Dignity at End of Life for the Lesbian, Gay, Bisexual, Transgender, and Queer Plus Population

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Acknowledgments

This Capstone project has worked me in every way possible. Who wants to talk about death, anyway? Why befriend the world of death and grief? How does my queerness fuel the work I'm creating? I asked myself these questions, often more than once, and the answer to each brought me closer to feeling more fully alive. That's what we all want, isn't it? To feel more fully alive. To be with endings so we can have new beginnings.

For this Capstone, I was immersed in scholarly literature on death and dying. Out of everything I read, I kept returning to a quote by Francis Weller, who describes himself as a psychotherapist, author, and soul activist. He said,

> There is some strange intimacy between grief and aliveness, some sacred exchange between what seems unbearable and what is most exquisitely alive. Through this, I have come to have a lasting faith in grief (2015, p, 2).

We all have an opportunity to innately witness and feel the intimacy between grief and aliveness. If you're reading this, promise me you'll step closer into this intimacy so you can feel more fully alive. The world needs your aliveness.

Dr. Rifkin: You pushed me deeper into academic excellence while acknowledging and honoring the human in me that sees this as more than a Capstone project. Your mirroring, reminders, countless revisions of my drafts and ideas, and belief in me during certain moments (you know which ones I'm talking about), showed me how much is possible. Thank you for everything, from the start and as we go, because this work is only just getting started. Are you ready?

Capital Caring Health staff and volunteers: These kinds of conversations are not always something that we enthusiastically sign up for, yet you were ready. You knew the importance of this topic and trusted me from the beginning. It did not go unnoticed. Thank you for trusting me, believing in this work, and showing me (and my colleagues) what true collaboration in service to quality care looks like. The world needs more of this, and you are showing us the way. Your vulnerability, honesty, and willingness to say, "I don't know what I don't know, but I want to learn," is how we honor the humanity and dignity in each of us. Thank you for your partnership in working towards changing the way that LGBTQ+ patients are cared for at our end of life.

Mom and Dad: I would not be close to writing this beginning-of-the-end without your deep love, the "You can do this. You already are doing it" phone calls, reflections, and consistently showing me by example that we always speak up for what is right. It meant everything to present the Capstone with you both there and have you witness me in my bigness, queerness, and love for humanity. I love you both so much. My heart comes from your hearts. Jimmy, I'm playing it cool when I say, I love you so much. Kristin, you've taught me everything I know about the intimacy between grief and aliveness. Do you know that? I think you have always known. What a gift you've given me.

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To my future self who will one day take her last breath: The Buddhist teacher Frank Ostaseski said that people dying ultimately have some form of these two questions at the end of their life:

Am I loved?
Did I love well?

To that I say, Yes, you are. Yes, you did.

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Executive Summary

For nearly 50 years, Capital Caring Health (CCH) has provided hospice care, palliative care, and grief support to over 200,000 patients and their loved ones, since its founding in 1977 (Capital, 2024b). CCH aspires to lead in providing advanced illness care of the highest quality to its lesbian, gay, bisexual, transgender, and queer plus (LGBTQ+) patients and their loved ones. While there has been some progress made in the medical system when providing care for this population, there is still much work to be done, and a paradigm shift is needed to change the way that LGBTQ+ people are cared for at their end of life (Acquaviva, 2017).

To better understand the research on end-of-life (EOL) care, EOL care for the LGBTQ+ population, and what medical care professionals are doing, and how they feel about the LGBTQ+ population, several scholarly areas guided this study. The major areas of study for this project were: death and dying, EOL care in general, EOL care for LGBTQ+ patients and their loved ones, dignity and care, inclusive practices, and inclusive excellence.

I used an adapted conceptual framework that combined Bernstein and Salipante (2023)'s Framework for Inclusive Practices with an Inclusive Excellence framework and organizational behavior model (Williams et al., 2005). The Bernstein and Salipante (2023) Framework is intended for organizations that seek to leverage diversity and increase equity and performance in their nonprofit settings. The Inclusive Excellence framework combines the four tenets of development, resources, cultural differences, and a welcoming community, with Bernstein and Salipante (2023)'s framework (Williams et al., 2005).

The adapted framework highlights how an organization can set up conditions to be inclusive and diverse, but first it must understand its own inclusive practices and how those practices impact interactions within and among the organization. Ultimately, this will uncover the impact of the lived experiences of the organization's staff and the communities it serves.

This Capstone project's aim was twofold: to understand CCH's current practices that demonstrate LGBTQ+ inclusivity and determine what additional actions CCH can take to demonstrate its commitment to supporting the LGBTQ+ population at their end of life. Using the results, findings, and recommendations from this project, CCH can better understand what LGBTQ+-inclusive practices exist and what practices are needed as it aspires to be the leading hospice organization supporting the LGBTQ+ population and their loved ones at the end of life.

To understand what LGBTQ+-inclusive practices exist at CCH and what more the organization could be doing to strengthen its commitment, I chose to conduct both a qualitative and quantitative-based study. This captured first-hand CCH staff and volunteers' understandings, perceptions, and practices towards the LGBTQ+ patients and their caregivers at the end of life. I found two findings related to the staff and volunteers' experience:

1. CCH staff and volunteers believe that being inclusive means treating LGBTQ+ patients the same as any other patient.
2. CCH volunteers do not feel prepared to work with the LGBTQ+ population.

Drawing on these findings and published research, if CCH wishes to be leading in EOL care for the LGBTQ+ population, I recommend the following:

1. Implement a CCH-wide, mandatory, and recurring LGBTQ+-inclusivity training.
2. Establish an education network of LGBTQ+ experts to accelerate learning.
3. Design and conduct a community-engaged exploration of LGBTQ+ patients and their loved ones regarding their lived experiences.
4. Implement an ongoing and iterative organizational reflection and assessment.

Introduction

A paradigm shift is required to change the way that the lesbian, gay, bisexual, transgender, and queer plus population (LGBTQ+) is cared for at the end of life (Acquaviva, 2017). Medical professionals and volunteers in the medical system who wish to practice LGBTQ+-inclusive care need to consider making an active choice to change current practices so they can better serve and care for this population with dignity and compassion (Acquaviva, 2017).

Death and the accompanying grief for caregivers and loved ones are universal experiences (Bristowe et al., 2016). Everyone is affected by death, but not everyone's end-of-life (EOL) experience is met with what Lintott et al. (2022) describe as "dignity, respect, and acceptance" (p. 610). For this Capstone project, I partnered with the hospice organization Capital Caring Health (CCH) in the Washington, D.C. metropolitan area. The project's aim was to determine the organization's current practices that demonstrate LGBTQ+ inclusivity and understand what additional actions this organization can take to better support this population.

CCH aims to be leading in hospice care for the LGBTQ+ population and this project and collaboration exemplifies this goal. Once CCH staff and volunteers have a deeper understanding of the LGBTQ+ community, the organization will have a stronger foundation as it pursues its goal of leading in EOL care for the LGBTQ+ community, continuing its legacy of providing advanced illness care of the highest quality.

Partner Organization

Capital Caring Health is a non-profit hospice organization and one of the fifteen original hospice providers established in the United States. It was founded in 1977 as Hospice Care of Northern Virginia and, as of 2019, it is known as Capital Caring Health. CCH is the largest nonprofit advanced illness care provider in the District of Columbia, Maryland, and Virginia (DMV) area. Its pioneering founder, Dr. Josefina Magno, knew that people with serious illnesses needed "substantial and sustained care," which led her to found the organization (Capital, 2024b).

In 1982, CCH assisted the 97th U.S. Congress with passing the Tax Equity and Fiscal Responsibility Act of 1982 (Capital, 2024b). This act added a hospice benefit provision to Medicare and universally increased access to care for the terminally ill (*History,* 2020). CCH also opened one of the country's first in-patient hospice care centers in Arlington, Virginia, and has provided hospice, palliative care, and grief support to nearly 200,000 patients and their families throughout its history (Capital, 2024b).

CCH's mission is to provide patients and their families with "advanced illness care of the highest quality," and its vision is to "be the best provider of advanced illness care and the best place to work in healthcare" (Capital, 2024a). Additionally, its core values are to "put patients and families first, always do the right thing, and respect everyone" (Capital, 2024a).

For nearly 50 years, CCH has provided hospice, palliative care, and counseling to its patients and their loved ones. In the 1980s, when individuals with AIDs were stigmatized and ostracized, CCH openly embraced and cared for this population. While that was 40 years ago, CCH knew then, as it knows now, how important it is for patients and their loved ones to feel understood, valued, and confident in the care they receive.

Nearly 1,000 employees and 1,000 volunteers provide care services to nearly 1,500 patients and their families each day, across two in-patient units and multiple community-based facilities (residential, nursing homes, memory care, and shelters). As one of the nation's oldest and largest non-profit providers of hospice and palliative care, Capital Caring Health provides $1 million annually in charitable care to families in need. Additionally, CCH does not turn any patient away, even if they lack the financial means to receive care.

Problem of Practice

CCH leadership anecdotally shared during our initial conversations that they know the lesbian, gay, bisexual, transgender, and queer plus (LGBTQ+) population is a demographic that does not get the care and treatment they deserve at the end of life. They know patients should be able to trust that their hospice and medical care providers will treat them with dignity. CCH understands that there is a level of distrust within the LGBTQ+ community toward the medical system, and this distrust has long-term implications for the quality and sustainability of their care. Acknowledging its importance and the opportunity for change, CCH committed to participating in this Capstone project.

CCH is dedicated to supporting the LGBTQ+ population during their end-of-life experience. CCH wishes to be the leading organization in hospice and end-of-life care for the LGBTQ+ population, continuing its mission to provide advanced illness care of the highest quality (Capital, 2024a). To continue to provide the best and highest quality care, and authentically uphold their mission, CCH must focus on LGBTQ+-inclusive practices when considering providing inclusive care to all its patients.

CCH Training Offered to Reduce Barriers to End-of-Life (EOL) Care

While these potential reasons likely vary by individual, CCH is committed to demonstrating openness and belonging, and building upon their LGBTQ+ -inclusive practices to support this population. CCH has already committed to several courses of action to support and serve the LGBTQ+ community in their advanced illness care. The organization is SAGECare-certified, as CCH staff completed the SAGE cultural competency training program. This training assists both service providers in becoming more LGBTQ+-welcoming and an organization that has SAGECare credentials helps the LGBTQ+ community find trained service providers (SAGE, 2024).

CCH staff has also undergone additional training centered around Diversity, Equity, Inclusion, and Belonging. Currently, however, there is an absence of data at CCH to validate whether the LGBTQ+ community is receiving advanced illness care of the highest quality and whether those caring for them reflect cultural diversity and sensitivity, and competence.

Literature Review

As the global population increases and ages simultaneously, the number of people dying each year is expected to rise. The dying process will also become more extended as innovations in medical diagnostics, treatment, and therapies advance; life-threatening diseases will turn to chronic conditions and terminal illnesses could mean death within years, instead of months, weeks, or days. Conversely, death resulting from non-medical causes (e.g. war, violence, motor vehicle accidents, infectious disease, natural and environmental disasters, human-made disasters and unexpected catastrophes) are complex and contribute to the challenges of providing EOL care across different circumstances and within different contexts (Centers for Disease Control and Prevention, 2024; Zaman et al., 2017).

While life expectancy is increasing, it’s naturally causing the growth in the older adult population to increase. The number and proportion of LGBTQ+ older adults are also increasing (Gates, 2011, as referenced in Orel & Fruhauf, 2015). By 2050, presumably there will be accurate statistics on how many LGBTQ+ adults exist in both the United States and globally, because as Hunter (2007) predicts, “...the pervasive homophobic attitudes of society that discouraged LGBT older adults from ‘coming out’ and being counted will no longer be prevalent” (p. xx). As the global population increases, a “once ‘invisible’ minority” will ideally become more visible (Orel & Fruhauf, 2015, p. 4). and therefore, their unique needs will need to be met with dignity and care.

Misleading Terms in Death and Dying-Related Literature

Scientific literature treats the terms “death” and “dying” as synonyms, but they carry two different meanings and signify two different phases. Wittkowski and Menzies (2020) break down the distinction between the terms:

> In the scientific literature, as in everyday life, *death* and *dying* are often used as if they were synonyms. For example, the *ideal* of end-of-life care is to have one’s last days and hours free of pain, as far as possible. This goal of caring is usually called a *good death*. Actually, what is intended is a *good dying*, whatever that might be for the people of focus. Thousands of book titles give evidence for the confusion of the terms *death* and *dying* (p. 41).

Further, “death” simply means, in a biological sense, nonexistence. Meanwhile, “dying” is a phase of an individual’s life accompanied by both psychic and physical changes. When a living organism is dying, this process is a phase of life and not a third state between living and being dead (Wittkowski & Menzies, 2020).

What is a Good Death?

The construct of a “good death” has been articulated as an “option for positive possibilities at the end of one’s life,” (Farber et al., 2004, as cited in Berzoff & Silverman, 2004, p. 102), but the term can be troublesome. Ira Byock, a palliative care physician and author of the book *Dying Well* (1997), “consciously reject[s]” the term “good death” because he sees it as implying that a good death that can be achieved if only one knew the right formula or prescriptive approach to someone’s end of life (p. 32). It is as if, Byock says, “a good outcome chiefly depended on the right mix of people, place, medications, and services” (p. 32). It also blurs the lines between death and the end-of-life period (Byock, 1997).

Farber et al. (2004) do not argue whether someone would want a good death, and Byock (1997) encourages the reader to use the term, “dying well” as it expresses both a sense of living and a process (p. 32). Drawing on critiques of the term “good death,” researchers caution against the “grave danger” that may occur if good death values become prescriptive or seen as a rigid formula for a “successful” or good death (p. 103, as cited in Berzoff & Silverman, 2004). The concept of a “good death” imposes certain values and implies judgment if those values are unmet (Farber et al., 2004, as cited in Berzoff & Silverman, 2004). It also imposes more alarming, impractical concerns, as if death can be controlled or that a “good death” can be planned for in advance. In Byock (1997)’s experience, asking someone to describe a good death would typically involve what they want to avoid (e.g. pain, suffering, and becoming a burden for loved ones). There are also instances in which a dying person does not experience affirmation or reconciliation before they die.

Steinhauser et al. (2000) distinguish a “good death” by conducting a four-month study of 75 adults, ages 26 - 77 years, participating in one of 12 focus groups. The groups included a “full spectrum” of individuals involved with end-of-life care, including physicians, nurses, chaplains, social workers, hospice volunteers, patients, and the patients’ bereaved family members. Steinhauser et al., (2000) found six themes of what constitutes a good death: (1) pain and symptom management; (2) clear decision making; (3) preparation for death; (4) completion; (5) contributing to others; and (6) affirmation of the whole person. They reported in their study that a physician’s view of what constitutes a “good death” is significantly different from other health professionals and ultimately, they concluded that while there exist six themes or components of a “good death,” there is “no single formula” for one (p. 830).

Avoiding the imposition of “good death” values and judgment requires framing death and dying in a different light. If we do not, it could have what Cottrell and Duggleby (2016) describe as damaging consequences and something that could destroy an individual’s opportunity “to grow, to find meaning, hope, and joy, and to live fully until they die” (p. 711). Cottrell and Duggleby (2016) found in Broom (2012)’s work, which consisted of interviews with 20 hospice inpatients, that framing a death as “good” can become an agenda for palliative and hospice care providers. Dying individuals could feel pressured into behaving a certain way or dying according to what a hospice care professional deems as “good” (Cottrell and Duggleby, 2016).

What is EOL Care?

End-of-life care is a term that describes the support and medical care given to someone during the time surrounding their death (National, 2022). There is no one definition of end-of-life care, although needs in end-of-life care are growing (Izumi et al., 2012). There is no consensus on when the end-of-life period begins, even though it clearly ends with a person's death. Lowey (2015) describes this uncertainty as common, particularly when one has an illness and is not sure when the exact end-of-life period begins. The time length for each person differs, but ultimately, when someone needs specialized medical care to ease their suffering and improve their quality of life, their end-of-life period has begun (Lowey, 2015).

Hospice care is a type of comprehensive comfort care for someone who is at their end of life. It focuses on making sure the person dying is cared for and comfortable, and it is provided to anyone with a terminal illness and a prognosis of six months or less to live (What, 2021). Hospice care consists of a team that works together to ensure the patient’s needs are met. The team is typically made up of clergy, home health aides, a physician, nurses, social workers, volunteers, and therapists (speech, physical, and occupational, if needed). This interdisciplinary team is responsible for managing a patient’s pain and symptoms, providing emotional support, administering medications, coaching caregivers and loved ones on how to care for the patient, providing short-term inpatient care when pain becomes too difficult to manage at home (or when caregivers need respite), and providing bereavement support to loved ones (CaringInfo, 2024).

To become a hospice patient means that at some level patients and/or their loved ones acknowledge that the patient cannot be cured of their illness(es). This does not mean that someone must accept death or abandon any hope. Hospices view their role as one that accompanies another on life’s last journey, as no one really knows how long any patient will live; hospice can, however, help them to live until death comes (Connor, 2017).

Palliative care is a specialized medical care for someone living with a serious illness, and its goal is to improve the quality of life for both the patient and their loved ones (Center to Advance Palliative Care, n.d.). It seeks to provide care to a wide range of patients who have life-limiting conditions and symptom problems (Connor, 2017). There are three main components of palliative care: symptom management (e.g. pain, nausea), psychosocial-spiritual support (e.g. counseling, social work, caregiver support), and facilitation of decision making (Prognostic awareness, understanding of outcomes, defining quality of life) (Buss et al., 2017). Palliative care is often equated with hospice or EOL care, but they are not the same. Although palliative care arose from the hospice movement, hospice can be one focused part of palliative care. Despite this connection, they should never be referenced interchangeably (Buss et al., 2017).

Anyone, at any age and stage of a serious illness, can receive palliative care. This “extra layer of support” is intended to treat illness symptoms and support a patient's loved ones (CaringInfo, n.d.). While both hospice and palliative are intended to support a patient’s (and loved ones’) needs and quality of life, hospice is focused on the patient’s end-of-life period.

Why is EOL Care Important?

While dignity is acknowledged in health-related disciplines, it can still be an ambiguous term with no clear definition (Guo and Jacelon, 2014). This can make it difficult for organizations to know how well they have adhered to their principles and codes of ethics when providing care. Varying definitions can “confuse the application” of dignity when it comes to care (Guo and Jacelon, 2014, p. 932).

Guo and Jacelon (2014) sought to provide a comprehensive understanding of dignity through their integrative review of end-of-life care. After synthesizing both empirical and theoretical literature, they synthesized ten major themes that summarized meanings of dying with dignity from the perspectives of patients, their families, and health professionals. These themes are: a human right; autonomy and independence; relieved symptom distress; respect; being human and being self; meaningful relationships; dignified treatment and care; existential and spiritual satisfaction; privacy; and [a] safe and calm environment. After learning that patients, their loved ones, and their health professionals have overlapping understandings of what it means to die with dignity, Guo and Jacelon (2014) proposed their own definition of dying with dignity:

> Dying with dignity is a basic human right; it is a subjective experience and also a value influenced by others; it signifies a dying process with the following characteristics: dying with minimal symptom distress and limited invasive treatment, being human and being self, maintaining autonomy and independence to the greatest extent, achieving existential and spiritual goals, having self-respect and being respected by others, having privacy, maintaining meaningful relationships with significant others, and receiving dignified care in a calm and safe environment (p. 937).

Dignity is different from respect in that dignity is a birthright, according to Dr. Donna Hicks (2011), a global conflict-resolution researcher, professor, consultant, and international advisor. We must, as Hicks insists, treat others as if they matter and they are worthy of care and attention (2011). Hicks is clear that one of humanity’s defining characteristics is that we are feeling beings, and because of scientific advances, we know that we are “hardwired” to feel what others are feeling without even needing to say anything (Iacoboni, 2008, as cited in Hicks, 2011, p. 6). This connection is particularly true at the end of life. We long for dignity, something that Hicks describes as our feeling of inherent value and worth. Our desire for it is our “highest common denominator” (Hicks, 2011, p. 17).

There is literature that suggests the use of the word “dignity” is a(n) “...uncertain attempt to find the right word or concept, and [it] reflects an indecisiveness and ambiguity in the discourse of a proper death,” (Johnson, 1998, p. 342). Johnson (1998) also acknowledges, however, that the general feeling among anyone who uses this word “through the discourse of dying well,” what remains is dignity’s “factor of humanness” (p. 342).

Nel Noddings, American philosopher and educator, in her work on caring and the experience of caring and being cared for, described this phenomenology as a relation. A caring relation, she wrote (1992), is a “connection or encounter between two human beings - a carer and a recipient of care, or cared-for” (p. 15). To care, she says, is to “really hear, see, or feel what the other tries to convey. The engrossment or attention may last only a few moments and it may or may not be repeated” (p. 16).

Noddings (2015) tells us to distinguish between caring-for and caring-about someone. Caring-for someone, she argues, requires the attention and response that one develops when in relationship with another. If we suppose, she argues, that the people about whom we are concerned want or need precisely what we would want or need in their situation, then we are likely doing more harm than good (as cited in Engster and Hamington, 2015).

Further, as we incorporate caring into organizations, Noddings asserts it should be clear that organizations cannot care-for directly. Instead, they must focus on creating conditions under which “caring-for” can occur, under which care relations and trust are established and maintained (p. 74, as cited in Engster and Hamington, 2015).

How is Optimal EOL Care Provided to Patients?

To provide optimal EOL care, a comprehensive assessment of both the patient and family’s needs is essential (O’Donnell, 2004, as cited in Berzoff & Silverman, 2004) (note: family includes either biological or chosen family when serving the LGBTQ+ population). Understanding the physical, psychological, social, and spiritual needs of both groups is a must, and so is managing ethical challenges that arise among the patient and family(ies) and the medical professionals caring for them (O’Donnell, 2004).

Concerns about EOL care are not bound by geographical location. In 2016, the Care Quality Commission (CQC), an organization in the United Kingdom, reported on inequalities in end-of-life care. The CQC report found that service providers and commissioners do not have a good understanding of the communities they serve. The report also found that service commissioners think that sexual orientation and gender identity have zero impact on palliative and end-of-life care. Further, there was little evidence that service providers are talking to and engaging with the LGBTQ+ community to learn about and consider their needs (Care, 2016, as cited in Chidiac et al., 2021).

Hicks offers that “being treated with dignity triggers the limbic system to release those pleasant feelings of being seen, recognized, and valued - all the life-expanding experiences that come with human connection” (2011, p. 11). Hicks (2011) reminds us that we can help others feel seen and worthy. To Hicks, it's hard to understand that such a significant part of our shared humanity has received so little attention, but she points to the lack of education about dignity as a contributing factor to those around us feeling hurt, unseen, or violated (2011).

Societal Beliefs Impact Experiences

Grief is a universal experience (Bristowe et al., 2016). Everyone is affected by death, others' and ultimately their own, so this is not a socially constructed experience; however, as Silverman (2004) describes, "*How* we react and how we experience [death] are socially constructed" (p. 128, as cited in Berzoff & Silverman, 2004). To that end, how we view death and how we mourn must be looked at contextually (Silverman, 2004, as cited in Berzoff & Silverman, 2004). Before we can begin to understand socio-cultural perceptions of death and mourning, it's critical to first understand the attitudes, values, and beliefs underlying these societal norms (Silverman, 2004, as cited in Berzoff & Silverman, 2004). Our attitudes and values affect how we relate to ourselves and to one another and give meaning to our experiences.

For an LGBTQ+ -identified person, the reality of discrimination can exacerbate the emotions and fears paired with dying. While the Biden-Harris Administration took regulatory action to strengthen federal nondiscrimination protections for the LGBTQ+ community, the number of state attacks targeting this community has surged (Medina & Mahowald, 2022).

In 2022, the Center for American Progress, in conjunction with the National Opinion Research Center at the University of Chicago, surveyed LGBTQ+ adults in the United States to better understand the LGBTQ+ communities' experiences during this time. This survey included interviews with 1,828 self-identified LGBTQ+ adults ages 18 or older and identified that more than 1 in 5 LGBTQ+ adults reported postponing or avoiding medical care in the past year due to disrespect or discrimination by providers (Medina & Mahowald, 2022). Their research critically established that the LGBTQ+ population experiences significantly higher rates of discrimination than non-LGBTQ+ individuals in healthcare, employment, housing, and public spaces;

generating substantial downstream impact to their economic, physical, and mental well-being (Medina & Mahowald, 2022).

Contrast in EOL Experiences

Coming to one's end-of-life is both a universal and inevitable experience, but there is no broad agreement on "how" one dies. Similarly, there is no consensus on appropriate societal responses that deliver both "culturally relevant and sustainable forms" of end-of-life (EOL) care (Zaman et al., 2017, p. 72). In sociological terms, aging is often framed by social, economic, cultural, and political influences. While there is data about aging and dying populations, King and Hall (2023) assert, "Much less has been written about why we need to approach aging and older people *differently*," (p. 1). What King and Hall (2023) mean by "differently" is that society can take a critical and sociological lens on aging and challenge the norms that shape lives.

Death is not a phenomenon that impacts only the old and aged. Approaching aging and older people differently due to their specific phase of life necessitates further discussion on what broadly constitutes dignified EOL care. Farber et al. (2004) reviewed years of data collected from researchers, educators, and social critics who have studied how health professionals provide this care. Their work identified the common need to provide care that is based upon the respective illness experience and values of the patient and their loved ones (as cited in Berzoff & Silverman, 2004). To do so is to provide care in accordance with the Hippocratic Oath to do no harm. However, not everyone's EOL experience is met with what Lintott et al. (2022) describe as "dignity, respect, and acceptance" (p. 610).

EOL Care for the LGBTQ+ Population

To deliver high-quality, EOL care, healthcare professionals must understand the cultural, social, and identity frameworks that shape the LGBTQ+ population (Javier, 2021). Long-standing prejudice, stigma, discrimination, and oppression are among the main reasons why this population has avoided seeking medical care and distrusts the healthcare system overall (Javier, 2021).

The available literature on EOL care for the LGBTQ+ population shows that there is still much work to be done, as the LGBTQ+ population continues to face health inequities when compared to cisgender and heterosexual people. These inequities not only occur throughout a person's life, but they are particularly harmful during the vulnerable periods of end-of-life, death, and/or bereavement (Sprik et al., 2020). To begin the conversation of LGBTQ+ inclusivity, and to change how this population is cared for, requires a paradigm shift (Acquaviva, 2017).

The study of the LGBTQ+ population, their health, and lived experiences is insufficient, especially when compared to those who are not LGBTQ+ (Meyer, 2003). This asymmetry took hold in the 1960s and early 1970s, likely a direct result of the formal classification of homosexuality as a mental disorder. The debate of whether homosexuality was a mental disorder ended in 1973, when the *Diagnostic and Statistical Manual of Mental Disorders* removed homosexuality, however the damage has been done; the stigma remains and has "tainted discussion" on lesbians' and gay men's mental health ever since (Meyer, 2003, p. 674).

Chidiac et al. (2021) note that much of literature shows that the LGBTQ+ population is less likely to access health and social services, especially when they are their most vulnerable (e.g. when they need palliative and end-of-life care). They attribute this to health services' lack of or biased understanding of the population's specific needs, "overpowering" heteronormative behaviors, discrimination, homophobia, and transphobia. Heteronormativity is defined as the "hegemonic system of norms, discourses, and practices that constructs heterosexuality as natural and superior to all over expressions of sexuality" (Robinson, 2016, p. 1).

Barriers to EOL Care for the LGBTQ+ Community

Prior literature has established that LGBTQ+-identified persons (and their loved ones) avoid pursuing hospice care for three primary reasons: perceptual, financial, and institutional barriers to care (Acquaviva, 2017).

Perceptual barriers to care include (but are not limited to) myths and misperceptions of hospice and for whom it is intended; what it means to be admitted to hospice; whether an LGBTQ+ patient will need to spend time and energy educating the health care providers; risk of being “outed” to loved ones and family members; and risk of being mistreated by medical staff (Acquaviva, 2017).

Financial barriers that could preclude an LGBTQ+ person from seeking hospice care include complexities around costs and insurance coverage. While worries about costs and insurance coverage can also be concerns for those who are cisgender and heterosexual, LGBTQ+ individuals, particularly those who are transgender, may worry a hospice admission would cause them to lose hormone therapy coverage (Acquaviva, 2017).

There is an additional layer of complexity when it comes to financial entitlements of same-sex couples when compared to heterosexual couples. Estrangements and strained relationships with biological families are more common among the LGBTQ+ population, and this opens possibilities of contesting a dying person’s wills and assets during the EOL period. (Bristowe et al., 2016). Hornjatkevyc and Alderson (2011) describe the relative value a partner’s family of origin places on the partnership can influence the feeling of privilege and claim to the bereaved partner’s belongings. All of this creates an additional level of stress among the patient and their loved ones (Bristowe et al., 2016).

Institutional barriers historically have prevented LGBTQ+ individuals from seeking hospice care (Acquaviva, 2017). Institutions that display symbols or gestures that imply environmental safety (such as adding a rainbow flag to a brochure or website) but are not practicing LGBTQ+-inclusive care is not enough and could be harmful (Rosa et al., 2023). In addition to inadequate or lacking training for health care professionals, there are discriminatory admission and employment policies (Acquaviva, 2017). At the time of this writing, there are 16 states that still do not have state laws to protect someone from being denied employment or fired because of their sexual orientation or gender identity (Movement, 2022).

Acquaviva (2017) describes peer-reviewed and seminal publications for palliative care and hospice professionals where the LGBTQ+ population is either "relegated" to one chapter or is mentioned briefly in chapters on sexuality, "special populations," "cultural considerations," or "HIV/AIDS," (p. xv). In a 639-page book, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,* the words and phrases "gay," "lesbian," "bisexual," "transgender," "sexual orientation," "sexuality," and "LGBTQ" are never used (*Dying*, 2015, as cited in Acquaviva, 2017, p. xv). Recent examples like these point to healthcare either ignoring that LGBTQ+ people even exist, placing them in a special category off on their own, or conceptualizing them as a group that belongs with discussions on disease (Acquaviva, 2017).

Long-standing prejudice, stigma, discrimination, and oppression are among the main reasons why the LGBTQ+ population has avoided seeking medical care and distrusts the healthcare system overall. This is why scholars and practitioners in this field say a paradigm shift is needed if we're going to change the way we care for this population (Acquaviva, 2017).

Understanding the LGBTQ+ Population EOL Experience

Sprik et al. (2020) list stressors that the LGBTQ+ population might face at end-of-life, which include the medical staff's homophobia and transphobia; previous discrimination experience with healthcare providers that further contribute to avoiding recommended end-of-life care; medical staff's forced outing of their patient's sexual orientation or gender identity; financial, institutional, and legal barriers which then limit partners or loved ones' abilities to make medical decisions for their dying loved one; false assumptions that death is related to having HIV/AIDS; and disenfranchised grief experienced by loved ones. Caring for the LGBTQ+ population at their end-of-life must include honoring and considering their dignity, and to consider their dignity means there is, as Johnson (1998) writes, a "factor of humanness" (p. 342).

LGBTQ+ people face unwanted EOL experiences that differ from the heterosexual population. Discriminatory laws, ambiguous policies, and health care provider attitudes impact LGBTQ patients in that the patients do not always receive EOL care that is aligned with their wishes (Marsack & Stephenson, 2017). Marsack and Stephenson's (2017) study suggests the LGBTQ population is knowledgeable about typical end-of-life documentation and processes (such as do not resuscitate orders, durable power of attorney for health care orders, and living wills). However, this population do not pursue getting the documentation because they assume it will not be respected or followed, especially in what Marsack and Stephenson (2017) refer to as "heterosexist health care settings" (p. 277).

Lintott et al. (2022)'s rapid review of LGBTQ+ EOL needs literature uncovered a lack of lived experiences supporting how LGBTQ+ individual's experiences affect their EOL care experience. Their findings point to the need for the medical and healthcare system to deliver, as Lintott et al. describe it: "…authentic inclusive care" (p. 618).

EOL Care Professionals' Attitudes and Beliefs Concerning the LGBTQ+ Population

To understand hospice care team members' language and explore underlying attitudes and beliefs regarding LGBTQ+ patients and their caregivers, Reynaga et al. (2023) conducted six focus groups and spoke to 48 hospice providers in three U.S. states regarding their knowledge, experience, and opinions about the provision of EOL care for the LGBTQ+ population (both patients and their caregivers). These members worked in hospice organizations in three states in the Northeast, Southeast, and Intermountain West. Within the focus groups, hospice care team (HCT) participants reflected upon how their views informed their communication and care practices. Reynaga et al. (2023) identified four framing categories as a result: normalizing, pathologizing, homogenizing, and individualizing. Out of these four frames, normalizing occurred the most often.

Normalizing is when a person uses language and provides examples that position LGBTQ+ individuals as no different than anyone else. It can be spoken with good intentions, but assuring someone that, "We treat everyone equally" ignores how the LGBTQ+ population is treated differently in many spaces (Reynaga et al., 2023, p. 603).

Pathologizing the LGBTQ+ population occurs when people use terms, metaphors, and other references that put this community in the same category (ies) as a disease, condition, abnormality, or unhealthy state. Reynaga et al. (2023) use the example: "Like I know when people are drinkers or drug addicts, many nurses have a preconceived notion about those patients and about patients who may be, you know, gay or transgender, or whatever" (p. 603). The use of the phrase, "gay or transgender, or whatever" indicates homogenization. Homogenizing portrays the LGBTQ+ population in terms of one or more stereotypical traits or assumed intrinsic traits, which then assumes every subgroup with the LGBTQ+ community is the same (if it even points to there being a subgroup) (Reynaga et al., 2023, p. 603). Some HCT members in Reynaga et al. (2023)'s study shared that they were surprised to learn when a patient was LGBTQ+ because the patient "did not fit the HCT members' pre-conceived notion of what being LGBTQ+ looked like" (p. 603).

When HCT members spoke with an individualizing frame, they "recognized the variance with the LGBTQ+ population" and knew to provide care specific to everyone's individual needs. HCT members acknowledged they needed to know more about the patient aside from their current health circumstance and expressed, "I try to find out about the person maybe from family or whatever, what they did before they were sick, who they were, what they enjoyed and try to talk to them just as a person" (Reynaga et al. 2023, p. 604). Even more encouraging, HCT members knew they must acknowledge their own cultural norms as well as the patients' and that "We have to understand each other to be able to be effective" (p. 604).

Reynaga et al. (2023) concluded through discursive framing theory that "our cognitive frames show up in the language we use" (p. 605). By analyzing the language that the HCT professionals used to describe their experience with the LGBTQ+ patients and their caregivers, we can more deeply understand the HCT's knowledge, attitudes, and comfort level in working with this population. Reynaga et al. (2023) used the frames to create space for conversation about biases and equitable care, both of which are critical in improving health disparities for this population. They also concluded that the language HCT professionals use may be just as important as the language they use when engaging in EOL care discussions in general. The next step, Reynaga et al. (2023) describe, is identifying and understanding the historical, cultural, and social biases within each of the frames, as that will be a “vital next step” in promoting health equity (p. 605).

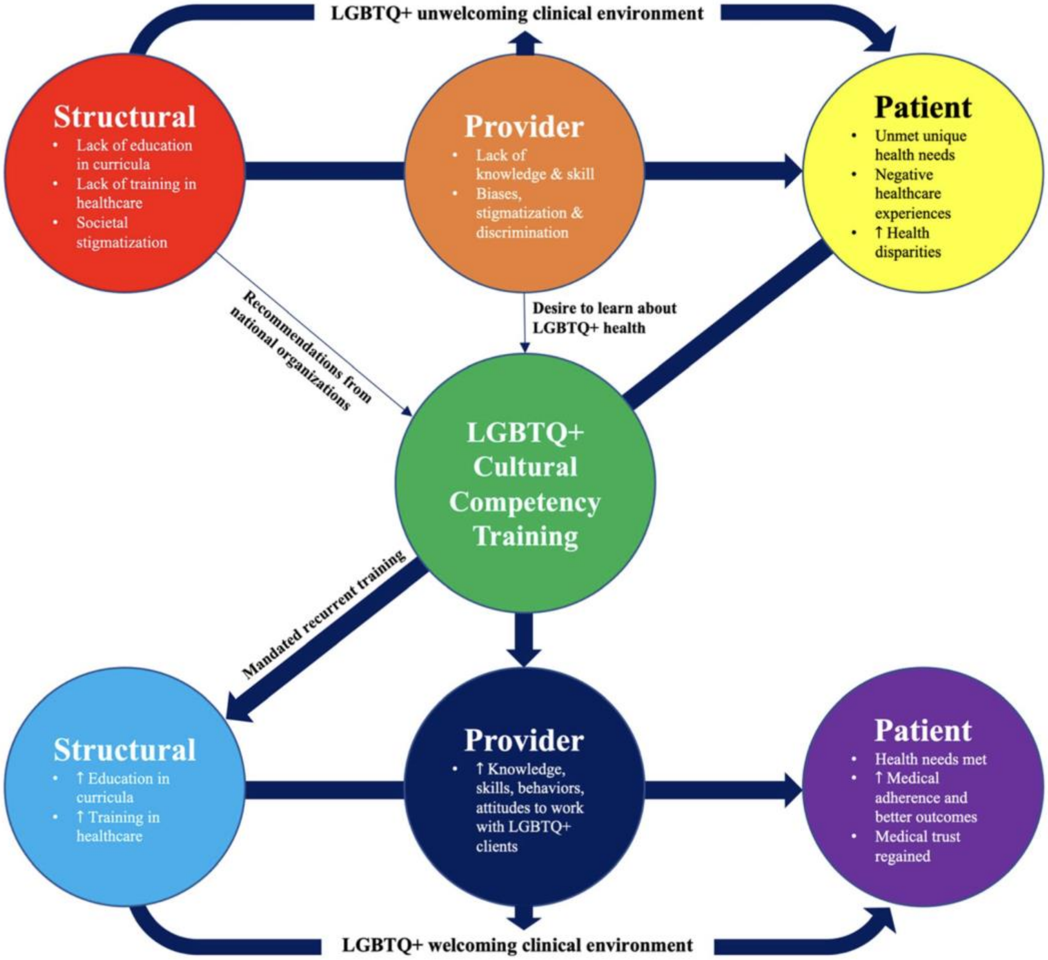
LGBTQ+ Cultural Competency Training is Key to an LGBTQ+ Welcoming Environment

Yu et al. (2023) conducted a systematic review of LGBTQ+ cultural competency trainings for health professionals across all disciplines in a variety of healthcare settings. They recognized a gap in the number of published LGBTQ+ cultural competency trainings and any quantitative appraisal and synthesis. Their review evaluated the design and effectiveness of these trainings and the magnitude of their effect on cultural competence outcomes. In Figure 1, Yu et al. (2023) break down levels of antecedents and consequences for LGBTQ+ cultural competency training in their conceptual model. The levels are broken down into Structural, Provider, and Patient, with the antecedent levels along the top and consequences of providing LGBTQ+ cultural competency training along the bottom. The middle level, “LGBTQ+ Cultural Competency Training” is the connecting piece in all of this.

Within the Structural-level antecedents, there is: (1) lack of LGBTQ+ health education in curricula, (2) lack of LGBTQ+-specific training in healthcare to provide optimal care to LGBTQ+ patients, and (3) societal stigmatization of LGBTQ+-identified people. This leads into the Provider-level antecedents, with (1) health professionals’ lack of knowledge and skills to work with LGBTQ+ clients and (2) their biases, stigmatization and discrimination against LGBTQ+ individuals. Ultimately, these two groups of antecedents create negative health experiences, increased health disparities, and unmet unique health needs for the patient, something Yu et al. (2023) call an, “LGBTQ+ unwelcoming clinical environment” (p. 2).

Figure 1

Conceptual model reflecting three levels of antecedents and consequences for LGBTQ+ cultural competency training (Yu et al., 2023, p. 3).



Once an organization mandates recurrent LGBTQ+ cultural competency training, there are three levels of consequences among the Structural, Provider, and Patient levels. First, the training in curricula and healthcare organizations enhance healthcare providers’ cultural competence, which enhances their ability to work with LGBTQ+ patients. Ultimately, the patient then finds their needs are met, they increase their medical adherence and see better health outcomes (improved sexual and reproductive health, mental health, cancer-related and cardiovascular-related outcomes), and for the organization, there is an opportunity to regain the trust of LGBTQ+ patients (Yu et al., 2023).

In their review, Yu et al. (2023) found that any systematic review of LGBTQ+-related training has mainly focused on training health professional students or mental health providers. While it is important to focus on education and incumbent health care professionals it is "equally crucial to assess the state and effectiveness of post-graduation LGBTQ+ cultural competency training programs for health professionals across all disciplines in various healthcare settings" (Yu et al., 2023, p. 4).

Conceptual Framework

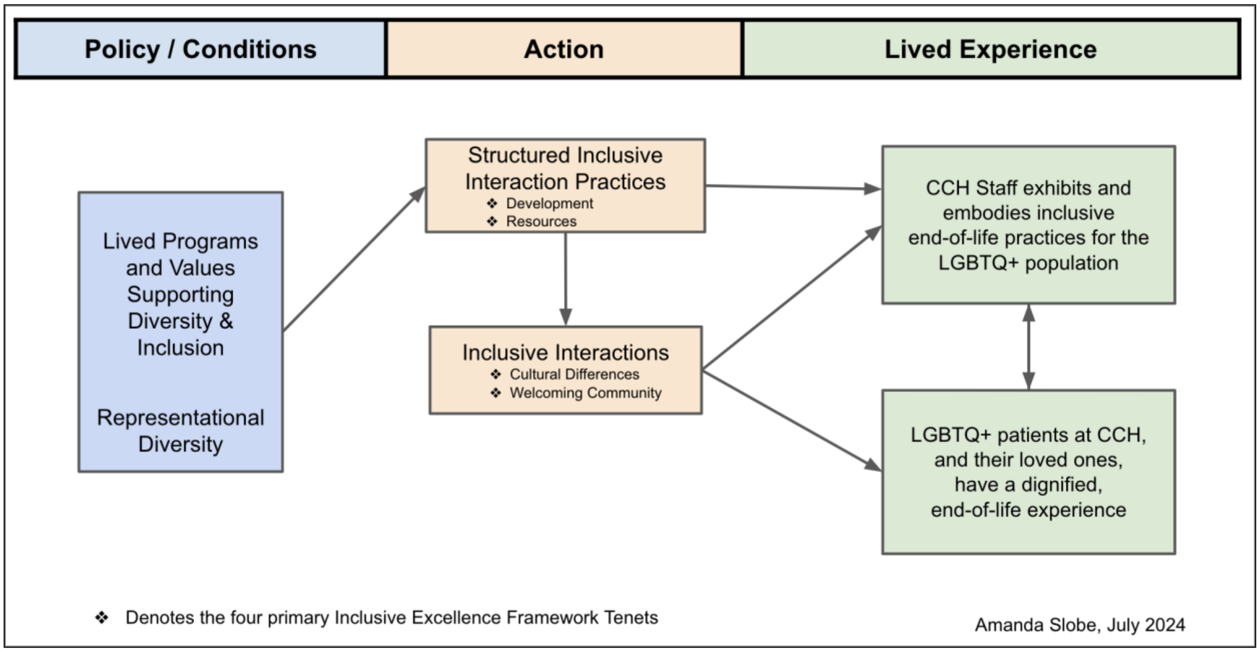
For this study, I used an adapted conceptual framework (Figure 2), combining concepts from Bernstein and Salipante's (2023) Framework for Inclusive Practices and an Inclusive Excellence (IE) framework and organizational behavior model (Williams et al., 2005). To assess the effectiveness and impact of CCH's current patient-facing and non-patient facing practices in promoting LGBTQ+ inclusivity, both frameworks were utilized, pointing to what Bernstein and Salipante (2023) assert: "Practices for inclusive interactions move policy to lived experience" (p. 17).

The Bernstein and Salipante (2023) Framework is an evidence-based and practiced-informed model. It is intended for use by organizations that strive to leverage diversity while increasing both equity and performance in nonprofit workgroups and boards. I constructed this framework from Bernstein and Salipante (2023) and added the IE Framework to demonstrate that it's more than an organization striving towards equitable inclusion is admirable, but aspirations are not enough to impact a community. It takes understanding the organization's inclusive practices and the interactions embedded in those practices to understand how those organizational conditions ultimately impact a community's lived experience.

The IE model was introduced in 2005 by the Association of American Colleges and Universities. While its initial focus was students, the framework is intended to be flexible, allowing for it to be used within a non-educational context (Williams et al., 2005). The IE model is supported by four overall unique tenets that can be summarized as: Development; Resources, Cultural Differences, and Welcoming Community (Williams et al., 2005). These four tenets live within the Structured Inclusive Interaction Practices (adapted from Bernstein & Salipante, 2023; Williams et al., 2005) of the organization and the resulting Inclusive Interactions.

Figure 2

Framework for inclusive practices. Adapted from Bernstein and Salipante (2023) and Williams et al. (2005).



Policy / Conditions

Policy begins with the organization’s conditions. Bernstein and Salipante (2023) explained that while an organization could have good intentions through its mission, values, and goal of representational diversity, it’s the “ubiquitous and complex social dynamics [that] undermine well-intentioned efforts" (p. 2). Well-intentioned efforts, describes Sterman (2001), can create unanticipated side effects or provoke reactions that were not foreseen. This type of "policy resistance" is what Sterman (2001) defines as: "the tendency for interventions to be defeated by the response of the system to the intervention itself" (p. 8).

CCH is a nonprofit operating in the District of Columbia, Maryland, and Virginia area, and because nonprofits possess a shared mission and values focus, along with potential resource scarcity, it has an opportunity to come up with alternative and evidence-based approaches that would support and incorporate inclusive practices (Bernstein and Salipante, 2023).

Action

Structured Inclusive Interaction Practices (Practices) are those that CCH staff and volunteers have implemented, and by default, those practices CCH is not implementing. The two IE tenets of Development and Resources fall within this category because this is where CCH would look at where its current practices could be lacking or could be supporting inclusive interactions among its staff and patients. The Inclusive Interactions stem from the Practices, and this is where Cultural Differences and Welcoming Community would be most apparent. How one responds and interacts with the organizational practices would point to cultural differences and whether the organization fosters a welcoming community.

Lived Experience

The Lived Experience is learned through sustainable inclusive practices. For CCH to be a leading hospice organization supporting the LGBTQ+ population at their end of life, the CCH staff must both exhibit and embody inclusive end-of-life practices for the LGBTQ+ population. As the staff does this, it will impact the lived experiences of the LGBTQ+ - identified patients at

CCH, and their loved ones. Ideally the LGBTQ+ patient and their loved one(s) will have a dignified, end-of-life experience.

This framework highlights an organization can set up conditions to be an inclusive and diverse organization, but until that organization deeply understands its inclusive practices and how those practices impact interactions, it will not know whether the inclusion outcomes are “favorable, rather than confounding” (Bernstein & Salipante, 2023, p. 19). The framework carries the study from understanding an organization’s policy and environmental conditions, to its practices and follow-on interactions, to how all of this impacts the communities it serves. For the purposes of this study, the focus will be on whether patients and their loved ones have a dignified, end-of-life experience.

It’s common for organizations to have visible diversity statements and programs that support diversity and inclusion (Bernstein et al., 2022). Within the conceptual framework, the arrow from *Lived Programs and Values Supporting Diversity & Inclusion* and *Representational Diversity* to *Structured Inclusive Interaction Practices* indicates how emphasizing diversity and inclusion leads organizational leaders to intentionally creating and structuring interaction practices. The goal is similar to Bernstein et al. (2022)’s framework from which this was adapted: “[T]o develop practices and behavioral norms that support productive inclusion interactions leading to the adaptive learning that fosters inclusion and sustainable inclusion” (p. 64).

The six inclusive interaction practices are: pursuing a shared task orientation or mission; mixing the [organization’s] members frequently and repeatedly; collaborating with member interdependence; handling conflict constructively; engaging in interpersonal conflict and self-efficacy; and ensuring equal insider status for all the organization’s members. When organization members follow these six practices, according to Bernstein et al., (2021), “inclusion is achieved in terms of actual behaviors” (p. 75).

The arrow from *Structured Inclusive Interaction Practices* to *Inclusive Interactions* denotes if an organization focuses on implementing some form of the aforementioned six practices, then “...inclusion is achieved in terms of actual behaviors” (Bernstein et al., 2022, p. 75). These behaviors are those inclusive interactions found within two IE tenets of cultural differences and cultivating and maintaining a welcoming community. It makes many practices, as no single practice will guarantee inclusion, and the goal of a set of practices for inclusive interactions is to “create a *high frequency of high-quality diversity interactions*” (Bernstein et al., 2022, p. 78).

Both an organization’s practices and the accompanying interactions lead CCH Staff to learning, understanding, exhibiting and embodying inclusive EOL practices. Ideally, if CCH Staff (including volunteers) exhibit both inclusive EOL knowledge and behavior, this will impact the LGBTQ+ patients and their loved ones under CCH Care. They ideally will have a dignified, EOL experience, which impacts CCH Staff, as they understand and feel the humanness in caring for the LGBTQ+ at the end of life. This creates an inclusive and dignified end-of-life lived experience.

Project Questions

This Capstone project sought to understand:

(1) What are Capital Caring Health’s current practices that demonstrate LGBTQ+ inclusivity?

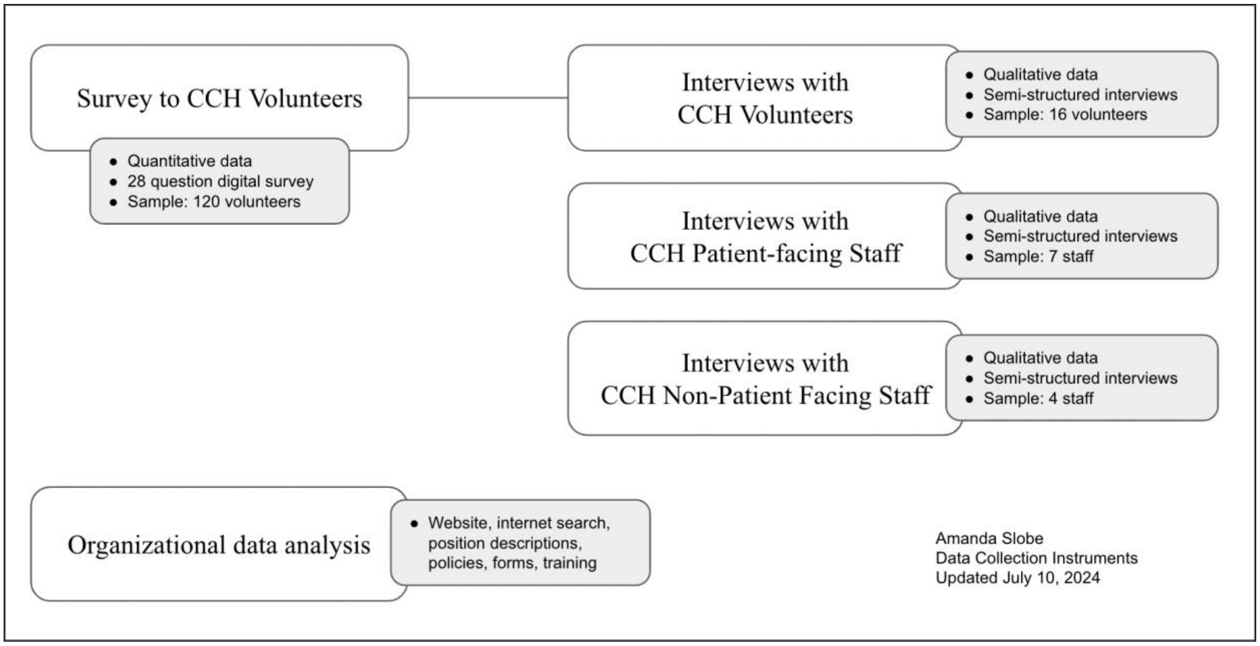
(2) What additional actions the organization can take to demonstrate its commitment to supporting the LGBTQ+ population at their end of life?

Study Design and Methods

The project questions in this Capstone were answered using a sequential mixed-methods design, beginning with a quantitative online survey sent to all CCH volunteers, which offered responders an opportunity to participate in a follow-up qualitative interview. Separately, non-volunteer constituents throughout CCH were invited to take part in the semi-structured qualitative interview component of the project. The goal of this sequential method was twofold: 1) to first capitalize on the knowledge gained via interview perspective; this data was used to identify where LGBTQ+ inclusivity was absent from CCH's current practices and then 2) conduct interviews to cross-compare perspectives throughout the organization. Document analysis was also performed as a supplement to the survey and interviews. CCH was the unit of observation, and the staff (patient-facing and non-patient facing) and volunteers were the units of analysis (see Figure 3 below).

Figure 3

Key Data Collection Instruments in this Capstone



Data Collection Instruments

I developed the data collection instruments and accompanying questions with the adapted framework for inclusive practices in mind. This framework highlights how an organization can set up conditions to be an inclusive and diverse organization, but until that organization deeply understands its inclusive practices and how those practices impact interactions, it will not know whether the inclusion outcomes are “favorable, rather than confounding” (Bernstein & Salipante, 2023, p. 19). The framework supports the project from understanding an organization’s policy and environmental conditions, to its practices and follow-on interactions, to how all of this impacts the communities it serves. For the purposes of this project, the focus will be on whether LGBTQ+ patients and their loved ones have a dignified, end-of-life experience at Capital Caring Health.

I designed the survey questions to capture the demographics of those who volunteer at CCH. The questions also helped me to understand what this population knows about inclusive practices in general (whether through CCH training or lived experience), and inclusive practices for the LGBTQ+ population and their caregivers at end of life. A five-point Likert scale was used.

The interview questions were intended to better understand the organization’s conditions and policies, who is involved in implementing policies, and how those policies and conditions impact staff to patient interactions. Bernstein and Salipante (2023) conceptualized that while an organization might have good intentions through its mission, values, and goal of representational diversity, it’s the “ubiquitous and complex social dynamics [that] undermine well-intentioned efforts” (p. 2). Well-intentioned efforts, describes Sterman (2001), can create unanticipated side effects or provoke reactions that were not foreseen. This type of “policy resistance” is what

Sterman (2001) defines as: “the tendency for interventions to be defeated by the response of the system to the intervention itself” (p. 8).

Sanchez et al. (2006) created a 13-item list of Attitudes Toward LGBT Patients Scale that summarized mean scores and ranges of medical students’ desire and willingness to care for LGBT patients. Wilson et al. (2014) modified Sanchez et al. (2006)’s scale and adapted their own to explore the relationship between demographic, professional, and training characteristics and health profession students’ attitudes toward LGBT patients. Using Wilson et al. (2014)’s scale, Cloyes et al. (2020) adapted their own so they could understand hospice interdisciplinary team providers’ attitudes toward sexual and gender minority patients and their caregivers. Several of this capstone project’s survey and interview questions were inspired by the work of Cloyes et al. (2020). Because of the iterative nature of this Scale, the tool has not yet been validated.

Additionally, the survey and interview questions stem from Bernstein et al. (2021) and their six structured inclusive practices. The six practices are: pursuing a shared task orientation or mission; mixing the [organization’s] members frequently and repeatedly; collaborating with member interdependence; handling conflict constructively; engaging in interpersonal conflict and self-efficacy; and ensuring equal insider status for all the organization’s members. When organization members follow these six practices, according to Bernstein et al., (2021), “inclusion is achieved in terms of actual behaviors” (p. 75). Drawing upon these six practices for the survey and interview questions provided the foundation to understand what behaviors exist (or do not exist) at CCH and how those behaviors could impact inclusive interactions at CCH. Understanding both would lead to understanding the lived experiences of CCH’s LGBTQ+ patients and their loved ones.

Data Collection

Once I created the volunteer survey and semi-structured interview guides, I proceeded to the data gathering phase. Quantitative data was collected from CCH volunteers through a self-administered, online survey of 28 questions across three sections: background data, general inclusivity, and inclusivity specifically toward the LGBTQ+ population. Volunteers were asked at the survey's end if they would participate in a follow-up interview to share more details about their CCH experience. For the survey email invitation and survey questions, see Appendix A.

The survey questions captured the demographics of those who volunteer at CCH and inform the semi-structured interview portion. The primary goal of the survey was to understand what CCH volunteers know about inclusive practices in general (whether through CCH training or lived experience) and inclusive practices for the LGBTQ+ population and their caregivers and loved ones at end of life. Volunteers answered 13 questions on a five-point Likert scale, with the options *Strongly Agree*, *Agree*, *Unsure*, *Disagree*, and *Strongly Disagree*. This data was treated as quantitative data. In addition, the survey captured some demographic data. Participants did have the option to leave some survey questions blank.

To understand the volunteer experience at CCH in greater depth and in the voices of the volunteers themselves, I conducted 16 semi-structured interviews with volunteers after they completed the survey. Volunteers interact with patients and their loved ones through in-patient units, at-home visits, and they likely come across CCH’s documents throughout their volunteer experience. Some volunteers assist in administrative duties only, so document analysis was critical throughout the entirety of the data collection process.

I interviewed both patient-facing and non-patient facing staff. I used semi-structured interviews to learn their understanding of the organization’s policies and conditions and how they impact staff's actions. The interviews with both patient-facing and non-patient facing staff provided space for the staff to elaborate upon CCH's training and their own experiences with the LGBTQ+ population. It highlighted expectations of CCH staff who interact with patients and their loved ones and provided insight into the kinds of interactions between CCH and the patients and their caregivers.

I conducted individual interviews via Zoom, digitally recorded for data fidelity and transcription purposes. I asked each participant group (volunteers, patient-facing staff, and non-patient facing staff) a set of interview questions tailored to the respective group at CCH. Questions were created in alignment with the conceptual framework and project questions. Aside from the survey and interview questions consisting of background data questions and questions asking for title and tenure at CCH, the questions sought to understand CCH's inclusive interaction practices and their effects. See Appendix D for the interview questions.

Document Analysis

I reviewed CCH's website, public online documents after searching for "Capital Caring Health" and "LGBTQ+," the CCH Employee Handbook, CCH policies, volunteer training, and position descriptions. Over 75 documents provided a view into what exists within CCH about the organization's policies and conditions. They provided a view into the organization's lived programs and values that support diversity and inclusion and what types of representational diversity might exist at CCH. I also completed the Home Care Pulse Training, *End-of-Life Certification Series: Hospice Direct Patient Contact Volunteer Training* that every CCH volunteer is required to complete before volunteering.

Sampling

The online survey was sent to all CCH volunteers (~500). A census method was used, as it was distributed to all volunteers and there was an equal opportunity for any volunteer who participated in the survey to agree to be interviewed.

For the interviews, purposive non-probability sampling was employed to conduct participant selection. Interviews consisted of volunteers and patient-facing staff, while the non-patient facing staff was selected according to their position within the organization and their presumed influence on CCH's inclusive policies and practices.

Participant Recruitment

Participation in this project was entirely voluntary, and an email was distributed through CCH's volunteer distribution list. The Volunteer Director distributed an email from the Volunteer Director and the Nursing Standards Director outlining this capstone's details, requesting participation, and reiterating the anonymity of the responses. For the volunteers that selected they were willing to be interviewed and provided their contact details, I contacted them to confirm a time, emphasizing again that the interviews were voluntary and their responses, like the survey responses, would remain anonymous.

For the interviews with staff (both patient-facing and non-patient facing), the Nursing Standards Director sent an email describing this project to prospective interviewees and encouraged staff to participate, if willing. The Nursing Standards Director forwarded my information sheet, and emphasized the interviews were voluntary and responses were anonymous. I shared the same message during the beginning of the interviews. Those who wished to refrain from participating did not need to reply to the email inviting them to be interviewed.

Response Rate

The desired response rate was that 20% of the volunteers completed the survey and at least five volunteers offered to participate in an interview following survey completion. Participants had one month to complete the survey, with weekly reminders at the beginning of each week for the first two weeks, and then a final reminder five business days before I closed the survey. Out of around 500 volunteers, 150 started the survey and 120 completed the survey, giving a 24% response rate. Of the 120 volunteers who completed the survey, 69 selected they would be open to participating in a follow-up interview.

Out of 69 volunteers who agreed to be interviewed, I contacted 18 (16 through email and two through the phone number they provided). In total, 16 volunteers participated in the interview. The 18 participants were selected based upon several demographic factors. These factors represent multiple characteristics of the CCH volunteers (e.g., religiosity, gender, volunteering tenure) and how the survey responded to several of the Likert scale questions. I used this method to ensure I incorporated multiple variables, highlighting interesting relationships between demographics and volunteers' thoughts on LGBTQ+-inclusivity at end of life.

I interviewed volunteers who self-selected; patient-facing staff; and non-patient facing staff. While not an exhaustive list, this demographic included administrative staff, patient-facing clinicians, and those in bereavement services.

Figure 4

Response rate by participant group

Group	Possible Participants (Total Invited)	Responded to Interview Invitation	Participated
Staff (Patient-facing)	14	11	7
Staff (Non-patient facing)	5	4	4
Volunteers (selected "Yes" on survey to participate)	18	16	16

Figure 4 shows the response rate by participant group summary. I included the table to demonstrate CCH-affiliate engagement in this project. As indicated above, the most popular area of engagement was from CCH's volunteers.

Data Analysis

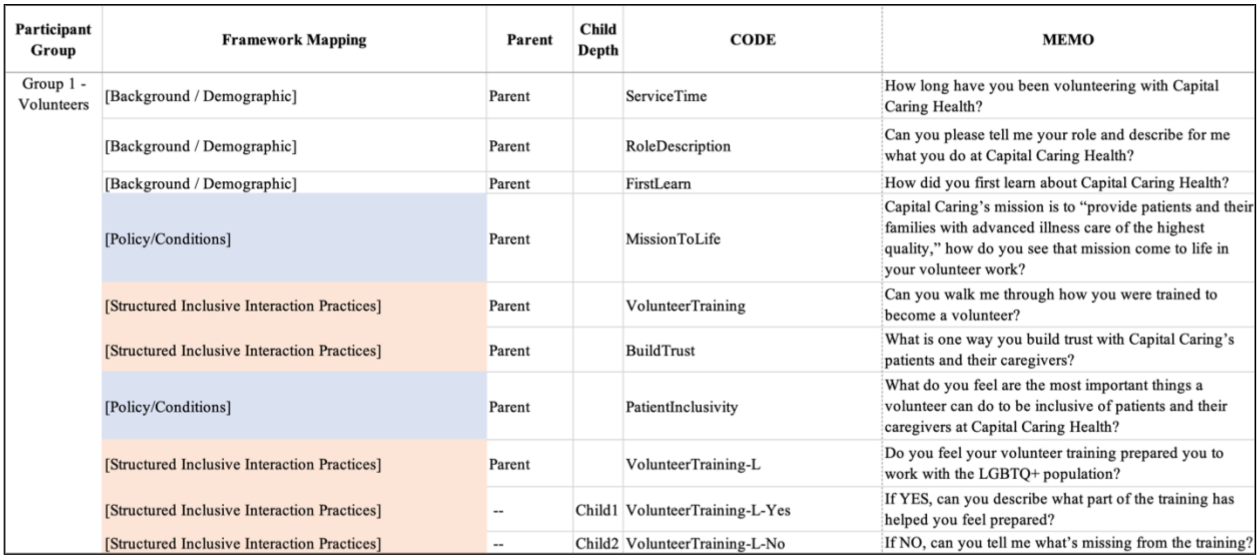
Coding Procedure

I coded all interview data using MAXQDA 24 Analytics Pro software. After each Zoom-recorded interview was complete, I downloaded the Zoom interview recordings after each live interview and then uploaded each recording to Microsoft Word to transcribe the interview. As every interview and respective transcription was complete, I compiled them together until I felt I had reached full saturation with interview data. Once I finished conducting interviews, I uploaded the transcripts into MAXQDA coding software. From there, I reviewed each transcript for data integrity and any spelling errors.

Once the transcripts were uploaded, I reviewed each multiple times, coding according to the Codebook that is mapped to the conceptual framework. See Figure 5 for an example of the interview questions and their respective Parent and Child codes. For the full codebook, see Appendix E.

Figure 5

Snapshot of the Codebook with respective mapping to the conceptual framework

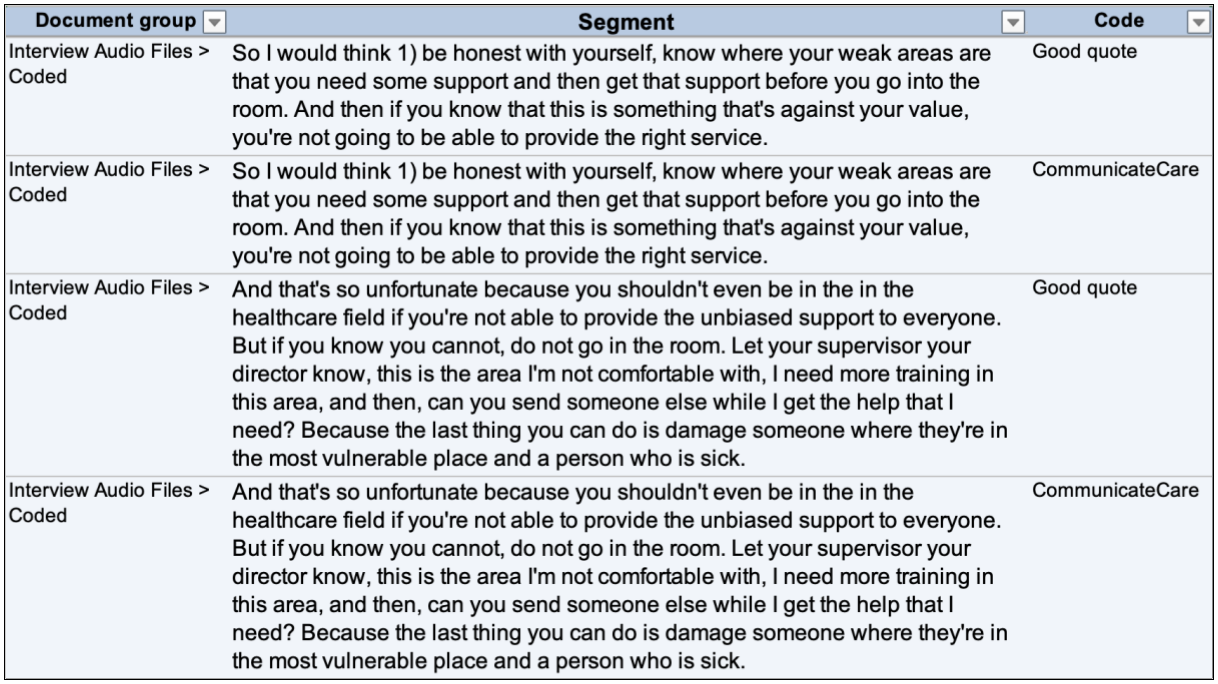


Participant Group	Framework Mapping	Parent	Child Depth	CODE	MEMO
Group 1 - Volunteers	[Background / Demographic]	Parent		ServiceTime	How long have you been volunteering with Capital Caring Health?
	[Background / Demographic]	Parent		RoleDescription	Can you please tell me your role and describe for me what you do at Capital Caring Health?
	[Background / Demographic]	Parent		FirstLearn	How did you first learn about Capital Caring Health?
	[Policy/Conditions]	Parent		MissionToLife	Capital Caring's mission is to "provide patients and their families with advanced illness care of the highest quality," how do you see that mission come to life in your volunteer work?
	[Structured Inclusive Interaction Practices]	Parent		VolunteerTraining	Can you walk me through how you were trained to become a volunteer?
	[Structured Inclusive Interaction Practices]	Parent		BuildTrust	What is one way you build trust with Capital Caring's patients and their caregivers?
	[Policy/Conditions]	Parent		PatientInclusivity	What do you feel are the most important things a volunteer can do to be inclusive of patients and their caregivers at Capital Caring Health?
	[Structured Inclusive Interaction Practices]	Parent		VolunteerTraining-L	Do you feel your volunteer training prepared you to work with the LGBTQ+ population?
	[Structured Inclusive Interaction Practices]	--	Child1	VolunteerTraining-L-Yes	If YES, can you describe what part of the training has helped you feel prepared?
	[Structured Inclusive Interaction Practices]	--	Child2	VolunteerTraining-L-No	If NO, can you tell me what's missing from the training?

The first level (Parent) codes are the interview questions, and the second level (Child) coding included the interview follow-up questions. I did not use any automation in this coding, and both levels were conducted after manually reading the transcripts and then re-reading for a second time. Please see Appendix F for the full list of codes and their frequency. In addition to the interview question codes, I assigned the code "Good quote" to anything I would potentially want to include in this paper or the Capstone presentation. See Figure 6 (below) as an example of the interview data coding review.

Figure 6

Example of interview data coding review



Document group	Segment	Code
Interview Audio Files > Coded	So I would think 1) be honest with yourself, know where your weak areas are that you need some support and then get that support before you go into the room. And then if you know that this is something that's against your value, you're not going to be able to provide the right service.	Good quote
Interview Audio Files > Coded	So I would think 1) be honest with yourself, know where your weak areas are that you need some support and then get that support before you go into the room. And then if you know that this is something that's against your value, you're not going to be able to provide the right service.	CommunicateCare
Interview Audio Files > Coded	And that's so unfortunate because you shouldn't even be in the in the healthcare field if you're not able to provide the unbiased support to everyone. But if you know you cannot, do not go in the room. Let your supervisor your director know, this is the area I'm not comfortable with, I need more training in this area, and then, can you send someone else while I get the help that I need? Because the last thing you can do is damage someone where they're in the most vulnerable place and a person who is sick.	Good quote
Interview Audio Files > Coded	And that's so unfortunate because you shouldn't even be in the in the healthcare field if you're not able to provide the unbiased support to everyone. But if you know you cannot, do not go in the room. Let your supervisor your director know, this is the area I'm not comfortable with, I need more training in this area, and then, can you send someone else while I get the help that I need? Because the last thing you can do is damage someone where they're in the most vulnerable place and a person who is sick.	CommunicateCare

Once the coding was complete, I downloaded the transcripts and codes to an Excel spreadsheet where I then began a thematic analysis, searching for recurring themes, patterns, or nuances in the language used by the interviewees. I uncovered the theme of there being generational differences when it comes to how much people know about the LGBTQ+ population. In the instances where I coded “Good quote” within another code, I was able to consider including these in both this paper and the Capstone presentation.

I saved the survey results, Zoom recordings, and interview transcripts in a personal folder both on my computer and on an external hard drive to ensure backup. I took every precaution to ensure participant anonymity and redacted interview quotes where necessary to maintain anonymity when included in this paper and the final capstone presentation. Below is an excerpt from the interview script in which I ask permission to record and describe details of the anonymity:

> [Before recording]: Once we get started, I'm going to hit record and ask you if I have your permission to record this interview. No one except me is going to see these interviews and your responses are anonymous. The only reason I'm recording is for data fidelity. I want to make sure I capture what you say, exactly the way you say it. [Presses Record on Zoom] Before we get started, I'd like your permission to record this interview for data integrity purposes. Do you agree? [Consent obtained] As a reminder, I am going to keep all of your responses anonymous; I will not publish anything that will identify you. Based on your role with Capital Caring Health, [staff or volunteer] you've been invited to take part in this interview about Capital Caring Health's policies around inclusivity toward the LGBTQ+ population. I sent you the information sheet in advance. Do you have any questions about that or any questions in general?

Limitations

There were some limitations to this study. It should be noted that no CCH patients or their caregivers participated in this study. The conceptual framework is organizationally based, so my focus was on an organization's policies and actions. I focused on CCH staff and volunteers, and while participants self-selected into the study, there was no information gathered about people who did not self-select to participate in both the survey and interviews. While there were respondents who did not self-select or volunteer to participate in the survey and interviews, the sample size was large enough to be comfortable with the results.

Additionally, no social workers, chaplains, or certified nursing assistants participated in this study because of the demands of their jobs at CCH. For example, one staff member agreed to be interviewed but then canceled due to a patient being admitted to hospice, so time was limited. When asked in total how many patients they interact with in a week, on average, volunteers reported that they interacted with patients 0 – 5 times per week. Including zero in the range is a limitation as it does not differentiate the volunteers who do not interact with any patients with those who interact with at least one per week.

Results

The following section summarizes the survey and interview results. Of the about 500 volunteers who received the survey via Qualtrics, 150 answered some questions and 120 participants fully completed the survey. While the number of completed surveys was 120, I retained partially completed responses for analysis to include as much data as possible. This explains the fluctuation in total responses that can be seen throughout the survey results (Appendix B); however, this did not impact the results.

58% of survey participants are new volunteers (80/139), and 74% identify as female in at least one of the identifying markers for gender (79 identified as female; 9 as female; cisgender; and 1 as female; male; transgender). More than half (53%) of volunteers who completed the survey are 60+ years old (64/120) and 22% identify as something other than straight or heterosexual. Out of 139 respondents, 112 volunteers (81%) reported that they interacted with patients 0 – 5 times per week, and of those 139 volunteers, 10% (14/139) report that they do not interact with patients in either the in-patient units or in the community. This could account for the volunteers who provide solely administrative support.

The survey questions that asked volunteers whether they would be comfortable if they became known among their volunteer peers, friends and family, and intimate partner(s) as someone who cares for LGBTQ+ patients and their caregivers/loved ones all resulted in respondents selecting Strongly Agree and Agree (83%; 123/148) with 25 respondents leaving the question blank. These responses, seen in Figures 7, 8, and 9 below, demonstrates the volunteers' openness and willingness to care for the LGBTQ+ population. See Appendix C for total survey results.

Figure 7

Responses to the survey question: I would be comfortable if I became known among my volunteer peers as someone who cares for LGBTQ+ patients and their caregivers/loved ones.

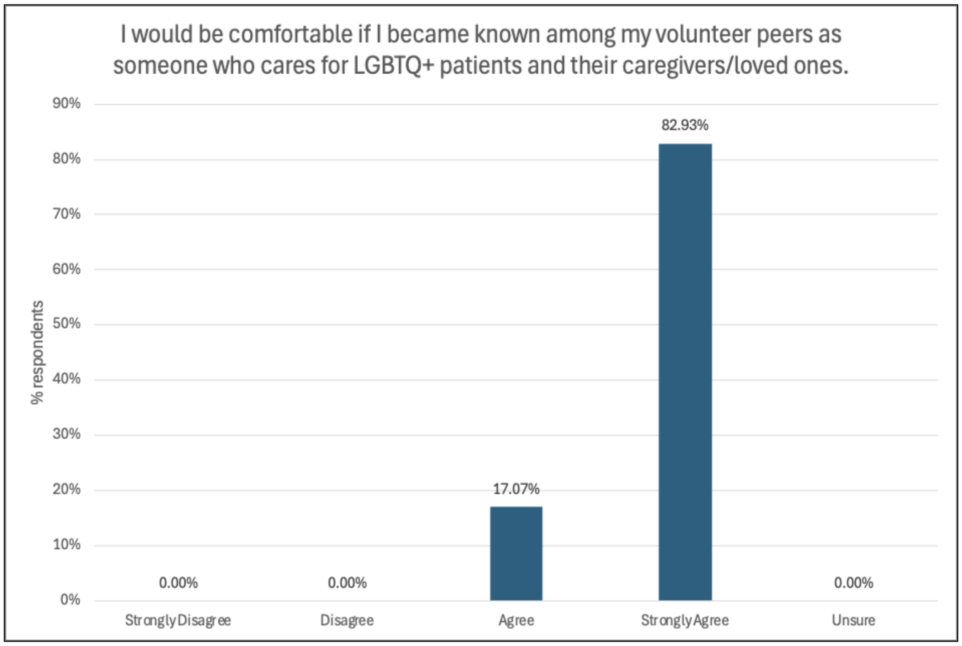


Figure 8

Responses to the survey question: I would be comfortable if I became known among my friends and family as someone who cares for LGBTQ+ patients and caregivers/loved ones.

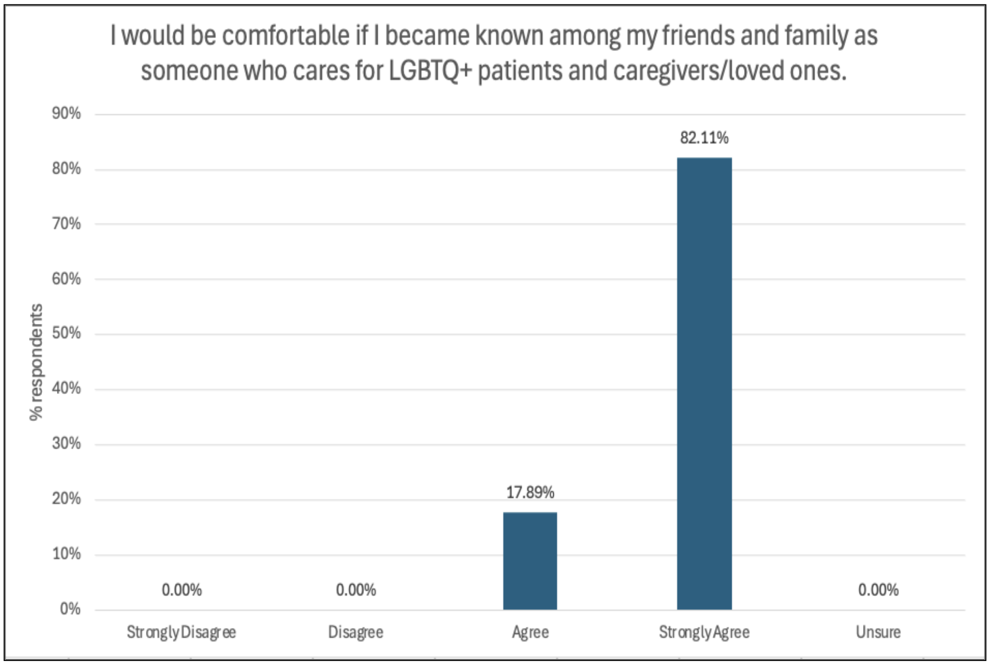
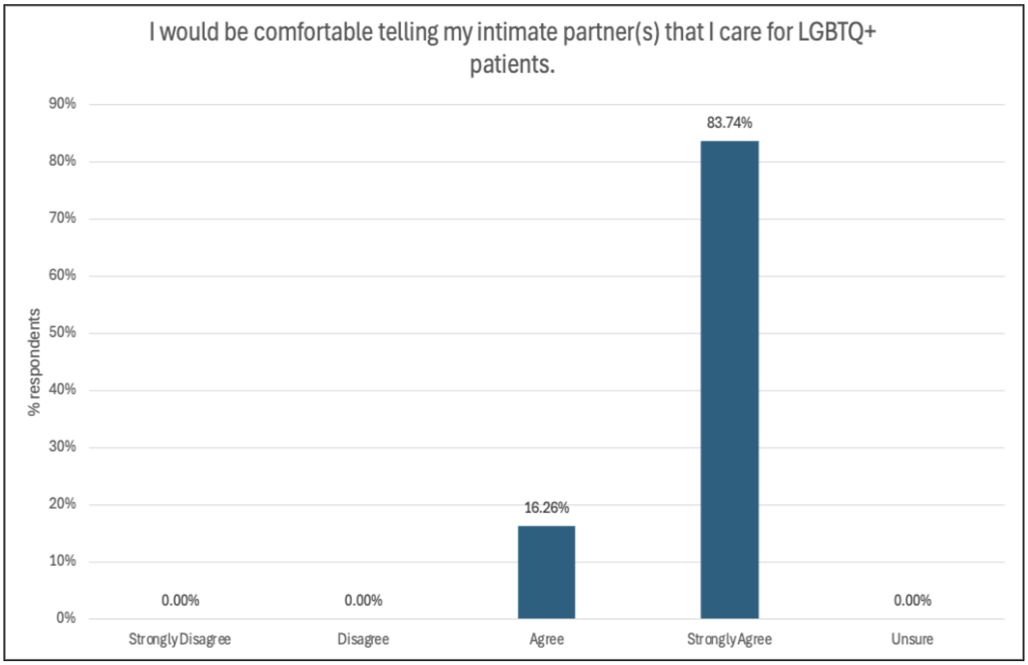


Figure 9

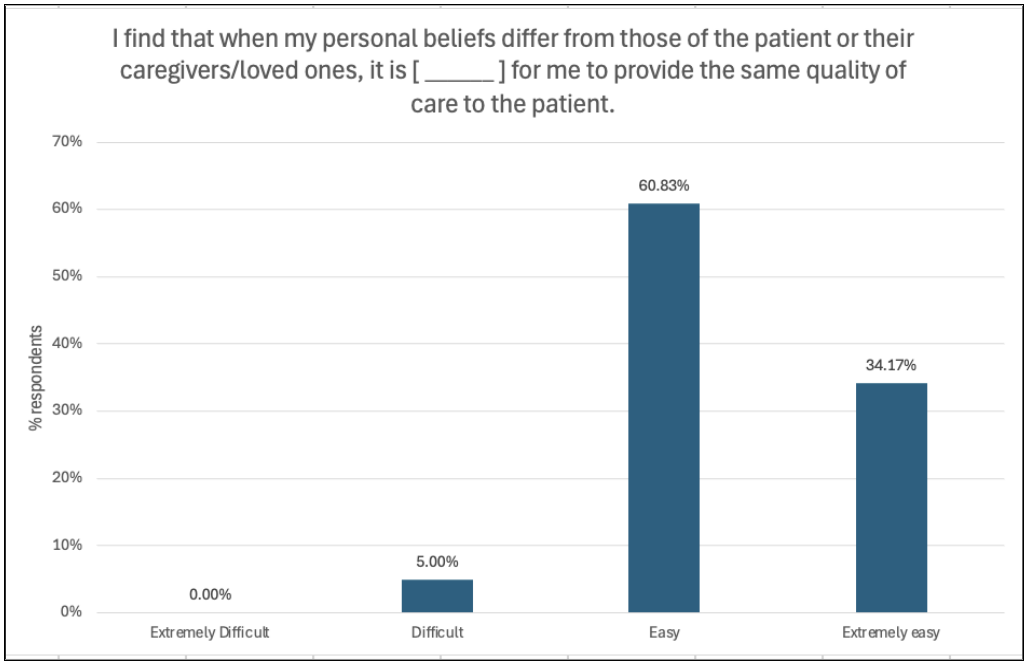
Responses to the survey question: I would be comfortable telling my intimate partner(s) that I care for the LGBTQ+ patients.



Additionally, a result that speaks to the type of volunteers that CCH attracts and hires comes from the survey question, "I find that when my personal beliefs differ from those of the patient or their caregivers/loved ones, it is [_____] for me to provide the same quality of care to the patient." Of 120 volunteers who responded to this question, 95% (114/120) selected that it is "Easy" or "Extremely Easy." Only 6 volunteers selected "Difficult" while "Extremely Difficult" had zero responses (see Figure 10). This openness and acceptance of the LGBTQ+ population is indicative of the volunteers' willingness to work with people from all kinds of backgrounds. The full list of survey questions and responses can be found in Appendix B.

Figure 10

Responses to the survey question: I find that when my personal beliefs differ from those of the patient or their caregivers/loved ones, it is [____] for me to provide the same quality of care to the patient.



Throughout the 27 qualitative interviews with CCH staff and volunteers, I heard a consistent theme that CCH treats all patients the same. One example is below:

> People are people. I don’t want to label somebody in any way for any reason, whether you’re a member of the LGBTQ+ community, whether you’re a member of the Hispanic community, I don’t care. You’re people, and so I just hope that when we go into the home, we treat everybody the same and there is no obvious difference [in the treatment that patients receive].

Staff consistently reiterated CCH’s mission to provide advanced illness care of the highest quality to all of CCH’s patients, and one member shared that the question, “What is most important to you today?” is a question that CCH staff ask at every single visit with a patient and their caregiver. This emphasizes the importance that CCH patients and their loved ones see that CCH areas and that the end-of-life care the team is demonstrating is one that the staff members said, “really honors exactly what [the patient] want[s] and what [the patient] need[s] and then [the CCH team] revisits it over time.

I reviewed over 100 CCH documents, including the Employee Handbook, position descriptions, and organizational policies. Within these, I conducted a thematic search for code words that matched the project questions’ aim, e.g. code words included, “sexuality,” “sexual orientation,” “gender identity,” and “LGBT,” LGBTQ,” and “LGBTQ+.”

Findings

CCH staff and volunteers do not appear to have a shared understanding of how LGBTQ+ people are harmed by heteronormative, societal practices. The volunteer survey, semi-structured interviews, and organizational document analyses showed that some Capital Caring Health staff and volunteers need and seek a deeper understanding of the LGBTQ+ population’s lived experience. While “LGBTQ+” is an umbrella term and risks homogenizing the population, there is an underlying truth that changing the way LGBTQ+ people are cared for at their end of life requires a paradigm shift. This paradigm shift, Acquaviva (2023) reminds us, changes the way health care professionals “approach the conversation about what it means to be inclusive in our compassion” (p. 2).

Some CCH staff and volunteers understood that there is variation within the LGBTQ+ population, both within the population and juxtaposed with current heteronormative society. They expressed this understanding through an individualizing frame, which emphasizes each patient (and their loved ones) require individual needs. (Reynaga et al., 2023). One CCH staff member stated in the interview:

> You have to understand everything that’s already happened up to this point [for this population]…stigmatization…it’s so important for [people] to understand the history and as a society where we’ve evolved from….and where [the patients] are now, and [that] there’s mistrust in the medical system.

A common desire expressed among staff and volunteers was for the LGBTQ+ population to understand that there are generational gaps when it comes to staff and volunteers' knowledge and internalized biases. Both CCH staff and volunteers mentioned generational differences impact their knowledge and understanding of this community. What was said then, participants described, is different than what is said now:

> I think [being in an older generation] creates significant challenges, let's call it, for people who are not contemporaries...things that were acceptable as jokes in the 1970s and 80s are no longer acceptable.

Another participant shared:

> I think [it's important] for the LGBTQ plus community to understand about someone not in their community is, we have these ways of thinking that we have grown up with [so] give us some grace to understand where you're coming from and trust that we're going to receive that information with compassion and empathy.

A third participant shared:

> ...in the 80s when AIDS exploded and AIDS was given the very narrow channel of [being] assigned to the gay population, in a very negative connotation [which was], if you had AIDS you were performing behavior that was inappropriate in our world and therefore look what happened - you're dying and you got what you d-…(participant started to say, "deserved").

There are numerous barriers to care that the LGBTQ+ population faces, including being stereotyped as existing in an "adverse or abnormal condition or unhealthy state" (Reynaga et al., 2023, pp. 603). When asked if they felt the volunteer training prepared them to work with the LGBTQ+ population, one CCH volunteer shared:

> Some of the tools [prepared me], as far as how to communicate openly and with kindness to individuals. [That] would apply across the board. [But] we also have people with intellectual disabilities that come through, and I don't recall there being any specific modules on that.

One staff member expressed their fear that CCH staff could be "missing things" when asked if they ever had a situation with an LGBTQ+ patient that they were not sure how to handle. This uncertainty is an opportunity for CCH to "open a new way of seeing, hearing, and feeling within a context" (Hansen and Trank, 2016). If there are things that CCH staff could be missing, it's an opportunity to be curious about what those "things" are and how CCH can begin a new way of seeing its LGBTQ+ patients and their loved ones within a heteronormative medical context.

Finding 1: CCH staff and volunteers believe that being inclusive means treating LGBTQ+ patients the same as any other patient.

During the interviews, when asked, "*What do you feel are the most important things that volunteers can do to be inclusive to a patient that is a member of the LGBTQ+ community? What about their caregiver?*" many staff and volunteers indicated that the most important thing(s) anyone can do to be inclusive is to treat them like any other patient and treat them equally. One volunteer shared, "Well, you know it's interesting. I don't think [CCH volunteers] need to treat them any differently than they would someone who's not in that community." Another participant shared that it's not something that's really talked about and it doesn't matter who the patients and caregivers are:

> We never really talk about Black versus Hispanic versus gay versus transgender. It never comes up. Our patients and their family [tell us what] they want to tell us, what they are or what they love. We'd like to hear it but our mission is the best care possible for everyone. It doesn't matter who they are, what they think, what their religion or lack thereof is. It doesn't register for us. We're always there for every single person.

A third participant shared:

> I think just treat them equally. Treat them with respect. They should be [treated] the same. I mean it shouldn't matter to anybody what choices people have in their lives, whether they're gay or trans or straight. That's life choices that people have made for their own personal reasons. And I think we should care for everybody the same. It should matter zero at the end of life [what] sexual orientation anybody has. What matters is that we keep them comfortable and clean and well cared for, you know.

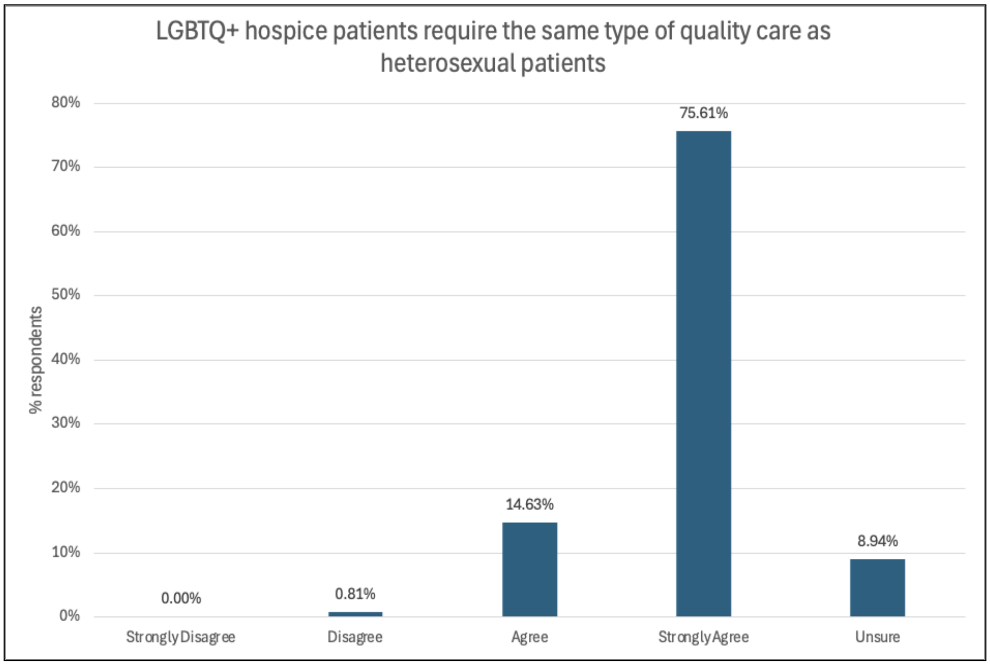
Others however, including this volunteer, understand there are differences among the communities that seek medical care:

> Here's what I would not want to see with the volunteers: for them to do the equivalent of, 'I'm color blind. I don't see race.' For someone to say, oh, you know, LGBTQ is the same as anything else and I don't see that. I think that's BS. I think it is necessary if we're going to volunteer with strangers, that we be aware of the LGBTQ community, of different things that are going on in society, about these prejudices that are out there. We just need to understand what's going on [in society].

Survey results in Figure 11 show there was a high number of volunteers who Strongly Agree (76%; 93/123) when asked if LGBTQ+ patients require the same type of quality care as heterosexual patients.

Figure 11

Responses to the survey question: LGBTQ+ hospice patients require the same type of quality care as heterosexual patients



Being inclusive does not mean treating everyone the same (Acquaviva, 2023). This form of normalization can be motivated by good intentions but insisting that "We treat everyone equally" ignores how the LGBTQ+ population is treated differently in many spaces (Reynaga et al., 2023, p. 603). Overlooking the unique lived experiences of the LGBTQ+ population has the opposite effect of inclusion. When the normalizing frame occurs, there is an underlying, well-intentioned effort to ensure everyone is treated equally. This assumed "positive social force" (Reynaga et al., 2023, p. 603) can have a negative, detrimental impact on the LGBTQ+ population. It ignores how LGBTQ+ individuals may be treated differently, does not consider that their needs are different at the end-of-life, and suggests that LGBTQ+ individuals have the same concerns and needs as cisgender, heterosexual people (Reynaga et al., 2023).

When CCH staff and volunteers assume that LGBTQ+ patients are the same as cisgender, heterosexual people, they are positioning LGBTQ+ patients and caregivers into a monolithic heteronormative context. This context that impacts CCH's interpersonal communication towards its patients, caregivers, and its care practices. The language we use "reflects and reproduces" attitudes and biases we hold, which Reynaga et al., (2023) stress ultimately affects healthcare professionals' communication and practice (p. 602). It also provides context that Reynaga et al., (2023) assert, points to the need for more understanding from both social and historical perspectives.

Finding 2: CCH volunteers do not feel prepared to work with the LGBTQ+ population.

Across 16 volunteers interviewed, there was an inconsistent understanding of whether CCH promoted LGBTQ+ cultural competency and sensitivity training. While some CCH staff recalled the SAGE training when reflecting on LGBTQ-specific training, volunteers provided varying responses to the interview question, *Do you feel your volunteer training prepared you to work with the LGBTQ+ population?* Some volunteers shared outright that the training did not prepare them ("I don't remember any specific training saying, 'Here are some special things that you might want to think about when helping a patient from this community,”). Others did not understand why there would need to be specific training to work with the LGBTQ+ population.

A volunteer shared, “I’m not sure I remember there being specifics about LGBTQ+…We also have people with intellectual disabilities that come through [Capital Caring Health], and I don’t recall there being any specific modules on that.” Another asked, “Should there be a [training] session on [LGBTQ+]? I never thought I needed any training like that…do you need training if somebody is a Catholic or Protestant? No. We’re all part of the same world.” One volunteer, when asked if the volunteer training prepared her, expressed the following:

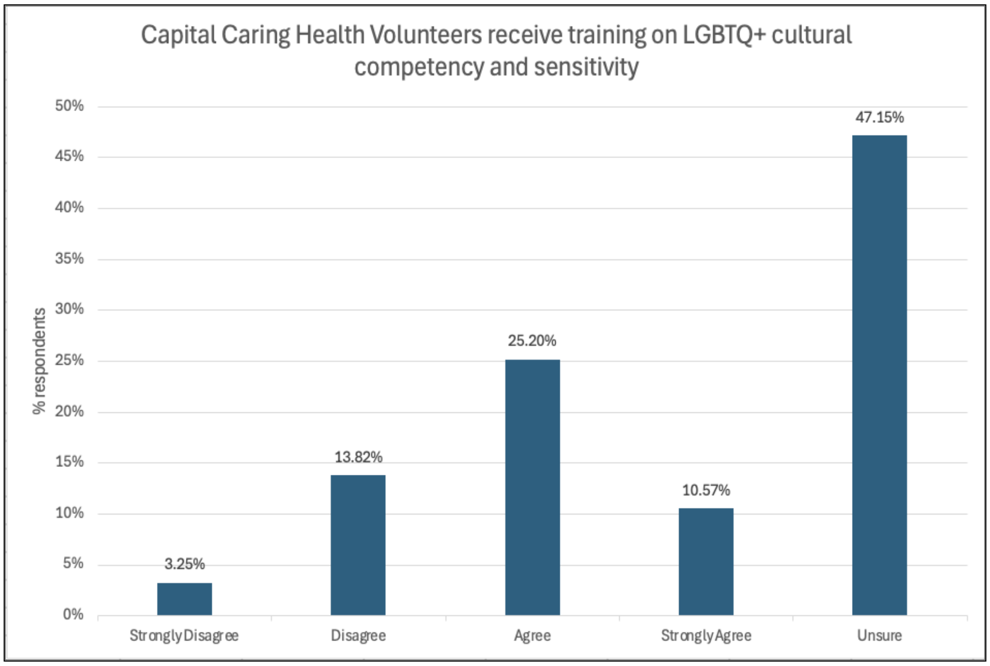
> No…and I don't even know if there was ever any mention of gender at all…I don't even know…LGB…T?…I don't understand what Q is…and I don't understand the plus…I'm sure there are people I come across [who are LGBTQ+], but that's not ever something that I would have a conversation with my friends [about]. I would never say, So [how] do you identify or what's your pronoun? That would not be a conversation that I would have with my age bracket.

The Home Care Pulse End-of-Life training contains a module for Spiritual and Cultural Diversity. Within this module are videos that interview people from varying backgrounds and identities, sharing their experiences and offering advice to others who may not understand the lived experience and are not sure what to do when they have questions or don’t understand. The Optional Resources section for this module contains Important and Additional Viewing materials that, while important and impactful, could be missed and skipped over as they are deemed “Optional.” It’s important to note, at the time of this writing, CCH is aware of this and making changes to ensure LGBTQ+-inclusive material is not offered in the “Optional” section of this online training.

Figure 12 shows the varied responses to the volunteer survey question, “Capital Caring Health Volunteers receive training on LGBTQ+ cultural competency and sensitivity.” Volunteers answered on a five-point Likert scale, with the options *Strongly Disagree, Disagree, Agree,* *Strongly Agree*, and *Unsure*. Participants did have the option to leave this question blank. Nearly half of the volunteers who completed the survey (47%; 58/123) were unsure whether they received training on LGBTQ+ cultural competency and sensitivity; 14% (17/123) disagreed that they received training, and 3% (4/123) strongly disagreed.

Figure 12

Responses to the survey question: Capital Caring Health Volunteers receive training on LGBTQ+ cultural competency and sensitivity.



Additionally, a third of the volunteers were unsure as to whether knowing if a patient identifies as LGBTQ+ influences the type of care they receive at the end of life; 22% strongly disagreed, and 23% disagreed (see Figure 13).

Figure 13

Responses to the survey question: Knowing whether a patient identifies as LGBTQ+ influences the type of care they receive at their end of life.

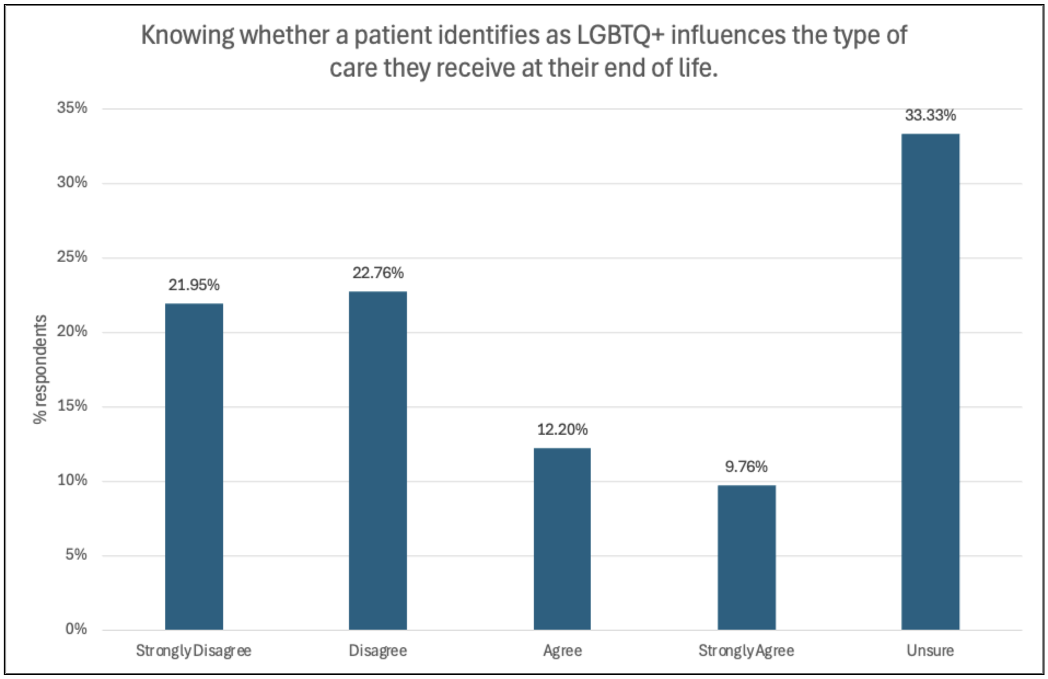
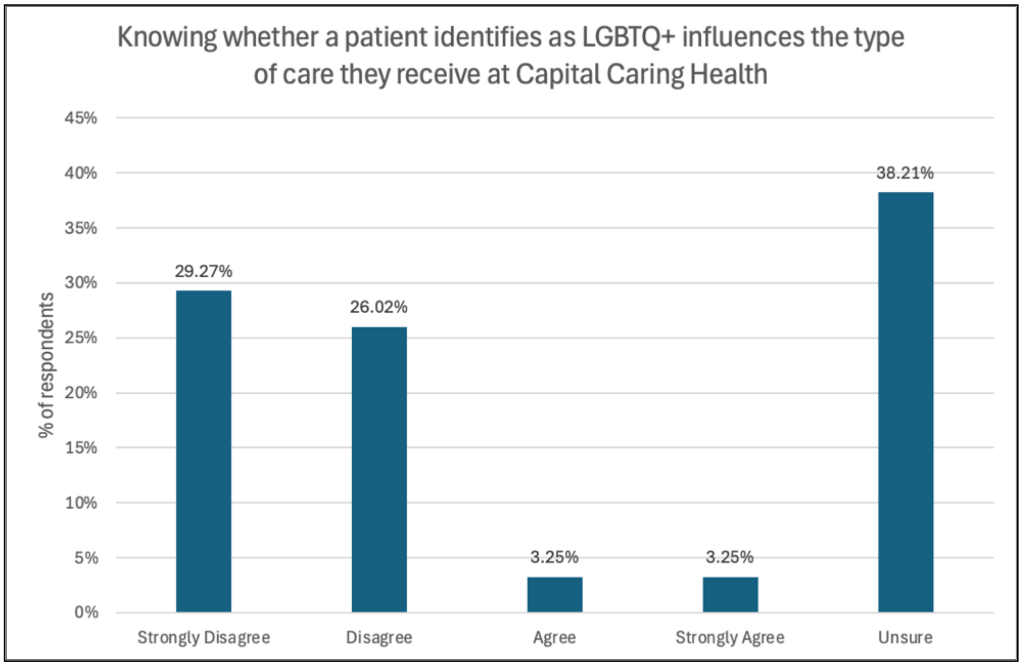


Figure 14 (below) shows that around 38% of the volunteers were unsure about whether knowing if a patient identifies as LGBTQ+ influences the type of care they receive at Capital Caring Health. Around 29% of volunteers strongly disagreed with the statement, and 25% disagreed.

Figure 14

Responses to the survey question: Knowing whether a patient identifies as LGBTQ+ influences the type of care they receive at Capital Caring Health



Recommendations

From the beginning of the partnership, CCH's leadership unanimously and emphatically agreed that this Capstone project is a necessary endeavor. In April 2024, CCH updated their electronic medical records so CCH staff can capture a patient's sexual orientation and gender identity. By doing this, CCH is already demonstrating that inclusion is achieved in terms of behavior. To continue this important work and based upon the literature review and data analysis of the survey results, interviews, and document review, I offer four major recommendations.

Recommendation 1: Establish a CCH-wide mandatory, recurring LGBTQ+ -inclusivity training.

Effective end-of-life care must occur within an established, safe, and respectful healthcare environment (Reynaga et al., 2023). To create a safe and respectful environment, hospice care teams must practice both clinical and cultural competency, which is best facilitated by direct communication with patients, their loved ones, and with other providers.

The Joint Commission's field guide on *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care* offers protocols to healthcare organizations so they can provide LGBTQ+ -inclusive care. The *Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health* offers information to healthcare professionals so they can better understand the LGBTQ+ population. While these national organizations have developed publications to assist healthcare professionals and organizations, there is still a “widespread scarcity” of LGBTQ+-focused trainings (Yu et al., 2023, p. 2).

The *National Coalition for LGBTQ Health Inaugural State of LGBTQ Health National Survey 2022* surveyed 2,329 individuals who provide services directly to LGBTQ+ people. One of the survey's major findings was that these providers want more education, training, and support when it comes to providing care to this population. The top training needs included the topics: LGBTQ+ health curriculum, trauma-informed care, stigma, and cultural competency training (*Inaugural,* n.d.).

Cultural competence is a complex and multidimensional concept and has evolved over time. While multiple definitions of cultural competence exist, Yu et al. (2023) point out that it’s been generally defined as, “the intricate integration of knowledge, skills, attitudes, and behaviors that improve cross-cultural communication and interpersonal relationships,” (p. 4).

LGBTQ+ often fear that disclosing key parts of their identity will impact their care. Chidiac et al. (2021) describe an association between positive and psychosocial adjustment and someone feeling as though they can disclose their sexual identity. An LGBTQ+-identified person who chooses to hide their sexual identity because they're afraid of discrimination or mistreatment may not have the same potential to experience positive psychosocial functioning compared to someone who does not face the challenges the LGBTQ+ community faces (Fredriksen-Goldsen and Muraco, 2010).

After reviewing quantitatively evaluated studies that measured the effectiveness of LGBTQ+ cultural competency training for health professionals, Yu et al. (2023) found that many training programs focused on providing factual information (through instructor-centered lectures) and only measured knowledge changes. The assumption, Yu et al. (2023) argue, is that once health professionals are considered well-informed of LGBTQ+ health issues, they will engage in LGBTQ+-affirming behavior. The behavior from there would ideally result in improved cross-cultural communication and improved interpersonal relationships between the healthcare professional and the LGBTQ+ patient. This is not the case, however; knowledge alone is not predictive of behavior, and it is not enough to affect behavior change (Ajzen et al., 2011).

Yu et al. (2023) insist that changes in health professional's attitudes and behaviors should be prioritized and that training programs need alternative approaches instead of strictly knowledge gain. They reference a 2011 study, in which Ajzen et al. question the assumption that being well-informed produces a desired outcome and whether accurate information affects people's decisions and attitudes. Ajzen et al. (2011) argue that instead of working to make sure people have accurate information, we must first learn what information people possess and how it affects their intentions and actions. Ajzen et al. (2011) also argue that we need to be more concerned with the information that guides people’s behaviors.

Drawing from earlier work, Ajzen et al. (2011) propose that knowledge is not enough to predict behavior. Yu et al. (2023) are in agreement and insist that training specifically aimed towards improvement of health professionals’ attitudes towards the LGBTQ+ population is essential. Ultimately, the goal is to achieve changes in practitioners’ behaviors and skills, improving interactions between patients and healthcare professionals and ideally contributing to better care outcomes for the LGBTQ+ patients (Yu et al., 2023).

Yu et al. (2023)’s findings in their review of 44 studies suggested that a “brief exposure” to training (typically less than 3 hours), may not be enough to improve one’s attitudes towards the LGBTQ+ population. They suggest that health professionals could benefit from longer and follow-up training, since greater exposure to LGBTQ+ patients is associated with more positive attitudes towards this population (Sanchez et al., 2006 and Burke et al., 2015, as cited in Yu et al., 2023).

Recommendation 2: Establish an education network of LGBTQ+ experts to accelerate learning.

To avoid patients and their loved ones feeling apprehension in seeking care for fear of needing to educate staff, CCH should establish an education network with both internal and external experts, speakers, and teachers to accelerate staff and volunteer learning. During the interviews, when anyone at CCH felt equipped to care for an LGBTQ+ person and/or their loved one, they shared their feeling of readiness came from personal experience, whether it was a family member, coworker, or neighbor. One interviewee expressed a desire to see more role-playing exercises and shadowing opportunities, in addition to the current online training.

As one CCH staff succinctly described:

> I think the most important thing [any patient-facing staff] can do is be honest with themselves. I think it starts with you, because they are going to read you. When you walk in the room, they're going to read your body language, your comments. So just be honest with yourself…being able to say, I don't know enough. And do not expect the patient or their caregiver to educate you.

In interviews with LGBTQ+ family caregivers of home hospice patients, Cloyes et al. (2023) found that all participants (N=20) could tell if their health care professional felt uncomfortable with them or their relationship to the patient. While most of the caregivers didn't expect the health care professionals to have all the knowledge to provide culturally competent care, the caregivers also described awkward communication while having to educate the providers during an already stressful and grief-filled time.

In their case study on faculty learning communities (FLC), O'Meara et al. (2019) examined how FLC spaces fostered professional interactions that were supportive and transformative. While organizational spaces are inherently bureaucratic and encompass the group's inherent biases, spaces can also "counter conditions of marginalization and imagine other ways of being" (hooks, 1994, as cited in O'Meara et al., 2019).

What O'Meara et al. (2019) intended to uncover was how and why FLCs foster professional, liberatory interactions. They used Ringer (2005)'s definition of liberatory as setting someone free from a situation in which they were or felt restricted, to examine how FLCs can create liberatory environments where people can feel free from constraining norms and interactions. By doing this, FLCs could provide opportunities for a more just and supportive workplace. The FLCs' goal was "helping faculty find support professional interactions, role models, and information that helped them transcend experiences that might have nod more generally [elsewhere]" (p. 290).

O’Meara et al. (2019) found was that FLCs fostered affirmation with their colleagues which influenced their experience with their workplace; FLCs helped faculty know they were not alone by virtue of their race, gender, or rank and instead felt a sense of allyship among their peers, and FLCs created a space where faculty felt they could bring their full selves into view.

Participants who shared they had prior experience in caring for an LGBTQ+ individual(s) indicated that their preparation in caring for LGBTQ+ CCH patients was directly attributed to prior personal experience. One participant shared, “I have a [child] who identifies as [LGBTQ+] and so that has been a learning experience and one that has made me more open and sensitive to others,” and another reflected: “This [demographic] is not something I ever learned [about] in nursing school…but I think that [previously mentioned] experience [caring for an LGBTQ+ -identified person] helped prepare me for the next experience.” CCH staff and volunteers who felt they had a knowledge gap with this population expressed both an acknowledgement that they have this gap and an appetite to learn.

Recommendation 3: Design and conduct a community-engaged exploration of LGBTQ+ patients and their loved ones regarding their lived experiences

CCH has already demonstrated its commitment to lead in providing end-of-life care for the LGBTQ+ population. The organization’s leadership emphatically and unanimously agreed that this Capstone project was a necessary endeavor, and earlier this year updated their electronic medical records for medical staff to add a patient’s sexual orientation and gender identity. After being asked in the interview, “Knowing that Capital Caring’s mission is to ‘provide patients and their families with advanced illness care of the highest quality,’ how do you see that mission come to life in your day-to-day?” one staff member shared:

> First and foremost, what I love about Capital Caring Health is [that] we will care for anyone regardless of their age, their race, their ability to pay, their sexual orientation, and

> that I think that really speaks to us just as an organization, that if you need hospice services, if you are eligible for it, we are going to make sure that you have it and that can be on our dime as well.

To continue its mission to provide advanced illness care of the highest quality, CCH has an opportunity to serve this disenfranchised population and demonstrate how compassion changes people (Hansen and Trank, 2016). Compassion changes perspectives and encourages people to look at their work, colleagues, and, in CCH's case, their patients, in new ways. Empathizing with others "sensitizes us to find the cause of the pain that may be embedded in broader phenomena, to see the circumstances and context" (Hansen and Trank, 2016, p. 355). Learning about the lived experiences of the LGBTQ+ population, including the historical and current-day barriers, can provide even deeper context for the LGBTQ+ patients that seek CCH's services.

In the beginning stages of the hospice admissions process, CCH provides an opportunity for the patient or loved one to share the patient's sexual orientation and gender identity. This is a time when CCH can open the door to deeper conversation and continue compassionate care by asking the patient or loved one if they would like to speak to a staff member who identifies as LGBTQ+ to sit with them during this vulnerable time. If the patient or their loved one shares that they are anything other than "Straight or heterosexual" when CCH staff is capturing information in their medical intake records, it should prompt a follow-up question asking that individual if they would like to speak with an LGBTQ+-identified person or have an LGBTQ+-identified volunteer support them. This provides CCH with an opportunity to better understand the patients and loved ones' desires at end-of-life. The patient or loved one might agree to a volunteer who is LGBTQ+ to sit bedside with them. Providing that opportunity for someone to share this part of their identity will signal to the patient that CCH does want to know what is important to the LGBTQ+ patient.

A key step for organizations to provide holistic palliative care is by collecting sexual orientation and gender identity (SOGI) information (Javier, 2021). It provides a deeper understanding of the LGBTQ+ patient's "intersectional identities, multiple minority stressors, and lived experiences" (Javier, 2021, p. 5). Capturing this data "opens up a gateway" to recognize a patient's values, needs, any existential or spiritual issues, and what the patient prioritizes when it comes to their health care.

Following an LGBTQ+-identified patient's death, an LGBTQ+-identified CCH staff member could choose to contact the bereaved loved one(s) to check in on them, learn of their experience with CCH as their hospice care provider, and offer additional resources the bereaved may desire. It's important to be mindful that this contact could be a member of the biological family and/or the chosen family. Keeping in mind these two groups may not interact together, or the biological family may not know about the chosen family, it's critical to be mindful that both may exist.

While a hospice admission is a tender and stressful time, CCH can incorporate a process in their initial hospice intake process to reflect to a LGBTQ+-identified patient, or their caregiver or loved one, that they care. It would reflect that CCH is aware of the historical and medical barriers that affect this population's trust, but they want to honor and acknowledge the patient and loved one's dignity in this vulnerable time.

"What is most important to you today?" is a question that the CCH team asks a patient at every single hospice visit, shared one CCH staff member. Continuing to have those conversations and opening the floor for compassionate discussions is vital in helping dying patients and their loved ones feel seen and demonstrates a dignified, caring relation. This upholds our feeling of inherent values and worth, and our “factor of humanness” (Hicks, 2011; Noddings, 1992; Johnson, 1998, p. 342).

One CCH staff member acknowledged, “You can’t build trust until you build trust,” and so, to begin to build trust, CCH must first create the conditions for a patient’s pain to be witnessed and then understood within the conditions that caused the pain (Hansen and Trank, 2016). CCH should provide openings for patients and their loved ones to share and discuss their sexual orientation and gender identity (SOGI). It is on the patient and loved ones to decide whether they want to share that important, innate part of themselves. There will be patients who do not volunteer this facet of their life, but to assume that patients don’t want to share it or it’s their privacy or personal life is what Noddings (2015) says is likely causing more harm than helping the patient or loved one. If we assume we know what people want or need, we are making a mistake and “evok[ing] distrust and resentment rather than gratitude” (p. 75, as cited in Engster and Hamington, 2015).

Recommendation 4: Implement an ongoing and iterative organizational reflection and assessment

Health systems and health care professionals are accountable for creating cultures that promote person-centered and holistic care (Rosa et al., 2023). Safety and support for the LGBTQ+ population must be “pervasive, consistent, and go beyond performativity” (p. 470). While displaying symbols such as the rainbow flag is intended to denote environmental safety, without an organizational culture shift, this display could be insufficient, performative, and potentially harmful. Creating an LGBTQ+-inclusive culture has the potential to alleviate fears and worries regarding mistreatment, as well as begin to build trust between LGBTQ+ persons, health professionals, and health care systems during the vulnerable time of serious illness and end of life (Rosa et al., 2023).

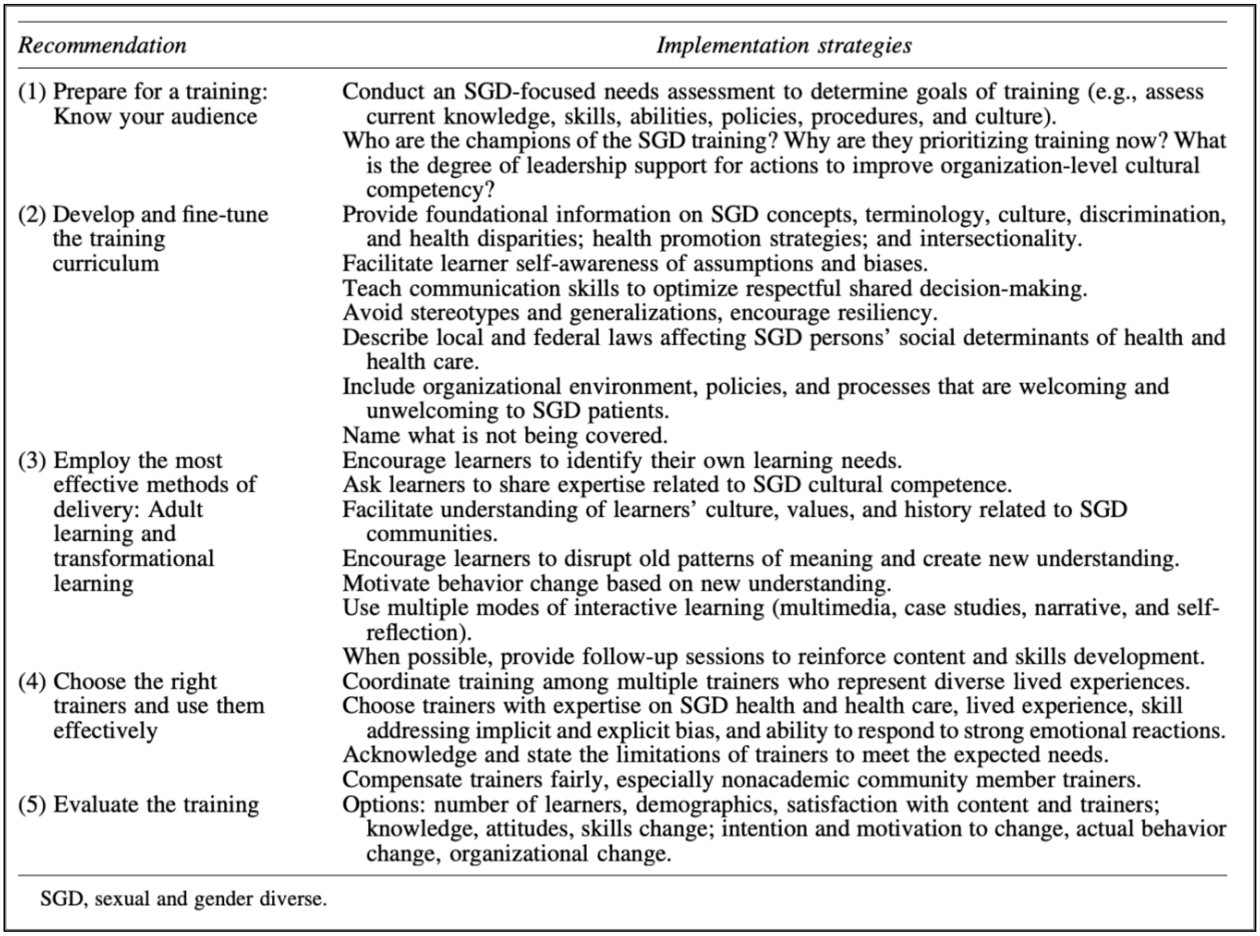
Langley et al. (2009) in their literature on enhancing organizational effectiveness describe two central principles of improvement: “(1) knowing why you need to improve and (2) having a way to get feedback to let you know if improvement is happening” (p. 16). For an organization to evolve, it needs the will to improve, ideas for improvement, and the skills to make the changes (Langley et al., 2009). The main responsibility for creating the will to change falls upon the organization’s leadership, and CCH has already demonstrated the will to improve by participating in this Capstone project.

CCH staff and volunteers expressed a desire to have more training and a deeper understanding of the LGBTQ+ population. Pratt-Chapman et al. (2022) encourage organizations to develop a long-term relationship with trainers so there can be a consistent set of training sessions over time. They remind us that “Skills building takes multiple sessions” (p. 345) and to reduce disparities of the LGBTQ+ population, skills building requires “ongoing and iterative refinements” (p. 345). Organizations can implement a regular reflection period during and following the training sessions to show an ongoing commitment to LGBTQ+-inclusivity and elevate leadership by selecting staff “champions” (p. 345). These champions can advance and implement the organization's policies, and practices, and from there, support CCH’s mission to provide advanced illness care of the highest quality to its patients.

Pratt-Chapman et al. (2022) spoke to a population of 30 participants who were leaders of community clinics and community-based organizations, cultural competency trainers, and medical professionals and researchers with experience in sexual and gender diverse (SGD) persons (a term used interchangeably with LGBTQ+). Their experiences ranged from urban and rural settings, and included leaders, trainers, and clinicians with lived experience (Pratt-Chapman et al., 2022). After two in-person convenings, reviewing peer-reviewed studies, publicly accessible curricula, and SGD cultural competency trainings, and through iterative feedback from diverse range of participants, Pratt-Chapman et al. (2022) produced five recommendations seen in Figure 15 below.

Figure 15

Sexual and Gender Diverse Cultural Competency Recommendations and Implementation Strategies (Pratt-Chapman et al., 2022, p. 343).



Recommendation	*Implementation strategies*
(1) Prepare for a training: Know your audience	Conduct an SGD-focused needs assessment to determine goals of training (e.g., assess current knowledge, skills, abilities, policies, procedures, and culture). Who are the champions of the SGD training? Why are they prioritizing training now? What is the degree of leadership support for actions to improve organization-level cultural competency?
(2) Develop and fine-tune the training curriculum	Provide foundational information on SGD concepts, terminology, culture, discrimination, and health disparities; health promotion strategies; and intersectionality. Facilitate learner self-awareness of assumptions and biases. Teach communication skills to optimize respectful shared decision-making. Avoid stereotypes and generalizations, encourage resiliency. Describe local and federal laws affecting SGD persons' social determinants of health and health care. Include organizational environment, policies, and processes that are welcoming and unwelcoming to SGD patients. Name what is not being covered.
(3) Employ the most effective methods of delivery: Adult learning and transformational learning	Encourage learners to identify their own learning needs. Ask learners to share expertise related to SGD cultural competence. Facilitate understanding of learners' culture, values, and history related to SGD communities. Encourage learners to disrupt old patterns of meaning and create new understanding. Motivate behavior change based on new understanding. Use multiple modes of interactive learning (multimedia, case studies, narrative, and self-reflection). When possible, provide follow-up sessions to reinforce content and skills development.
(4) Choose the right trainers and use them effectively	Coordinate training among multiple trainers who represent diverse lived experiences. Choose trainers with expertise on SGD health and health care, lived experience, skill addressing implicit and explicit bias, and ability to respond to strong emotional reactions. Acknowledge and state the limitations of trainers to meet the expected needs. Compensate trainers fairly, especially nonacademic community member trainers.
(5) Evaluate the training	Options: number of learners, demographics, satisfaction with content and trainers; knowledge, attitudes, skills change; intention and motivation to change, actual behavior change, organizational change.

SGD, sexual and gender diverse.

These five recommendations from Pratt-Chapman et al. (2022) stem from five principles: (1) healthcare is interdisciplinary and cultural competence recommendations must address the range of personnel engaged in health care systems; (2) there is a "core" to SGD cultural competence; (3) cultural humility is fundamental and a lifelong goal - not an achievement at a point in time; (4) community engagement is critical; and (5) qualified, diverse trainers are crucial (p. 342). Using these recommendations and guiding principles, CCH can recognize the diversity of its staff, volunteers, and patients, to build stronger cultural competence. Pratt-Chapman et al. (2022) insist that the five recommendations form a cultural competency core from which already-existing organizational standards can build.

Future Work Considerations

This project offers conclusions from only one hospice organization in the Washington, D.C. metropolitan area. It would benefit the LGBTQ+ population and staff caring for CCH to compare organizational performance, employee training, and programmatic initiatives with other hospice organizations who serve this population. Broadly benchmarking these metrics can establish goals across the hospice care field and highlight specific considerations beneficial to the LGBTQ+ community (e.g. training certifications, patient satisfaction statistics).

Future research should address how hospice care volunteers' religiosity plays a role in caring for the LGBTQ+ population, as this study uncovered around 72% of CCH volunteers identified as "Very religious/spiritual" and "Somewhat" religious.

If hospice organizations like CCH want to make progress in caring for the LGBTQ+ population, they will need to make a much-needed paradigm shift. This project is intended to support those efforts. CCH can use the results of this project and accompanying recommendations towards its goal of being the leading hospice organization that supports the LGBTQ+ population and loved ones at the end of life. As hospice organizations like Capital Caring Health develop a deeper understanding of the LGBTQ+ community, they will be better able to serve patients and their loved ones with dignity.

Conclusion

It is a human right to die with dignity (Guo and Jacelon, 2014). While dying with dignity is a subjective experience in that we each have our individual desires of what we would like our end-of-life period to include, it is also a period of life that medical professionals and caregivers can influence for the better (Guo and Jacelon, 2014). To treat someone as if they matter and that they are worthy of care is to treat them with dignity and recognize their humanness (Johnson, 1998). We all want to be treated as if we matter and we are worthy, but treating everyone the same could cause harm if we do not recognize and seek to shift the reality that an LGBTQ+-identified person disclosing their identity comes at a high price, especially in a medical system that still carries major barriers to LGBTQ+ people seeking medical care.

This Capstone project sought to understand Capital Caring Health's current practices that demonstrate LGBTQ+ inclusivity at the end of life and to understand what additional actions CCH can take to demonstrate its commitment to serving the LGBTQ+ population as they are dying. The results of this project could have a range of impacts. It has the potential to inform staff education and training, volunteer education and training, marketing and research, decisions that donors and funders and partners make, patient data gathering (e.g. referral and admissions/intake process), CCH's Business Development Team which has customer relations with executives, and the decisions that LGBTQ+ population and their loved ones make when choosing their end-of-life care.

Those impacted by this project include patients; families (biological and chosen), loved ones, and caregivers; CCH leadership, marketing and communications, clinical staff, volunteers, partners such as community-based organizations, donors and funders, sponsors, and healthcare providers in the community who would refer people to CCH and its hospice care.

Approaching and coming to terms with one’s end-of-life is already a deeply emotional and often scary facet of life. For an LGBTQ+-identified person, the fear and reality of discrimination exacerbate emotions and fears around dying. CCH knows patients should feel and trust their hospice and medical care provider treats them with dignity. To continue to provide the best and highest quality care, and to ensure a person’s dignity is maintained through their end-of-life, CCH must focus on LGBTQ+-inclusive practices.

References

Acquaviva, K. D. (2017). *LGBTQ-inclusive hospice and palliative care: a practical guide to transforming professional practice*. Columbia University Press.

Acquaviva, K. D. (2023). *The handbook of LGBTQIA-inclusive hospice and palliative care*. Columbia University Press.

Ajzen, I., Joyce, N., Sheikh, S., & Cote, N. G. (2011). Knowledge and the prediction of behavior: The role of information accuracy in the theory of planned behavior. *Basic and applied social psychology*, *33*(2), 101-117.

American Psychiatric Association. (1973). *Diagnostic and statistical manual of mental disorders* (2nd ed.). Washington, DC.

Bernstein, R. S., & Salipante, P. (2023, August). Embedding Inclusive, Equitable Diversity Practices in Nonprofit Organizations: Developing Policy to Account for System Dynamics. In *Nonprofit Policy Forum* (No. 0). De Gruyter.

Bernstein, R., Salipante, P., & Weisinger, J. (2021). *Performance through diversity and inclusion: Leveraging organizational practices for equity and results*. Routledge.

Berzoff, J., & Silverman, P. R. (Eds.). (2004). *Living with dying: A handbook for end-of-life healthcare practitioners*. Columbia University Press.

Bristowe, K., Marshall, S., & Harding, R. (2016). The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: a systematic review, thematic synthesis and modelling of the literature. *Palliative medicine*, *30*(8), 730-744.

Broom, A. (2012). On euthanasia, resistance, and redemption: the moralities and politics of a hospice. *Qualitative Health Research*, *22*(2), 226-237.

Burke, S. E., Dovidio, J. F., Przedworski, J. M., Hardeman, R. R., Perry, S. P., Phelan, S. M., Nelson, D.B. Burgess, D.J., Yeazel, M.W., & Van Ryn, M. (2015). Do contact and empathy mitigate bias against gay and lesbian people among heterosexual first-year medical students? A report from the medical student CHANGE study. *Academic Medicine*, *90*(5), 645-651.

Buss, M. K., Rock, L. K., & McCarthy, E. P. (2017, February). Understanding palliative care and hospice: a review for primary care providers. In *Mayo Clinic Proceedings* (Vol. 92, No. 2, pp. 280-286). Elsevier.

Byock, I., & Byock, A. (1997). *Dying well: The prospect for growth at the end of life*. New York: Riverhead Books.

Capital Caring Health. (2024). *Mission and Core Values*. https://www.capitalcaring.org/about-us/mission-and-core-values/

Capital Caring Health. (2024). *Our history*. https://www.capitalcaring.org/about-us/our-history/

Care Quality Commission, & Ending, A. D. (2016). Addressing Inequalities in End of Life Care. *London, UK: Care Quality Commission*.

CaringInfo. (2024). *Types of Care: What is Hospice Care?* https://www.caringinfo.org/types-of-care/hospice-care/

CaringInfo. (n.d.). *What is Palliative Care?* National Hospice and Palliative Care Organization. https://www.caringinfo.org/types-of-care/palliative-care/

Center to Advance Palliative Care. (n.d.). *About Palliative Care*. Icahn School of Medicine at Mount Sinai. https://www.capc.org/about/palliative-care/

Centers for Disease Control and Prevention. (2024, May 2). Leading Causes of Death. National Center for Health Statistics. https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm

Chidiac, C., Grayson, K., & Almack, K. (2021). Development and evaluation of an LGBT+ education programme for palliative care interdisciplinary teams. *Palliative Care and Social Practice*, *15*, 26323524211051388.

Cloyes, K. G., Tay, D. L., Iacob, E., Jones, M., Reblin, M., & Ellington, L. (2020). Hospice interdisciplinary team providers' attitudes toward sexual and gender minority patients and caregivers. *Patient education and counseling*, *103*(10), 2185-2191.

Connor, S. R. (2017). *Hospice and palliative care: The essential guide*. Routledge.

Cottrell, L., & Duggleby, W. (2016). The "good death": An integrative literature review. *Palliative & supportive care*, *14*(6), 686-712.

Dying in America : improving quality and honoring individual preferences near the end of life / Committee on Approaching Death: Addressing Key End-of-Life Issues, Institute of Medicine of the National Academies. (2015). National Academies Press.

Engster, D., & Hamington, M. (Eds.). (2015). Care ethics and political theory. OUP Oxford.

Farber, S., Egnew, T., Farber, A., Berzoff, J., & Silverman, P. R. (2004). What is a respectful death? *Living with dying: A handbook for end-of-life healthcare practitioners*, 102-127.

Fredriksen-Goldsen, K. I., & Muraco, A. (2010). Aging and sexual orientation: A 25-year review of the literature. *Research on aging*, *32*(3), 372-413.

González, N., Moll, L. C., & Amanti, C. (Eds.). (2006). *Funds of knowledge: Theorizing practices in households, communities, and classrooms*. Routledge.

Guide, A. F. (2011). for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community.

Guo, Q., & Jacelon, C. S. (2014). An integrative review of dignity in end-of-life care. *Palliative medicine*, 28(7), 931-940.

Hansen, H., & Trank, C. Q. (2016). This is going to hurt: Compassionate research methods. *Organizational Research Methods*, *19*(3), 352-375.

Hicks, D. (2011). *Dignity: Its essential role in resolving conflict*. Yale University Press.

History of Hospice. National Hospice and Palliative Care Organization. (2020, July 13). https://www.nhpco.org/hospice-care-overview/history-of-hospice/

Hooks, B. (2014). *Teaching to transgress*. Routledge.

Hornjatkevyc, N. L., & Alderson, K. G. (2011). With and without: The bereavement experiences of gay men who have lost a partner to non-AIDS-related causes. *Death Studies*, *35*(9), 801-823.

Iacoboni, M. (2009). *Mirroring people: The new science of how we connect with others*. Farrar, Straus and Giroux.

Inaugural State of LGBTQ Health National SurveyTM 2022. National Coalition for LGBTQ Health. (n.d.). https://healthlgbtq.org/wp-content/uploads/2022/06/State-of-LGBTQ-Health-National-Survey-2022.pdf

Izumi, S., Nagae, H., Sakurai, C., & Imamura, E. (2012). Defining end-of-life care from perspectives of nursing ethics. *Nursing ethics*, *19*(5), 608-618.

Javier, N. M. (2021). Palliative care needs, concerns, and affirmative strategies for the LGBTQ Population. *Palliative Care and Social Practice*, *15*, 26323524211039234.

Johnson, P. R. (1998). An analysis of “dignity”. *Theoretical Medicine and Bioethics*, *19*, 337-352.

King, A., & Hall, M. (2023). Queer(y)ing aging—potentialities and problems in applying Queer Theory to studies of aging and later life. *Frontiers in Sociology*, *8*.

Langley, G. J., Moen, R. D., Nolan, K. M., Nolan, T. W., Norman, C. L., & Provost, L. P. (2009). *The improvement guide: a practical approach to enhancing organizational performance*. John Wiley & Sons.

Lintott, L., Beringer, R., Do, A., & Daudt, H. (2022). A rapid review of end-of-life needs in the LGBTQ+ community and recommendations for clinicians. *Palliative Medicine, 36*(4), 609-624.

Lowey, S. E. (2015). *Nursing care at the end of life: What every clinician should know*. Open SUNY Textbooks.

Makadon, H. J., & Potter, J. (Eds.). (2008). *The Fenway guide to lesbian, gay, bisexual, and transgender health*. ACP Press.

Marsack, J., & Stephenson, R. (2017). Exploring the utilization of end-of-life documentation among an online sample of sexual-and gender-minority individuals in the United States. *Journal of Gay & Lesbian Social Services*, *29*(3), 273-279.

Medina, C., & Mahowald, L. (2023, June 6). *Discrimination and Barriers to Well-Being: The State of the LGBTQI+ Community in 2022*. Center for American Progress. https://www.americanprogress.org/article/discrimination-and-barriers-to-well-being-the-state-of-the-lgbtqi-community-in-2022/

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychological bulletin*, *129*(5), 674.

National Institute on Aging. (2022, November 17). *Providing care and comfort at the end of life.* National Institute of Health. https://www.nia.nih.gov/health/end-life/providing-care-and-comfort-end-life

Noddings, N. (1992). *The challenge to care in schools: an alternative approach to education*. Teachers College Press.

Noddings, N. (2015). *The challenge to care in schools* (2nd ed.). Teachers College Press.

'O'Donnell, P. (2004). Ethical issues in end-of-life care: Social work facilitation and proactive intervention. *Living with dying*, 171-187.

O'Meara, K., Nyunt, G., Templeton, L., & Kuvaeva, A. (2019). Meeting to transgress: The role of faculty learning communities in shaping more inclusive organizational cultures. *Equality, Diversity and Inclusion: An International Journal*, *38*(3), 286-304.

Orel, N. A., & Fruhauf, C. A. (2015). *The lives of LGBT older adults: Understanding challenges and resilience* (p. 256). American Psychological Association.

Reyes, I., Da Silva Iddings, A. C., & Feller, N. (2016). Building relationships with diverse students and families: A funds of knowledge perspective. *Journal of Early Childhood Literacy, 16*(1), 8-33.

Reynaga, M., Bybee, S., Gettens, C., Tay, D. L., Reblin, M., Ellington, L., & Cloyes, K. G. (2023). "We Treat Everyone Equally": Hospice Care Team Members' Language Use Regarding Sexual and Gender Minority Patients and Caregivers. *American Journal of Hospice and Palliative Medicine®, 40*(6), 601-606.

Ringer, J. M. (2005). Liberating" Liberatory" Education, or What Do We Mean by" Liberty" Anyway?. *Jac*, 761-782.

Roberson, Q., & Scott, W. (2024). Contributive justice: An invisible barrier to workplace inclusion. *Journal of management*, *50*(3), 877-897.

Robinson, B. A. (2016). Heteronormativity and homonormativity. *The Wiley Blackwell encyclopedia of gender and sexuality studies*, 1-3.

Rosa, W. E., Roberts, K. E., Braybrook, D., Harding, R., Godwin, K., Mahoney, C., Mathew S., Atkinson, T.M., Banerjee, S.C., Haviland, K., Hughes, T.L., Walters, C.B., & Parker, P. A. (2023). Palliative and end-of-life care needs, experiences, and preferences of LGBTQ+ individuals with serious illness: a systematic mixed-methods review. *Palliative medicine*, *37*(4), 460-474.

SAGE: Advocacy & Services for LGBTQ+ Elders. (2024). *SAGECare: Creating more welcoming care for LGBTQ+ elders*. SAGE. https://www.sageusa.org/what-we-do/sagecare/

Sanchez, N. F., Rabatin, J., Sanchez, J. P., Hubbard, S., & Kalet, A. (2006). Medical students' ability to care for lesbian, gay, bisexual, and transgendered patients. *Family Medicine-Kansas City-*, *38*(1), 21.

Seelman, K. L., Lewinson, T., Engleman, L., & Allen, A. (2019). Motivations for advance care and end-of-life planning among lesbian, gay, and bisexual older adults. *Qualitative Social Work*, *18*(6), 1002-1016.

Sprik, P., & Gentile, D. (2020). Cultural humility: a way to reduce LGBTQ health disparities at the end of life. *American Journal of Hospice and Palliative Medicine®*, *37*(6), 404-408.

Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine*, *132*(10), 825-832.

Sterman, J. D. (2001). System dynamics modeling: Tools for learning in a complex world. *California Management Review*, *43*(4), 8-25.

Weller, F. (2015). *The wild edge of sorrow: Rituals of renewal and the sacred work of grief*. North Atlantic Books.

Williams, D. A., Berger, J. B., & McClendon, S. A. (2005). *Toward a model of inclusive excellence and change in postsecondary institutions* (p. 39). Washington, DC: Association of American Colleges and Universities.

Wittkowski, J., & Menzies, R. (2020). Death-related attitudes and perspectives. In Servaty-Seib, H. & Chapple, H. (Eds.), *Handbook of Thanatology* (pp. 38-63). Association for Death Education and Counseling.

Wilson, C. K., West, L., Stepleman, L., Villarosa, M., Ange, B., Decker, M., & Waller, J. L. (2014). Attitudes toward LGBT patients among students in the health professions: Influence of demographics and discipline. *LGBT health*, *1*(3), 204-211.

Yu, H., Flores, D. D., Bonett, S., & Bauermeister, J. A. (2023). LGBTQ+ cultural competency training for health professionals: A systematic review. *BMC Medical Education*, *23*(1), 558.

Zaman, S., Inbadas, H., Whitelaw, A., & Clark, D. (2017). Common or multiple futures for end of life care around the world? Ideas from the ‘waiting room of history’. *Social Science & Medicine*, *172*, 72-79.

Appendices

Appendix A: Survey Email Invitation and Survey Questions

Survey Email Invitation and Questions for **Volunteers**
Background/Demographic

Hello,

You are being invited to participate in a quality improvement project at Capital Caring Health.

My name is Amanda, and I'm in my final year of Vanderbilt University's doctoral program in Leadership and Learning in Organizations. As part of my final project, I am working with Capital Caring as they consider their current inclusive practices for the Lesbian, Gay, Bisexual, Transgender, and Queer Plus (LGBTQ+) population at their end of life, and how Capital Caring can further demonstrate its commitment to supporting the LGBTQ+ population during this tender and sensitive time.

I would like to invite you to participate in this project because you are a volunteer here at Capital Caring and I am interested to learn about your experiences working closely with all members of the organization.

The survey link can be found here: [Volunteer Survey Link]
Participation is voluntary and your responses will remain anonymous.

The survey should take about 10 minutes to complete. At the end of the survey, you will have the option to select whether you'd be willing to participate in an interview with me (your interview responses will remain anonymous, as well). If you agree to a 30 minute interview, I will use the contact information you provide to set up a time most convenient for you. Again, the interview is voluntary and your responses will be anonymous.

[Volunteer Survey Link]

Survey Questions
Are you a volunteer with Capital Caring Health?
( ) Yes
( ) No

Please indicate your pronouns: (check all that apply)
[ ] she/her/hers
[ ] he/him/his
[ ] they/them/theirs

[ ] Not listed (please specify below)
[ ] Prefer not to answer

How many years have you volunteered at Capital Caring Health? Please round up to the total number of years.

( ) 0 – 2 years
( ) 3 – 5 years
( ) 6 – 10 years
( ) More than 10 years

In your volunteer role with Capital Caring Health, please select where you have interacted with a patient:

( ) In-Patient Unit, patient-facing
( ) In the community, patient-facing (includes residential, nursing home, memory care, or shelter)
( ) Both
( ) Neither

When you volunteer, in total how many patients and caregivers do you interact with in a week, on average?

( ) 0 – 5
( ) 6 – 10
( ) 11 – 15
( ) More than 15

How would you describe your level of religiosity/spirituality?

( ) Very religious/spiritual
( ) Somewhat
( ) Not very
( ) Not at all

To which gender do you most identify with? (check all that apply)

[ ] Female
[ ] Male
[ ] Cisgender
[ ] Transgender
[ ] Nonbinary
[ ] Two-spirit
[ ] Genderfluid
[ ] Agender

[ ] I’m not sure
[ ] Not listed (please specify below)
[ ] Prefer not to answer

How do you describe your sexual orientation and/or sexual identity? (check all that apply)
[ ] Straight or heterosexual
[ ] Lesbian
[ ] Gay
[ ] Homosexual
[ ] Bisexual
[ ] Queer
[ ] Pansexual
[ ] Polysexual
[ ] Asexual
[ ] Not listed (please specify below)
[ ] I’m not sure
[ ] I prefer not to answer

Please select your age:
( ) 18 – 29
( ) 30 – 39
( ) 40 – 49
( ) 50 – 59
( ) 60+

What is your highest level of education?
( ) Less than a high school diploma
( ) High school diploma or equivalent (e.g. GED)
( ) Some college, no degree
( ) Associate degree (e.g. AA, AS)
( ) Bachelor’s degree (e.g. BA, BS)
( ) Master’s degree (e.g. MA, MS, MEd)
( ) Professional degree (e.g. MD, DDS, JD)
( ) Doctorate (e.g. PhD, EdD)

Are you open to participating in an interview following this survey?
Your interview responses will remain anonymous.
( ) Yes
( ) No

If participant selected Yes: You are here because you selected “Yes” that you are willing to participate in an interview. Your interview responses will remain anonymous. Please provide your contact details (name, email address and/or phone number) so you can be contacted to set up a time for the interview.

Conceptual Framework	Project Question	Survey Questions for **Volunteers**
Policy/Conditions Lived Programs and Values Supporting Diversity & Inclusion Representational Diversity	What are Capital Caring Health (CCH)’s current practices that demonstrate LGBTQ+ inclusivity? What additional actions can CCH take to demonstrate its commitment to supporting LGBTQ+ people at their end of life?	Beside each of the statements below, please indicate whether you Strongly Agree (SA), Agree (A), Disagree (D), Strongly Disagree (SD), or are Unsure (U): - Hospices have a responsibility to serve (or provide care for) LGBTQ+ patients and families.* - Capital Caring Health actively promotes and implements policies and practices that foster quality end-of-life care for the LGBTQ+ population. - Capital Caring Health Volunteers receive training on LGBTQ+ cultural competency and sensitivity. Beside each of the statements below, please indicate whether you Strongly Agree (SA), Agree (A), Disagree (D), Strongly Disagree (SD), or are Unsure (U) - Patients who identify within the LGBTQ+ community are more likely to experience discrimination when accessing healthcare when compared to heterosexual patients. - LGBTQ+ patients and their caregivers/loved ones should only seek services from hospices with LGBTQ+ specialization.* - Patients who identify within the LGBTQ+ community face unique challenges or barriers when seeking healthcare services, compared to heterosexual patients.
Structured Inclusive Interaction	What are Capital Caring Health (CCH)’s current	Beside each of the statements below, please indicate whether you Strongly Agree (SA), Agree (A),

Practices Development & Resources	practices that demonstrate LGBTQ+ inclusivity? What additional actions can CCH take to demonstrate its commitment to supporting LGBTQ+ people at their end of life?	Disagree (D), Strongly Disagree (SD), or are Unsure (U) - I would be comfortable if I became known among my volunteer peers as someone who cares for LGBTQ+ patients and their caregivers/loved ones.* - I would be comfortable if I became known among my friends and family as someone who cares for LGBTQ+ patients and caregivers/loved ones.* - I would be comfortable telling my intimate partner(s) that I care for LGBTQ+ patients.* Q: Beside each of the statements below, please indicate whether you Strongly Agree (SA), Agree (A), Disagree (D), Strongly Disagree (SD), or are Unsure (U) - LGBTQ+ hospice patients deserve the same level of quality care as heterosexual patients.* - LGBTQ+ hospice patients require the same type of quality care as heterosexual patients. - Knowing whether a patient identifies as LGBTQ+ influences the type of care they receive at their end of life. - Knowing whether a patient identifies as LGBTQ+ influences the type of care they receive at Capital Caring Health. Q: Do you feel as though you have access to resources that help you in your role caring for the LGBTQ+ population? Definitely not Probably not Probably yes Definitely yes Q: I find that when my personal beliefs differ from those of the patient or their caregivers/loved ones, it is [______] for me to provide the same quality of care to the patient. Extremely difficult

		Difficult Easy Extremely Easy

Questions with * are directly quoted from the Cloyes et al., (2020) ATPLS questionnaire.

Appendix B: CCH Volunteer Survey Data Responses

Table 1

CCH Volunteer Characteristics

Are you a volunteer with Capital Caring Health?	Percentage	Response Count
Yes	100%	150
No	0%	0

Please indicate your pronouns: (check all that apply)	Percentage	Response Count
she/her/hers	73%	101
he/him/his	22%	30
Prefer not to answer	6%	8
Not listed (please specify)	1%	2
they/them/theirs	1%	1

To which gender do you most identify with? (check all that apply)	Percentage	Response Count
Female	74%	89
Male	24%	29
Cisgender	8%	9
Prefer not to answer	2%	2
Transgender	1%	1
Nonbinary	1%	1
Two-spirit	0%	0
Genderfluid	0%	0
Agender	0%	0
I'm not sure	0%	0
Not listed (please specify)	0%	0

How do you describe your sexual orientation and/or sexual identity? (check all that apply)	Percentage	Response Count
Straight or heterosexual	80%	96
Bisexual	13%	15
Gay	3%	4
Prefer not to answer	3%	4
Pansexual	3%	3
Lesbian	2%	2
Queer	2%	2
Polysexual	1%	1
Asexual	1%	1
I'm not sure	1%	1
Homosexual	0%	0

Not listed (please specify)	0%	0

Please select your age	Percentage	Response Count
18 - 29	9%	11
30 - 39	7%	8
40 - 49	10%	12
50 - 59	21%	25
60+	53%	64

What is your highest level of education?	Percentage	Response Count
Less than a high school diploma	1%	1
High school diploma or equivalent (e.g. GED)	0%	0
Some college, no degree	8%	10
Associate degree (e.g. AA, AS)	7%	8
Bachelor's degree (e.g. BA, BS)	39%	47
Master's degree (e.g. MA, MS, MEd)	32%	38
Professional degree (e.g. MD, DDS, JD)	8%	9
Doctorate (e.g. PhD, EdD)	6%	7

How would you describe your level of religiosity/spirituality?	Percentage	Response Count
Very religious/spiritual	35%	48
Somewhat	37%	52
Not Very	17%	23
Not at all	12%	16

Table 2

CCH Volunteer Experience

How many years have you volunteered with Capital Caring Health? Please round up to the total number of years.	Percentage	Response Count
0 - 2 years	58%	80
3 - 5 years	22%	30
6 - 10 years	12%	16
More than 10 years	9%	13

In your volunteer role with Capital Caring Health, please select where you have interacted with a patient:	Percentage	Response Count
In the community, patient-facing (includes residential, nursing home, memory care, or shelter)	42%	58

Both	28%	39
In-Patient Unit, patient-facing	20%	28
Neither	10%	14

When you volunteer, in total how many patients do you interact with in a week, on average?	Percentage	Response Count
0 - 5	81%	112
6 - 10	14%	20
11 - 15	4%	6
More than 15	1%	1

Table 3

CCH Volunteer Perceptions of LGBTQ+ Healthcare, Hospice Care, and Palliative Care

Beside each statement below, please indicate whether you Strongly Agree (SA), Agree (A), Disagree (D), Strongly Disagree (SD), or are Unsure (U)		Response Count
Hospices have a responsibility to serve (provide care for) LGBTQ+ patients and families.	Strongly Agree	116
	Agree	6
	Disagree	0
	Strongly disagree	0
	Unsure	1
Capital Caring Health actively promotes and implements policies and practices that foster quality end-of-life care for the LGBTQ+ population.	Strongly Agree	38
	Agree	24
	Disagree	1
	Strongly disagree	0
	Unsure	60
Capital Caring Health Volunteers receive training on LGBTQ+ cultural competency and sensitivity.	Strongly Agree	13
	Agree	31
	Disagree	17
	Strongly disagree	4
	Unsure	58
Patients who identify within the LGBTQ+ community are more likely to experience discrimination when accessing healthcare when compared to heterosexual patients.	Strongly Agree	32
	Agree	45
	Disagree	14
	Strongly disagree	4
	Unsure	28
LGBTQ+ patients and their caregivers/loved ones should only seek services from hospices with LGBTQ+ specialization.	Strongly Agree	4
	Agree	18
	Disagree	55
	Strongly disagree	23
	Unsure	23
Patients who identify within the LGBTQ+ community face unique challenges or barriers when	Strongly Agree	32
	Agree	52

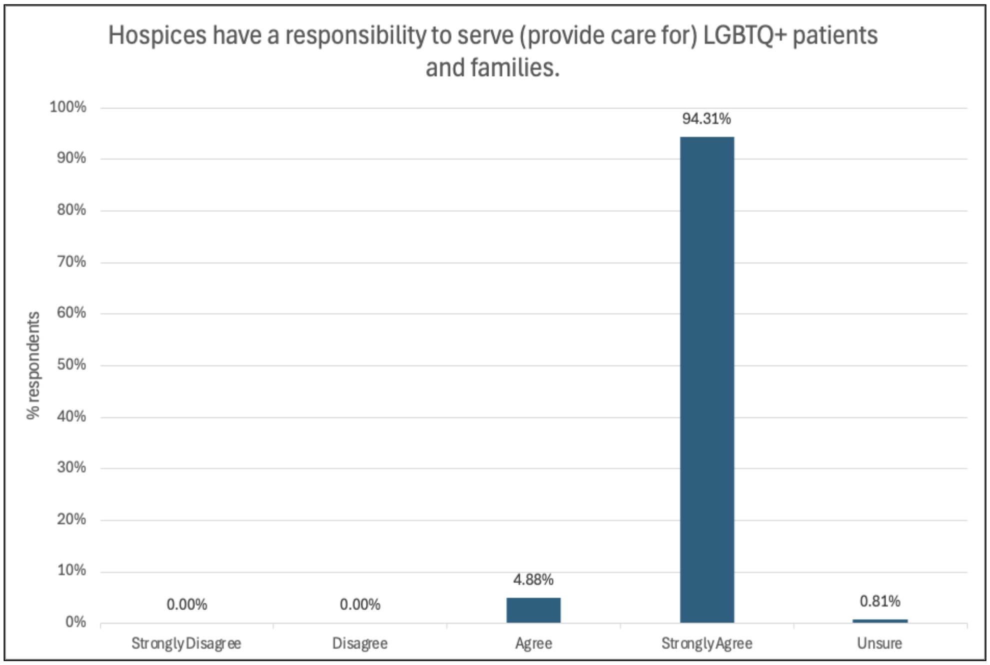
seeking healthcare services, compared to heterosexual patients.	Disagree	4
	Strongly disagree	3
	Unsure	30
LGBTQ+ hospice patients deserve the same level of quality care as heterosexual patients.	Strongly Agree	116
	Agree	7
	Disagree	0
	Strongly disagree	0
	Unsure	0
LGBTQ+ hospice patients require the same type of quality care as heterosexual patients.	Strongly Agree	93
	Agree	18
	Disagree	1
	Strongly disagree	0
	Unsure	11
Knowing whether a patient identifies as LGBTQ+ influences the type of care they receive at their end of life.	Strongly Agree	12
	Agree	15
	Disagree	28
	Strongly disagree	27
	Unsure	41
Knowing whether a patient identifies as LGBTQ+ influences the type of care they receive at Capital Caring Health.	Strongly Agree	4
	Agree	4
	Disagree	32
	Strongly disagree	36
	Unsure	47

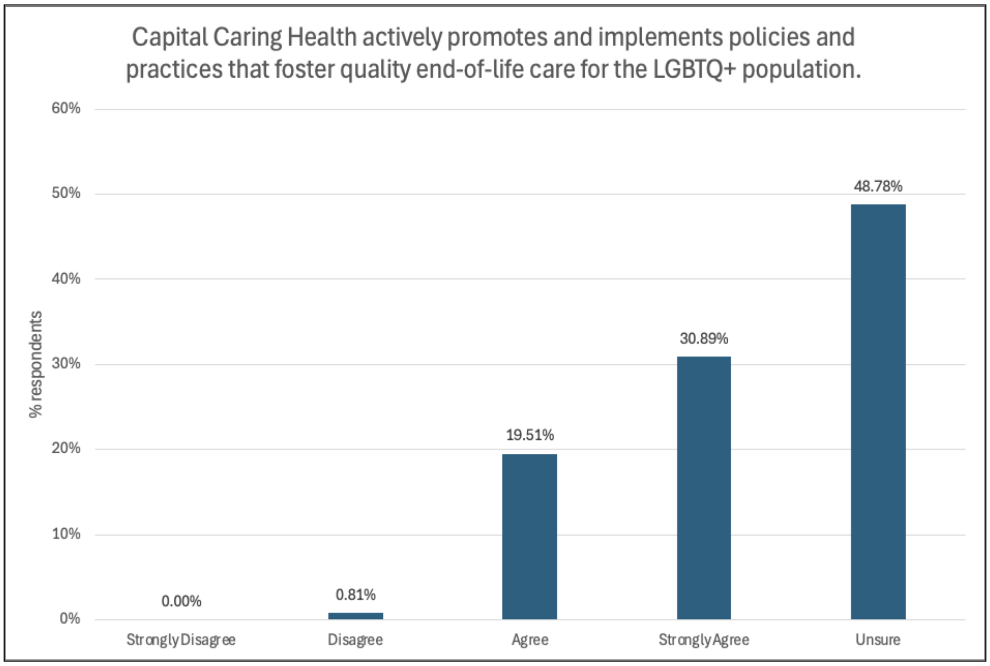
Do you feel as though you have access to resources that help you in your role caring for the LGBTQ+ population?	Percentage	Response Count
Probably yes	68%	81
Probably not	18%	22
Definitely yes	13%	16
Definitely not	1%	1

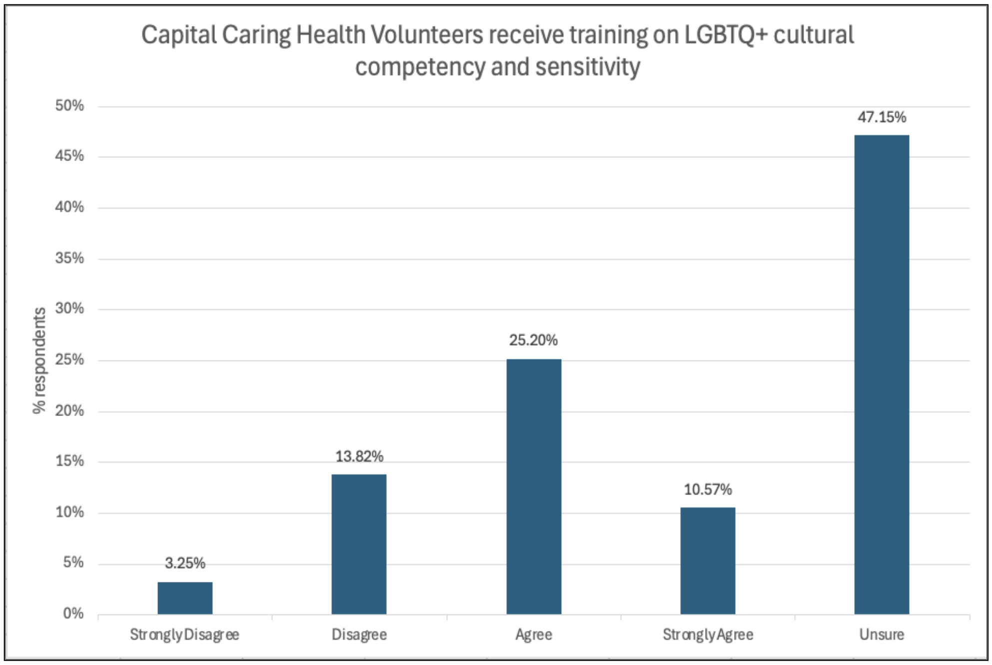
I find that when my personal beliefs differ from those of the patient or their caregivers/loved ones, it is [______] for me to provide the same quality of care to the patient.	Percentage	Response Count
Easy	61%	73
Extremely easy	34%	41
Difficult	5%	6
Extremely difficult	0%	0

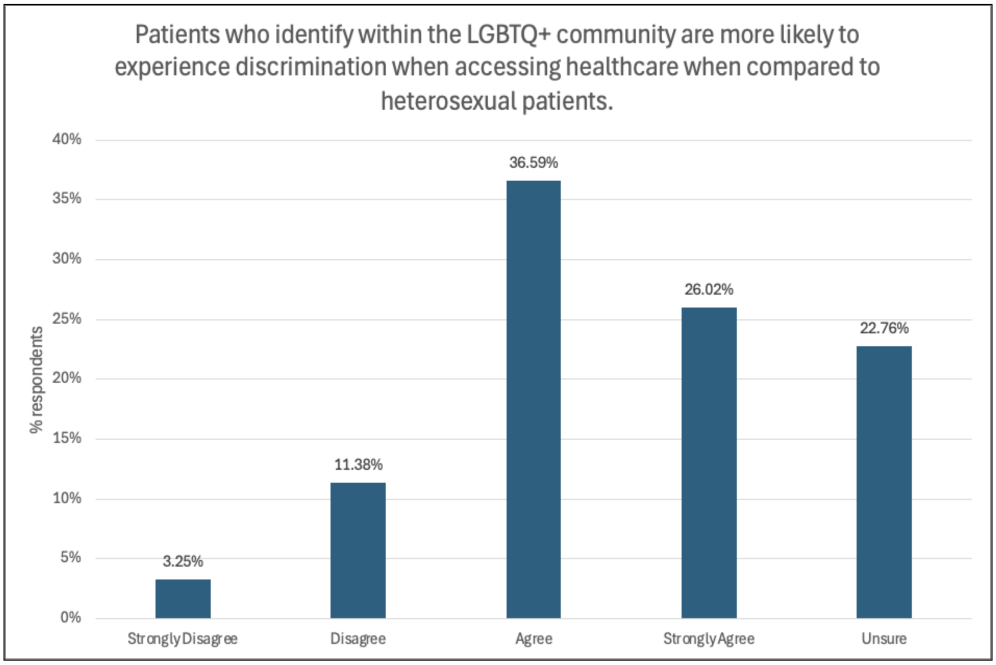
Are you open to participating in an interview following this survey?	Percentage	Response Count
Yes	58%	69
No	43%	51

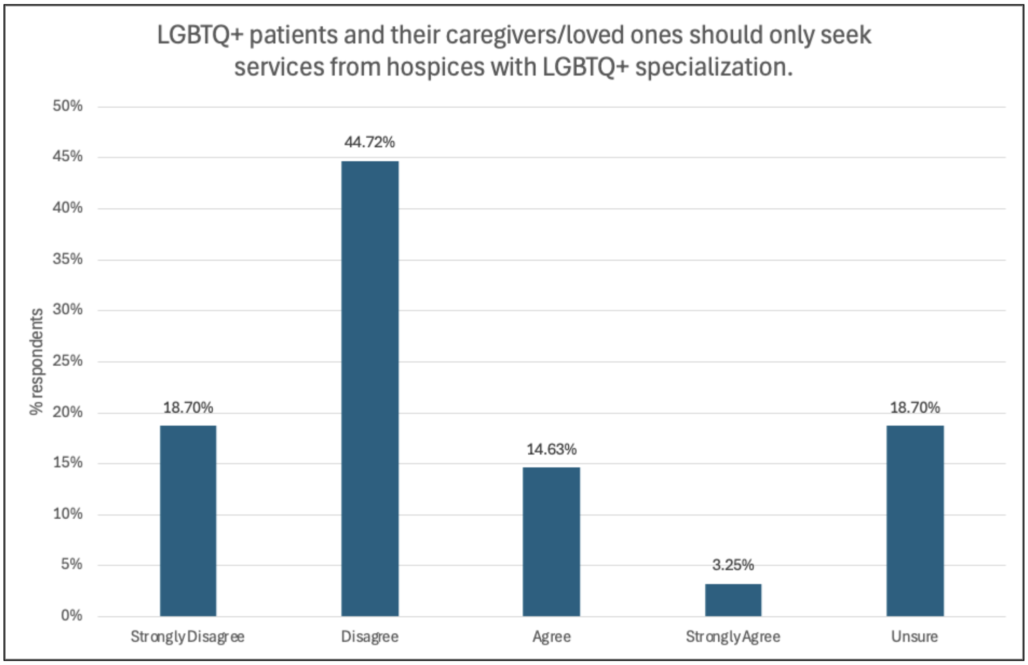
Appendix C: Survey Results

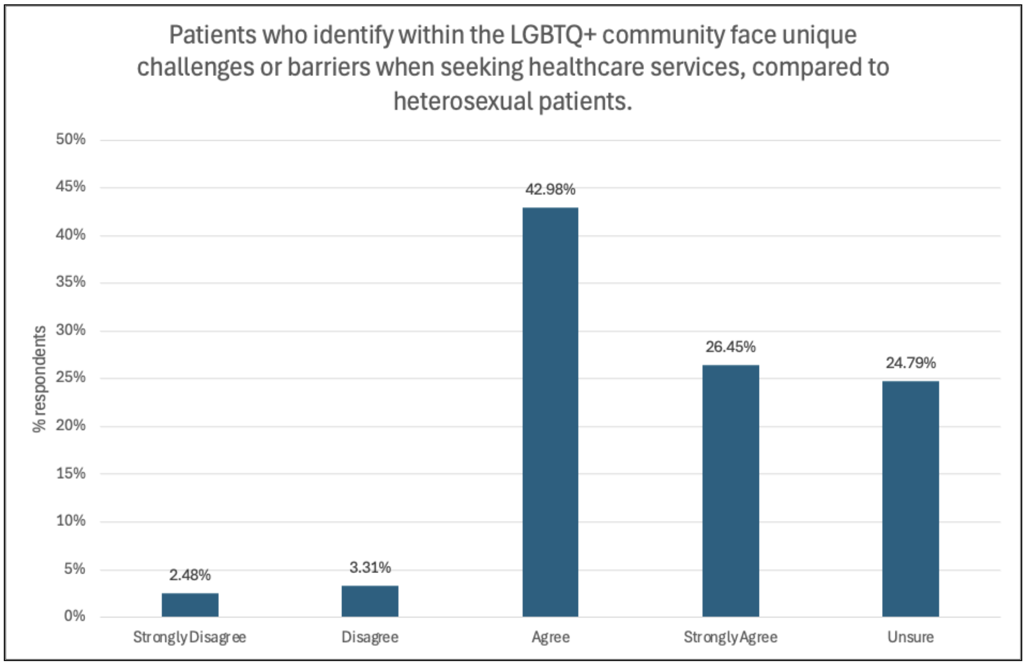


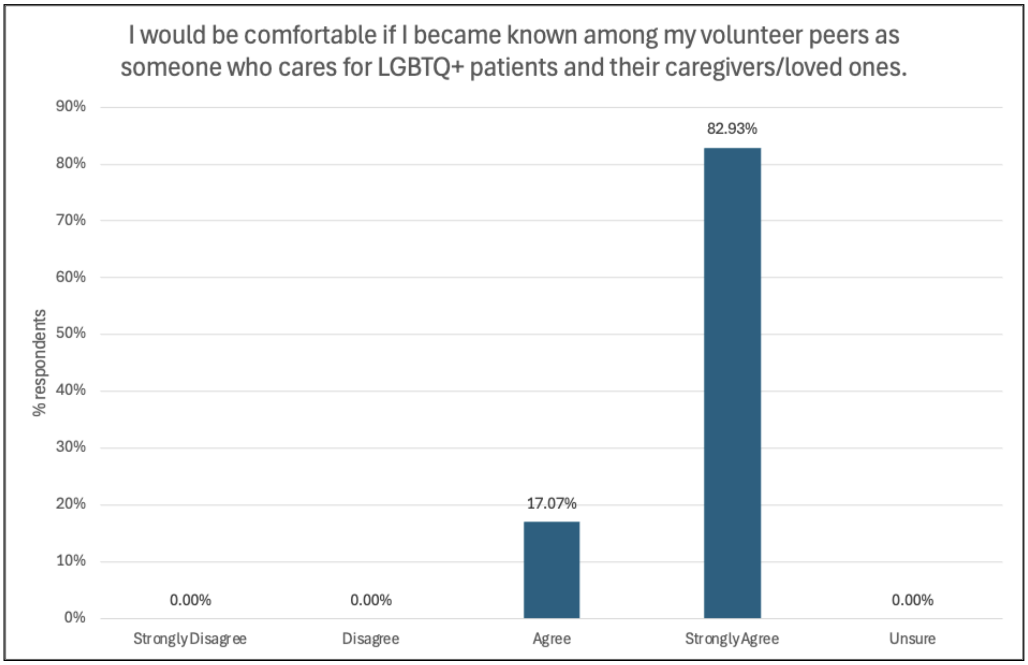


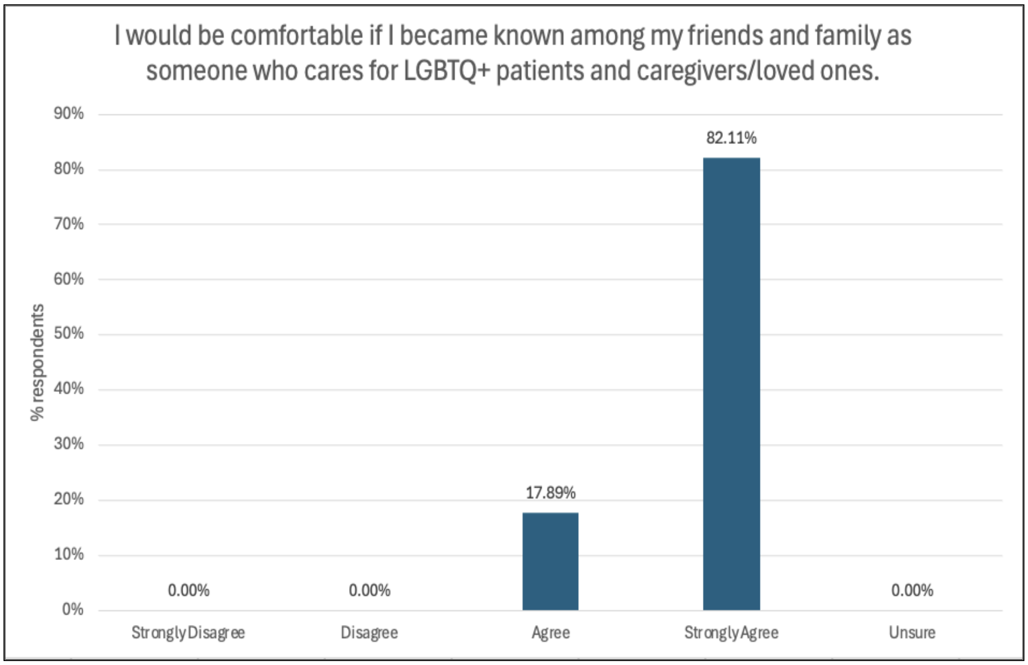

Capital Caring Health Volunteers receive training on LGBTQ+ cultural competency and sensitivity

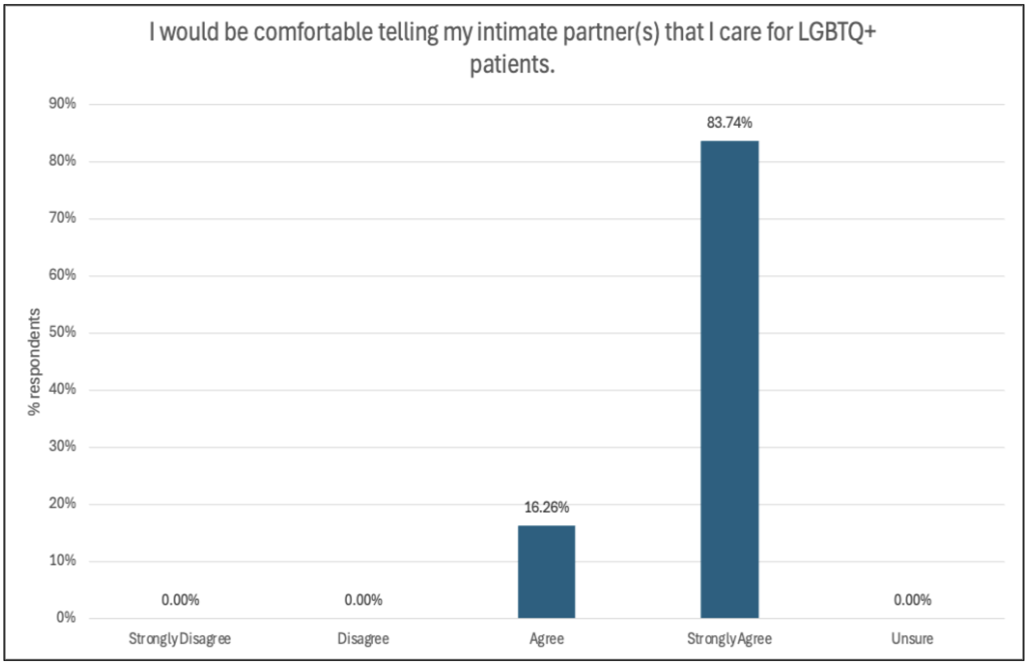

Patients who identify within the LGBTQ+ community are more likely to experience discrimination when accessing healthcare when compared to heterosexual patients.

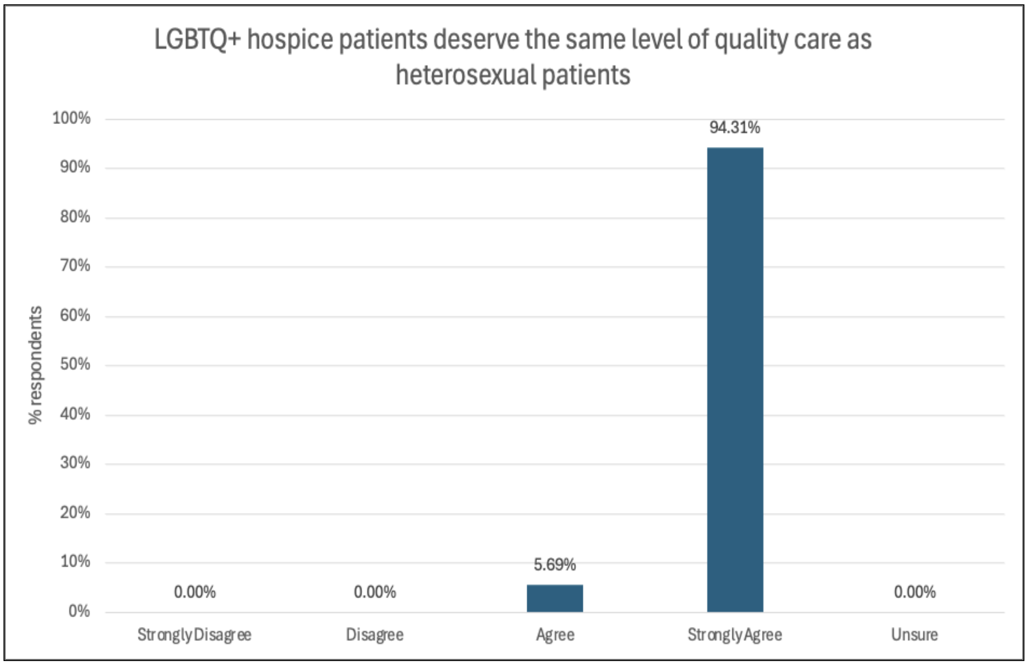

LGBTQ+ patients and their caregivers/loved ones should only seek services from hospices with LGBTQ+ specialization.
% respondents
50%
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
18.70%
44.72%
14.63%
3.25%
18.70%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure

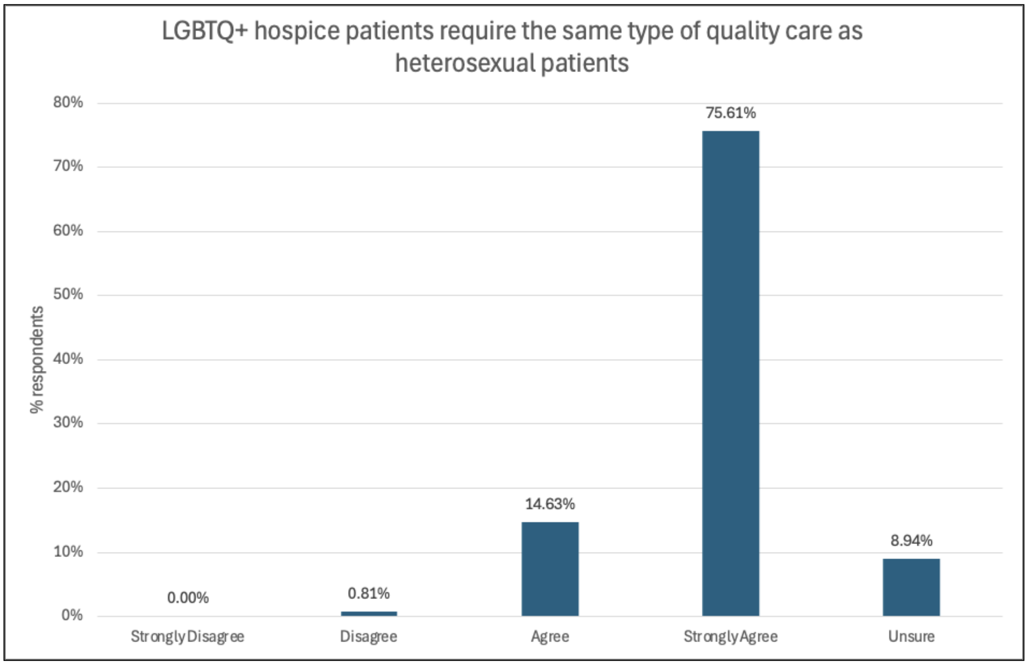

Patients who identify within the LGBTQ+ community face unique challenges or barriers when seeking healthcare services, compared to heterosexual patients.
% respondents
50%
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
2.48%
3.31%
42.98%
26.45%
24.79%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure

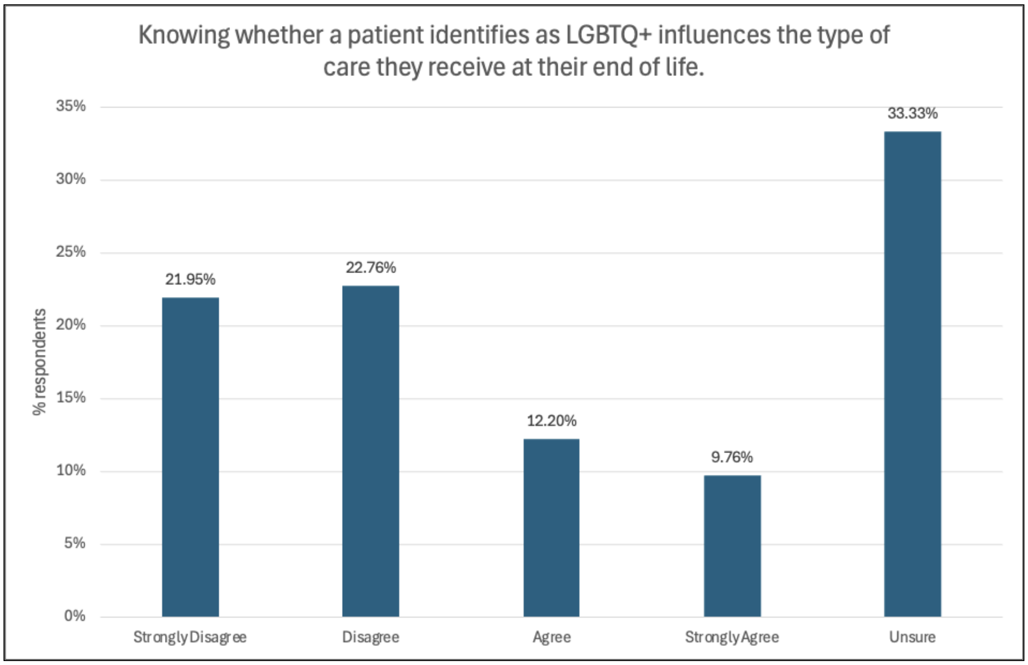

I would be comfortable if I became known among my volunteer peers as someone who cares for LGBTQ+ patients and their caregivers/loved ones.
% respondents
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
0.00%
0.00%
17.07%
82.93%
0.00%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure

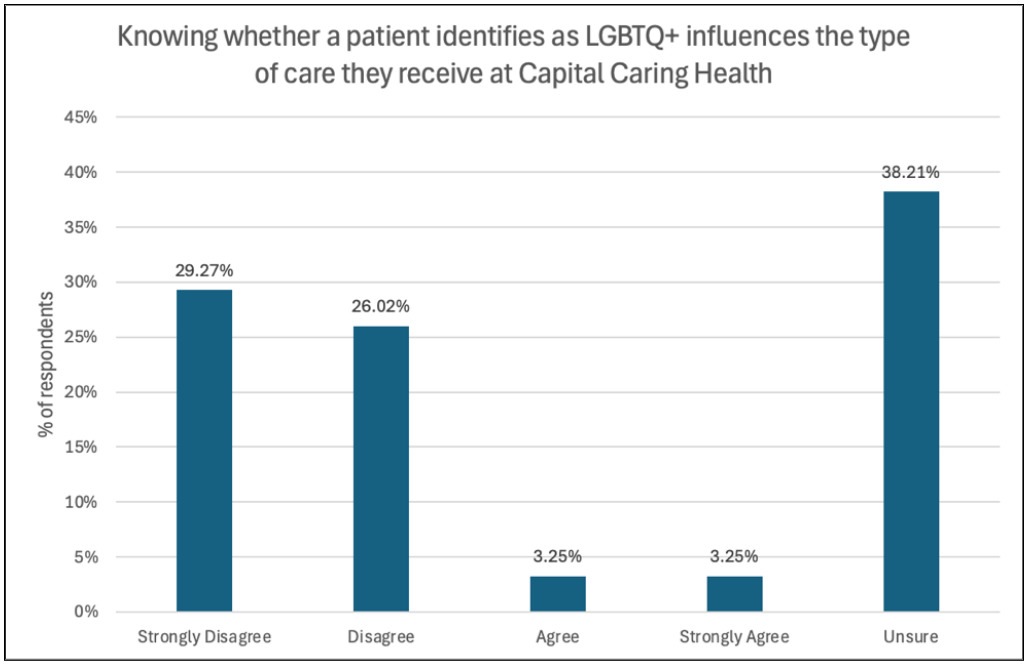

I would be comfortable if I became known among my friends and family as someone who cares for LGBTQ+ patients and caregivers/loved ones.
% respondents
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
0.00%
0.00%
17.89%
82.11%
0.00%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure

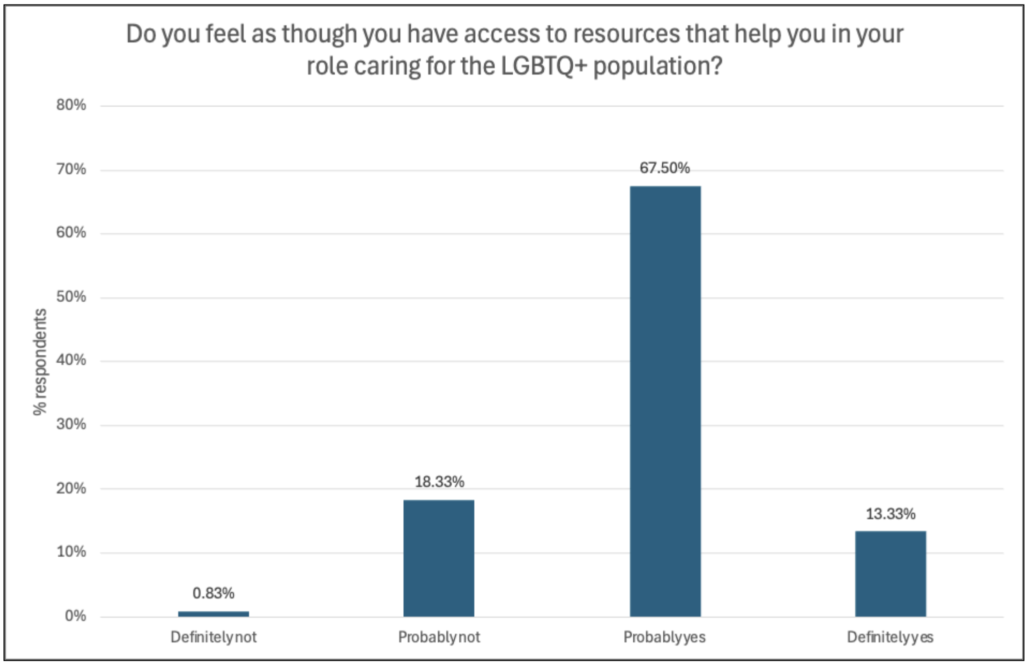

I would be comfortable telling my intimate partner(s) that I care for LGBTQ+ patients.
% respondents
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
0.00%
0.00%
16.26%
83.74%
0.00%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure

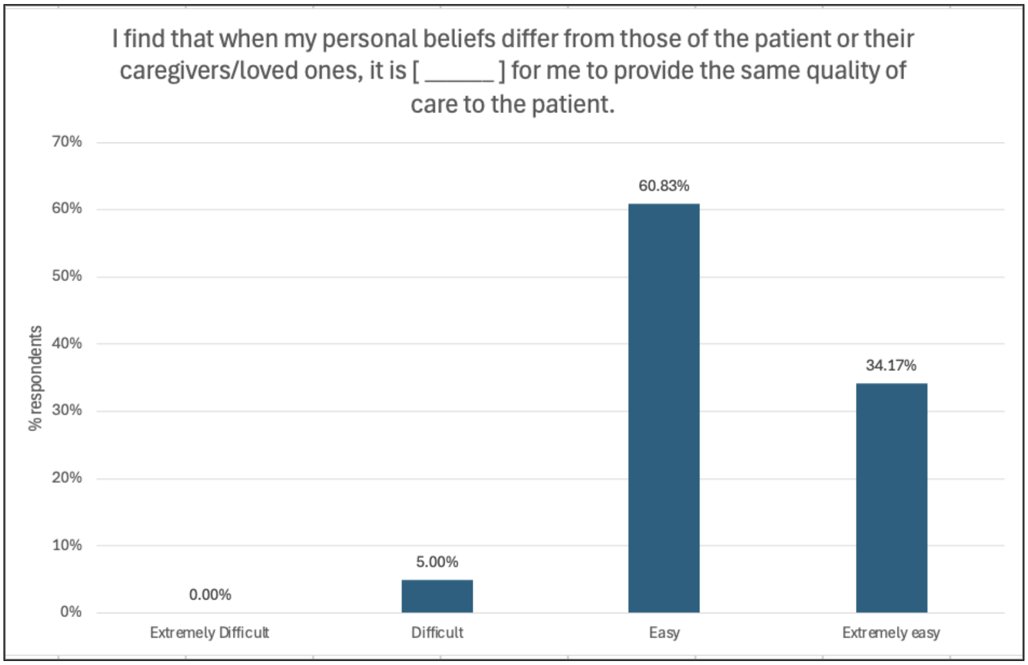

LGBTQ+ hospice patients deserve the same level of quality care as heterosexual patients
% respondents
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
0.00%
0.00%
5.69%
94.31%
0.00%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure


LGBTQ+ hospice patients require the same type of quality care as heterosexual patients
% respondents
80%
70%
60%
50%
40%
30%
20%
10%
0%
0.00%
0.81%
14.63%
75.61%
8.94%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure


Knowing whether a patient identifies as LGBTQ+ influences the type of care they receive at their end of life.
% respondents
35%
30%
25%
20%
15%
10%
5%
0%
21.95%
22.76%
12.20%
9.76%
33.33%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure


Knowing whether a patient identifies as LGBTQ+ influences the type of care they receive at Capital Caring Health
% of respondents
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
29.27%
26.02%
3.25%
3.25%
38.21%
Strongly Disagree
Disagree
Agree
Strongly Agree
Unsure


Do you feel as though you have access to resources that help you in your role caring for the LGBTQ+ population?
% respondents
80%
70%
60%
50%
40%
30%
20%
10%
0%
0.83%
18.33%
67.50%
13.33%
Definitely not
Probably not
Probably yes
Definitely yes


I find that when my personal beliefs differ from those of the patient or their caregivers/loved ones, it is [______] for me to provide the same quality of care to the patient.
% respondents
70%
60%
50%
40%
30%
20%
10%
0%
0.00%
5.00%
60.83%
34.17%
Extremely Difficult
Difficult
Easy
Extremely easy

Appendix D: Semi-Structured Interview Questions

Semi-structured Interview Questions for **All Participants** Background/Demographic
Can you please share with me how long you have been [volunteering / working] with Capital Caring Health? Can you please tell me your role and describe for me what you do at Capital Caring Health? How did you first learn about Capital Caring Health? Final questions in each interview: Is there anything else that we haven't talked about that you'd like to share? Would you like a copy of the final paper where I'll write about this work?

Conceptual Framework	Project Questions	Semi-structured Interview Questions for **Volunteers**
Policy/Conditions Lived Programs and Values Supporting Diversity & Inclusion Representational Diversity	What are Capital Caring Health (CCH)'s current practices that demonstrate LGBTQ+ inclusivity? What additional actions can CCH take to demonstrate its commitment to supporting LGBTQ+ people at their end of life?	Q: Capital Caring's mission is to "provide patients and their families with advanced illness care of the highest quality," how do you see that mission come to life in your volunteer work? Q: What do you feel are the most important things a volunteer can do to be inclusive of patients and their caregivers at Capital Caring Health?
Structured Inclusive Interaction Practices Development & Resources	What are Capital Caring Health (CCH)'s current practices that demonstrate LGBTQ+ inclusivity? What additional actions can CCH take to demonstrate its	Q: Can you walk me through how you were trained to become a volunteer? Q: What is one way you build trust with Capital Caring's patients and their caregivers?

	commitment to supporting LGBTQ+ people at their end of life?	Q: Do you feel your volunteer training prepared you to work with the LGBTQ+ population? If Yes, can you describe what part of the training has helped you feel prepared? If No, can you tell me what's missing from the training? Q: Have you had any experiences caring for a member of the LGBTQ+ population, that you are aware of? A. If Yes, can you tell me what was unique about this population versus another demographic? B. If Yes to A: Did you feel adequately prepared for caring for them? C. If yes to B: Are you open to sharing what you think prepared you for caring for the LGBTQ+ population? It can be either professional or personal experiences, or both. D. If no to feeling adequately prepared: What do you feel could have helped you be more prepared in this situation? E. No, I haven't had any that I'm aware of. Q: Have you ever had a situation while volunteering that included a patient who identified as LGBTQ+, that you were not sure how to handle? Y/N A. If yes: can you describe it for me and tell me what you did? Q: There's growing literature that says when patients who are LGBTQ+ are at their end of life, it's important to

		acknowledge and include the patient's spouse or partner in the process, especially in decision-making for the patient. What are some ways that Capital Caring does this? Q: What do you feel are the most important things that volunteers can do to be inclusive to a patient that is a member of the LGBTQ+ community? What about their caregiver?

Conceptual Framework	Project Questions	Semi-structured Interview Questions for **Patient-facing Staff (i.e. patient-facing clinicians)**
Policy/Conditions Lived Programs and Values Supporting Diversity & Inclusion Representational Diversity	What are Capital Caring Health (CCH)'s current practices that demonstrate LGBTQ+ inclusivity? What additional actions can CCH take to demonstrate its commitment to supporting LGBTQ+ people at their end of life?	Q: Knowing that Capital Caring's mission is to "provide patients and their families with advanced illness care of the highest quality," how do you see that mission come to life in your day-to-day? Q: There are policies that Capital Caring Health must follow in order to provide the highest level of quality care. Are you able to describe for me how those policies are created and decided upon? Q: How often are these policies reviewed to ensure they're up-to-date?
Structured Inclusive Interaction Practices Development & Resources	What are Capital Caring Health (CCH)'s current practices that demonstrate LGBTQ+ inclusivity? What additional actions can CCH take to demonstrate its commitment to supporting	Q: As you were training for your role, what are some of the things you learned about being inclusive towards patients and their caregivers? Q: How do you communicate or demonstrate to your patients and their caregivers that you care about them?

	LGBTQ+ people at their end of life?	Q: What do you feel are the most important things any patient-facing staff can do to be inclusive to a patient who is a member of the LGBTQ+ community? What about their caregiver? Q: Can you give me an example of how patients at Capital Caring are treated with care and respect regardless of their sexual orientation or gender identity? Q: There's growing literature that says when patients who are LGBTQ+ and at their end of life, it's important to acknowledge and include the patient's spouse or partner in the process, especially in decision-making for the patient. What are some ways that Capital Caring does this? Have you had any experiences caring for a member of the LGBTQ+ population that you are aware of? A: If Yes, can you tell me what was unique about this population versus another demographic? B: If Yes to A: Did you feel adequately prepared for caring for them? C: If yes to B: Are you open to sharing what you think prepared you for caring for the LGBTQ+ population? It can be either professional or personal experiences, or both. D: If no to feeling adequately prepared: What do you feel could have helped you be more prepared in this situation? E: No, I haven't had any that I'm aware of. Q: Have you ever had a situation with an LGBTQ+ patient that you were not sure

		how to handle? If yes: can you describe it for me and tell me what you did?

Conceptual Framework	Project Question	Semi-structured Interview Questions for **Non-Patient facing Staff (i.e. administrative or senior leadership)**
Policy/Conditions Lived Programs and Values Supporting Diversity & Inclusion Representational Diversity	What are Capital Caring Health (CCH)'s current practices that demonstrate LGBTQ+ inclusivity? What additional actions can CCH take to demonstrate its commitment to supporting LGBTQ+ people at their end of life?	Q: Can you please describe to me your understanding of what Capital Caring Health does? Q: Knowing that Capital Caring's mission is to provide patients and their families with advanced illness care of the highest quality," how do you see that mission come to life in your day to day? Q: There are policies that Capital Caring Health must follow in order to provide the highest level of quality care. Can you please describe for me how these policies are created and decided upon? Q: How often are these policies reviewed to ensure they're up-to-date?
Structured Inclusive Interaction Practices Development & Resources	What are Capital Caring Health (CCH)'s current practices that demonstrate LGBTQ+ inclusivity? What additional actions can CCH take to demonstrate its commitment to supporting LGBTQ+	Q: What do you feel are the most important things the staff and volunteers can do to be inclusive of the patients at Capital Caring Health? And what about their caregivers? Q: What do you feel are the most important things that Capital Caring's staff can do to be inclusive to a patient that is a member of the LGBTQ+ community? What about their caregiver?

	people at their end of life?	Q: Can you give me an example of how patients at Capital Caring are treated with care and respect regardless of their sexual orientation or gender identity? Q: What are some important things someone in your role can do to ensure a patient who is a member of the LGBTQ+ community receives the highest quality care at their end of life?

Appendix E: Qualitative Codebook Thematically Mapped to Conceptual Framework

Group 1 - Volunteers

Framework Mapping	Parent	Child Depth	CODE	MEMO
Background / Demographic	Parent		ServiceTime	How long have you been volunteering with Capital Caring Health?
Background / Demographic	Parent		RoleDescription	Can you please tell me your role and describe for me what you do at Capital Caring Health?
Background / Demographic	Parent		FirstLearn	How did you first learn about Capital Caring Health?
Policy / Conditions	Parent		MissionToLife	Capital Caring's mission is to "provide patients and their families with advanced illness care of the highest quality," how do you see that mission come to life in your volunteer work?
Structured Inclusive Interactive Practices	Parent		VolunteerTraining	Can you walk me through how you were trained to become a volunteer?
Structured Inclusive Interactive Practices	Parent			What is one way you build trust with Capital Caring's patients and their caregivers?
Policy / Conditions	Parent		PatientInclusivity	What do you feel are the most important things a volunteer can do to be inclusive of patients and their caregivers at Capital Caring Health?
Structured Inclusive Interactive Practices	Parent		VolunteerTraining-L	Do you feel your volunteer training prepared you to work with the LGBTQ+ population?
Structured Inclusive Interactive Practices	-	Child1	VolunteerTraining-L-Yes	If YES, can you describe what part of the training has helped you feel prepared?
Structured Inclusive	-	Child2	VolunteerTraining-L-No	If NO, can you tell me what's missing from the training?

Interactive Practices				
Structured Inclusive Interactive Practices	Parent		CareforL	Have you had any experiences caring for a member of the LGBTQ+ population, that you are aware of?
Structured Inclusive Interactive Practices	-	Child1	CareforL-Y-Unique	a. If Yes, can you tell me what was unique about this population versus another demographic?
Structured Inclusive Interactive Practices	-	Child2	CareforL-Y-Preparation	b. If Yes to a: Did you feel adequately prepared for caring for them?
Structured Inclusive Interactive Practices	-	Child3	CareforL-Y-HowPrepared	c. If yes to b: Are you open to sharing what you think prepared you for caring for the LGBTQ+ population? It can be either professional or personal experiences, or both.
Structured Inclusive Interactive Practices	-	Child4	CareforL-N-Preparation	d. If no to feeling adequately prepared: What do you feel could have helped you be more prepared in this situation?
Structured Inclusive Interactive Practices	-	Child5	CareforL-N	e. No, I haven't had any that I’m aware of.
Structured Inclusive Interactive Practices	Parent		LUnhandledSituation	Have you ever had a situation while volunteering that included a patient who identified as LGBTQ+, that you were not sure how to handle? Y/N
Structured Inclusive Interactive Practices	-	Child1	LUnhandledSituation-Y-Description	If yes: can you describe it for me and tell me what you did?
Structured Inclusive Interactive Practices	Parent		EOLPartner	There’s growing literature that says when patients who are LGBTQ+ are at their end of life, it’s important to acknowledge and include the patient’s spouse or partner in the process, especially in

				decision-making for the patient. What are some ways that Capital Caring does this?
Structured Inclusive Interactive Practices	Parent		MostImportantInclusiveofLforV	What do you feel are the most important things that volunteers can do to be inclusive to a patient that is a member of the LGBTQ+ community?
Structured Inclusive Interactive Practices	-	Child1	MostImportantInclusiveofLforV-Caregiver	What about their caregiver?
Background / Demographic	Parent		Other	Is there anything else that we haven't talked about that you'd like to share?
Background / Demographic	Parent		PaperCopy	Would you like a copy of the final paper where I'll write about this work?

Group 2 - Clinical Staff (i.e. patient-facing clinicians, social workers, chaplains)

Framework Mapping	**Parent**	**Child Depth**	**CODE**	**MEMO**
Background / Demographic	Parent		ServiceTime	How long have you been working at Capital Caring Health?
Background / Demographic	Parent		RoleDescription	Can you please tell me your role and describe for me what you do at Capital Caring Health?
Background / Demographic	Parent		FirstLearn	How did you first learn about Capital Caring Health?
Policy / Conditions	Parent		MissionToLife	Knowing that Capital Caring's mission is to "provide patients and their families with advanced illness care of the highest quality," how do you see that mission come to life in your day-to-day?
Policy / Conditions	Parent		Policies-Created	There are policies that Capital Caring Health must follow in order to provide the highest level of quality care. Are you

				able to describe for me how those policies are created and decided upon?
Policy / Conditions	Parent		Policies-Reviewed	How often are these policies reviewed to ensure they're up-to-date?
Structured Inclusive Interactive Practices	Parent		ClinicalTraining	As you were training for your role, what are some of the things you learned about being inclusive towards patients and their caregivers?
Structured Inclusive Interactive Practices	Parent		CommunicateCare	How do you communicate or demonstrate to your patients and their caregivers that you care about them?
Structured Inclusive Interactive Practices	Parent		MostImportantInclusiveofLforPF	What do you feel are the most important things any patient-facing staff can do to be inclusive to a patient who is a member of the LGBTQ+ community?
Structured Inclusive Interactive Practices	-	Child1	MostImportantInclusiveofLforPF-Caregiver	What about their caregiver?
Structured Inclusive Interactive Practices	Parent		ExampleCare	Can you give me an example of how patients at Capital Caring are treated with care and respect regardless of their sexual orientation or gender identity?
Structured Inclusive Interactive Practices	Parent		EOLPartner	There's growing literature that says when patients who are LGBTQ+ and at their end of life, it's important to acknowledge and include the patient's spouse or partner in the process, especially in decision-making for the patient. What are some ways that Capital Caring does this?
Structured Inclusive Interactive Practices	Parent		CareforL	Have you had any experiences caring for a member of the LGBTQ+ population, that you are aware of?

Structured Inclusive Interactive Practices	-	Child1	CareforL-Y-Unique	a. If Yes, can you tell me what was unique about this population versus another demographic?
Structured Inclusive Interactive Practices	-	Child2	CareforL-Y-Preparation	b. If Yes to a: Did you feel adequately prepared for caring for them?
Structured Inclusive Interactive Practices	-	Child3	CareforL-Y-HowPrepared	c. If yes to b: Are you open to sharing what you think prepared you for caring for the LGBTQ+ population? It can be either professional or personal experiences, or both.
Structured Inclusive Interactive Practices	-	Child4		d. If no to feeling adequately prepared: What do you feel could have helped you be more prepared in this situation?
Structured Inclusive Interactive Practices	-	Child5	CareforL-N	e. No, I haven't had any that I'm aware of.
Structured Inclusive Interactive Practices	Parent		LUnhandledSituation	Have you ever had a situation with an LGBTQ+ patient that you were not sure how to handle? If yes: can you describe it for me and tell me what you did?
Structured Inclusive Interactive Practices	-	Child1	LUnhandledSituation -Y-Description	If yes: can you describe it for me and tell me what you did?
Background / Demographic	Parent		Other	Is there anything else that we haven't talked about that you'd like to share?
Background / Demographic	Parent		PaperCopy	Would you like a copy of the final paper where I'll write about this work?

Group 3 - Non-Clinical Staff (i.e. administrative or non-patient facing)

Framework Mapping	Parent	Child Depth	CODE	MEMO
Background / Demographic	Parent		ServiceTime	How long have you been working at Capital Caring Health?
Background / Demographic	Parent		RoleDescription	Can you please tell me your role and describe for me what you do at Capital Caring Health?
Background / Demographic	Parent		FirstLearn	How did you first learn about Capital Caring Health?
Policy / Conditions	Parent		CCHMission	Can you please describe to me your understanding of what Capital Caring Health does?
Policy / Conditions	Parent		MissionToLife	Knowing that Capital Caring's mission is to "provide patients and their families with advanced illness care of the highest quality," how do you see that mission come to life in your day-to-day?
Policy / Conditions	Parent		Policies-Created	There are policies that Capital Caring Health must follow in order to provide the highest level of quality care. Are you able to describe for me how those policies are created and decided upon?
Policy / Conditions	Parent		Policies-Reviewed	How often are these policies reviewed to ensure they're up-to-date?
Structured Inclusive Interactive Practices	Parent		PatientInclusivity	What do you feel are the most important things the staff and volunteers can do to be inclusive of the patients at Capital Caring Health?
Structured Inclusive Interactive Practices	-	Child1	PatientInclusivity-Caregiver	What about their caregiver?
Structured Inclusive	Parent		ExampleCare	Can you give me an example of how patients at Capital Caring are treated with care

Interactive Practices				and respect regardless of their sexual orientation or gender identity?
Structured Inclusive Interactive Practices	Parent		RoleSpecificQualityEffort	What are some important things someone in your role can do to ensure a patient who is a member of the LGBTQ+ community receives the highest quality care at their end of life?
Background / Demographic	Parent		Other	Is there anything else that we haven't talked about that you'd like to share?
Background / Demographic	Parent		PaperCopy	Would you like a copy of the final paper where I'll write about this work?

Appendix F: Qualitative Codebook Frequency Table

Codes	Frequency
Final Thoughts	69
Good quote	44
ServiceTime	29
RoleDescription	37
FirstLearn	32
MissionToLife	55
Volunteer Training	34
BuildTrust	25
PatientInclusivity	25
PatientInclusivity-Caregiver	22
VolunteerTraining-L	17
VolunteerTraining-L-No	26
VolunteerTraining-L-Yes	6
CareforL	23
CareforL-Y-Unique	18
CareforL-Y-Preparation	15
CareforL-Y-HowPrepared	18
CareforL-N-Preparation	2
CareforL-N	10
LUnhandledSituation	21
LUnhandledSituation-Y-Description	9
EOLPartner	31
MostImportantInclusiveLforV	34
MostImportantInclusiveLforV-Caregiver	32
PaperCopy	25
Policies-Created	17
Policies-Reviewed	14
ClinicalTraining	7
CommunicateCare	14
MostImportantInclusiveofLforPF	18
MostImportantInclusiveofLforPF-Caregiver	15
ExampleCare	18
CCHMission	7
RoleSpecificQualityEffort	8

Legend
1st level code
2nd level code