated on the specific histories of LGBT people can help clarify their spiritual perspectives and beliefs.

Spirituality can be an outlet for LGBT older adults who have internalized their emotions as a result of discriminatory acts against them. When discussing spirituality and end-of-life decisions for LGBT older adults, *it is important to consider historical timing and the impact of generational memories* on their views and beliefs in relation to what society

perceived at the time to be ‘normal.’ ... [P]ractitioners must be mindful of the painful generational memories that LGBT older adults may possess. It is important that both LGBT older adults and care providers find ways to confront any internalized negative beliefs concerning sexual orientation and gender identity to support the provision of care and to meet the needs of LGBT older adults; these efforts include the context of their spirituality (Swartz and Fruhauf 94).

Therefore, for the remainder of this chapter, I will share a bit of LGBTQ history—with an emphasis on Colorado. I will then share specific stories about growing up and growing old as an LGBTQ person shared by the LGBTQ elders from this sample. Together, this gives chaplains a glimpse of what might be salient amongst older LGBTQ patients.

Life Course Perspective and LGBTQ History

One way of addressing the unique experiences of elders in Gerontology is a model known as “Life Course Perspective.” Swartz et al. as well as Begston and Allen describe that gerontologists use “Life Course Perspective” to recognize how historic events and generational experiences impact the ways elders see and interact with their world. “Life Course Perspective” is useful to clarify the intersectionality of LGBTQ elders’ experience—at the intersection as both older adults and LGBTQ individuals.

Younger LGBTQ people have a different experience of discrimination than LGBTQ elders because of LGBTQ elders’ experiences as older adults. In many cases, younger LGBTQ individuals are the beneficiaries of activism and political action of LGBTQ elders. LGBTQ history is marked by this form of activism. Similarly, non-LGBTQ elders have a different experience of history when compared to LGBTQ elders. LGBTQ elders who felt oppression because of their gender identity and/or sexual orientation experienced history differently than non-LGBTQ elders. Non-LGBTQ people are dominant in society; therefore, LGBTQ history is

not reflected in most history textbooks. Considering this, it is helpful to take a brief look at LGBTQ history over the last hundred years.

To help chaplains and other readers, I offer a (very) brief summary of important LGBTQ milestones in the history of the United States. This timeline features prominent events that specifically took place in the Colorado Front-Range for the LGBTQ community. On several occasions Colorado was (and continues to be) pivotal to the national LGBTQ movement, with lasting effects today. The emphasis on Colorado history is necessary because the specific context of this research is the Colorado Front-Range. For LGBTQ elders lived here their entire life, the history in Colorado shaped them.

- 1914:** A Denver professor publishes “Homosexuality in Men and Women” reporting on his experience of the gay underground network (“A Brief LGBT History of Colorado”)
- 1939:** First Gay bar in Denver, The Pit, opens (“A Brief LGBT History of Colorado”)
- 1948:** Alfred Kinsey publishes *Sexual Behavior in the Human Male*. This was followed five years later by *Sexual Behavior in the Human Female*. Momentously, Kinsey proposed that about 10% of the population is homosexual (Alexander et al. 64).
- 1950:** Joseph McCarthy charges individuals he believes are Communist or homosexuals—he said homosexuals are a threat to national security because they “[are] all easy to blackmail”(Alexander et al.)

- 1952:** Christine Jorgensen’s “sex change” [now called gender confirmation surgery] is widely publicized, changing the lack of role models for transgender people (Harley and Teaster).
- 1959:** Post World War II, lesbians and gay men begin to recognize their minority status and oppression. This is marked by rise of the homophile(same-sex loving) movement in the early 1950s (Alexander et al. 65). In 1959, the Mattachine Society, a famous gay homophile group, holds a convention in Denver (“A Brief LGBT History of Colorado”).
- 1969:** The Stonewall riots break out June 27th and 28th in response to police harassment of patrons at the Stonewall Inn, a gay bar (Alexander et al.). Following Stonewall, activism in Denver during the 70s increases greatly (“A Brief LGBT History of Colorado”).
- 1972:** Colorado becomes the 3rd state in the nation to repeal sodomy laws. The Gay Coalition of Denver, a gay liberation group, is founded (“A Brief LGBT History of Colorado”).
- 1973:** Homosexuality is removed from the Diagnostic and Statistical Manual (DSM) (Cook-Daniels 289)
- 1974:** The First Metropolitan Community Church forms, it provides welcoming place of worship for LGBTQ people (“A Brief LGBT History of Colorado”). During this year, Harvey Milk—one of the first openly out, publicly elected officials—organizes a boycott of Coors Beer, a company out from Golden, Colorado (Faderman 304).

- 1975:** In Boulder, Colorado Clela Rorex issues first same-sex marriage license in the history of the United States (“Colo. Clerk Recalls Issuing Same-Sex-Marriage Licenses — In 1975”).
- 1977:** Aspen, Colorado passes an anti-discrimination ordinance, first in the state (Taylor).
- 1978:** The Harry Benjamin International Gender Dysphoria Association founded. In 2007 the organization changes its name to World Professional Association for Transgender Health, WPATH. This organization since its conception has issued standards of care for professionals (Harley and Teaster). This same year, Harvey Milk is assassinated (Alexander et al. 70).
- 1980:** In the early 80s, HIV/AIDS crisis is felt in the Denver community, prompting the creation of the Colorado AIDS Project (“A Brief LGBT History of Colorado”). The American Psychological Association introduces Gender Identity Disorder (GID), taking its first notice of transgender people. The term remains in the DSM for over 30 years until it is changed to Gender Dysphoria in 2013 (Cook-Daniels 289).
- 1983:** The Denver Principles are drafted by AIDS activists. This manifesto articulates basic rights for people with AIDS as well as mandates for treatment of people with this diagnosis. These principles are very relevant to the conversation of EOL care! (*Denver Principles*).
- 1987:** While the community of gay men are struggling with the HIV/AIDS crisis, a group of lesbians in Boulder form the Equal Protection Coalition and eventually pass a measure to include protections of sexual orientation with

regards to discrimination. Boulder is the second city in Colorado to do so (Taylor).

- 1991:** City of Denver follows Aspen and Boulder in establishing an anti-discrimination policy (“A Brief LGBT History of Colorado”).
- 1992:** Colorado voters approve Amendment 2 with 53% voting in favor. This amendment—which retaliates against anti-discrimination ordinances in Aspen, Boulder and Denver—is pushed by a Colorado Springs organization called Colorado for Family Values and prevented any government body in the state from including sexual orientation as a protected class status. This amendment is struck down by the U.S. Supreme court in 1996 in *Romer vs. Evans* (“A Brief LGBT History of Colorado”).
- 1994:** The U.S. military implements “Don’t Ask, Don’t Tell.” Previously, homosexuality was banned in the military. DADT allows someone to be gay/lesbian, as long as they do not talk about it. It is repealed in 2010 (Faderman 519). While DADT was repealed, discrimination towards transgender members of the military continues to this day (Cooper and Gibbons-Neff).
- 1998:** Matthew Shepard, a young gay man, passes away at a hospital in Fort Collins, Colorado. He dies as a result of injuries from being beat up because he was gay in Laramie, Wyoming. His death helps usher in hate-crime protection for LGBTQ people (Josue).
- 2001:** Colorado passes a hate-crime law, protecting both gender identity and sexual orientation as identities (“A Brief LGBT History of Colorado”).

- 2003:** U.S. Supreme Court rules through *Lawrence vs. Texas* to repeal all state sodomy laws (Faderman 593).
- 2006:** Amendment 43 passes in Colorado with the support of 56% of voters. It defines marriage as a union between one man and one woman (“A Brief LGBT History of Colorado”).
- 2008:** Colorado Governor Bill Ritter signs the Colorado Anti-Discrimination Act, thereby protecting LGBT people from discrimination in housing and public accommodations (“A Brief LGBT History of Colorado”).
- 2015:** U.S. Supreme Court *Obergefell vs. Hodges* decision extends the fundamental right to marry to same-sex couples (Faderman 635).
- 2017:** U.S. Supreme Court hears *Masterpiece Cakeshop vs. Colorado Civil Rights Commission*. This case, from Highlands Ranch, Colorado, pits religious freedom, freedom of speech and freedom of expression against CO’s public accommodations law. Decision of the court pending (Bravin).

A dramatic shift in society’s views regarding LGBTQ identities took place in a short period. LGBTQ elders alive today remember much, if not the majority, of this history. The unfolding of these events undoubtedly impacted how LGBTQ older adults in the U.S. see themselves, changed how they interact with each other, and shaped how open they could express their identities. The Silent Generation was at the forefront of civil rights and Stonewall liberation—seeing the demedicalization of homosexuality. Following that, the Baby Boomer generation was hit hard by the AIDS crisis but fought just as hard for recognition of that health crisis while caring for each other during a time when few else would. Both of these generations of elders lived through the steady decriminalization of same-sex relationships and legalization of

same-sex marriage. Similarly, transgender older adults have seen a shift from being a voice silenced in the queer community to now standing at the forefront of the conversations taking place (Faderman).

The “Life Course Perspective” tells us that these historic events—amongst others that were not included here—shaped the ways LGBTQ elders interacted with each other, with their communities, and with healthcare systems. In fact, several of the elders directly mentioned some of these events as mile markers in our interviews. Fortunately, I knew what they were talking about and could judge if it was important to follow-up on or not. That might not be true for all EOL chaplains. This would indicate EOL chaplains could benefit from knowing LGBTQ history. Clearly, this history impacts LGBTQ elders’ spirituality and their ways of making meaning during EOL. While this timeline is presented as relatively detached from personal experience, I will now share how the elders in my sample embodied this history on a personal level.

Growing Up, Growing Old LGBTQ

As the 15 LGBTQ elder in my sample were telling their stories, they consistently shared experiences that were uniquely LGBTQ and that are important to share with chaplains in order to facilitate more inclusive EOL spiritual care. Many of them talked about their experiences of discrimination and how U.S. culture has changed over their lifetime. Several shared their personal experiences of being LGBTQ—including realizing they were gay/trans, coming out, experiences of personal discrimination, as well as how their family’s response to them has changed over the years. While several talked about finding support in the LGBTQ communities, others wanted to point out that being LGBTQ was only one part of who they were. A few of the participants discussed what it’s like to be both an older adult and an LGBTQ individual. Lastly, few talked about how being LGBTQ shaped how they see the world.

As made obvious by the timeline shared in the previous section of this chapter, a lot has changed for LGBTQ people in a relatively short amount of time. When sharing their stories with me, a third of the participants commented on how societal changes had impacted their own lives. Some talked about the changes that have taken with respect to marriage. One participant, who grew up in the Caribbean, talked about how buggery (same-sex sexual behavior) laws are still in existence in his country of origin, and reflected on the history of colonization that established those laws. For others, however, rather than talking on a larger societal scale, they shared their shifting relationship with their family members.

Family dynamics were diverse in LGBTQ elders' experience. Some folks had no issue being gay in their family—they received support, regardless. Others talked about having to distance themselves from their family when they were younger. For several of those who needed to distance themselves, they described how their relationships with their siblings may have been or may still currently be strained. Younger generations such as their nieces, nephews, and grandchildren, on the other hand, were often fine with the participant being LGBTQ.

Nine of the fifteen participants, when sharing their stories, talked about the process of realizing that they were LGBTQ. One participant, Elder 8, she told me she knew she was a lesbian from a very early age. Despite growing up in a conservative town, which was not a good place to grow up as a gay kid, she knew she was lesbian when she was very young.

I knew I was a lesbian since when I was a little, tiny kid. You know, it was like, I used to pray to grow up to be a homosexual, yeah, when I was little kid. I'd read every magazine article I could get my hands on at like six, seven years old. It's like, when I grow up, I want to be a homosexual. That's what we called it back then, you know... I've always known, never a doubt. No problems, no questions.

For others, the process of realizing they were LGBTQ happened much later and was accompanied by feelings of discomfort. Along with the discomfort of realizing this, several had

discomfort when they were expected to be someone they were not. For example, several of the LG people talked about being very uncomfortable dating individuals of the opposite gender. One of the transgender participants mentioned “putting on a façade” at her work before transitioning.

This process of realizing and/or discomfort did by not follow an identical path for everyone in this sample. Several of the participants told me they had been married to an opposite-gender partner at one point in their life. Interestingly some of the participants also talked about, having recognized they were lesbian or gay, reconciling with attraction that did not necessarily fit that mold either (i.e., they were not exclusively homosexual either). For LGBTQ Elder 5, even after realizing he⁴⁰ had same-sex attraction, there was another stage during which he had to uncomfortably reconcile with the fact that his attractions were not exclusively homosexual. Eventually he became comfortable identifying as pansexual which for him meant “being attracted to the person, not the plumbing.” Another elder also did not have exclusively homosexual attraction but was content to continue to identify as a lesbian. After working through this stage of discomfort, several of the LGBTQ elders shared the subsequent experiences of accepting who they were and feeling comfortable with their identities.

After that experience of discomfort, several of the participants expressed a comfort that came with accepting who they were. Often this was accompanied with “coming out of the closet.” For Elder 6, a man who did not “come out to himself” until he was in his 50s, he talked about going from his initial experimentation with his sexuality to organizing a supportive community.

Elder 6: I could go [and get] anonymous sex, never having a relationship with anybody just go, anonymous sex.

⁴⁰ Elder 5 told me he prefers no pronouns. However, he also told me that he had a few friends who used he/him pronouns and he really enjoyed that. As a result, I chose to use he/him/his rather than repeating “Elder 5” dozens of times.

Interviewer: Gotcha, so you would cruise⁴¹, in a bookstore?

Elder 6: Oh yeah, oh yeah. Or parks... There were some cruisy parts, you know, and I then would go to some white parties. I don't know if you know any of that kind of stuff.

Interviewer: I've never heard of a white party.

Elder 6: Underwear party. You see, white party, yeah. And you know, these dark orgy things. So I'd do everything. I'm just experimenting, trying to do it all 'cause I'd never done any of it... I was just reliving my sexual adolescence.

Interviewer: Yeah, you had to catch up to everyone else.

Elder 6: Had to run quick. Yeah. So then I started a gay fathers book group [in that city] and started making more healthy connections with fathers who were struggling with trying to understand how they got married, had children, had families, and transition into identifying as a gay man. So that whole piece is not as prevalent in your generation as it is in mine because we were raised in a generation that lived by certain rules. And you, it wasn't, it was way before Don't Ask Don't Tell, it was way before gay marriage.

After going through this “reverse exploration of sexual adolescence,” Elder 6 was able to start to move away from the anonymous sex and start to develop relationships—which eventually led him to dating his partner. They have been together for more than two decades now.⁴² Elder 12 talked about realizing she was transgender—which for her provided a huge amount of relief, clarifying a lifetime of discomfort. As I mentioned, often this period of becoming comfortable

⁴¹ Cruising is how, prior to the development of apps like Tinder and Grindr, gay men would pick up other men. There were specific locations like bookstores, parks, record stores, etc., where gay men would go to scope out other men who were interested in hooking up. Cruising usually entailed staring at a guy one was interested in to express that interest. This project educated me personally on this process because I grew up during the gay dating/hookup app generation.

⁴² This quote is particularly powerful because it demonstrates how being gay is different for youth today. Many young LGBTQ today have a better chance of landing in a life situation in which they can be who they are, date who they are attracted to relatively early in life. That blessing is a gift from older generations of LGBTQ activists.

with who the participants were followed by a coming out experience. Elder 7 had a particularly moving coming out story which took place in a Catholic monastery.

I was up late one night, and I was staring out of the window from the monastery down over this big field. And it was like these thoughts just kept coming to my head. Why am I here? What am I doing? Where am I going? What's happening with this whole thing? What's the meaning of all this?... And it was probably about 1 o'clock in the morning... [I was in a] great big living room type thing and that's where all of us would gather in the evening to talk and stuff. And [a priest who walked in] was like, you know he started talking, he said, '[Elder 7's name], what's wrong' or 'what are you doing?' And I said, 'I'm just trying to figure stuff out.' And so we were talking, and he's a very good listener. And while we're talking, I just looked at him and said, '[Priest], I think I just figured it out. I am a gay man. I have been all my life and it's ok. I need to leave the order and live my life as a gay man and be out about it and be ok with it. And it really was just this sense of relief and weight lifted. And I think I was like 21, 22 at the time or something like that. And I just got so excited and so free I just started running around the room—I was jumping around the furniture, bouncing, bouncing, bouncing. And six months later I left [the order].

For several of the participants, their coming out stories were integral moments in their lives.

These stories of discomfort and then coming to an authentic sense of who they were became deep parts of their stories. Chaplains would benefit from learning more about these experiences and listening to these types of narratives.

For the majority of the LGBTQ participants, the LGBTQ community—especially during the early part of their lives—was an important part of their social lives and support systems. Many of the participants talked about LGBTQ people, spaces and groups that helped support them. This ranged from one lesbian who was part of a “radical lesbian separatist group” during one part of her life to a gay man expressing feeling free and authentic to dance and be who he was at a gay bar. For many of the participants, the LGBTQ community was also a source of support for them in their lives currently as well. Furthermore, many participants told me about their involvement in activism around LGBTQ causes (e.g., Pride marches, volunteering/running LGBTQ organizations, political action around marriage equality, and AIDS-oriented activism).

For the majority of the lesbian participants, they often commented feminism was a huge piece for them, particularly as they were growing up. They expressed distaste for how they were expected to act as women. Several of them were deeply involved with the women's movement and other feminist activism. LGBTQ Elder 14 talked about how being a feminist had been a barrier to connecting with older adults in her community, especially the women. While she went to college and had a career, the older women in her community did more "traditional" things.

I just don't think of them as peers. I don't think of women who were married and home all day everyday as a peer... I think they were much more 'traditional,' you know, and probably took on the, you know, patterns of living according to, you know, where they came from. I think they think their husbands are the head of the household—ain't nobody the head of my household but me.⁴³

For these women, feminism was an important part of the process in becoming who they were.

When it came to being both older⁴⁴ and LGBTQ, three participants explicitly commented on that intersectional experience. Several of the participants in my sample, especially the lesbians, were part of organizations or meetings exclusively for older LGBTQ adults. For many this intersectional time in their lives was extremely pleasant. While Elder 12 expressed an immense amount of joy and happiness in her life, she also expressed her concern as a transgender woman—that there will come a time when she cannot take care of herself. She mentioned that many of the care centers—aging communities—are Christian-based and she worries that people who care for her may be have prejudice against her as a transgender woman.

⁴³ She later admitted that her dog might be the one who runs things in her house, but the dog was a feminist too so it's okay.

⁴⁴ This "older" language, even "elder" for that matter, was a point of contention amongst my participants. Two of the gay men expressed a discomfort with that kind of language, one preferring the term "unyoung." In direct opposition, most of the lesbians were loud and proud about being "old." For them, it was about reclaiming the position of respect and authority that is supposed to come with being old in society. Elder 15 put it best when she told me that they've earned the white hair and the wrinkles—they want to be the wisdom keepers in society.

She expressed that while she felt comfortable going to a hospital in the Colorado Front Range, if her job moved her to a politically more conservative area she would be fearful about even going into the emergency room: “What if they let me die?” she asked. She then went on, without me having to ask, to talk about the struggles of LGBTQ elders in assisted living and hospice settings.

You know, I do a lot of visits in assisted living centers and hospice centers and I can see, I don’t know if anyone there is gay or lesbian because it’s not said, it’s not talked about... A lot of the care centers where I go to are Christian-based. And so, yeah. I wonder and worry uh about some of the people I visit—whether or not they are being cared for properly, if they have to go back into the closet in order to be cared for. I don’t know if [being LGBTQ] matters that much when you’re 85, or 90, or 95, but it should. I wonder, I don’t know, I can’t go back into the closet and I refuse to.

She put it better than I ever could have. She is right, it *should* matter that these elders are LGBTQ. Those stories of pain, triumph and love should not be filed away just to receive care.

For some of the elders, it was important to point out that being LGBTQ was only one important part of who they were, it was not the entirety of their personality or their story. I think this was an important dimension of my work that came up—especially given the fact LGBTQ is an integral component of my research. Being LGBTQ was just one part of the puzzle that made them who they are. While every LGBTQ elder I interviewed were complicated individuals with quirks and their own particular story, being LGBTQ should not be disregarded.

Finally, a few of the LGBTQ elders shared how they saw the world differently as a direct result of being LGBTQ.⁴⁵ For example, LGBTQ Elder 1 mentioned that being gay has forced him to develop social sensors (i.e., he is more aware of how people are thinking and feeling because he had to pay attention to that growing up). Being different because of sexuality helped him to notice and see his world differently than others. And he told me, looking back, he would

⁴⁵A stunning example of this comes from EOL Chaplain 7, a gay man discussed in Chapter 6. These sentiments are similar to Gloria Anzaldúa’s description of *la facultad* mentioned in Chapter 2.

not change that part of him. In a similar way, LGBTQ Elder 7 talked about how being gay during the middle of the AIDS crisis, caring for his friends and partner, impacted how he sees his work now in EOL care (note, he was not a chaplain). He shared that experiencing discrimination helped him to see discrimination toward others. He said how witnessing the stigma towards men with AIDS opened his eyes to how sick people are treated—“society doesn’t like people to be sick.” He pointed out that this discomfort with people who are sick is a fear of death itself. Nobody gets out of life alive, he told me, and that we might as well help to make other people’s journey into death more comfortable. In classic EOL language, he told me his goal is to make it easier for his patients “to do the work of dying.” Like this example, HIV/AIDS was a dominant theme when it came LGBTQ elders’ reflection on death, dying and their lives.

HIV/AIDS

Several of the participants talked about experiencing HIV/AIDS as LGBTQ individuals during their younger years. Some elders talked about supporting their friends and/or lovers who had HIV/AIDS. Other participants, gay men, talked personally about how living with HIV shaped their way of spiritually seeing the world and their view of death/dying. It is crucial that if this comes up with a patient, EOL chaplains have a solid working knowledge of the HIV/AIDS crises, how it was handled by the government, the activism that took place, and how that time might impact their LGBTQ patients—particularly gay men—when it comes to their work in the dying process.

I want to start by discussing a statement created in Denver by leaders of AIDS activist communities at the start of the AIDS crisis. Written in 1983, the Denver Principles provided recommendations for society and people with AIDS. The document tells allies to support people with AIDS against wrongful firing, eviction, and stigma; and not to scapegoat people with AIDS

or generalize their lifestyles. For people with AIDS, these principles encouraged them to form politically active communities, to educate themselves and educate others, and to inform their sexual partners of their status as well as practice low-risk sexual behaviors. Finally, the Denver Principles offers the “Rights of People with AIDS” which are particularly relevant to EOL conversations. People with AIDS have the right...

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
5. To die—and to LIVE—in dignity (*Denver Principles*)

Overall, these guidelines, written relatively early during the Hospice movement and the AIDS crisis, provide powerful expectations for all providers. They are particularly applicable to EOL care. People with AIDS should die and live in dignity. But notably, part of that dignity includes a right to “as full and satisfying sexual and emotional lives as anyone else.” What interests me here is that these principles go hand-in-hand: dying with dignity should include a conversation about “full and satisfying sexual and emotional lives” (his idea is explored in Chapter 8).

The Denver Principles speak to patterns regarding HIV/AIDS in my interviews. When LGBTQ elders talked about the AIDS crises, they did so either talked about others or spoke to their personal experience living with HIV. Those who shared experiences of others, they followed the following sub-themes: HIV/AIDS was a death sentence; there was huge stigma placed on people with HIV/AIDS; there were several organizations and activist communities that sprung up out of this time; and several participants talked about supporting friends and/or lovers who were dying with AIDS.

Many participants talked about HIV/AIDS being a death sentence in the 80s and 90s. When someone was diagnosed, they had two years or so to live. One participant, Elder 2, talked about his brother telling his parents he had HIV and, as a result, the brother also had to come out as gay. The whole family expected Elder 2's brother would be dead in a few years given the death sentence at the time, however, Elder 2 told me his brother is still alive today. Elder 11, a gay man, talked about living in an apartment with a group of other gay men in a major U.S. city on the East Coast. He estimated that 98% of that friend group was dead and nearly 90% of those deaths were a direct result of AIDS. Elder 13, a lesbian, talked about being in Alcoholics Anonymous throughout the crises and being surrounded by people who were dying. She talked about going to funerals for people in AA who died with AIDS and how half the people in the crowd at the funeral were “next up in line to die.”

Accompanying this death sentence, perhaps because of it, participants described the stigma placed on people with HIV/AIDS in the early stages. People told me about that fear of the disease “[brought] out the ugliest parts of humanity.” This seems to be perfectly embodied by the Denver Principles: providers should not need reminded that people have the right to health care when they are dying. However, during the early years of the AIDS crises, providers would refuse to work on people dying with AIDS. LGBTQ Elder 10, who later was diagnosed with HIV himself, talked about walking with friends who were dying with AIDS. He described that people would stare in horror. He discussed “the look” that dying individuals would have—face sunken, eyeballs bar back in the socket, a perpetual frightened appearance. This stigma deepened the discrimination towards the LGBTQ community at the time.

As demonstrated by the writing of the Denver Principles, organizations began to rise up. Sometimes these groups were formed by people with AIDS—ACT UP or the Gay Men's Health

Crisis (GMHC). Many of these groups were geared towards activism—trying to get health agencies and the federal government to take notice and take action. ACT UP, for example, would have their protesters lie “dead” in the street or in town hall meetings to represent the people dying of AIDS while the government did nothing (Faderman 435). Another example was a group of activists draping a condom-shaped parachute over the house of an anti-gay politician, Jesse Helms, who had called gay men “perverted human being[s]” and had tried to amend a \$300 million AIDS education bill to be “abstinence only.” The condom draped over his house said, “A Condom to Stop Unsafe Politics: Helms is Deadlier than a Virus” (Faderman 438). In addition to this activism, HIV/AIDS communities also established support networks for people dying with AIDS such as “buddy” systems. Elder 7 described the buddy network he was a part of.

What the volunteers did is we became what we called ‘buddies.’ Uh, and you as a buddy would get paired up with someone who was diagnosed with HIV. And the goal was get to know them while they’re fairly healthy. That way, become friends and when they start failing and things start happening, they know you and they feel comfortable with you coming in, helping them, doing things with them, for them, whatever. And especially at that time since everything was very closeted, was if you were diagnosed with HIV, at some point you’re going to start turning uh and you’re going to start having opportunistic infections. At that point, 10 to 1, your friends are going to find out, friends pulled away. Family finds out, ‘don’t come home we don’t want you to bring that here.’ Employer finds out, you get fired. All the sudden all these support structures start to drop away and you’re left there by yourself moving into a death sentence. So that way the buddies were right there to—as much as they could—pick up some of the pieces. And say ‘no no no, you’re not alone at least. You don’t have as much help but you’re not alone. We’re with ya.’

Several participants talked about this kind of work. Notably, three of the lesbian participants talked about how lesbian women stepped up during this crisis too. Often, they would care for gay men during a time other gay men were too sick to do so. In fact, according to several participants told me that many AIDS organizations were created and run by lesbians during this time.

Lastly, several participants described supporting their friends or lovers through AIDS. For example, Elder 14 talked about being with her good friend who was a gay man, during the last Christmas he was alive.⁴⁶ Elder 13 talked about going in to the hospital to support her friend who was dying of AIDS, feeding him so many cans of Ensures that cases of empty bottles started stacking up around the room. Lastly, Elder 7 told me the story of supporting his partner who was dying with AIDS

I mean, when he was going through dealing with opportunistic infections and stuff like that and losing energy so that he couldn't go to work. That wasn't, it wasn't hard. I never considered it hard because we, it was a thing. We were soul mates. And I don't know why, you just never feel you're really given that much when it's someone you love that strongly. It's like, well why wouldn't I do this for you? It's like, I love doing it for you. I don't care, I want to do it for you. So it's like, it's never a burden. But he did a thing, he had uh, he developed Kaposi's [sarcoma]. And what happened was his load for the T-cell count went down so far he developed cancer and it went to his brain. And so, I remember we had dinner one night—we had invited a bunch of friends over—and at the end he just said 'I got to go upstairs and go lay down, I'm just so tired.' And I said, 'well go ahead, I'll be up in a little bit; I'll clean up.' And so he did, and he never came downstairs again.

Elder 14 talked about how caring for his partner and being a buddy shaped his view of death. As mentioned in the previous section, he eventually started working for a hospice—helping others authentically do the work of dying. He told me that this partner had called death “the next great adventure” and how now, working in hospice, Elder 14 helps others to enter their next great adventures.⁴⁷

⁴⁶ She told me that this friend had wanted Freddy Mercury and Monserrat Cabellé's song “Barcelona” played at his funeral but his mother refused. Nevertheless, Elder 14 told me she has that song on a CD that she plays every time she gets into her car.

⁴⁷ Another powerful takeaway that Elder 14 shared from this experience, as well as several other elders, is AIDS taught him that sometimes life is just full of bad luck—just a poor hand in the poker game of life. Rather than being the “wrath of God” the gay men who were most impacted by AIDS in this sample tended to see these experiences as simply bad luck, a matter of chance.

Two of my participants I interviewed were living with HIV. Having this experience shaped their relationship with death and their spirituality in remarkable ways. For example, Elder 11 was a gay man who told me that he had two brushes with death during his lifetime—one was in the 90s when his HIV developed into full-blown AIDS, causing him to go into a coma. The second was a year prior to our interview, when he had a severe blood clot that almost ended his life. While he was in perfect health when we met, he said that as a result these experiences, he understood death to be a relief. He described it like a relaxing Saturday morning at the end of a stressful week. And as a result, he believed he would be able to “lean into” death when it comes again. Throughout his experience with HIV/AIDS and subsequent recovery, he talked about his spirituality being closely tied to coming back from having full-blown AIDS—especially in his artistic expression as a painter.

Elder 10, another gay man living with AIDS, talked about how receiving a death sentence through an HIV diagnosis was sobering. He told me that he now sees it as a positive event but it took some reflection to get to that point. Rather than some of the men who were diagnosed who worried constantly and freaked out after their diagnoses, he said he was a survivor. He just had the ability to get through. He negotiated his treatment in a way any healthcare professional should with their patients.

You don't expect to—other than hearing about your grandmother, your grandfather, or something like that—at the age of 33 you don't expect death to be on your front door suddenly. And that's kind of a sobering, um, it's a sobering event. And, I think the way that I see it mostly is it's a positive event. And I'm not sure if that has anything to do with survival as well. I mean, you don't see it as positive immediately. It's something more upon reflection later on—and sometimes many years later on. But, it kind of propels your life in a different way... And so, it's just um, yeah, just sort of continuing on with life as it is. And doing the best that you can, medically, um, with what's available. When new drugs come out, go to your doctor, talk about it, say, 'well do you know about this? Is this a good one?'... [My doctor] was kind of conservative [with the treatment]. And I was like, eh, I kind of like it actually that he's conservative about it. He says, 'well you're doing well; there's not enough data on this one yet, let's hold out for a while and unless

this one is causing you a lot of problems, let's... stay there.' So I kind of worked with my doctor in this collaborative way. I mean I would take his his information and and uh or but, then again if I was really having some side-effect that really didn't like dealing with, I would say 'listen, I don't want to deal with this anymore. Is there a drug that doesn't do this side-effect?' You know, or. Of course, in the early stages you didn't have much of a choice. Now you have a whole gamut of different thing. I just changed drugs a short while ago again. Uh, but I think continuing on with life is a way to deal with death. You need to be aware that death is there, but you don't have to live with it every second of the day. You know what I mean?

This quote embodies several goals of EOL. That is, what does death represent when it comes to making meaning? What does death mean for the moment at hand, the now? What does hope mean in the context of death and dying? Elder 10 was forced to ask these questions at age 33—decades before people typically do, at a time when there was huge stigma towards him because of his diagnoses. Furthermore, his depiction of the relationship between his doctor and him (i.e., navigating symptom management, side-effects, and goals of treatment) perfectly embodied the sorts of conversations meant to happen in an EOL care setting.

Elder 10 shared one episode where he was having dinner with his father. Elder 10's father was going on and on about Elder 10's retirement, his 401K, "yada yada dada, etc." and he just yelled at his dad. "Dad! Just shut. Stop talking about this! I'm probably going to be dead in five years. I'm not going to make it to that age." He never expected to make it to his 60s.⁴⁸

⁴⁸ In *Queer Time and Place: Transgender Bodies, Subcultural Lives*, Judith Halberstam writes about how HIV/AIDS impacted queer conceptions of time and place. Halberstam quotes poet Mark Doty who writes about living with HIV, "All my life I've lived with a future which constantly diminishes but never vanishes." Halberstam says this diminishing future "creates a new emphasis on the here, the present, the now, and while the threat of no future hovers overhead like a storm cloud, the urgency of being also expands the potential of the moment and... squeezes new possibilities out of the time at hand." Another gay poet, Thom Gunn, wrote in his poem 'In Time of Plague' "My thoughts are crowded with death / and it draws so oddly on the sexual / that I am confused / confused to be attracted / by, in effect, my own annihilation." Queer theorists have said this relationship with death results in a "rethinking the conventional emphasis on longevity and futurity" and instead focusing on "making community in relation to risk, disease, infection and death." As displayed by Elder 10's story, there is a

Elder 10 goes on to also share a powerful ritual that organically developed as a tool in his struggle with HIV.

I like swimming. And, I'd heard about the Gay Games and I thought 'oh, that sounds kind of interesting and might be fun to do.' I sort of [knew] how to swim but I'[d] never done swimming, you know like competitively. I [didn't] even know how to do a flip turn. But there was a gay swim team, masters swim team in [my city]. And so I thought 'let me check that out.' So I went to my first swimming thing and they welcomed me, wholeheartedly. And I got in the pool and they started the one and a half-hour training class—which is what it is—you swim for an hour and a half, doing various exercises and things... So I took off and swam... I got to the end of the pool and I was like hanging off to the side of the pool [dramatically inhales and exhales]. Gunna have to go back. Okay, here we go—swim back. Right? Practically collapsing at the end. And I made it through the whole workout and I was just blown apart... But I went back the next week. And I continued on. And they didn't think I would come back... And um, I swam with them for ten years. But, what's more important, I suppose. An important aspect for me was a part of my driving force in that, in making myself deal with the sensation of drowning all the time, when you're trying to swim and you're not good at it yet or efficient and you're exhausted and can't catch your breath and you have to continue on. I would put in my mind my friends' faces who had died. And I said, 'you're going to go to the Gay Games and you're going to swim. And you're going to do this for them.'... You know in [Alcoholics Anonymous] how they say 'it's finding something greater than yourself?' That's what I did with the swimming... not just because I wanted to, but I'm tired, I can't breathe, I'm drowning, but I'm going to do this for you, I'm going to swim for you, I'm going to make it to the end, I'm going to keep going. And I just kept pushing myself to swim for [all the friends who had died with AIDS].

I asked Elder 10 if this was spiritual after he told me this story, he responded with a solemn "yes."

EOL chaplains should be aware that experiences with death, especially in a way that is heavily stigmatized like HIV/AIDS, shaped the lives of LGBTQ elders like those shared in this portion of the chapter. Being present with patients who share these sorts of stories can be hard especially for older chaplain who might have been members of religious communities that

rejection of inheritance and other societal expectations of aging—saving money, childrearing, etc. (Halberstam)

thought “AIDS is God’s wrath on the gays.”⁴⁹ I encourage EOL chaplains to be witness to these stories. To be present. To grieve. It’s time for LGBTQ elders to be the teachers, to share this wisdom.

Conclusion

There were two troubling themes that emerged with EOL chaplains. First, chaplains indicated that “out” LGBTQ individuals were fairly rare. This is a problem because LGBTQ elders who are not “out” may not be having their spiritual needs met during their EOL if they do not feel comfortable sharing their LGBTQ stories with their EOL chaplains. Second, chaplains indicated that LGBTQ individuals had “normal” spiritual problems. This alludes to a larger issue, namely, the specific pain experienced by LGBTQ elders over the course of their lifetime was potentially not being heard or acknowledged.

To assist EOL providers in understanding the experiences of LGBTQ elders, I have provided suggestions for chaplains to make in order to be more inclusive—do not make assumptions, make organization-wide changes, and educate themselves on LGBTQ theory and history. I shared a timeline of LGBTQ history, emphasizing Colorado, to give EOL chaplains an idea of the lives of LGBTQ elders. I provided some of the experiences that LGBTQ elders shared with me about growing up and growing old as members of the LGBTQ community—experiences of discrimination, relationship history with their family, discomfort being LGBTQ and coming out. Finally, I shared the stories of HIV/AIDS that were explored by the LGBTQ elder participants. Taken together, these help EOL chaplains understand how the spiritual

⁴⁹ A mentor once told me “If HIV/AIDS was God’s wrath on gay men, then lesbians must be God’s chosen people because hardly any of them got it.”

worldview of LGBTQ elders, especially around death, is impacted by their histories of discrimination and oppression.

Chapter 6: The Spiritual, The Religious, and Everything Beyond and Between

Birth, copulation, and death. That's all the facts when you come to brass tacks

- T.S. Eliot (seen in Pedersen-Gallegos 97)

What [chaplains] do is hard to describe. The essence of any meaningful spiritual care is, by its nature, nebulous and ineffable, and trying to describe it tends to make you sound silly.

- Kerry Eagan, Hospice Chaplain (Eagan 16)

I will now build upon the previously discussed role of an EOL chaplain's role in order to identify helpful definitions for both spirituality and religion. I will then present how chaplains and LGBTQ elders' defined spiritual and religion in comparison to the established definitions. In addition to their definitions of "religion" and "spirituality," I will also include themes that emerged when LGBTQ elders talked to me about their experience with religion—both positive, neutral, and negative—as well as their current spiritual beliefs and practices.

A useful mixed-methods survey conducted by Perry Halkitis et al. both highlights the struggle of defining spirituality and significantly aids in clarifying how LGBT people view and define spirituality and religion in their own lives. Halkitis et al. asked 498 LGBT people at a 2009 Pride event in a major northeastern city to share their own definitions of "religion" and "spirituality" as well as their identification with those terms. The authors share that "little about the relative importance of religion and spirituality" is known. Even less is understood about their LGBT(Q) conceptualizations of these terms and how LGBT(Q) people enact religiosity and spirituality (Halkitis et al.)⁵⁰. Rather unsurprisingly, what existing research shows is LGBT(Q)

⁵⁰ I would further add that LGBTQ elders' views on religion and spirituality, is even more poorly understood. Perhaps because this survey was conducted at a Pride festival in a Northeastern city, the mean age of LGBT (Q not included) participants was around mid 30s (Halkitis et al.). Therefore, my project helps to elucidate if the resulting definition categories also reflect older LGBTQ adults in the Colorado Front Range. Spoiler alert, they do.

expressions of faith—a loaded term in and of itself—are “influenced by tensions between religiosity and sexuality” (251). These “tensions” were explained.

Religion has often been used to legitimize the ostracism of LGBT individuals. Sacred religious texts have been deployed as authoritative means of verifying that LGBT patterns of attraction and intimacy are sinful (i.e. antithetical to the will of the divine), to make claims about the end that will inevitably befall LGBT individuals (e.g., divine punishment, damnation), and to monitor and control the behaviors and identities of LGBT men and women. These uses of religion have meant that LGBT individuals often have had to cultivate their religious and spiritual identities in contexts that are hostile, as evidenced particularly by the politically zealous attacks of religious conservatives of the United States (258).

This complex history might, in part, explain why three-fourths of participants in that study were raised in religious households but only a quarter of participants indicated that they were still members of a religious institution. Furthermore, the study showed that significantly more participants identified as spiritual rather than religious. Taken together, the themes collected regarding the participants’ definitions of ‘spirituality’ reveal what the spiritual and religious lives of LGBTQ elders in the Colorado Front Range likely look like.

According to the Halkitis study, for LGBT people ‘spirituality,’ meant the following: belief in, knowledge of, or relationship with a higher power; understanding self, accepting self, being in touch with self; commitment to prosocial values, attitudes, and behaviors including respect for all life, compassion, kindness, forgiveness, and love; interconnectedness and unity of all life and experience. Other, less common themes included “belief in soul, spirit, transcendent

dimension of life;” “meaning, purpose and understanding” as well as specific practices such as meditation, prayer and/or church. These definitions are depicted in Figure 3.

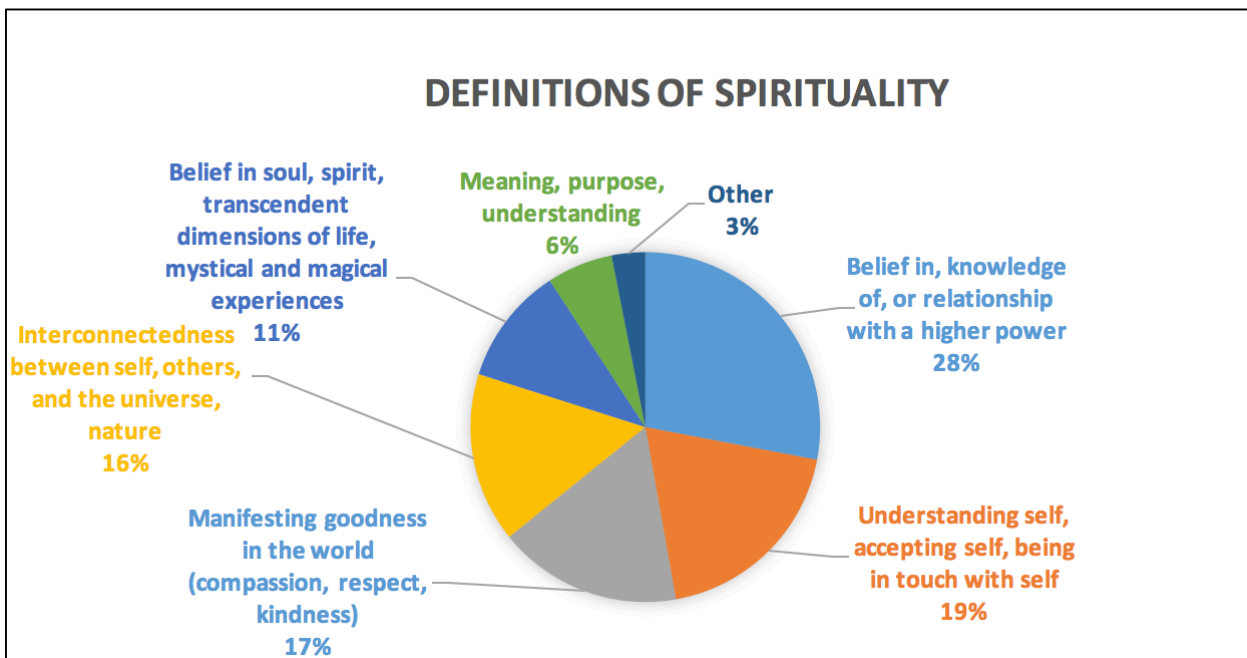


Figure 3: Halkitis’ Definition of Spirituality – This is a graph created to represent the data from the Halkitis study. Here, LGBTQ participants defined spirituality. This included pointing out a higher power, relationship with self, good or kindness, and interconnectedness, etc.

The picture of ‘religion’ on the other hand was quite different. Most of participants defined religion either along the theme of “organized or structured worship, rules and regulations associated with devotional or worship life” or as the “belief in existence of a divine, sacred and/or powerful force that is external to the individual and as personal relationship with God.” Other themes that came from this research, albeit with less frequency, demonstrated a more negative view of religion. 12% of participants said that religion was “man-made” or in other words a “cultural institution that is concerned principally with political, social, economic power, or wealth;” similarly, another 12% said religion was a “means of achieving cognitive control;”

and 7% described it as an “agent of divisiveness, deception, greed, hatred, punitive, war and harm.” Figure 4 depicts the breakdown of these definitions.

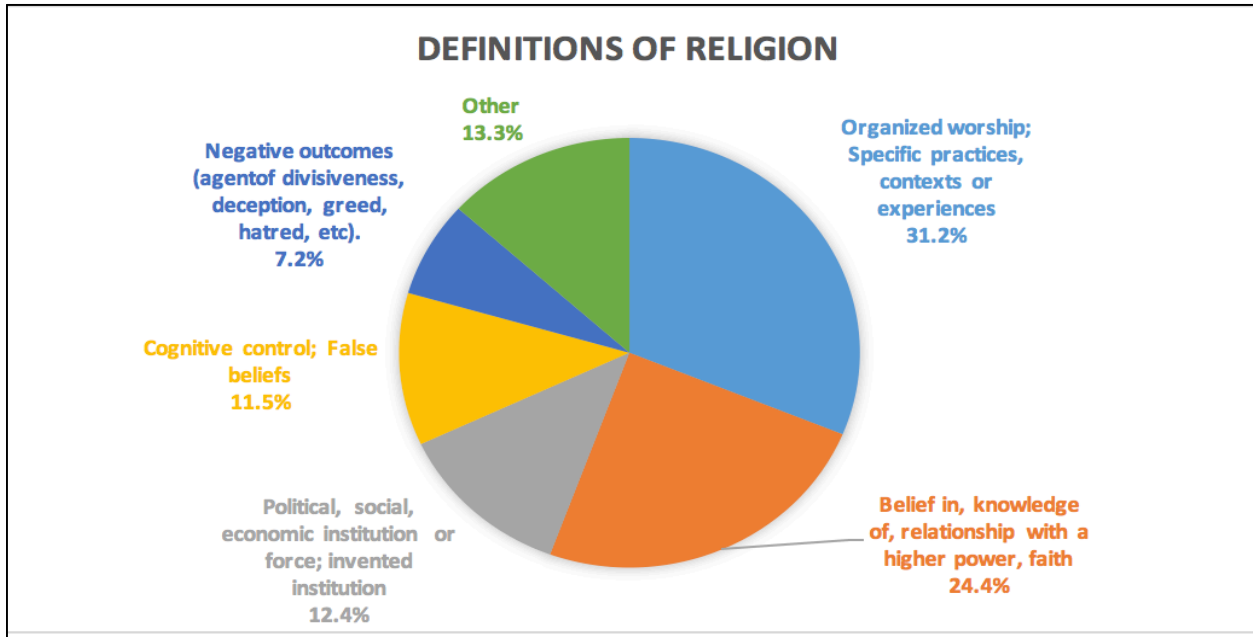


Figure 4: Halkitis’ Definitions of Religion – This image represents the themes collected in the Halkitis study when LGBTQ individuals were asked to define religion. Most common results were fairly neutral with some participants mentioning more negative definitions like “cognitive control” and “negative outcomes.”

While these definitions of religion are important to understand the experiences of LGBTQ people, they are impractical for the overall definition for religion to be used in this project. As mentioned, the definition of religion selected for this thesis has already been used in palliative care literature. ZinnBauer & Pargament and shared by VandeCreek’s definition: “[Religion] is defined as a personal or group search for the sacred that unfolds within a traditional sacred context”(VandeCreek 3). When I use the word religious in this section, this definition is what I am referring to.

Qualitative researcher, storyteller and social worker⁵¹, Brené Brown defines spirituality in her book *Braving the Wilderness* as follows: “Spirituality is recognizing and celebrating that we are all inextricably connected to each other by a power greater than all of us, and that our connection to that power and to one another is grounded in love and compassion”(Brown, *Braving the Wilderness* 45). When Brown gave a talk at the University of Colorado the Fall of 2017, she also added that “Practicing spirituality brings a sense of perspective, meaning and purpose to our lives.” She added that while some people may find this in church others might in fishing or through another activity or setting (Brown, *An Evening with Brené Brown*). This definition, while a personal favorite, poses some problems for this research. Primarily, “power” could potentially be divisive; “*something* greater than ourselves” would perhaps be a nice substitution—people might understand that *something* as love, justice, the universe. Attention to this seemingly minor word change is relevant because some people—both within and outside of the LGBTQ community—do not identify with often anthropomorphized view of “a power.” They may not believe in a higher power, per se, that has interest in an individual person’s affairs or life.

Definitions of spirituality currently exist in palliative care literature. In *The Journal of Palliative Medicine*, Puchalski et al. shared their developed definition of spirituality.

Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices” (Puchalski et al.)

⁵¹ and another personal hero

Based on and in combination with the themes from the Halkitis research, these definitions are helpful before examining what the EOL chaplain and LGBTQ elder participants in my interviews said.

Beyond the definitions and survey results, it is important to expand on the specific experiences with religion and spirituality that the LGBTQ elders in my sample have had. What kinds of experience might indicate why so many LGBT participants in the Halkitis study no longer are part of a religion? If “spirituality is expressed through beliefs, values, traditions, and practices” as Puchalski indicates, what spiritual beliefs, values, and practices are common amongst LGBTQ elders?

Religion

Defining Religion

The EOL chaplains, when asked to give their definitions of spirituality and religion said notably different things than the LGBTQ elders. When defining religion, the EOL chaplain participants were entirely neutral. Generally, they said that religion was narrower than spirituality. Many of them expressed that religion, for them, was a public or community expression of one’s belief system. They also mentioned that religion is attached to a building, a specific tradition of practice, or a major system of thought. All of them were also notably pluralistic (as would be expected after Chapter 3): they indicated that there were many religious paths that people take. Their definitions reflected the definition of religion shared already existing in palliative care literature.

When the LGBTQ elders defined religion in our one-on-one interviews, there was stark difference. Three major forms of definition that were offered by the elders: negative, neutral or positive—negative being, by far, the most common. See Table 3.

Table 3: LGBTQ Elders’ Definitions of Religion		
<u>Emotional Tone of Definition</u>	<u>Example: Religion is...</u>	<u>Number of participants (out of 9)</u>
Negative	“like a business”; “propaganda”; “just comfort from reality”	7
Neutral	“more like a ritual: mass, recited prayers, etc.”	1
Positive	“the framework that helps me to focus on God”	1

The positive definition came from LGBTQ Elder 8, a devout Christian.

Interviewer: You are, it sounds like, both spiritual and religious.

Elder 8: Well yeah! Absolutely, yeah.

Interviewer: What is... If you had to define religion what would you say?

Elder 8: Um. Never been asked this. For me, it’s like the framework that helps me focus. On um, on my God and on Jesus—I’m a Christian so I love Jesus like, like my brother, like my brother or sister.

The only neutral definition came from Elder 11, who identified as both Catholic and Buddhist. He defined it as “more of a ritual,” providing examples like mass, the Liturgy, recited prayers.

As mentioned, most of the definitions—the other six people who offered one—were negative. There was still diversity in the negative definitions. For example, Elder 1 (a former Catholic priest who left the church not because he was gay but because he did not believe what he was expected to tell people) said that religion is a structure of reality that people create to not feel so lost in the universe. Others offered different sorts of negative definitions. They would say

something similar to religion is “like a business” or “it’s propaganda.” Others defined it as dogma that must be regurgitated whether believed or not. They said it was often external and came with expectations that they change their behavior. They also expressed that it fell short when compared to fulfilling their spiritual needs and explaining their experiences of the world. In other words, religion did not seem to reflect how the world worked or how they believed the world should work. Overall, these definitions mirrored the definitions found in Halkitis survey remarkably well. However, my sample was more likely to share the negative definitions than the sample in the Halkitis survey did.

LGBTQ Elders’ Experiences with Religion

On August 29, 2017, the second day of classes of the Fall 2017 semester and the second day of me officially working on my thesis, I saw a friend on Facebook post something about a group of fundamentalist Christian leaders that made homophobic and transphobic comments. Nothing too new. Upon looking into the content of his post, however, I was concerned—especially in light of my then new project and how this kind of event would impact LGBTQ elders approaching EOL. A large group of Evangelical Christians (the document as accumulated 20,000+ signatures officially, many of whom are leaders of evangelical churches) came together to construct what they called the *Nashville Statement*. In the document, the authors mourned the state of society, which they depicted as moving away from the “will of God.” They then decried transgender, homosexual, and queer people via a series of fourteen articles, in which they made wide-sweeping statements about sexual behavior, biological sex, as well as gender and sex more generally⁵² (“Nashville Statement”).

⁵² The only chaplains I could find that had signed the document in their official capacity were military chaplains, none in EOL or healthcare chaplaincy.

This statement was an echo of what LGBTQ elders have been hearing their entire lives.⁵³ These experiences most certainly influence their views on spirituality and religion and therefore also influence their needs in EOL spiritual care. Importantly, the stances shared by the *Nashville Statement* have no relevance whatsoever in EOL spiritual care. The LGBTQ elders I spoke with have been “out” for decades. Therefore, the only conversation relevant for chaplains at that point in the lives of LGBTQ elders is how to make LGBTQ elders feel comfortable. EOL chaplains should focus entirely on how to not only stay open with their patients but how they can educate themselves about how their LGBTQ patients experience their world and be witness to the unique sources of strength that the LGBTQ population can pull from. Part of this process of understanding is learning about the history of conflict between Christianity and LGBTQ people in this country.

In this section, I will outline how LGBTQ elders in my sample talked about their personal history with religion. When my fifteen LGBTQ participants discussed their personal history with religion and religious people, they did so in three ways. They individually provided a negative, a neutral, or a positive experience—sometimes a mix. Positive and neutral experiences were then broken down into sub-themes, neutral experiences were not common enough to identify sub-themes. See Table 4 below.

⁵³ Similarly, *Masterpiece Cakeshop vs. Colorado Civil Rights Commission* is a U.S. Supreme Court case coming out of Highlands Ranch, Colorado, seemingly pits religious freedom against protection of same-sex couples from discrimination (Bravin).

Table 4: LGBTQ Elders’ Experiences with Religion, Religious People

<u>Emotional Tone of Category</u>	<u>Sub-themes</u>	<u>Examples</u>	<u>Number of participants</u>
Negative	It’s a show/politics	“All religions behind the curtain are the same;” “It’s all just a show”	3
Negative	Doesn’t make sense/Don’t believe	Bible isn’t sufficient to describe their experiences; got kicked out of community for disagreeing	7
Negative	Rules/Close-Minded/Hypocrisy	“I’m supposedly going to hell because I didn’t follow all the rules;” hypocrisy	5
Negative	Discrimination/Oppression	Experiences of discrimination/oppression as a person of color, woman, LGBTQ person	6
Neutral	(No Identified Sub-Themes)	All of the religious drama doesn’t matter; “Church didn’t work for me but it did for a lot of queer people”	5
Positive	Inclusion/Welcoming	Got married in the church; wasn’t laughed or stared at	3

Positive	Favorable Personal Experience	Enjoyed going to specific church, message of love; specific influential youth group leader	3
Positive	Committed to denomination/community	Part of an LGBTQ-inclusion organization as part of their denomination	2
Positive	Jesus/God	Separating Christians from Christ; reclaiming teachings of Jesus	3

Negative experiences

When they shared negative experiences, which were the most common, there were four patterns in the LGBTQ elders’ answers: they expressed that religion “is a show” or expressed distaste for the political side of religious communities or institutions; they expressed that religious teaching didn’t make sense to them or they did not believe the teachings; they talked about frustration with the rules and close-minded approach amongst people in the church; or finally, they talked directly about their experiences of discrimination and/or oppression in Christian communities.

Three of the participants when sharing a negative experience with religion—which was exclusively with Christianity in my sample—complained about the political, competitive nature of religious communities or they commented on how it was all “just a big show.” Notably, two of the three people who described an experience in this way were formerly Christian leaders themselves—one pastor and the other a priest. For example, Elder 6 said he had a first-hand experience with a diverse set of religions in his various roles as a religious leader. What he saw behind the curtain were well-intentioned communities that quickly became competitive, political

and self-serving. Elder 1, the priest turned scientist, shared an experience of carrying the incense in a Catholic mass, wearing long robes. He described this as a show, specifically comparing it to a drag queen performance⁵⁴. Instead of faith, he saw this entire service and tradition as superstition. If there was a God, he told me, that God wasn't impressed by all of this.

Several of the participants expressed that Christian teachings simply did not make sense to them. What they were forced to listen to—sometimes preach—simply did not feel right to them. Several of them talked about experiences that made them question teachings of the church—predestination, if there could even be a God amid of all this suffering, the divinity of Jesus. Others mentioned how what they had been taught just wasn't “livable,” it wasn't sufficient (i.e., religion did not align with their experiences of the world). Elder 1, gives an interesting example of religious teachings not making sense to him and how that impacted his mental health at the time he was a priest.

My advisor was great [about being gay] and said, ‘yeah, that’s one thing you’re going to deal with but it’s more a question of what you really believe.’ And for me, it was the anxiety of being up in front of people, officiating in any manner—a funeral or a wedding or whatever, just regular mass—and not believing but having to pretend. The emotions, I hated that. It just killed me. Anxiety attacks on top of anxiety attacks. It just wasn't me.

For Elder 1, and six other LGBTQ participants, things just did not make sense or didn't feel right to them which is from where their negative experiences stemmed.

The third way people expressed having a negative experience with Christians or Christian institutions was a frustration with the close-mindedness and hypocritical rule-orientation of Christians. Elder 7, another gay man who had lived in a Catholic monastery, talked about his frustration with the many the rules he was supposed to follow. He also talked about hypocrisy

⁵⁴ RuPaul Charles says “we all are born naked and the rest is drag” so maybe Elder 1 was onto something.

amongst the leadership in the monastery—especially when it came to sexuality. Several LGBTQ elders expressed frustrations with people being so tied to their beliefs that they were unwilling to consider any other belief systems. This was true for people who grew up in a religious environment, but also my single participant who did not have religion growing up. Elder 10, who was not raised religious but eventually found Buddhism and The Dharma, talked about a frustrating conversation with a coworker.

I was reading a book on anthropology that my sister had given me that was really fascinating. [I had this coworker] and I really enjoyed speaking with her. And uh, I, had lunch with her and talked to her about this book I was reading so bringing up these aspects of anthropology and early humans and etc, etc. And she just went ballistic on me— ‘stop right there, I don’t want to hear anymore, no it’s not true.’ I mean it was like iron curtain, totally black and white. It did not exist, total denial. Didn’t even want to question, think about. And that to me is absolutely baffling. It’s hard for me to understand how people can, I understand having a conviction. Fine, have your religious conviction. But can we just talk about this? Tell me about your conviction! Why won’t they even talk about their conviction?... And I think it comes down to this aspect of faith in a certain way. Their faith, it’s a blind faith. There’s no room for question. There’s no room for intelligence and debate on anything. It’s just no, it doesn’t exist. What do you do with that? There’s no place to go.

Even though Elder 10 was not raised Christian, he expressed the close-minded nature of this coworker who was not even willing to engage him on these topics

The last way that LGBTQ elders talked about having a negative experience in the church was describing experiences of oppression. For several interviewees, this had to do directly with being LGBTQ. For several of the women, it had more to do with being told they were expected to be subservient to men, husbands, etc. LGBTQ Elder 12, who is a woman, transgender, and Latina, expressed an overall frustration with a combination of oppressive histories in the Catholic church. Even though Elder 12 was one of the two active Christians in my sample, she shared a distaste for the oppression of the Latino people by the Catholic church.

Just going through [a major university in the Colorado Front Range], being part of the Chicano studies program, there was that whole oppression, and marginalization, and

subjugation of the Mestizo people—the people here in the Southern United States. That’s where all my family comes from is New Mexico and Southern Colorado. And everybody was Catholic because there was no other choice. You became Catholic, that’s it. So I left the [Catholic] church because of the patriarchal, hierarchal oppression of my people.

LGBTQ elders—especially women and people of color—in my sample expressed frustration with oppressive teachings and treatment in the church.

Neutral experiences

Neutral experiences were the least common and therefore sub-themes of neutral experiences were not observed as readily. Experiences belonged to the neutral category if the experience was described as neither good nor bad, both some good and some bad, or the bad portions of religion just did not matter in a certain context. Several participants just mentioned they had an experience with religion but did not go into much detail about that specific experience. Others shared that while their experience with religious communities was not great, but they had LGBTQ friends who were very happy in progressive churches. Another participant mentioned that while he had his political disagreements with the denomination he grew up in, he could typically put that all aside and allow his spiritual contemplation of “existential existence” take over. In other words, while he disagreed with some Christian teachings he could let that “wash away” when he was in a place conducive for spiritual reflection; when he was asking himself the big questions, the religious drama simply did not matter. Overall, neutral experiences with religion or religious people were rare but did come up.

Positive experiences

When an LGBTQ elder shared a positive experience with religion, they did so by referring to one of four sub-themes: they expressed feeling welcome and included in a specific religious community; they talked about a good personal experience; they talked about being

committed to their denomination or community and trying to improve it; and/or they talked about Jesus or God which was separate from the church for them⁵⁵. Overall, most comments about positive experiences came from the two devout Christians in the sample—Elder 12 and 8. However there were four additional participants who also shared positive experiences with religion or in religious communities.

When the LGBTQ elders shared a positive experience in a church, congregation or religious community, they often spoke about feeling welcomed and included as LGBTQ individuals. For example, LGBTQ Elder 14 talked about growing up Quaker and how her specific Quaker meeting were very supportive of same-sex marriage. She told me that because Quakers teach that “the nature of human relationships is that of God in me connecting with that of God in you,” that made for an open and accepting interaction—including for gay people in her community. LGBTQ Elder 8 got emotional when she shared her experience of getting married to her wife in her church and how the whole community showed up in whole-hearted support. And Elder 12, a transgender woman, shared her experience of going to her church for the first time expecting people to make fun of her but instead finding a lot of love.

I walked into the back of this church fully expecting people to say, ‘look at that man in a dress.’ But they didn’t. They were warm and they were welcoming and they were kind. And they asked me if I liked the service.

For these participants, being able to be who they were and be supported in their religious community was a common pattern when it came to descriptions of a positive experiences with religion or religious communities.

⁵⁵ For religious communities that want to be more inclusive of their LGBTQ members, these four sub-themes might deserve to be considered.

Outside of their LGBTQ identity, many of the participants simply shared having positive experiences in a religious community. Several of them stated that they liked singing and enjoyed listening to sermons of love. Others, while they did not identify as religious anymore told me that they still carried lessons taught to them by important Christians in their life. For example, Elder 15 told me that she had a youth group leader who was a very positive influence—encouraging her to live out her beliefs and teaching her how to engage in conflict. Even though she is now a shamanistic healer, good personal experiences like these were lessons she kept with her.

For the two practicing Christians in the sample of LGBTQ elders, they both expressed being committed to their community and being part of the movement of making it better. For example, Elder 12 discussed joining a task-force in her denomination that worked on LGBTQ-inclusion of its churches on a national level. Participant 8 summarized this type of positive experience well.

[A]s Christians, we can be holier than thou, and we can be self-righteous, and we are gigantic hypocrites. And in the Episcopal church, we work really hard to not be those things. We admit our failings; we admit that we're jerks. We admit that we have, in our profession of faith, all have sinned and fallen short of the glory of God. You know, it's like we're not perfect. You know, we call out when we see racism and when we see injustice. And um, we work really hard to be, um, the hands and feet of Christ on earth.

Elder 12 was quick to admit that her experience with the church and with Christians had not always been wonderful, but she decided to stick around to try and improve it as part of the community.

Lastly, when people talked positively about religion, they often spoke less about the church and more about their God and/or Jesus. Again, both Elders 8 and 12 talked about being huge fans of Jesus or having personal relationship with God even during periods of their lives when they were not part of a specific church. An example came from LGBTQ Elder 9; she was a 64-year-old lesbian and former hospice chaplain who had previously done congregational

pastoring. Elder 9 described how she was not a huge fan of Christians or Christianity but had recently reclaimed the teachings of Jesus.

Elder 9: I've kind of come back to my Christian roots a little bit. Uh, just in the last few years in an odd kind of way... Like, I see the value in that. Cause I kind of pushed it to the side for a while—I don't believe that anymore. And now I'm kind of incorporating it in my life more these days.

Interviewer: What does that mean? What aspects of Christianity are you incorporating?

Elder 9: Um, the teachings of Jesus and um. Uh, in other words kind of separating Christianity from Christians and what Christians have become these days, especially recently um with the Christians being so right-winged. It's like, I don't identify with that at all. But I, but as far as who Christ is for me, I try and follow that... I couldn't separate that years ago but I do separate it out now. And I just, that's just really a deep part of me that I'm reclaiming.

For these three participants, Jesus and God were religious figures that they had valuable and important relationships with that was worth sticking around for.

Spirituality

Defining Spirituality

When defining spirituality, the chaplains indicated that it is what gives one meaning and purpose. They clarified that while religion was public and took place in a community, spirituality was considered individual and internal. While religion was narrower, spirituality was larger.

Chaplain 3 defined spirituality (and spiritual care) in the following way:

Spiritual care is really encompassing a more whole-person approach to things. You know, I kind of. Sometimes a way I will introduce it when we're meeting with people for the first time is that, is kind of saying, when we're walking this life-path we're on, that there's a spiritual journey to that that I think all people go through. And it's. And we go through it with our own lens but it's a journey that's not something only like a religious person of one tradition or another would experience. It's something we all experience in our own way... I think of it as spirituality, big circle, religion, inside that circle. And just to be clear, I don't, I'm not really dismissive of religion. I would say actually a huge

portion of my patients are explicitly religious. But it's more that I think there's many ways to follow a spiritual path and that religion does not represent the only one.

Other chaplains made a point to say that spirituality is that which connects individuals to the “greater whole” and to each other. Lastly, Chaplain 6 mentioned it was the connection to “the beyond” or the unseen—later telling me about several experiences with “the beyond” with both spirits and a ghost. She was the only chaplain to mention this dimension of spirituality in her personal definition.

(I want to take some time to share an important reminder. If the reader does not agree or share a participant's definition, I remind them of the purpose of this thesis: to help chaplain's provide more inclusive care for LGBTQ elders. Therefore, personally agreeing with a definition or experience of spirituality is irrelevant. What matters is trusting the participants when they are vulnerable enough to share their experiences. Watching many of the participants break into tears as they shared their spiritual stories demonstrates those experiences were very real for the participant. Therefore, their journeys will be respected. A helpful comparison could be made for trusting LGBTQ people about their identities. One may never personally experience what it is like to be pansexual, transgender, queer, lesbian. That may be entirely different than one's experience of sexuality, gender, the world. Nevertheless, that does not mean those experiences are not true for the individuals who have different identities, different standpoints. Similarly, just because one may not have the same exact spiritual experience as another person does not render that other person's spirituality fake. The goal of this project is not to prove that one spiritual view or another is “correct” or “better”—just as one gender expression or one sexual orientation could never be “correct” or “better.” If one viewpoint shared by a participant resonates, that does not mean they were right. It simply means the reader may share a similar spiritual/existential worldview as that participant).

There were four sub-themes that emerged when the LGBT elders defined spirituality: it is recognizing something bigger than one’s self or something beyond; it is an intuition or a sense of comfort when something “felt right;” it as an experience of guidance that many participants said listen to, or follow; lastly, it is a “personal connection with God.” Notably, many of the participants described these experiences as starting at a very early age and being important parts of who they were⁵⁶. See Table 5.

Table 5: LGBTQ Elders’ Definition of Spirituality		
<u>Definition Sub-Theme</u>	<u>Examples: Spirituality is..</u>	<u>Number of participants</u>
Bigger than self, the beyond	“Recognizing there’s something bigger out there;” “wider than religion” “being connected to the larger universe”	8
Intuition, it feels right, comfort	“Perception;” “I something I feel inside me”	3
Guidance	“A feeling of being guided;” “listening to that internal voice”	2
Relationship with God	“my connection with God”	1

When speaking of “something bigger,” which was by far the most common sub-theme, there were a few ways that participants would describe this. For example, some described it as

⁵⁶ Not all LGBTQ elders offered direct definitions. That said, all did talk about their spiritual beliefs—found in the next section of this chapter.

being about the universe, more of an existential or scientific description. For example, LGBTQ Elder 1 describes his rather unique take on spirituality.

I just, what, what I realize is I'm not the center of this crazy universe. And I've realized that that kind of feeling that there's something more out there is kind of built into how we evolved. But it doesn't mean it's true—that there's some sentient being out there. But there is a bigger, whatever it is, unity, or. The universe has its own stuff. And maybe there's no end-game or purpose to it, it's pursuing its own path. And that, you know, what I think about that doesn't matter.

When he spoke of “the universe” and “bigger unity,” he did so in a more secular, scientific way.

Unlike other participants, he did not believe having a transcendent or spiritual experience necessarily makes it true. On the other hand, he also said he was not necessarily “unspiritual.” His “spirituality” was just a sense of insignificance in a much larger universe that he had no control over instead of a connection to a spiritual beings or a divine presence⁵⁷.

When talking about this “something bigger,” or the beyond, other LGBTQ elder participants had less scientific definitions. Most of the time this wasn't necessarily spoken of as a God but rather just “something beyond.” Regardless, accepting there's something bigger than one's self in this universe was by far the most common component of LGBTQ elders' definitions of spirituality. In addition to describing spirituality as something “deeper” or “bigger,” several of the participants noted that religion—in their experience—did not capture it well enough. They felt that spirituality went beyond religion. Spirituality was “broader” than religion.

The second major theme when defining spirituality was it was a spiritual feeling, a sense that something “felt right,” a visceral comfort. They described “just knowing things” would be

⁵⁷ Elder 1 was perhaps the least “spiritual” participant in the sample. Overall, he might prefer “existential care” instead of “spiritual care” during EOL. That said, he didn't seem opposed to “spiritual,” as long as people recognized what he personally meant and what wasn't meant by that. This example speaks well to the fact that LGBTQ elders are a diverse group. Even though these themes arose, everyone is obviously different and should be treated as such.

ok.⁵⁸ Spirituality, for them, was this type of sensation that they felt. Several of my participants would touch their chest when talking about this sort of feeling. This theme connects well and often accompanied the third major definition theme described: guidance.

As will be explored later in this chapter, many of the elders talked about spiritual experiences as a form of guidance. This was seen in the direct definitions of several of the elders. For example, LGBTQ Elder 11, a gay man, talked about receiving a message or being guided by a divine guiding “voice” that was part of himself.

Elder 11: I believe spirituality... lends to your feeling like you're receiving a message or a gift from God—if you want to put it that way. I don't believe in God as a person or an individual, I believe more in the universe and, and um energy. And where that comes from and how that manifests itself depends on what I am meditating on or what I am thinking about—what affects me.

Interviewer: So spirituality is a gift from some sort of energy or the universe?

Elder 11: Yes

Interviewer: And you said it affects you?

Elder 11: It helps me to listen to my little voice. I have this thing with the little voice and I have never allowed that little voice to go unheard. And I think that's one of the reasons that I feel I don't question as much about my path and what I want for myself or what I do.

While others didn't necessarily directly define spirituality as this experience of guidance, many of the elders described such experiences, which will be explored in the next sub-section about LGBTQ elders' spiritual beliefs, experiences, and practices.

⁵⁸ It might be helpful for the reader to pull in their personal experience of gender and sexuality here. How does a person know that they have a certain sexual orientation? They just know it because that's who they are. They are attracted to that/those gender(s). How are they attracted? They feel pulled to certain people and not to others. Sounds spiritual to me... This might be helpful for a reader who hasn't had a spiritual feeling like this to conceptualize what the participants meant by such a feeling.

Finally, only one participant, Elder 12, directly defined spirituality as her relationship with God. After telling me she was both spiritual and religious, she broke down for me what spirituality meant to her.

Spirituality is having that connection with God. Having that deep personal connection where I talk to God daily, sometimes constantly⁵⁹.

For this devout Christian, the connection with God and relationship with God was how she defined spirituality.

Overall, when directly defining spirituality, LGBTQ Elders in this sample did so relying on four primary themes: “greater than self;” an intuitive sense of comfort or credibility; an experience of guidance; and a personal relationship with God. The next section is dedicated to the spiritual beliefs and practices of these elders. The four themes in this section are mirrored in the experiences, practices and belief systems of elders. Note, unlike the definitions of religion shared by the LGBTQ elders, the definitions of spirituality do not appear to align as well with that Halkitis study shared at the beginning of this chapter. The spiritual experience, discussed in the next section, however, do align with the Halkitis categories.

Pinball, Meditation and a Direct Line to God: Spiritual Beliefs of LGBTQ elders

Not all elders provided direct definitions of spirituality. However, all of them did provide descriptions of their belief systems, their practices, and their history of spiritual experiences. When describing these parts of themselves, the following trends emerged: people shared their experiences of spiritual guidance, helping them to learn lessons they need to; participants described developing and sustaining a relationship with the spiritual parts of themselves; people

⁵⁹ Elder 12 told me she does not think of herself as a “child of God” but instead a “toddler of God.” Because, she told me, toddlers ask questions. “It’s important to ask God questions and expect answers,” she shared.

explained the importance of increasing love, goodness, and kindness, etc in the world.; many participants described a relationship with a higher power or God; several of the lesbian participants discussed spirit guides and guardian angels; a scientific/existential worldview arose, particularly amongst gay men; and finally, a few of the participants shared specific practices they use in their spirituality. Refer to Table 6 below.

Table 6: LGBTQ Elders’ Spiritual Beliefs, Experiences, and Practices		
<u>Sub-Theme</u>	<u>Examples</u>	<u>Number of participants</u>
Guidance/Lessons	“Overhear a snippet of conversation that answers a question I posed the universe;” “I follow the [spiritual] bread crumbs;” “following internal voice;” “spirit prompts me to do things;” “we are here to receive an education of sorts”	6
Relationship with Self	Self-compassion; “light within;” “getting in touch with my internal teacher;” “spiritual is within us”	3
Goodness/Kindness	“Kindness is... God’s work;” “loving the world and people is enough for me;” “I love seeing my relationship with my higher power help others”	8
Relationship with Higher Power	“My God is wonderful;” “I always felt that I had a direct line to God;” “I wake up every morning and make a connection with that [higher power] that keeps me sober”	8

Spirit Guides, Guardian Angels	Shamanism, wiccan, natural religions, spirits, animals guide in this life	4
Scientific, Existential Worldview	“you are stardust;” you are at a specific time and place in the universe and evolution; “science has become my belief system”	2
Specific Practices	Tarot cards, prayer, meditation	5

One clear sub-theme that emerged when LGBTQ elders talked about their spiritual histories was the presence of spiritual guidance or “learning a lesson they were meant to learn on this earth.” Like Elder 11 discussed above, who defined spirituality as following his little inner voice, six of the elders talked about this type of experience. One Christian LGBTQ participant, Elder 8, described being given a path out a huge financial debt which for her involved rather direct intervention from God. Although the path was not easy, a way out of debt emerged. She described what this difficult “path” felt like—not exactly what one might expect.

Elder 8: Do you know what pinball is?

Interviewer: Oh yeah sure, I played it on the computer but.

Elder 8: Well you need to get out and play with real steel balls, my friend [both laugh]. Get out there with the balls! And it’s like, you know, there are places in pinball games you can get the ball stuck between these bumpers and it goes bapadapadapadap and it’s like aaaaaah—you’re not going anywhere. You know? Or walking through something dark and you can’t see and then all the sudden it’s like bam, you hit a wall. Oh crap, that was not the right way to go... I feel like sometimes that’s what it is. It’s not yellow brick road, but sometimes it’s like just trying to be open to what spirit’s trying to say and lead. It’s like ‘grrrrrr, stupid! NOOOOO!’ [both laugh]. It’s like, ‘nah, nah, bam’ [slaps hand] brick wall. That didn’t work? Why did that not work? Well, it’s not [God’s] will, I didn’t do it the way [God] said to.

As you can tell, this “path” was not always described as a fun time or easy, it was not a “yellow brick road.” Sometimes the “spirit” informed her when she was going the wrong way. Another elder talked about waking up every morning and following the spiritual “bread crumbs through the day.” For those two examples, God or a higher power was part of the picture. Several other gave specific examples of spirit guides helping them with their paths.

Another common sub-theme when elders talked about their spiritual history was building and sustaining a relationship with the spiritual part of themselves. This often was attached to a practice, discussed later, like meditation. Particularly, LGBTQ Elder 10, a Buddhist, talked about learning to look at himself in a non-judgmental way, with self-compassion but also being able to look more objectively—not sugar coating when “the self” was not looking so good. This was an interpersonal relationship-building process for him⁶⁰. Others, like Elder 7, mentioned how his spirituality is no longer bound to a building or a church because spirituality is inside himself—allowing him to experience it anywhere and everywhere. Elder 6, formerly a Christian pastor who no longer identifies with that tradition, discussed the “soul” as being the light that is unique part of you that is inside you. He discussed trying to build a relationship and stay in-tune with that light that helps guide him, his “internal teacher.”

The third sub-theme when people shared their spiritual histories and beliefs was, overall, a sense and cultivation of “the good” in the world. Rather than abiding by religious teachings or doctrine, participants that commented on this type of belief system just tried to live out of a place of love and share kindness with those around them. Eight of the fifteen LGBTQ elders talked about simply treating others with honesty and respect. For example, Elder 7 discussed trying to

⁶⁰ This is also super Buddhist. If you haven’t heard of them before, check out Pema Chödrön and Thich Nhat Hanh—two of my favorite Buddhist teachers I enjoyed listening to during my personal time while working on this project.

increase the positive energy in the world—as opposed to contributing more to the negative energy.

I see the world, the universe—I should say the universe not just the world—is very interconnected. And, I've actually, I've moved from any thought of a God... There's almost an energy side to it of, and it's not so much electrical energy, a positive energy. That if things are treated well and done well, or for a good purpose, that ends a good energy to the rest of the universe to keep it moving. And that is what I think makes, will make, this world better to be in. Whereby, positive will create more positive, negative creates more negative. So let's move it to the good side rather than to the bad side.

Elder 7's experiences moved his spiritual beliefs from a God-based belief to seeing spirituality as improving the world with kindness and good acts. For him, in particular, being gay and living through the AIDS crisis in a very intimate, painful way helped him to come to these conclusions. Elder 13, said something similar. She was raised Christian but no longer identifies with that religion. Instead, she simply tries to live from a place of creating more good in the world.

I think there are things that are right and then there are things that are wrong. And I, there are certainly tenants in the Bible that I subscribe to. I'm like a big Golden Rule person. There's pieces like that that I think that I don't, like connect to Jesus Christ, my personal Lord and savior, but that I that certainly think are the right things to do for people and the right way to be in the world... I think kindness is the best attribute that anyone can have. And so I try to function out of kindness at all times. Do I fail? Yes... And then I usually look someone in the face and apologize and then start over... You know, that's, that's, I think that's God's work.

Despite not feeling a huge connection to all the teaching of the Christian Bible, Elder 13 held on to what she saw as important: being kind to people. This sub-theme was one of the most common. Interviewees often said, whether they were religious or not, they believe in doing the right thing and being a good person.

The fourth sub-theme used by LGBTQ elders to discuss their spirituality was a belief in a higher power. Eight of the fifteen participants talked directly about believing in a higher power or God. Those who believed in such a power often did not see this power as the Christian God—only two of the LGBTQ participants were regular Christian church-goers. As a result, some

interesting trends immersed⁶¹. For example, this God was almost never described to have a masculine gender by most participants—God was both male and female or neither. In fact, “God” often was not even seen as a person-like being, per se, but rather an energy or a spirit that connects everything. Many of the participants described having a very personal relationship with their higher power. I particularly enjoyed the relationship that Elder 14 described between her and God. This 82-year-old lesbian who identified as a Quaker but who was “not too Jesus-oriented” had a very intimate connection to God. Her description not only represented the higher power sub-theme but also other themes discussed above—like the guidance trend and a “feeling” that goes beyond intellectual knowledge.

Elder 14: I have always felt that I had a pretty direct line to God. So you know, I’m a Godian if there’s anything.

Interviewer: I like that. How has that come up for you? Perhaps outside of Quakerism, how has that direct line to God arisen?

Elder 14: It’s really strong. I don’t know how much I project that into the world, but what I know is that I have a very strong core of values and beliefs about, sort of, how things connect and that I trust my own core more than I trust anything else in the world—even what I know. And, and that’s, you know, It just all goes back to God... I mean, it leads me places where I know I’m right.

Elder 14, like others, recognized her relationship with God—which provided her with guidance—was very important and prominent in her life. Like other participants, she also described how she did not rely on “anything organized” in order to maintain this relationship with her God.

The next two sub-themes are interesting because there was a clear gender divide. Several of the women, four of the six, described having guardian angels, spirit guides/helping spirits,

⁶¹ Interestingly, even the church-going Christian elders didn’t necessarily appear to conceptualize of God like dominant Christian culture often does (i.e., white man with a beard).

and/or having a spirituality based in nature. Interestingly, three of these women identified as lesbian and the fourth identified as bisexual and had been partnered with a woman for more almost three decades. One of these women was a shamanistic⁶² healer and another had previously owned a metaphysical shop—they both spoke extensively on their experiences with the spirit world. The third, married to the former owner of the metaphysical shop, spoke of several experiences with her spirit guides and guardian angels. The fourth mentioned having two guardian angels in her life but did not mention the spirit guide component.

There was a minor sub-theme of individuals who had a more scientific world-view. The two individuals who talked most in these terms were both gay men—one who had a PhD in scientific fields and another who was not necessarily trained in science but indicated it framed how he saw his existence in relation to the universe. Elder 1 (the trained scientist who had been a priest) told me he eventually settled on a more existential and scientific worldview.⁶³ The other participant, Elder 10, who was a Buddhist, described his spirituality in a similar way—specifically referencing the universe, evolution and “just chance that we are here when we are” when describing his scientific/existential worldview. Notably, neither of these men—while quite secular—denied that they had spiritual experiences. Their spiritual experiences simply had nothing to do with other “spiritual beings” or divine forces.

⁶² Shamanism was described by her as the core belief system from which other religions have sprung. She shared there are three primary beliefs: everything is energy, we are all connected, there is no death. Her beliefs heavily involved nature.

⁶³ Nevertheless, Elder 1 does not reject that “transcendent” experiences take place—indeed, he mentioned times in his life when he felt them himself, including in the monastery and listening to moving music. Unlike other elders who described these experiences, however, he doesn’t make the jump that there must be a higher power or divine force attached to that transcendent experience. For him, these experiences are just neurons firing in the right way at the right time.

Finally, a few of the people talked about practices they used to help integrate their spiritual beliefs. Mostly, this was meditation. Others talked about prayer. The bisexual woman who owned a metaphysical shop discussed using candles and Tarot cards to “welcome spirit.” The shamanistic healer discussed a practice called “journeying” which she spoke of extensively.

In conclusion, all of the participants expressed some sort of spiritual belief—albeit in very diverse ways. Generally, the way they talked about their belief systems included experiencing a feeling of being led, a higher power, increasing general goodness in the world. In addition to these, several talked about cultivating and sustaining healthy relationship with the spiritual parts of themselves. Several lesbian and bisexual women shared that helping spirits and guardian angels were important in their spirituality while two gay men shared a uniquely scientific existential worldview. Lastly, some people talked about specific practices that they used. While the definitions of spirituality shared by the LGBTQ elders do not necessarily align with the categories shared in the Halkitis study, these experiences and worldviews shared in this section do support those categories very well—confirming that study is immensely useful when speaking not only about LGBT individuals surveyed at a Pride parade but also LGBTQ elders speaking one-on-one, usually in their homes (refer to Figures 3 and 4).

Conclusion

Experience with religion for LGBTQ elders has not been smooth sailing. When talking about religion, LGBTQ participants primarily referred to Christianity. Several elders expressed negative experiences with Christianity while others were more neutral or positive in their description of Christianity and/or Christians. EOL chaplains should not assume that all LGBTQ elders have negative experiences; however, those in my sample who did share negative experiences expressed that religion was “just a show”/political for them, that the teachings did

not make sense to them, they expressed a distaste for the rules or close-minded nature of some religious people, and/or they shared specific experiences of oppression/discrimination. On the other hand, individuals who expressed positive experiences with religion described feeling welcome in their community, having a good personal experience, sticking around to improve their denomination, and having a good relationship with Jesus/God outside of Christianity.

Despite the majority of LGBTQ participants indicating they were not religious, all LGBTQ elders described themselves as spiritual. There was significant diversity regarding what spirituality meant from participant to participant. Overall, when defining spirituality and talking about their experiences, LGBTQ elders generally shared the following sub-themes: they had experiences of spiritual guidance; their spirituality meant cultivating a personal relationship with themselves; they were motivated to be kind and share goodness in the world; several expressed a relationship with a higher power; some believed in spirit guides and/or guardian angels; others held a scientific/existential worldviews; and lastly, a few shared specific spiritual practices in their lives.

Taken together, this information aids EOL providers in their interactions with LGBTQ elders. These experiences and definitions of religion and spirituality from LGBTQ notably align with the study conducted by Halkitis et. al and reveal that while varied, LGBTQ elders have similar views of religion and spirituality indicated by that study.

Chapter 7: LGBTQ Addiction, Recovery as a Spiritual Journey

This is an intervention. A message from that space in the margin that is a site of creativity and power, that inclusive space where we recover ourselves, where we move in solidarity to erase the category colonized/colonizer. Marginality as site of resistance. Enter that space. Let us meet there. Enter that space. We greet you as liberators.

- bell hooks (hooks 159, emphasis added)

When conducting my initial literature review and writing my introduction, I recognized the fact that addiction and substance abuse was a prevalent issue in the LGBTQ community (see Chapter 5). However, I only came across this as an issue of public health. In other words, my initial research only pointed to substance abuse as a reason why LGBTQ patients would potentially be overrepresented in the EOL care setting (i.e., LGBTQ individuals are more likely to be involved in substance abuse, heavy drinking and smoking; together these and other factors put this population at higher risk for developing cancer and other chronic illnesses). My personal research findings, beyond the statistics, indicated that elders who had recovered from substance abuse and addiction described that as a powerfully spiritual process. Fully five of my fifteen LGBTQ participants talked about their alcoholism or history with substance abuse. Not only did one third of these LGBTQ elders—33% of my participants—described a personal history of substance abuse/alcoholism, but 100% of those five participants described recovery as part of their spiritual journeys. This was entirely unexpected for me as a researcher. The connections the elder participants drew between addiction, spirituality, and their LGBTQ lives embodied the nuanced, intersectional stories that this thesis represents. Furthermore, the stories they shared personified the statistics about addiction in the LGBTQ community with a soul that I simply missed while reading the existing literature.

Notably, unlike other chapters where chaplains were asked to speak to something specifically or brought up a shared topic, addiction was not something chaplain participants

independently mentioned. Therefore, this chapter will only share data from interviews with the LGBTQ elders. Specifically, the stories these elders told focused on the LGBTQ community and substance abuse, as well as how spirituality and service was incorporated for them in the process of getting, and staying, sober.

LGBTQ Identity and Addiction:

Several of the participants, when discussing addiction for either themselves or for others talked about how being LGBTQ and substance abuse interact. One individual, LGBTQ Elder 15, shared how, even though she was never addicted to alcohol or other drugs herself, being part of the lesbian community put her in contact with people who are reliant on these substances. In Elder 15's previous relationship, drugs and alcohol posed a barrier to that type of sexual connection she needed—her partner had previously never had sex unless under the influence of drugs or alcohol. This, Elder 15 noted, was not uncommon in the lesbian community.

LGBTQ Elder 8, another lesbian woman, shared her explanation for why substance abuse is disproportionately high amongst members of the LGBTQ community.

“In [the LGBTQ community] ... most of our life is based around bars... It's all alcohol. When you first start coming out, where are you going to go to meet people? You're going to go to a bar, meet people. Then you're all nervous so you drink. So I think there's a portion of that. I think there's people like me who had a predisposition to alcohol ... alcoholism. ... In this environment, in this world today, everything is based on numbing senses and alcoholism in [the LGBTQ] community, I think, is rampant. And I think it's not good for us and if we survive it, yay, and many of us don't survive it and I think it leads to other drugs and alcohol. Now, I came up in disco days—it's like poppers and you know, loved that stuff. But, you know, I think it's pretty easy. When you get a little alcohol in your system ... your good sense goes out the door. And yes, I'll try that drug, or I'll try this, or I'll shoot this, or I'll snort this. I think that kinda just snowballs for people.”

From her perspective, the setting that LGBTQ community members meet and the context in which they interact lends itself to developing reliance and addiction towards various substances.

Commenting on drug and alcohol culture amongst the LGBTQ participants was not unique. Many others also talked about the bar and drug culture prominent in their lives growing up in the LGBTQ community. For many, however, this was mentioned positively. Gay bars, for several of the participants, were places of freedom where they could find sense of community and be themselves. But as the perspectives shared in this chapter demonstrate, not all participants shared that positive perspective. Multiple elders also mentioned a history of alcoholism in their immediate family which to their own abuse of alcohol. In addition to these social structures, several of the participants described how oppression and being LGBTQ contributed.

Beyond the social context associated with addiction, other participants spoke to how their experience of stress and discrimination—both generally and as an LGBTQ person—interacted with their addiction. For example, LGBTQ Elder 12 talked not only about how partying contributed to developing an addiction but also how her experience as a transgender woman was always in the background, contributing to her alcoholism.

All through the 80s. From about '83/84 through '89, I partied really hard in [city in Colorado Front Range]. I would wake up next to people I didn't know, wearing clothes I didn't remember putting on—and half of the time they were women's clothing. Yeah, I was kind of just out of control. So in '89 I ended up living the back in one of my cousin's trailer. Managed to get a job... Within a couple months of moving in with my cousin I ended up in detox. So that was in 1989, and that was the first time I ended up in [Alcoholics Anonymous] and started getting sober. ... I heard that people were surprised I got married to a woman. So in order to dispel those rumors and feel confident with myself that I was now the man of my family, I went into law enforcement. ... [A sergeant] took me under his wing and taught me how to be a man, how to be an officer. ... But after a while, I would put on the uniform and put on a façade. And when I came home and took off the uniform, in order just to calm down and mellow out again, I started drinking again 'cause that was the only way I could get mellowed out.

LGBTQ Elder 12 was able to draw connections for herself between how stress, her experience of oppression associated with being transgender, and substance abuse that took place in her life.

Together, these quotes give context to how becoming addicted to substances as a member of the

LGBTQ community is not uncommon: they explain how internal stress associated with their LGBTQ identity as well as how partying, bar and drug culture that exists in certain LGBTQ spaces can contribute to addiction for some individuals. For Elder 12, she went into criminal justice to prove her masculinity. In doing so, she encountered not only the stress of carrying the “façade” but also the general stress of that already challenging job. The stress she experienced was different than her colleagues—as was her alcoholism and the spiritual process that eventually helped her to get help. Beyond why LGBTQ people experience high rates of addiction, what was perhaps most striking was how spirituality was integrated into those stories.

Spirituality, Sobriety and Service

As I stated in the beginning of this chapter, I wasn’t necessarily surprised that the occurrence of alcoholism and substance abuse existed in my participant sample. My preliminary research and personal experience had prepared me for that. Rather, what surprised me was that for all five of the people who spoke about their sobriety, they noted spirituality in some form as an integral component in their recovery process. This makes it absolutely necessary that EOL chaplains are aware of this finding. For example, all of the participants described supportive communities that were grounded in spirituality whether that was a recovering community like Alcoholics Anonymous or a religious community that allowed them to look at their addiction differently. For four of my participants, Alcoholics Anonymous was a reintroduction to spirituality after leaving religious communities. For one of my participants, his spiritual journey to Buddhism combined with recovery was described as his earliest, or at least most salient, memory of a spiritual moment in his life.

Elder 10: The [first spiritual memory] that really stands out is when I came to Buddhism for the first time.”

Interviewer: Tell me about it.

Elder 10: I had been in a four-year relationship with a man... When I got together with him I didn't know he was ... a meth addict. And uh. I got involved with him. I tried to get him off the drug but he's been an addict for 10, 12 years. Um. I eventually got involved with the drug with him and on my own eventually too ... And by the fourth year I was using pretty regularly... When I broke up with him I was then sort of floundering on my own and I was so miserable and unhappy and didn't know myself anymore... I continued using after that, of course—engaging in drug-fueled weekends of sex and, you know. And it got so bad I was taking meth to work with me and snorting small amounts of it in the bathroom to keep going during the day... I thought, I can't carry on like this. I've got to get control of what's happening... And then I ran into a friend... and he told me that there was a retreat happening and they would teach me meditation out there.

Almost poetically, Elder 10 talked about how this meditation retreat took place at a disco joint where he'd been several times over the years during the peak of “sex, drugs, and disco” but when he returned to that location, the room was dark, all the mirrors had been covered and cushions were on the ground. It was there that he had his first experience with spirituality when six Buddhist teachers all chanted in a cacophony of voices, “Who are you?”—“That is the question,” Elder 10 told me. He describes how this profound experience was the beginning of his spiritual journey. Later, he described how his addiction and meditation practice came to a head.

When I was trying to get off the drugs, uh, and don't get me wrong that was really fucking hard... I had come to Buddhism ... a month after breaking up with my boyfriend. And so I was just beginning... to learn and meditate. ... I mean, I'd be sitting on my cushion. I'd be meditating for 10, 15 minutes or something like that. And then I'd get up and get some meth from the thing and have a weekend of meth-fueled sex. I mean it was ridiculous... And I would fall into really dark, the depths of meth-fueled bizarre, dark, twisted, deviant kind of behavior. Um. That, I think at one point I felt like I had lost, lost all of [what had been experienced on the retreat]... The only way I can describe [what I experienced at the retreat] is it's like a door that's been opened. And suddenly you're able to see outside the door. You're able to see beyond. And, as I'm engaging in this drug, and sex, and all kinds of stuff and my world is getting narrower and narrower and narrower and more closed... and closing and closing. But it never did. If I turned and looked, if I took the moment to actually look at this spiritual thing that I had come in contact with—even though I didn't fully understand it—it was always there. This idea that I had gained during that retreat, I think what I saw was truth. That's the closest I can put it. But if I

took a moment to actually look, it was there. And all I had to do was [blows air between his hand] push the door open a little bit. And if I worked I could push it a little further [opens his hands a bit]. It is work to do that!

The dissonance he felt between this recently-discovered spiritual side and the part of him that was using meth eventually contributed to him stopping his use of the drug. Elder 10 described how with the support of his partner, he was able to throw out his meth kits entirely. Elder 10's continued contact with this spiritual side of himself was inextricably attached to his recovery from being addicted to meth. For him the subsequent spiritual journey was a process of learning to be nonjudgement and compassionate relationship with himself—to look at who he was honestly without that extra layer of aggression.

LGBTQ Elder 10 described this “spiritual thing” that he had made contact with, this enlightenment of sorts. Others talked about their spirituality in terms of a higher power. For some of the participants this higher power was a traditional Christian God. For example, both Elder 12 and Elder 8, who are devoted and devout Christians, recognize God's role in guiding them out of alcoholism. Other participants had a rather different picture of their higher power. LGBTQ Elder 5 discussed how integral Alcoholics Anonymous has become in Elder 5's spirituality. Elder 5 not only is a sober alcoholic but also has been diagnosed with dissociative personality disorder or multiple personality disorder. This next quote is part of an introduction to an important part of Elder 5:

This is PEGOWATOMI. And that is probably my, my inner spiritual advisor maybe would be the way to describe that. Um. The letters mean “please give me knowledge of your will for me and the power to carry it out” so it's my connection to that power. To that, um. You know, that helps me do. PEGOWATOMI and I can do what I cannot do myself—including being open to people and other kinds of help.

This, for those who don't know, is part of one of the 12 steps of AA. Step 11 states: “Sought through prayer and meditation to improve our conscious contact with God, as *we understand*

Him, praying only for knowledge of His will for us and the power to carry that out” (*Alcoholics Anonymous : What Is A.A.?*; emphasis as published). What this participant was sharing is that this spiritual process of connecting with a higher power is a very real part of LGBTQ Elder 5 is—personified as a particularly spiritual part of himself named PEGOWATOMI. This part of A.A.’s teachings is a spiritual guide, literally, in his life. And as he said later, Elder 5’s “God” isn’t necessarily how others might define God.

I was taught in AA. Every morning I get on my knees... I don’t particularly get on my knees as a Christian, I get on my knees just to remember that I’m not in charge. And I get on my knees and I ask God—whether it’s Group Of Drunks, or Great OutDoors, or Good Orderly Directions, or Grow Or Die—to keep me sober, away from a drink or a drug or a substitute... Sometimes I just graze my knees as I’m running up and sometimes I tarry. Then at night I say, ‘I guess you did it again, we did it again. Thanks. I really appreciate that.’

This definition of God is more expansive. For Elder 5, his relationship with a higher power was open—nature, community, personal growth, guidance. Other participants echoed this type of sentiment. For them, God didn’t have to be the Christian God. What appears to be important was recognizing there is a power out there greater than oneself. This sentiment—whether someone had picked up that belief at A.A. or elsewhere, was an undeniable theme for all five participants who commented on their personal history with addiction.

Interestingly, outside of the higher power component, another component of the 11th step from A.A. also reemerged with Elder 5’s reference of prayer. Prayer and meditation, it turns out was another theme that emerged from the participants who described their spiritual journeys. This has already been shown with previous quotes. However, what I enjoyed most was how several participants described prayer as an uncomfortable, or even a confrontational interaction with their higher power. For example, Elder 12 described being at her lowest point and her calling out to God in fury, calling “him” a “son of a bitch,” and telling God, “You better show up

this time.” She told me God did: helping her out of depression, alcoholism and suicidal ideation. Elder 13 talked about initially being uncomfortable with praying. One quote in particular from Elder 13 demonstrates how her sponsor helped her become more comfortable with the idea and practice of praying.

And then what [my friend] had me start doing—because I had never prayed. She had me start throwing my keys under my bed when I went to bed at night so that in the morning when I got up to go to work, I’d have to get on my knees to get my keys. And while I was down there, I might as well [pray].

This mentorship that Elder 13’s story demonstrates an important component of the journey for these participants.

Each one, in one way or another, mentioned how giving back through service or sponsorship was a final, integral part of their recovery. For several, this took on the form of directly helping other alcoholics or addicts through recovery. For others, this took the form of other community service endeavors. Helping others, regardless of the form it took, was often mentioned as important for the recovery process. Elder 13 discussed how growing up in an alcoholic home she was always a caretaker—which is where her profound knack for service and advocacy started in her mind—however she also mentioned A.A. as instilling part of that mentality in her.

Then I got into A.A., most of recovery is based upon service work. On your worst day, and you think you’re going to die, the solution is to call somebody else and check in on them. And it really reframes everything. And I did that for 25 years, I was sober for almost 25 years.

This community of support and service orientation was a common theme of their collective stories.

Conclusion

As explored in Chapter 5, LGBTQ elders are at a higher risk for a history of substance abuse. This was revealed in my sample. One third of LGBTQ elders in this sample expressed a history of alcoholism or a methamphetamine addiction. Some commented on stress associated with being LGBTQ was connected to their addiction while others commented on LGBTQ communities being centered around drug use and alcohol use (i.e., gay bars). Whereas past research, specifically in public health, talked about substance abuse in the context of a health disparity, the elders in this sample talked about recovering from their addiction in terms of a spiritual journey. They provided a soul to the statistics.

Because all five of these participants described their recovery process as spiritual, this needs to be addressed by EOL chaplains. Communities like A.A. may be important support systems and spiritual communities of LGBTQ elders. Notably, some recovering addicts may not be comfortable with opioids during EOL for pain management. One participant told me this directly. EOL chaplains can help support patients who make these decisions and advocate on their behalf with the interdisciplinary EOL team. Furthermore, EOL chaplains must be prepared to go with LGBTQ elders, and any other patients, as they share their histories with addiction. This is potentially an important source of spiritual strength that cannot be ignored. Lastly, because these elders talked about the connection between their sexuality/gender identity in relation to their substance abuse or alcoholism, EOL chaplains must be aware that for some, these are connected and intersectional (i.e., addiction for LGBTQ people is not the same as addiction for non-LGBTQ individuals). The nuance must be part of the conversation.

Chapter 8: Gender, Sexuality and Spirituality

People don't somehow transform drastically into something else when they're dying. They're just doing something you haven't done yet. I think of it sort of like sex. Remember back when you were a teenager, before you'd had sex for the first time? The mystery, the fascination, the ridiculous rumors? The fear? The sense that something about your very being would change when it finally happened? Now it's just something you do, not who you are. Happy, healthy sex can be a powerful experience and expression of who you are, but it doesn't fundamentally change you. Dying isn't going to change who you fundamentally are, either.

–Kerry Eagan, Hospice Chaplain (Eagan 187)⁶⁴

At the crux of my argument with this project are a few questions. Is sexuality and or gender relevant for EOL spiritual care? Is there any connection for LGBTQ elders between their sexuality and their spirituality? Between their gender and their spirituality⁶⁵? It turns out, according to my interviewees, the answer to each of these questions is yes. While all participants agreed that these parts of themselves were somehow connected, there were interesting differences between chaplains and LGBTQ elders—especially when comparing non-LGBTQ chaplains to LGBTQ elders.

Discussing sexuality and gender in the context of spiritual EOL care is crucial for LGBTQ elders, but also for non-LGBTQ patients. Therefore, exploring this topic with the LGBTQ population holds benefits for everyone.⁶⁶ I will first share current literature on sexuality and intimacy in EOL care, especially with respect to older adults. I will then continue with my

⁶⁴ While Kerry Eagan may not be LGBTQ herself, this has to be the queerest description of death I have ever come across.

⁶⁵ Gender is unexplored in existing literature for EOL care in comparison to sexuality.

⁶⁶ Working in palliative care and assisted living, myself, I have been pleasantly surprised to see how sexuality and intimacy have come up—in particular at a cancer caregiver support group and in respecting and facilitating the consensual sexual activity of residents in assisted living.

own findings, forming my argument for why EOL chaplains and the interdisciplinary EOL team should not only be engaging in these conversations but be doing so in an inclusive manner.

Denial, STIs and Heterosexist Assumptions: An Introduction to Elder Sexuality

I am not the first person to consider the sexual and intimacy needs of patients in EOL care. Hordern and Street conducted a study in Australia that took on this issue head-on. This article focused on semi-structured interviews of 32 palliative care or cancer health professionals.⁶⁷ The authors pointed to several studies done from the patient perspective which indicated that patients would like to talk with their providers about their sexuality and physical intimacy but were not given the opportunity to in the palliative care or cancer setting (50). They also commented that their interviews revealed “health professionals were not aware that patients were searching for information and support about living with the intimate and sexual changes they had experienced after their cancer diagnosis” (58). The authors pointed to the work of Anthony Giddens who writes extensively on sexuality, intimacy and reflexivity—that is, reflecting on the social construction of intimacy and sexuality (50-51).⁶⁸ Overall, they identified five primary clusters in the responses from EOL providers. These clusters are listed from least reflexive to most reflexive approaches including the following: denial, avoidance, vulnerability, risk taking, and negotiated communication. The researchers found that “few health professionals viewed the patients in their care as sexual beings whose cancer experience had the potential to impact on sexual and intimate aspects of their lives”. This was attributed to culturally

⁶⁷ Notably, only one of those 32 providers was a pastoral care provider so chaplain’s views remain relatively unexplored (Hordern and Street 51).

⁶⁸ For example, how is one’s personal definition of sexuality and/or intimacy impacting how one engages the topic with their patients? What are one’s stereotypes about older patients and patients from other cultures regarding these topics? Etc.

constructed ‘asexual’ patient in healthcare and medical training. Providers who were in denial believed that patients would feel too bad or that sexuality wasn’t a priority in comparison to survival (53). Other providers had an avoidant approach—redirecting attention to what providers believed to be more pressing medical issues, assuming another provider was addressing it, or believing the clinical environment wasn’t appropriate to have those conversations (53-54). More reflexive health professions commented more on their own vulnerability—mentioning that they would be worried about what their coworkers would think about them, mentioning they joke about it when it comes up, or reflecting on their own discomfort talking about sex in their personal life (55-56). Other providers were unwilling to take the risk of talking about sex, indicating they were not comfortable talking to single patients, older patients, or patients with different, specifically Muslim, backgrounds (56). Lastly, the most reflexive providers spoke about negotiated communication—recognizing their personal definition of sexuality and intimacy and how that impacted their role, building rapport with patients, and checking with the patient to ensure they were comfortable talking about their intimacy and sexual life (57). Very useful suggestions were offered to help improve the reflexivity of providers when it came to their own beliefs about sexuality and intimacy, as well as their comfort communicating with patients about these topics⁶⁹. Helpful questions and comments were also suggested to assist providers in opening up this type of conversation with patients⁷⁰.

⁶⁹ E.g., “What do the terms ‘sexuality’ and ‘intimacy’ mean to me?; How do I define the term ‘sexuality’ and ‘intimacy’ in my personal world?; What factors have influenced the personal meanings I have attributed to these terms throughout my life?; How comfortable do I feel discussing issues of intimacy and sexuality in my personal world? ... Have I asked the patient how this treatment or cancer experience has impacted on intimate or sexual areas of their life?” etc. (52).

⁷⁰E.g., “Many of the patients I see express concerns about how treatment may affect their sex lives. How has this been for you?; How has this experience affected intimate or sexual aspects of

Through the Hordern and Street study, several things become clear. First, patients want to talk about issues of sexuality and intimacy and are not given the space to do so. Second, providers are not aware of this and when they do talk about it, which was rare, it is often medicalized (e.g., anatomical discussions of erectile dysfunction, infertility). Third, providers often left their assumptions about the meaning of sexuality and intimacy—especially with respect to age, partnership status⁷¹, disease status, and culture—unchallenged and unchanged. The definition should belong to the patient and should be talked about, recognizing that sexuality and intimacy change as someone ages but that doesn't diminish its importance. Looking to the intersectional experience LGBTQ elders, even though this article left the topic of homosexuality unexplored, there are significant implications (Griebling). Primarily, if the provider reshapes their conceptions of sexuality and intimacy but leave heterosexist assumptions unchallenged, LGBTQ elders will still be left out of these conversations (i.e., this woman is older so she's probably not a lesbian, asks if a lesbian woman has a boyfriend).

As has already been discussed, older adults are assumed to be asexual or at least not sexually active. This assumption that is not supported by research (Davis and Soka; Somes and Donatelli; Makimoto et al.). In fact, more than half of 60+ year olds have engaged in some form of sexual activity in the last month and one-fourth of 80+ year olds describe themselves as 'sexually active' (shared in Somes and Donatelli). These "asexual older adult" misconceptions can lead to missed opportunities to discuss sexuality with older patients. This is problematic

your life?; Has your role as a parent, partner, spouse or intimate friend changed since you were diagnosed or treated for cancer?; Is this the right time or place to discuss these issues further?" etc. (57).

⁷¹ In my very first interviews with a lesbian participant, she told me someone can have a great sex life even if they are single right now—i.e., masturbating. Providers should be prepared for this.

given sexually transmitted infections are increasing among older adults (Davis and Soka; Somes and Donnatelli)⁷². There exists a belief that older adults, because of their age, are informed about how to avoid STIs. This is untrue because that generation grew up when standardized sexual health education was not part of the picture (Davis and Soka). Again, these assumptions are compounded for LGBTQ individuals—especially if they are single or not “out” to their providers. When a provider is unwilling to bring up these topics with their patients, this can make older adults who want to know more ashamed to ask. This shame is unnecessary and unfortunate because research indicates that not only are older adults sexually active, but data from AARP indicates that older adults who have sexual contact tend to have “better health, higher relationship satisfaction, and better stress management” (Davis and Soka). It is important for EOL providers to address the physiological dimensions of helping patients to fulfill their needs and desires when it comes to sexuality and intimacy for all patients—but with special considerations to keep these conversations inclusive for LGBTQ people.⁷³

Sex and sexuality are innately human, they are creative and immensely important means of communication and connection. They are “core components of the human experience” (Griebing). Beyond the public health statistics above this is important to EOL care because that time is about centering quality of life, dignity, and helping a patient live and die authentically. Sex, sexuality, and gender should be part of that journey, or at least part of the conversation. Furthermore, chaplains—as uncomfortable as it might feel at first—need to be part of the

⁷² A vignette shared by Somes and Donnatelli is particularly compelling—talking about a 72-year-old woman whose blood samples were assumed to not belong to her because they showed signs that she had an STI. She had gotten into a relationship but didn’t use protection because she knew she wouldn’t get pregnant (Somes and Donatelli).

⁷³ Furthermore, EOL care is also about supporting family, friends and caregivers. Sex, sexuality and intimacy could conceivably not be an issue for a patient but what about their partner?

conversation, need to be advocates for talking about these topics. This is because as it turns out, for LGBTQ elders, sexuality and gender *are* spiritual.

EOL Chaplains on Spirituality, Sexuality, Gender

All 22 of the participants in this sample were asked “Is there a connection between spirituality and sexuality/gender?” Not a single participant said there was not a connection, specifically regarding sexuality. Few chaplains spoke much to gender. For non-LGBTQ EOL chaplains, the only pattern that emerged was some chaplains were more willing to reflect on their own life than other chaplains (i.e., sharing their own history how that impacted their views). One chaplains reflected less on his personal experience of sexuality, saying that sexuality and gender come from organic places in us. He believed they come from the same spiritual place as our political convictions. Another shared that spirituality and gender are sacred parts of ourselves, sacred identities—not unlike race. Neither of these two elaborated. While the first two non-LGBTQ EOL chaplains spoke more broadly, the other two answered the question by reflecting more on their own experiences. For example, Chaplain 6 provided her Tibetan Buddhist interpretation—conceptualizing sexuality as a powerful passion that she, and many others, must mindfully examine and learn to work with.

[Chuckles] I think there’s a deep connection [between sexuality and spirituality]. . . And um, that’s been my path, very much so. . . It’s not all people, sex isn’t the [passion] for everybody. Some people they really love food with a huge passion, or music or something else. It’s not always, but usually it is—because that’s the strongest. That’s the strongest passion. That’s something that most of us really need to look at and work with and understand. It’s very powerful and very dangerous and um, so through the practice of meditations. . . in my experience, it’s become kind of freed from [that passion]. Also through the process of aging, that helps, because the fires die down a bit and you can deal with it. When I was young I was so burning up [sexually] all the time that I couldn’t deal with it. . . You keep putting your hand on the stove and getting burned—you keep doing it over and over and over again ‘cause you can’t keep your hand off of it. And eventually you learn, oh, I have to deal with it a little differently. Um but decentralizing through meditation practice has been a very joyful experience in my life.

Unlike the previous two chaplains, Chaplain 6 was able to share her own observations of how spirituality and sexuality are connected in her personal life. Notably, aging was a joyful part of her sexuality because aging and meditation allowed her to appreciate this sexual passion differently. When I asked about gender and spirituality, she initially said she didn't know if there was a connection. After giving it a little thought, however, she reasoned that the male and female have different approaches to spirituality. She told me we all have a mix of those dimensions in us and as a result, a mix of those spiritual approaches. Chaplain 3, the youngest EOL chaplain participant, put it in an interesting way. He considered how being LGBTQ for others influenced how they see God. For example, he reasoned that an LGBTQ person would perhaps see God as less of an authoritative, masculine figure (my data seems to confirm this, see Chapter 7). As a result, he told me he felt attached to the spiritual journeys that LGBTQ people undergo because those are views of God he has come to share.

Chaplain 3: I think a connection I've seen is um. I think in some ways our gender and sexuality can really influence our understanding of God. I think, um, you know when I've worked with LGBT folks over the years—um, in [the EOL] setting and in the hospital setting, um—one thing I think that has often come up is a sense of kind of an adopted community, of kind of creating your either your community or your family. And also creating a religious identity that supports [being LGBTQ]. And um, and I guess for me, I sort of feel connected to that journey, in a way. 'Cause even though my story is kind of boring in a sense: I was born Catholic, baptized Catholic, and I still identify. I've found my journey was one of kind of forming my own faith more as an adult than as a child... [My spirituality] has kind of been something I came to more on my own. It was rooted in my background but it felt more created than that. So I think just kind of our understanding of God. Um, I have an understanding that's pretty far-off the more traditional male ideas of God that come from the Bible—especially the old testament stuff and church traditions and stuff. But um.

Interviewer: I guess what do you mean by that?

Chaplain 3: Um, I think in coming to faith as an adult and really working with people, it's this understanding of God as a person and a particular type of person

rings less true at all times. It just kind of. I don't know if I ever fully was into that, God as not just a man but also like an angry or controlling or a those kinds of qualities. That kind of fatherhood that's, um—not just fatherhood but a certain type of fatherhood.

Interviewer: Like authoritative?

Chaplain 3: Yeah. And um, and I just think kind of seeing all these different, um, perspectives on what God is, that comes through in subtle ways. Like people can often say the same words but the meaning have different takes. In a way I've had to learn from a lot of different perspectives on that—learn from people who have formed their own spirituality.

Part of Chaplain 3's history was examining God differently—critiquing not only God's supposed gender but the construction of God as a person. He also said that the religious/spiritual journey that LGBTQ people undergo in order to integrate their beliefs is connected to the journey that he had undergone.

LGBTQ-identified EOL Chaplains reflected on this question in a more personal way, similar to Chaplains 6 and 3. Chaplain 5, a gay man, said that he does not see a connection between spirituality and sexuality/gender in his work. But he remained open to the possibility, saying that if it's important to the patient, that's where they would go together. However, in his own life, he said that they were very connected: he shared with me a vulnerable story about having experienced homophobia in a particularly conservative Christian background. It was clear that for him, his journey with his sexuality was spiritual for him because it meant staying true to himself and finding Zen Buddhism which aligned better with his beliefs and allowed him to be who he was as a gay man. This “staying true to self” was a central theme that came up for LGBTQ elders when they were asked this question.

When I asked Chaplain 4, a lesbian, she said that gender was not something she's questioned in her life so she could speak better to the connection between spirituality and sexuality. While this is in direct response to the gender/sexuality/spirituality question, she

previously made comments about being introduced to women's music, women's theology and lesbian music when she was in seminary which seems to point to a feminist influence to her spirituality. With regards to sexuality, however, she shared her journey of finding who she really was. She also talked about sexual experience with her (now) wife being spiritual—again the sexual act as spiritual was another sub-theme discussed below that emerged with LGBTQ elders.

I will say that before I came out, I was not comfortable with my sexuality. And there were reasons for that—let me just say as part of my history that I was married to a man, I did have a child with him, um, was married to him for what? 12 years? 12 years. And one of the very important parts of my journey was acknowledging that I had been sexually abused as a child by a music teacher. Um, and that was a part of why I wasn't in touch with myself early in life. So I just kind of went through the motions of a relationship that wasn't authentic and wasn't in touch with my sexuality. So when I did um come out, when I did meet my now spouse and come out, and had sexual experiences that were just at a completely different level than I had ever experienced before, I feel like I was able to—she helped me to—touch that deeper part of my spirit. And the sexual experience was part of how I'd say I was able to tap into that.

For LGBTQ elder 4, she felt that she was spiritually disconnected from her sexuality as a result of sexual abuse. As a result, she followed the social expectations of a woman at her time.

Nevertheless, when she met her now wife, they were able to discover deeply spiritual and sexual parts with each other.

For Chaplain 7, he reflected on how being LGBTQ impacted his way of seeing the world—echoing Gloria Anzaldúa's conception of *la facultad*. (see Chapter 2). Knowing I was LGBTQ, myself, he talked to me directly.

You grew up having to translate every look. Is he looking at me because he's going to punch me because he thinks I'm a queer? Is he gay? Is he attracted to me? Is he not attracted to me? Is he figuring out who he is? Does he know who he is? Is he judging me? Is he, just on and on and on and on. And I think when we grow up that way, with that—and I don't want to say insecurity because that's not the right word—but knowing that you are among the 10%, or wondering that you are, or denying that you are, or whatever, it forces a sensitivity and a sensibility toward life that is the opposite of white, heteronormative privilege even if you are, if you present as white and privileged.

For Chaplain 7, he believed that growing up LGBTQ forced him to be hyper-aware of his world, forced him to see what others might not (this is also similar to statements made by Elder 1, discussed towards the end of Chapter 5).

Overall, EOL chaplains saw sexuality/gender and spirituality as connected. Two participants talked more broadly, recognizing there was a connection without speaking to their personal experiences. They said that that gender/sexuality came from a spiritual place or that they were sacred identities. The other two participants were more reflexive about this, thinking about their own spiritual journey and how gender and/or sexuality came up in that. For LGBTQ EOL chaplains, the connection between sexuality and spirituality was described rather intimately. They talked more about their spiritual journeys—especially talking about staying authentic to themselves and talking about the sexual experience being spiritual. One gay EOL chaplain uniquely talked about how being LGBTQ influences one’s social sensors. Amongst EOL chaplains, gender was typically discussed much less, sometimes not at all.

Orgasms, Love Stories, Authenticity— “It’s All Spiritual”: Spirituality and Sexuality

When it comes to the LGBTQ Elder participants’ responses when they were asked if there was a connection for them between sexuality and spirituality, they all said that there was a connection. More specifically, they spoke about this following five sub-themes: the sexual act itself could be a spiritual experience; their experiences of attraction or falling in love with their partners was spiritual for them; being authentic with their sexuality, and staying true to themselves was a spiritual journey; their sexuality and spirituality were inseparable; and finally, a few said that it was experiential, it was spiritual but it was hard to express in words (see Table 7 below).

Table 7: LGBTQ Elders' Connection Between Sexuality and Spirituality		
<u>Sub-Theme</u>	<u>Examples</u>	<u>Number who described in this way</u>
Sexual Act	“All orgasms are spiritual aren't they?”	9
Falling in Love/Attraction is Spiritual	Love at first sight, spiritual guidance in meeting partner, deep love/connection	5
Authentic LGBTQ Journey is Spiritual	Staying true to myself, journey as an LGBTQ individual	6
“It's All Spiritual”/Inseparable	“I'm spiritual, therefore it must be connected;” “they are inseparable for me”; “they always seem to come hand-in-hand”	4
It's Experiential/Hard to Put Into Words	You just know it when you know it, can't really describe it; “it's hard to put into words”	3

When LGBTQ elders talked about the connection between their sexuality and their spirituality, the most common type of answer they provided was that for them, the sexual act or a component of having sex, itself, was somehow a spiritual experience. For example, Elder 3, a bisexual woman who had been in a relationship with a woman for nearly 30 years, gave it to me the most directly: “Well, all orgasms are spiritual aren't they.” For many of the participants, not all sexual experiences were spiritual but with specific people it became spiritual. When I asked

Elder 7 this question, he told me that when he had sex and got to the point that he wanted to see his partner fulfilled, that made for a deeper experience than some of the hookups that he engaged in growing up.

And one of the things that after awhile, I learned was that most of the time it was just sex. And that's what most people wanted out of it. But there is a thing that once you get into a sexual encounter but when it gets to the point of, I'm here and one of the things that would fulfill me is seeing you fulfilled. At that point, you're taking it out of the physical and putting it into the relational. And that was the one thing. I think, when people do that within sex, if they're able to do that—and I'm not putting any value judgement on that or anything—if you're able to do that, it becomes a much deeper richer experience. And that's what a lot of people want to go for.

That deeper connection that could be achieved with specific sexual partners was spiritual for Elder 7. Other LGBTQ elder participants said similar things; sometimes it was just sex but other times it was spiritual. For example, Elder 13 told me that sometimes the sex could be taken to another level. She shared that had happened twice in her life—she married them both. Elder 8 shared a similar story.

Interviewer: Is there a connection between your sexuality and your spirituality?

Elder 7: Oh yeah!! I think so.

Interviewer: Walk me through what that means for you.

Elder 7: This gets really personal now. I mean, this is not Christ stuff, this is like personal... Boy there's a lot to that question. If you're talking the physical sexuality, like the act of having sex or making love with somebody—when it's right it is spiritual. It is like [loud exhale], we're dropping the mic, Niagara Falls. And I really didn't have that until I met [my wife]. That really intimate, deep experience of being together.

Importantly, several people said this spiritual side of sex really only happened to folks when they were with people who they really cared about and who cared for them in return. Other elders—specifically Elders 10 and 1, who had the more scientific/existential spiritual approaches talked about the sexual act being spiritual because it involving a “loss of sense of self.” It was a “transcendent” experience in that way. An orgasm, Elder 1 told me, could shut down the “social

sensors.” Elder 10 put remarkably similarly but his Buddhist background was notable in his description.

There can be [a connection between sexuality and spirituality]. Uh, I think at its ultimate, when you’re having oh, when you’re having sex with somebody who you’re in love with and who—hey, I think it can even happen with people who you’re not necessarily in love with, although I think that makes a major difference... It contributes in a major way. That, the feeling of being, when you say ‘at one with someone’. Yeah, you’re in a sexual union and you’re engaged in a totally physical, uh, process. Um. But, yeah, I think when you’re coming to orgasm with somebody who you’re incredibly connected with—not just physically but also emotionally—uh, is is spiritual, feeling. There is a, I think in spiritual events—or in sometimes what we call spiritual emergence—there can be a feeling of loss of sense of self. So, and in Buddhism, the loss of the ego allows you to merge, be one with all of existence, with everything.

For the majority of the participants, their sexuality was described as spiritual and somehow this involved the sexual act—an orgasm or climax. Most of the participants indicated that this “transcendent” experience was facilitated by having a partner with whom they were in love with or who had deep mutual feelings of affection. This transitions nicely into the next sub-theme that participants used to describe the connection between their sexuality and spirituality: love and attraction.

For several participants, they spoke about the connection between sexuality and spirituality in terms of their love story or attraction. For many, spirituality was part of the chemistry between them. Spirituality was part of their love connection. For example, when Elder 2 was asked the question about spirituality and sexuality, he talked about meeting his husband and their instantaneous bond.

[The] connection [between my husband and me] is much greater than anything physical that can be described... It’s just very very deep. And it was from the first moment that we met. It was just bigger than anything I’d ever experienced before. I didn’t, oh, I’d totally never believed in love at first sight. The moment I went into his presence... It was just, his presence, our presence together just, it blew me away and it was something bigger. I was shocked that he was interested... It’s very, it was a very strong, deep relationship. And I don’t know the words to paint the picture... Yeah, it’s like, it goes to the core of my being.

As Elder 2 tried to describe, his love for his husband was immensely deep—going “to the core of [his] being.” Others made similar sentiments. For example, Elder 8 said that her relationship between her and her wife was the relationship they had been waiting for their entire life. Elder 3 said that her experience of finding her was “spiritually guided” (i.e., her spirit guides assisted her in that process). While exploring her spirituality in her interview, specifically how her spirit guides and her spiritual intuition come up in her life (discussed in Chapter 6), an example Elder 3 eventually gave me was being guided to meet her now wife.

Elder 3: Spirit talks to me

Interviewer: How so?

Elder 3: How so? Guidance, dos and don'ts: don't do that, don't do that, go over here. And just in so many ways. And it seems that older I get the more blessed I am, the more fortunate. Now you understand, I really had a long way to go to get to that point. Growing up in [my hometown] was not a privileged background for anybody. But, um, no I just feel like I'm guided. And sometimes I hear things and sometimes I just know things.

Interviewer: Kind of like an intuition?

Elder 3: [Nods] Yes.

Interviewer: Do you have a story that kind of exemplifies that, where you were, you just knew?

Elder 3: Um. I probably have a lot of stories.

Interviewer: A lifetime of stories I bet.

Elder 3: [Long period of silence] I can't think of an example. Now you walk through that door and I'll think of 50 of them [both laugh]. Um, my partner. It was in my late-30s. And uh, kind of lonely—I had close friends but not really anybody that I could team up with. And I remember sitting in my house, looking at a flier for adult education. And there was this little description of [a specific course] and something says, 'go here, go here, don't delay, sign up, go here.' So that [points to where wife is in the house] was my teacher. So, you know, 30 years it's been good.

For Elder 3, her spirit guides helped her find her partner of almost 30 years. While some participants, like those described above, claimed that their spirituality was involved in their finding and connecting with their long-time partner, others talked about it being a critical component of experiences of attraction. For example, Elder 9 shared that her sexual attraction was interconnected with her spiritual attraction.

Who I was attracted sexually was also who I was who I was attracted to spirituality. So it was kind of a way of developing my spirituality to to, um, to pursue an attraction and try to understand that connection between the two, sexuality and spirituality. Because, for the people I was attracted to, there was always a spiritual element to that too. Sort of a knowing. A deep knowing of that person. And I think that's still true for me—the people I'm most drawn to are, you know, my my sexuality sort of, as far as having that drive has changed as I've gotten older but I still very much of a spiritual attraction to people that I may not feel as much on a physical level.

For these participants, their attraction for individuals and often their subsequent love was a spiritual experience. Elder 3 talked about how her physical attraction has gone down with time but the spiritual attraction is still there. As an important note to this section, when asked if there was a connection between spirituality and sexuality, chaplains did not talk about love. However, in other parts of our interviews, several of the chaplains mentioned that they enjoy listening to patients' "love stories." My suggestion, based on what the LGBTQ elders told me is to dig into those stories with LGBTQ patients too. Do not avoid those sources of strength. Furthermore, be prepared to hear those stories with single patients too—not assuming all single patients are straight. Give LGBTQ patients a space where they can trust the chaplain enough to share these stories.

Another sub-theme important for EOL chaplains was the third sub-theme when LGBTQ elders discussed the connection between their spirituality and sexuality. LGBTQ elders told me that "being true to themselves" was spiritual. They described that being authentic to the LGBTQ parts of themselves as a spiritual journey. A good example comes from LGBTQ Elder 11. When

asked the sexuality/spirituality question, he told me a story of shame. He shared that he grew up being told he was wrong for being gay. He told me about his father being embarrassed by Elder 11 when he would sing in front of church because “that’s what queers did.” For him, learning to love himself despite what his family and society said about being gay was an incredibly important connection between spirituality and sexuality. Others shared similar stories, telling me “you have to be who you are.” They shared that one must have integrity to one’s spirituality and to one’s identity as an LGBTQ person. Elder 9, formerly an EOL chaplain herself, embodied this sub-theme wonderfully in one of her comments⁷⁴.

I think it’s just. It’s that. The thing in common between those two is being who you are. Um, [long pause] sexuality and spirituality. Yeah um. I think there’s something in both of those things that. I mean, I think being different in my sexual orientation helped me to be spiritually stronger. ‘Cause I had, you know, only myself to rely on without a context for being able to share that with anybody. It’s like, you know, I don’t know what it was like for you, but for me growing up when nobody talked about it, I didn’t know anybody who was gay. You know, there were a few kind of snickering jokes about some men who went down to a tearoom in the town where I grew up. And um. But it’s like, where do you find a context or a framework for that? And not having that, was like I just, I had to kind of build that from the inside. Um. So I think the connection for me with spirituality is that it just, it taught me a lot about just being who I was and not trying to be, not trying to be different than who I was, or not trying to fit in.

Elder 9 shared that her spirituality and sexuality were related because her spirit helped get her through all the discrimination, oppression and immense loneliness during a time that her sexual orientation was seen as a sin. This connection provided strength to get through life. When EOL chaplains say they “try and find the sources of spiritual strength in their patient’s life” no doubt this is the kind of strength they are referring to. These stories must be heard! EOL chaplains must

⁷⁴ Completely self-indulgent side note: during my interview with Elder 9, she told me that I “ask really good questions.” She appreciated me taking her “places she doesn’t often go”, and giving her space to share her rather touching story. Let me just say, if a former EOL chaplain—professional listeners and question askers—gives you [me] that compliment, especially a chaplain who is also an LGBTQ elder, you just might be onto something.

create inclusive spaces where LGBTQ elders feel comfortable to share their journeys. If LGBTQ elders have relied on their spirituality to get them through a life of hate and discrimination, then there is no doubt that in order to be authentic in their EOL, their sexuality must be part of the conversation with EOL chaplains.

The fourth sub-theme that emerged when LGBTQ elders shared the connection between spirituality and sexuality was that those two dimensions of themselves were “inseparable.” For some elder this was expressed as “well I am spiritual and they are both part of me so they must be connected.” Elder 3 who described herself as an incredibly spiritual individual said “there’s a connection between spirituality and everything.” Others phrased this sub-theme differently. They expressed that for them sexuality and spirituality always went hand-in-hand; those two parts of themselves was never not connected in their lives. Elder 14, the 82-year-old lesbian, perhaps expressed this theme the best.

Interviewer: Would you say your feminism and your sexuality and your spirituality are somehow related?

Elder 14: Oh yeah! I mean, I. I don’t even know if I could, you know, separate them. I mean in the sense of ok, this is about spirituality, this is about my sexuality. I mean there are several, you know, things that interact and intersect. . . Um, but, for example, I know that my spirituality as a Quaker that ‘that of God in me meets that of God in you’ and that’s the basis of relationships. And I know, I know, that that’s in my feminism—well there’s a little bit in feminism that puts being a woman ahead [both laugh]. But, you know, they just all interact and intersect and think they’ll all of a piece. And I don’t think. It’s not anything that I worked at. It’s just when I think about me, uh, it’s just that I know that those things are comingled in together. I can’t think of anything that would make that not true.

Clearly, if an EOL chaplain wants to talk about spirituality with this woman, they best be prepared to talk about her sexuality as a feminist lesbian as well.

The final sub-theme that arose when LGBTQ elders attempted to describe the connection between their sexuality and spirituality was a difficulty putting words to the experience. “It’s

hard to put into words” several of them told me. Elder 10, the Buddhist told me that it’s something that is experienced rather than talked about.

It’s something that you experience, it’s so hard to put into words. I can tell you certain elements of it, like I’m telling you. But it doesn’t quite encapsulate, really, the sense that you feel. This is why we do so much experiential work [in Buddhism].

So many of the elders expressed that they had a hard time describing the connection. It just was. It was something you knew but couldn’t describe. As Elder 10 put it, the connection between sexuality and spirituality was something that had to be experienced.⁷⁵

Overall every single participant—both the seven chaplains and the fifteen LGBTQ elders—told me that there was a connection for them between spirituality and sexuality. For the elders, their description followed a theme. They talked about the sexual act being spiritual; they talked about love and attraction; they shared that staying true to themselves, living authentically as LGBTQ individuals, was a spiritual journey; they expressed that spirituality and sexuality was inseparable for them; and finally, a few told me that the connection was harder to describe and had to be experienced instead of talked about.

Feminist and Transgender Lenses: Connection Between and Gender and Spirituality

The connection between gender and spirituality was discussed with far less frequency than spirituality and sexuality. When it was explored, it was exclusively by the two participants who were transgender and several of the lesbians. When participants discussed the connection between spirituality and gender, they did so in one of two ways. They either referred to it in feminist terms or talked about gender more generally.⁷⁶ See Table 8.

⁷⁵ I’ll let the reader consider what that means in their own life.

⁷⁶ Indicating this was feminist *or* transgender/androgynous lens may appear to suggest that those are mutually exclusively. They are not. All of the participants who talked about gender from a

Table 8: LGBTQ Elders’ Connection Between Gender and Spirituality		
Sub-Theme	Examples	Number who described in this way
Feminist	Conflict with religious teachings were always on feminist grounds; discussing “the divine feminine”	5
Transgender, Androgynous Lens	I have both masculine and feminine qualities; “being transgender provided a lens to examine scripture”	3

Most of the participants who shared a connection between spirituality and gender described the connection by talking about their feminism. These descriptions were often similar to those of Elder 14 above. Feminism was somehow “comingled in” with spirituality. Others demonstrated connection between spirituality and gender by sharing their distaste for masculine-dominated religions or patriarchal treatment of women. Elder 4, for example, described herself as a Wiccan. For her, the core of that belief was a woman (or group of women) determining her own path, putting together her own belief system rather than relying on a source that is outside of her to dictate it for her. Elder 4 told me that a community of women is an important location for the exchange of ideas—spiritual and otherwise. Having grown up on a rural farm, Elder 4 described the process of canning as a feminine community where women could exchange ideas and alter their views of the world. Elder 15 also shared her innately feminist and feminine

transgender and/or androgynous lens were also feminists and many of the lesbians who spoke about their spirituality were trans-inclusive.

spirituality. She shared that she had lived previous lives during the matriarchy. As a result, she was born a feminist—she came at this time with this life “to get the [Equal Rights Amendment] passed.” She rejected what white men had the market cornered on religion—especially when it came to religious denigration of women. She also taught me about the divine feminine.

I really believe the divine feminine energy is the dark, it is the mystery, it is the womb, it is the energy that every human has within to go to, to receive. It's that receptive place. So, tapping into your higher self, to your spirit guides, to God, to whatever you believe there is energetically to get marching orders. And then you take that out through your divine masculine. 'Cause the divine masculine is the go out and get'er done energy. And what we've been having happening on our planet is all this masculine energy running amok because it's not coming from the divine feminine: here's what you need to do. In the old days when we didn't have electric lights and everyone in a community, all the women, had the menses at the same time, they would go into a red tent to bleed into the ground. Before they went in, the men would say 'here are the issues that our community needs information on.' The women would go in, they would be at their highest intuitive peak, they would work together, they would get the ideas, they would bring them out to the men, and the men would do it. That's balance. That's absolute balance. Now, where we're headed is every person's gonna be both their divine masculine and divine feminine—masculine and feminine within—so that every person can come from that place.

For several of the lesbian and transgender elders, feminism was intimately integrated into their spirituality, if not the foundation of their beliefs. For EOL chaplains, this has huge implications. Beyond not presenting “God” as exclusively a man, which chaplains would likely not do, EOL chaplains—especially men—need to educate themselves on feminist thinkers, theology, etc. Furthermore, they must challenge their assumptions about gender at every level in order to understand the views of individuals like these participants. It also would be helpful for chaplains to have a working knowledge of Wiccan beliefs and Shamanism if they do not already and establish connections with individuals in their community who are leaders in those spiritual traditions.

Other participants spoke of the connection between gender and spirituality referring to gender more generally. A total of three individuals shared comments that fit this sub-theme. Two

were transgender and the third was a lesbian. For these participants, expressing their gender differently than the rest of society allowed them to see the world differently. Furthermore, people who talked about gender in this way indicated that understanding their gender better was a process of finding spiritual wholeness. For example, Elder 12, a transgender woman who is a devout Christian and a Latina, told me being transgender provided a lens with which to view scripture. It allowed her to read the Bible from the perspective of oppressed people: she told me that “Jesus picks those who are not in power, those who are looked down upon, those who are trodden upon.” Being transgender and Latina helped her to see her faith in that way. For Elder 5, a gender queer individual, he was able to open up to me about being diagnosed with dissociative personality disorder or multiple personality disorder. Recognizing he was transgender, specifically, gender queer, was an important way to ensure all parts of himself were represented. He told me it was very empowering, it was like “hail, hail, the gang’s all here.” The last participant who commented on this, LGBTQ Elder 9, was not transgender. However, she commented on how she always felt androgynous. While that was not always a part of herself that she liked, she told me she grew to see it as a powerful gift.

I’ve always felt that I was kind of androgynous. I’ve always had male and female qualities and characteristics and ways of expressing myself. And that’s just, um, that’s a part of accepting who I am. Um. As far as how people react to that in the world, it’s um, I get strange looks sometimes because I think when people see me they see both and I don’t think people are used to that. Uh, sort of the male female balance. But I see that, more and more, in the second half of my life I see that as a strength and a real gift to have both qualities.

Elder 9 shared that this androgynous piece of herself was something she had learned to recognize as strength. She feels a kinship with both men and women and men respected her in ways they did not with her woman colleagues. She was able to bridge the masculine and feminine worlds within herself. Overall, it is important for EOL chaplains to recognize that this is an important

piece of some LGBTQ folks' experience of spirituality. An EOL chaplain should become more informed about what it means to be transgender. Beyond that, they should also start to recognize that some folks do not see their gender as exclusively male or exclusively female. Furthermore, EOL chaplains are also encouraged to vulnerably reflect on their own experiences of gender.⁷⁷ Vulnerable explore the role of gender in their life. What do these individuals have to teach us?

Conclusion

Past research in the EOL setting reveals that the sexual and intimacy needs of patients are not being met. Generally, providers assumed patients “were past all of that” or were not interested in those forms of connection because of illness. In contrast, patients demonstrate they want that support and guidance from their providers. Older adults are sexually active, despite stereotypes that state otherwise. They are at risk for untreated STIs because stereotypes that assume older adults are asexual prevent providers from giving them appropriate support. LGBTQ elders are at a particularly precarious position because they are assumed to not only be asexual (as elders) but also heterosexual. This can be a source of shame for LGBTQ elders. Providers should make fewer assumptions not only about sexuality of older adults but also regarding sexual orientation of older patients; they are also encouraged to ask more questions to patients on this topic.

Profoundly, LGBTQ elders revealed that EOL chaplains must be part of this conversation because for them, sexuality/gender and spirituality are deeply connected. Specifically, for LGBTQ elders, sexuality and spirituality were connected because the sexual act/orgasm was

⁷⁷ As a woman did they ever feel discriminated or limited because of their gender? As a man were they ever told not to be emotional or felt limited in their ability to make physical contact with another man? Is there a connection between gender and spirituality in their life? Why or why not?

somehow spiritual, especially with partners they loved; they described their attraction or falling in love as a spiritual process; they described staying authentic or true to themselves as LGBTQ individuals was part of their spiritual journey; they expressed that their spirituality and sexuality were inseparable; and/or they said it was not something that could be explained in words but was meant to be experienced.⁷⁸ Similarly, regarding gender, participants indicated there was a deep connection. Respondents who spoke about this were women and/or transgender. Both transgender and lesbian participants indicated that spirituality and feminism was connected in various ways. Similarly, transgender participants expressed their experiences of their identity being connected to their spirituality—talking about their transgender journey and/or talking about their spiritual lens from being trans. Lastly, one lesbian participant described how being androgynous gave her a unique experience of both the masculine and feminine spiritually. In contrast, chaplains were not able to speak much to the connection between spirituality and gender. When it comes to sexuality and spirituality, EOL chaplains who were LGBTQ had descriptions very similar to LGBTQ elders. Non-LGBTQ chaplains, on the other hand, did not share similar descriptions as LGBTQ elders—often giving very vague answers or not reflecting on the question in their own lives.

EOL chaplains are encouraged to explore the connection between gender/sexuality and spirituality in their own life to better understand the worldviews of their LGBTQ elder patients and to learn from LGBTQ elders' experiences. Many patients have indicated they want to talk about intimacy and sexuality, therefore more than just LGBTQ patients will benefit from this reflection.

⁷⁸ EOL chaplains may need to help their patients process the grief of losing their sex drive. Furthermore, they should also be there to support the partner(s) of patients whose needs are unmet with regards to their sexuality/intimacy.

Chapter 9: Conclusion, Being “Expanded”

So live your life that the fear of death can never enter your heart. Trouble no one about their religion; respect others in their view, and demand that they respect yours. Love your life, perfect your life, beautify all things in your life. Seek to make your life long and its purpose in the service of your people. Prepare a noble death song for the day when you go over the great divide. Always give a word or a sign of salute when meeting or passing a friend, even a stranger, when in a lonely place. Show respect to all people and grovel to none. When you arise in the morning give thanks for the food and for the joy of living. If you see no reason for giving thanks, the fault lies only in yourself. Abuse no one and no thing, for abuse turns the wise ones to fools and robs the spirit of its vision. When it comes your time to die, be not like those whose hearts are filled with the fear of death, so that when their time comes they weep and pray for a little more time to live their lives over again in a different way. Sing your death song and die like a hero going home.

- Chief Tecumseh, Leader of the Shawnee Tribe
(*Chief Tecumseh, Shawnee*, quote shared with me by EOL Chaplain 7)

Research

Regarding the future of inclusive EOL spiritual care research, this project is just the start. LGBTQ individuals should be studied further—especially as younger, non-Baby Boomer LGBTQ individuals render these findings less representative of LGBTQ elder experiences and needs. Furthermore, other oppressed populations should be studied (a few examples include people of color, immigrant populations, people with disabilities) when it comes to their spirituality during end-of-life.

This project contributed extensively to several disciplines and theories. With regards to queer theory, intersectional experiences of both older and LGBTQ individuals have been examined in terms of spirituality. In terms of work in the chaplain literature, this project appears to be the first that compares and bridges EOL chaplains and LGBTQ elders.

As mentioned in Chapter Three, there are several limitations to this project. Therefore, the generalizability is limited. Nevertheless, the underlying takeaways for chaplains remain:

avoid assumptions, ask questions, do research on inclusive practices, listen and “be expanded” by the stories shared by LGBTQ elders. If every patient—LGBTQ or otherwise—is approached in this way, the necessary changes (i.e., regarding geography and change over time) will come naturally.

Personal

Towards the end of my interview with her, Elder 14, the 82-year-old lesbian in the LGBTQ elder participant group, showed me around her home. She showed me a picture of her mom and told me a story about how her mother let Elder 14’s girlfriends stay at their house around the time the picture was taken. Elder 14 started tearing up when she told me about driving in a car with her mom and girlfriend during that trip. “I know why you have these women and why you need these women,” her mother told her, at this point looking completely out the window, “because everybody needs love, and everybody deserves love.” Despite this being 50 years ago, Elder 14’s mother was able to open her heart to her daughter and expand her understanding of love.

Over and over again, the participants in my sample told me about things they had accomplished that gave them meaning and made them proud of their time here. They talked about their activism: women’s marches, Pride marches, ACT UP, legal battles for marriage equality. They told me about the volunteering in their community—telling their LGBTQ story to middle schoolers, facilitating a group for LGBTQ elders, leading an LGBTQ Bible Study. Some talked about caring for their friends and partners who were dying with AIDS, sitting with a LGBTQ girl who had just been kicked out of her house. Without a doubt, the work of these LGBTQ elders made it possible and continue to make it possible for younger LGBTQ people like me to be myself, to be authentic and whole.

Sixty years from now, when I'm Elder 14's age, I hope EOL spiritual care providers do not turn away from my story. I hope they are not uncomfortable recognizing my sexuality and gender as deeply spiritual. I hope work like this thesis will facilitate making that possible. However, when I am in a hospice, I will not have the same stories of struggle that these elders did. The efforts of LGBTQ elders made that a reality. They improved this community and this country for all young LGBTQ people. When I tell my own EOL story, I will not have to talk about what it was like to not be able to get married. Opening up to an EOL chaplain about my journey, I will not have to reflect on watching hundreds of my friends die of AIDS while the government did nothing. Reflecting on what gave me meaning, I will not speak to the same levels of substance abuse, mental illness, and suicide that so many of my participants talked about. This is beautiful. I cannot help but be deeply grateful. Nevertheless, as each LGBTQ elder in this country gets closer to their "next great adventure" these stories will begin to be lost. This project was, in a part, a mission to document these spiritual LGBTQ stories.

The LGBTQ elders in my sample were told for much of their lives that they were inherently perverted, tainted, shameful, mentally ill. They were told they were innately unclean, unworthy of belonging to a religious community. Christianity tossed them to the side, "surely these people could never have a connection with God and also follow their 'sinful' ways." Spiritually worthless, some Christians assumed. They were wrong. In being tossed aside, in being pushed to the margins, these LGBTQ elders were able to find a deep spirituality where most would not have even looked. They found transcendence in the sexual, in the orgasm. They found their higher power and a compassionate relationship with themselves through a process of recovering from addiction. They reclaimed the divine in the feminine. They saw God and Jesus differently because they were transgender. They rejected binaries and saw the non-dual in

themselves—sexually, in gender, in their journey. They witnessed something beyond them, something greater in the universe, in evolution, in simply existing despite all the odds. They walked with their spirit guides and dreamed of their guardian angels. They allowed themselves to be guided, to listen to their “inner voice,” to trust their spiritual intuition. And when it was all said and done, they decided that “God’s work” is just about sharing kindness, increasing the good in the world by just a bit. Representing both the queer and the elder, they formed spiritual epistemologies unique to their struggles.

There was one question that I asked all seven of the EOL chaplains whom I interviewed. “Have you ever had an interaction with a patient in which your own spiritual views were changed in some way?” All but one said yes. The one who said “no” told me “changed, no, but expanded.” He then went on to share the quote at the beginning of this chapter. I ask that readers and EOL chaplains to allow themselves to be expanded by these stories. Like Elder 14’s mother, expand your understanding of love, expand your understanding of God, expand your understanding of spirituality. I pray that these struggles are made visible, recognized for what they are. I hope that never again will LGBTQ elders feel uncomfortable sharing their story with anyone, especially at the end.

I do not know if this thesis will make it into the hands of EOL chaplains. What I do know is I got to hear these stories. I know that I got to share them with you. I know that, even if I were to die myself, I created something beautiful: I cried with these LGBTQ elders as they got to reflect on what gave them meaning; I was witness to a generation of people who had torment and hate thrown at them and yet came out of it saying “despite all of that, I wouldn’t have changed being LGBTQ.”

At the end of the day, I was expanded. I was healed. For the reader, EOL chaplain or otherwise, I pray you examine your own “woundedness.” I pray you examine your own spirituality in the places society says it does not belong—in what was once shameful, in your sexuality, in your gender, in your struggles. I pray you see the “outsider within” not as the outcast but as a source and creativity and perspective. That your own marginalization becomes your deepest source of strength. I pray you find what these elders found: you are worthy of love. And like these elders no doubt will, when your own time comes, may you also “sing your death song and die like a hero going home.”

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Appendix A: Interview Guides

Interviews with LGBTQ Individuals:

Demographic Information:

- How old are you? What year were you born?
- What is your race and/or ethnicity?
- Where did you grow up?
- Would you describe where you grew up as a liberal or conservative place?
- Are you currently in a relationship? How long have you been in this relationship? Are you married?
- What words would you use to describe your sexuality?
- What words would you use to you describe your gender?

Research Questions:

- What was your religious/spiritual background or belief system when you were younger?
 - o How often did you or your family attend services?
 - o Would you say that your family was “devout”?
 - o Did religion play a large role in shaping your own worldview?
- What is you religious/spiritual background or belief system now?
 - o What does religion mean to you?
 - o What does spirituality mean to you?
 - o What is the difference, if any?
- What was it like for you being LGBTQ growing up?
 - o What are some important moments for you?
 - o What are some changes you’ve noticed in the LGBT community or in society as a whole?
 - o What role did religion or spirituality play in your process of growing up?
- Who do you see with you at your death?
- What is it like for you being LGBTQ now?
- What have been your experiences with end-of-life care, death?

- Have you ever had a family member, friend or loved one who you provided care for during their final days?
- Is there a connection for you between spirituality and sexuality?
 - What words would you use to describe that connection?
- Is there a connection for you between spirituality and gender?
 - What words would you use to describe that connection?
- Thank you very much for participating in this interview. Is there anything else you would like to share?

Interview with Hospice/Palliative Care Chaplains

Preliminary Demographic Questions:

- What is your age? What year were you born?
- What is your race and/or ethnicity?
- What was your path to becoming a chaplain? How long have you been a chaplain?
- Where did you grow up?
- What words would you use to describe your sexuality?
- What words would you use to describe your gender?

Research Questions:

- What was your religious/spiritual background or belief system when you were younger?
 - How often did you or your family attend services?
 - Would you say that your family was “devout”?
- What led you to your profession as a chaplain?
- What is your role as a chaplain?
 - What does end-of-life care look like at your organization?
 - How long have you been providing this form of care? What is your experience?
- What is your religious/spiritual background or belief system now?
- What does religion mean to you? What does spirituality mean to you?

- What is the difference, if any?
- What has been your experience with LGBTQ people in your practice? outside life?
 - What was your training regarding working with LGBTQ people?
- What are some misconceptions about end-of-life care that are common in your experience?
- What are some misconceptions about chaplains that you encounter often in your practice?
- As a chaplain, how do you engage with individuals from different religious/spiritual backgrounds or belief systems from yours? Beliefs you didn't agree with?
- What are some specific needs that an LGBTQ individual might have during end-of-life care?
 - Have you ever experienced this personally?
- Is there a connection for you between sexuality and spirituality?
- Is there a connection for you between gender and spirituality?
- How does gender/sexuality come up in your work outside of the LGBTQ context?
- Have you ever been rejected by a patient? Why? How did you respond?
- Have you ever had an experience with a patient in which your own views of spirituality were changed?
- Thank you very much for participating in this interview. Is there anything else you would like to share?