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Death with Dignity: Queer Representation in Deathcare Systems

by

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Thesis Advisor

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Dedication

This thesis is dedicated to those of my community who
were not afforded the privilege of old age.

Buddhism's "Five Remembrances"

"I am of the nature to grow old. There is no way to escape growing old.

I am of the nature to have ill health. There is no way to escape ill health.

I am of the nature to die. There is no way to escape death.

All that is dear to me and everyone I love are of the nature to change. There is no way to escape
being separated from them.

My actions are my only true belongings. I cannot escape the consequences of my actions. My
actions are the ground upon which I stand."

-Translated by Thich Nhat Hanh

Abstract

This thesis examines the ways that elderly members of the LGBT community lack representation within deathcare systems. Currently, the LGBT community is vastly underrepresented in research relating to the dying process and deathcare. This lack of representation creates barriers for LGBT individuals at the end of their lives and creates difficult end-of-life experiences. I utilized previous research that studied how LGBT populations interact with and are treated by a variety of death care-related systems, including health systems, legal systems, and therapeutic systems. This research highlighted the need for the LGBT community to be better represented within both research relating to these systems and within these systems directly. This thesis argues that without this representation, aging LGBT community members lack safety when dying and that these systems need to be changed in order to achieve equitable deathcare.

Keywords: LGBT, representation, aging, safety, deathcare.

Queer Representation in Deathcare

Introduction

Historically, the LGBT community in the United States has had a profoundly complicated relationship with death and dying. For many who are Queer, death and violence can often feel to be entangled concepts. Between the AIDS epidemic that defined a generation and continues to impact the LGBT community, the elevated risk of suicide amongst Queer youth, and the rising rates of hate crimes against LGBT individuals, violence feels to be a common theme amongst Queer death. Within this idea sits another sentiment: not everyone is afforded the privilege of aging. Being able to live a long life is a great feat, especially for those who are Queer. Yet, even those of the LGBT community who are afforded long lives may still become victims of discriminatory violence during their dying experiences.

America's LGBT community has faced many unique challenges surrounding end-of-life experiences. These challenges can be seen within deathcare systems, such as hospice, where Queer individuals have been excluded and, at times, actively discriminated against. Both this passive form of discrimination through omission and active discrimination contribute to a lack of safety within the realm of deathcare. Culturally competent and compassionate care for Queer identities is not often seen within deathcare, and this lack of regard and representation can further marginalize already vulnerable individuals, leaving them to be/feel unsafe.

The lack of representation in death care systems for Queer individuals is an understudied and undervalued issue. Despite this, there are currently more than 2.4 million Queer Americans who are over the age of 65 (Pereira & Banerjee, 2021), a population that will only continue to grow with time. Because of this, it is vital that the LGBT community is better represented within

deathcare systems to ensure better care for the future. Yet, current literature does not properly examine the different experiences and needs Queer individuals may have within deathcare systems compared to their heterosexual and cisgender counterparts. Often when discussing palliative care, Queer identities are completely overlooked, and if they are acknowledged, research is often brief and/or dismissive of certain LGBT identities. While Queer experiences within death systems have not been well researched, there seems to be growing interest surrounding the topic, which can particularly be seen in the small but emergent field of Queer Death Studies. The field of Queer Death Studies is based on queer-feminist and decolonial theories that promote changing how we view death. Queer Death Studies, though, seem to be primarily concerned with theoretical concepts, such as queering death, rather than conducting and implementing research into modern practices. While theory builds the groundwork for change, it is also important to directly address how we achieve this change. As a result, I am examining how the lack of Queer representation in death care systems impacts individuals and how we can better these systems for the LGBT community.

This thesis will include a literature review that will pull research from multiple disciplines. Research from three primary frameworks will be examined, including medical care, end-of-life planning, and grief theory/support. Medical care will describe literature that focuses on medical care received during the dying process; end-of-life planning will cover end-of-life personal wishes, such as wills and estate planning; and finally, the section covering grief will look at the care for a deceased individual's loved ones. By analyzing this topic through a multi-disciplinary lens, I intend to create a comprehensive analysis of how members of the LGBT community lack representation and, therefore, lack safety within deathcare. However, it is to be noted that this thesis can not comprehensively assess every aspect of this topic. Due to the

lack of research regarding this subject, most literature does not account for participants' socioeconomic status or race when analyzing their received treatment/care. Further research must be conducted outside this thesis to gain a more in-depth understanding of this topic.

Positionality

Before continuing, I want to make my identity known, as it greatly impacts my work. As a young Queer individual in my early twenties, I have witnessed firsthand the confusion and struggle that exists within my community, a struggle that largely stems from losing so many of our elders. Most of us do not know our own history, and when history is forgotten, it allows for dangerous cycles to repeat themselves. I see these cycles repeating in that within the past year (2023), over 520 anti-LGBTQ bills were introduced across the United States (Fernandez, 2023). The bubbling disdain for my community weighs on many of our shoulders, and because of this, it feels urgent to promote positive changes for the LGBT community. For this reason, I feel that understanding how Queer individuals are treated within death care systems is important, not just as a bystander, but as a Queer person who will one day face dying as well.

Additionally, my choice to employ the term 'Queer' throughout both my writing and my research is an important and intentional decision. The term Queer began to be widely reclaimed by the LGBT community in the early 90s as a response to the AIDS epidemic (Brontsema, 2004). My choice to utilize Queer is an acknowledgment of this reclamation, as well as a way to represent the spectrum of LGBT+ identities. I myself identify as Queer and do not intend for this term to be viewed as derogatory. Instead, I use Queer as an act of reclamation of power and identity.

Methodology

To obtain my information, I conducted a comprehensive search of palliative care journals, hospice care journals, law reviews, psychology journals, and LGBT-specific journals. This allowed me to understand how anti-LGBT discrimination affects individuals and the LGBT community across both fields and lifespan. As discussed earlier, the treatment of LGBT individuals within deathcare systems is vastly under-researched. Therefore, I chose a broad research scope to address how LGBT elders are treated within these systems. It is important to note that various other factors, such as race, disability, and socioeconomic standing, also impact how Queer elders are treated within death care systems. Similarly, the care amongst different Queer identities, such as transgender or bisexual individuals, can vary vastly, and identity-specific reviews are important as well. Again, due to the lack of research on the overall topic, I did not look at specific identities only and instead looked at treatment for LGBT elders as a whole.

Literature Review

Healthcare

One common and concerning theme that appears repeatedly throughout literature addressing end-of-life medical care and the LGBT community is the overwhelming lack of previous research on this topic. Despite the increased visibility of LGBT identities in mainstream culture, the healthcare system and related research have continued to fail at recognizing the unique needs and experiences of this community. Literature such as “Hospice and Palliative Care for Older Lesbian, Gay, Bisexual and Transgender Adults” aimed to address this lack of information by examining the history and needs of LGBT individuals in palliative care and hospice settings. This review found existing disparities in accessing healthcare between LGBT individuals and their heterosexual counterparts due to a lack of resources, discriminatory

practices, and lack of healthcare provider knowledge (Deborah F. Farmer and Cecile N. Yancu, 2015). These disparities in accessing healthcare create situations where LGBT individuals are not ensured to receive the necessary care they require and are put at risk.

When addressing disparities in health care, it has been found that Queer individuals were less likely than heterosexual couples to be covered under their partner's health insurance (Deborah F. Farmer and Cecile N. Yancu, 2015). This discrepancy results from discriminatory policies that some employers hold regarding whom insurance can be dispersed (Deborah F. Farmer and Cecile N. Yancu, 2015). Similarly, a Harvard study found that “sexual minority women and men were about twice as likely as their respective heterosexual counterparts to have been unemployed and uninsured” (Charlton et al., 2018). The study’s sample consisted of participants who were mostly white and of high socioeconomic status, which makes their findings even more alarming. Deducing from current research, LGBT individuals who are either/both low-income and racial minorities may be at an even further risk for lacking health insurance. Suppose LGBT individuals of higher socioeconomic are still less likely than heterosexuals to have insurance. In that case, the vast majority of Queer people are even less likely to have access to insurance. These findings indicate a stark reality: many lack insurance and, therefore, lack equal access to medical care.

While there has not been much research demonstrating an increased likelihood of being Queer and an increased risk of physical health concerns (Deborah F. Farmer and Cecile N. Yancu, 2015), lacking health insurance is an incredible impediment to long-term health and allows for existing conditions to go unmet. Furthermore, research *does* show that individuals who identify as being Queer are more likely to experience mental health issues (Yarns et al., 2016). This is a significant concern, especially during the end-of-life stage. Having access to

mental health care can be profoundly beneficial for those who are either dying or watching someone die. If mental health care is denied to an already marginalized community, their suffering will only be compounded as they pass.

Additionally, it was found that LGBT individuals are more likely to avoid healthcare systems “due to fears of discrimination and poor treatment within the system” (Deborah F. Farmer and Cecile N. Yancu, 2015). Burton et al., (2019) found that many Queer individuals were concerned about their medical care being negatively affected if they disclosed their identity to their healthcare providers; this concern, specifically, is high amongst transgender individuals, with 44% of those sampled worried about the impact in their care if their identity was revealed. Further, Farmer and Yancu (2015) found that roughly 6% of physicians reported being uncomfortable treating LGBT patients. While this population may be relatively small, it does not detract from the potential harm when providers are uncomfortable with their patients. One article titled “‘She’s Dying and I Can’t Say We’re Married?’: End-of-Life Care for LGBT Older Adults” interviewed a woman named Esther at her residential community. Esther, a lesbian and residential community member, recalled, after the death of her wife Cathy, a negative change in how she and her wife were treated after nurses learned of their relationship (Candrian & Cloyes, 2021). The couple reported feeling anxious about how this might impact Cathy’s medical care and decided to disclose their relationship status no longer. Eventually, Cathy died, and her wife Esther was viewed as a mere friend rather than a grieving widow (Candrian & Cloyes, 2021). In this instance, both women were made to feel less than and unimportant during their final days together. Additional research has also found that 8% of LGBT elders reported being either neglected or abused by caretakers due to their identity (Movement Advancement Project and

SAGE, 2010). Experiences like this or like Esther and Cathy's, perpetuate discriminatory practices that leave LGBT members abandoned as they die.

Similarly, many who are Queer report feeling uncomfortable within healthcare systems due to past discrimination they have experienced. While American culture has become more tolerant of LGBT identities in recent years, older generations of Queer individuals were not met with the same acceptance. This history of discrimination has created a learned response within individuals, and because of this, many innately do not feel safe within healthcare settings. In “‘Things Are Different Now But’: Older LGBT Adults’ Experiences and Unmet Needs in Health Care,” it is revealed how past trauma impacts older Queer individuals and how they interact with healthcare settings. Vicarious trauma was found to be a significant component in those worried about the possibility of discrimination. In this instance, vicarious trauma is defined as ‘trauma endured through being exposed to someone else's traumatic experiences.’ Older LGBT adults reported a heightened feeling of stress and fear within healthcare settings after hearing about others' discriminatory experiences (Burton et al., 2019). Individuals were also concerned about how they would be treated due to being doubly disadvantaged by being both Queer and of an older age group (Burton et al., 2019). Due to belonging to a variety of marginalized identities, older Queer people lack important social capital within healthcare systems, causing individuals to feel threatened (Burton et al., 2019). This concern is especially heightened amongst people of color who also identify as being LGBT and being a senior. This study highlights the need for healthcare providers to be aware of the intersectionality of marginalized identities and how patients will experience the healthcare system because of these identities.

It is similarly important to note that more passive forms of discrimination also impact how older LGBT individuals interact with the healthcare system. As mentioned, one disparity

between Queer individuals and cis-heterosexual individuals within medical care is a lack of provider knowledge (Farmer and Yancu, 2015). Many healthcare professionals lack the knowledge of how to treat LGBT individuals with a trauma-informed method or lack general knowledge about LGBT populations altogether. Lacking knowledge on how to treat LGBT patients can come in many forms; some examples include not understanding hormone therapy, not discussing preferred pronouns, not understanding why an individual may be anxious during an appointment, and far more.

Without equal access to healthcare services, Queer individuals are disproportionately affected by the negative health and financial outcomes of not having health insurance. It leaves an individual with unmet medical needs and, moreover, a lack of knowledge on navigating healthcare systems. Trying to learn how to navigate these complex systems when at an already extremely vulnerable and difficult point in life can make these situations far more arduous. When struggling to navigate systems for the first time, Queer individuals are revoked of the ability to comfortably receive care. In addition, not knowing how to navigate these systems can also cause individuals to feel further excluded, creating a sense of discomfort.

While there is a lack of literature addressing end-of-life medical care for Queer individuals, the scholarship which does exist indicates systemic barriers and discrimination for those trying to access care. LGBT community members are likely to have difficulty accessing the same insurance benefits as their heterosexual counterparts, leaving them lacking in healthcare and not knowing how to navigate healthcare systems. Even if Queer individuals have access to medical care, they may still experience or fear discrimination, leading them to avoid seeking care altogether. These issues perpetuate a cycle of discrimination and harm for the LGBT community

within the healthcare system, and they must be addressed in order to achieve equitable access to care.

End-of-life planning

End-of-life planning is a crucial component of many end-of-life experiences and is the process of making decisions regarding oneself and their wishes before passing away. Up until the overturning of *Obergefell v. Hodges* in 2015, which legalized gay marriage in every state across the United States, generations of Queer couples had previously been unprotected within their end-of-life decisions. While the legalization of gay marriage had tremendous impacts on the rights of Queer individuals planning their lives, there are still many barriers that stand in the way for many. The barriers that interfere with end-of-life planning for LGBT individuals tend to be life-span-oriented and systemic based.

As discussed previously, many LGBT community members tend to either avoid healthcare systems or do not have the means to access these systems. Because of this, as one is aging or dying, navigating these systems becomes even more difficult due to not learning how to previously. This concept applies to the legal component of end-of-life planning as well (Stinchcombe et al., 2017). One study, in particular, found that “when [LGBT] participants were presented with a fictitious scenario, only 27% of the sample was able to correctly identify who had the legal right to make treatment decisions for an unconscious person following a car crash” (Stinchcombe et al., 2017). This data represents a need for education and resources to help Queer individuals trying to plan for the end of their life.

Other barriers to end-of-life planning are largely systemic based. Even with the legalization of gay marriage, there are still many obstacles, especially for chosen families. Chosen families, sometimes referred to as lavender families, are non-biological, highly

committed friendships. While an individual may have both a biological and a chosen family, it is not uncommon for Queer individuals to rely solely on their chosen family. This makes end-of-life planning difficult as “the default rules governing substituted decision-making, guardianship, and inheritance still privilege the interests of relatives defined by blood” (Marsack & Stephenson, 2018). Favor for the biological family is especially concerning when looking at data on who commonly cares for Queer elders. Research suggests only 11% of LGBT elders are cared for by relatives, with the rest being cared for by their chosen families and adult children (Marsack & Stephenson, 2018). Without equal decision-making rights for lavender families, this can leave partners and chosen family members as nothing more than “legal strangers” (Marsack & Stephenson, 2018), giving biological relatives, who may not have been in an individual's life for years, the final say over what happens to them.

Many LGBT elders also encounter economic obstacles that prevent them from properly being able to plan for the end of their lives. Studies report that same-sex households “lag behind different-sex married households on all major economic indicators” (Linott et al., 2022). Economic inequalities also exist within the LGBT community itself, with certain groups of the Queer community, such as transgender individuals, making far less than cisgender gay individuals (Linott et al., 2022). The issue of finances may also grow over time as research indicates that LGBT elders “are not equally eligible for Social Security benefits” (Movement Advancement Project and SAGE, 2010) despite contributing to Social Security the same amount as their heterosexual counterparts. These financial hardships can accumulate over time, making it more difficult to save and properly plan for the end of one's life.

Grief

You may remember from earlier, Esther and Cathy, two women who suffered at the end of Cathy's life due to discrimination they had experienced while trying to seek health care. Cathy and Esther had been a couple for over 30 years (Candrian & Cloyes, 2021), a long and meaningful relationship that deserved to be treated as such. Sadly, though, Cathy passed with Esther only being known as her close friend. This was due to them hiding their identities after noticing the negative treatment they had begun to receive from professionals at a hospital; negative treatment they felt was because of their relationship. In this story, we can see how identity concealment and disenfranchised grief can then complicate grief and make the bereavement process even more strenuous.

Identity concealment pertains to 'the use of strategies such as lying and social isolation to avoid identity detection' (Camacho et al., 2020, p. 29). Identity concealment is common among Queer individuals, especially among those who are older. Older LGBT+ community members grew up in a social context that was not accepting of Queer identities, and because of this, were often forced to conceal their identities, something which became the norm to many. This concealment of identity persists throughout the lifespan of many, and "adults aged 56 and older are the least likely of any age group to self-identify as lesbian, gay, bisexual, or transgender" (Jones, 2021). While this is a protective measure for many, it does not allow individuals to feel they belong or are understood. When one feels forced to conceal their identity throughout the dying process, not only will they feel trauma, but so may their partners and/or loved ones as well. The use of identity concealment does not exist on its own, though, especially not through the dying process. The use of identity concealment can potentially set individuals up to experience disenfranchised grief later, potentially exacerbating feelings of isolation and disconnection.

Disenfranchised grief is a broad and difficult concept to define, but for the purpose of this thesis, I will define it as, ‘grief that is not socially accepted and can not be openly mourned’.

Disenfranchised grief forms from a variety of components, but its formation and impacts have rarely been studied with regard to the LGBT community. One of the few times disenfranchised grief has been assessed in this capacity was after the AIDS epidemic when the grief of gay men was researched.

One of the most prominent examples of homophobia within death care continues to be the AIDS epidemic. During the early 1980s, concern about AIDS spread throughout America and was quickly attributed to being a gay issue despite its ability to impact anyone. Soon after, AIDS would be dubbed “gay cancer” and “Gay-Related Immunodeficiency Disease” (“Timeline of the HIV and AIDS epidemic”), and those impacted by AIDS would be severely impacted by not only the virus itself but also the ramifications of homophobia as well. Since AIDS was seen as a gay issue, and neither the government nor American culture was accepting of homosexuality at the time, the grief experienced by those impacted by AIDS was not largely recognized. Not only did individuals face shame in their mourning, but they were further stigmatized for their identity as well, all of which led to a disenfranchisement of grief. While the AIDS epidemic may be the most widely known example of disenfranchised grief, it did not stop nor begin with AIDS.

Disenfranchised grief was first described by Dr. Kenneth J. Doka in 1989, who identified three primary forms of disenfranchised grief. These three forms included a lack of recognition of the relationship, of the loss itself, and of the griever (Doka, 1989). Lack of recognition of the relationship includes when the relationship and its importance are minimized. In the case of Esther and Cathy, we can see how their relationship was overlooked. They were made to feel as though they had to present strictly as friends, and they are not the first Queer couple to have this

experience either. Furthermore, Dr. Doka has described a second form of disenfranchised grief where the loss itself is not recognized, and the significance of the relationship or the person who has passed is downplayed. This can lead to a lack of validation for those who are grieving and isolate them in their grief. It is crucial to acknowledge the importance of the loss and offer support to those who are grieving to help them cope with their emotions. The final form of disenfranchised grief described by Dr. Doka is when there is a lack of recognition for the griever themselves. Discrimination Queer individuals face at the end of their lives does not only impact them. Rather, their loss and how others receive their loss also impact those who are grieving them. If the loss is not seen as important, or a miscellaneous external factor becomes the main focus, the griever's trauma potentially goes completely unrecognized and effectively disenfranchises their grief.

All grief is difficult, and there is no ideal path or duration for people to grieve. While grieving is a natural response to loss, complicated grief goes beyond the typical grieving process in its intensity, duration, and impact on daily functioning. Complicated grief is defined as grief that "is unusually severe and prolonged, and it impairs function in important domains" (Shear et al., 2013). Recognizing complicated grief is incredibly important due to how it can impact the lives of griever. Those experiencing complicated grief are likely to experience "negative mental, physical, and social health outcomes, including chronic depression, sleep disturbances, substance misuse, anxiety sensitivity, physical illness, and long-term difficulty with daily living, relationships or work activities" (APA, American Psychiatric Association, 2013; Lannen et al., 2008; Parisi et al., 2019; Robinaugh et al., 2014; Shear, 2012). Because of the vast amount of issues complicated grief can cause, those suffering are at great risk of additionally experiencing

suicidality and other mental disorders, such as major depressive disorder (Latham & Prigerson, 2004). The risks associated with complicated grief can not be ignored.

In recognizing complicated grief, it is crucial to understand the ways it mentally, physically, and socially impacts individuals in order to support them fully. Without receiving the necessary support and care they deserve, those grieving may be forced to handle the struggle of complicated grief alone. When individuals are made to face such a hardship alone, or when they go through the process of dealing with either/both disenfranchised grief and complicated grief, they become victims of discrimination. The discrimination Queer individuals face in the dying process does not impact them alone, and those who loved them can also be susceptible to the same adversity, compounding their grief and increasing their vulnerability to adverse mental health outcomes.

When discussing grief, it is also important to address grief counseling and other resources for grief support. I have identified three major points of the dying process: accessing medical/palliative care, planning for the end of life, and finally, the grief that is left behind after someone is gone. From previous discussions, we understand that when grief is not addressed properly, it can lead to further harm, but what does good grief support look like?

For many struggling with bereavement, turning to support groups can often be both supportive and therapeutic. Queer individuals deserve culturally competent care, though, and this is often lacking within group therapies. LGBT-specific support groups are not the norm, and even when they are accessible, they are not typically for a singular identity. While Queer people are more likely to understand the grief of other Queer individuals, this still might not be enough. One study specifically looked at how older lesbian women may form bonds and experience grief differently than their male gay counterparts (Valenti et al., 2021). This study analyzed a sample

of lesbian women over the age of 65 who had experienced the loss of a significant other in order better to understand the needs of lesbians throughout the bereavement process. One of the largest themes found throughout interviews was participants feeling as if they spoke a different language from both non-LGBT individuals and male gay individuals (Valenti et al., 2021).

The lesbian experience is its own distinct experience, and so is being a gay man. Without others in the room who had lived similar experiences, many women reported feeling isolated during their time in counseling (Valenti et al., 2021). Furthermore, participants interviewed also discussed feeling more supported when able to talk with a group of other lesbian women. Feelings of other women just knowing how it felt and feelings of camaraderie were two significant points in why participants felt more comfortable (Valenti et al., 2021). This study highlights the unique experiences of LGBT identities and why specific bereavement support is important. By creating support groups that center identities and culturally competent care, individuals will be better able to cope with the loss of their loved ones.

While creating support groups for individual identities may not always be accessible, their positive impact cannot be diminished. Identity-specific support groups also vocalize a more comprehensive need amongst the LGBT community: understanding. The need for understanding and compassionate care lies at the heart of what is truly needed for those who are bereaved. Losing a loved one, especially a life partner, is an incredible and often traumatic hardship; this is especially true for LGBT community members facing additional discrimination and alienation. Creating supportive communal environments that acknowledge these struggles and work to reduce discomfort plays an important role in the healing process.

Discussion

The purpose of this review was to examine how representation is lacking for the LGBT community in deathcare systems and how this creates a lack of safety for dying LGBT individuals. By analyzing medical care, end-of-life planning, and bereavement support research for Queer folks, I conducted a comprehensive examination of the ways in which the absence of representation impacts LGBT individuals as they navigate the dying process. By compiling this research, I demonstrated how these problems can accumulate, which is often overlooked when examined individually. Through this analysis of scholarship, I found a wealth of research indicating the lack of representation for LGBT people in death care systems, and where there was no research, a lack of representation could also be inferred.

My review focused on several key areas, including medical care. The lack of LGBT representation in medical care was found to be a pervasive theme throughout all the literature. This lack of representation was primarily a systemic issue that caused problems across the lifespan. LGBT people are more likely to lack necessary medical insurance due to economic and a variety of discriminatory barriers. This creates situations where LGBT individuals are effectively excluded from the same medical care as their cisgender heterosexual counterparts throughout their lifespans. Without obtaining medical care throughout life, health issues may be ignored and worsen with time. The implications of this neglect are especially stark when considering end-of-life medical care. The outcome of this neglect can lead to a worse deterioration of health and well-being for older Queer people, compounding and potentially making death a painful experience that could have been avoided.

Another issue presented within the literature is that members of the LGBT community are more likely to avoid seeking medical attention due to fear of discrimination. While it was found that only a small number of physicians reported discomfort in treating Queer patients, this

does not detract from the anxiety that surrounds having to engage in these environments. This is especially true when the effects of vicarious trauma are recognized. Though many physicians are comfortable with treating LGBT patients, there may still be anxiety surrounding this care if individuals have heard of other Queer folks being mistreated due to their identity. Not only can hearing of experiences of discrimination create anxiety when trying to seek treatment, but these experiences also set a precedence for how Queer individuals expect to be treated within healthcare systems.

Understanding and being comfortable with treating the LGBT community is important, but not enough on its own. Research has shown that many medical providers lack the knowledge of how to effectively and compassionately treat their LGBT patients. This lack of understanding can contribute to the exclusion of Queer individuals from receiving adequate medical care, especially for those who fear discrimination. Even though most uninformed healthcare providers do not consciously discriminate, their unintentionally harmful practices can inadvertently retraumatize LGBT patients by dismissing or invalidating their experiences. For this reason, it is crucial for healthcare providers to receive education and training, and also *seek* out education and training, on how to provide inclusive and affirming care to LGBT patients.

The second area this thesis focused on was end-of-life planning. While literature researching how the LGBT community interacts with this system is lacking, the scholarship that does exist demonstrates an increased hardship in the ability to plan compared to heterosexuals. These difficulties are similar to those associated with medical care in that they also stem from systemic disparities, creating issues that span the lifetime. This can be demonstrated in that Queer individuals, on average, make less money per year than their heterosexual counterparts. Many of the LGBT community are solely focused on trying to survive financially and often

cannot save for end-of-life costs such as funeral planning. These economic inequalities make it difficult to plan for end-of-life and, in turn, cause significant stress and anxiety for Queer elders over the lifespan of both individual and system issues.

These economic barriers are capable of creating issues for those going through the legal process of planning for death as well. This can be seen in the ways in which rights for chosen families are severely lacking. While many Queer individuals rely on their chosen family for support, especially into older age, decision-making rights regarding an individual are commonly granted to their biological family. Without support from their chosen family, their true wishes regarding dying may not be carried out. Yet, this issue can be negated if an individual can access legal services. As demonstrated, without being able to afford legal access, their desires may not be protected, and care will be handed over to the biological family if they can find an LGBT-friendly attorney. The systemic issues aggregate against LGBT communities.

Grief support is the final subject of this thesis, and the disparities that exist between Queer people and heterosexual people were shown to persist after death as well. Three specific issues— identity concealment, disenfranchised grief, and complicated grief were identified as significant challenges that can further exacerbate the bereavement process for the loved ones of Queer individuals. It was not only found that these issues can complicate mourning but that these issues can accumulate and evolve into another.

Identity concealment is a critical factor in the grief experience of the LGBT community, as it is an issue that can begin long before death. Often, the concealing of one's identity is a lifespan issue, one which older generations of the LGBT community are especially prone to. Many have not been afforded the privilege of authenticity throughout their life course due to societal pressures, stigma, and violence. Those forced to conceal their identity will likely

continue this even up until death out of fear, specifically out of fear of how their treatment will be altered if their identity is revealed. Those forced to conceal their identity are robbed of being able to experience a dignified death. Additionally, they are not able to fully celebrate their life because a fundamental aspect of who they are is being kept secret. This is especially true for those who have concealed their relationships, as the importance of these relationships is dismissed through concealment.

The painful effects of identity concealment can continue even after death, and surviving loved ones may be forced to reckon with this issue as well. If compelled to hide the identity of the deceased, the ability to authentically celebrate and mourn this individual is diminished. The acknowledgment of a person for who they were in their entirety is necessary for healthy grieving. When this is not possible, the bereaved are left with feelings of isolation and a lack of closure. Moreover, when someone conceals their identity, it can have a direct impact on the bereaved, potentially leading them also to hide their own identity. In this instance, both individuals are deprived of the ability to be themselves authentically.

Members of the LGBT community are also susceptible to experiencing disenfranchised grief, especially if identity concealment is utilized as a survival tactic. When the grief of an individual is not properly recognized or supported by others, the grieving process is made even more difficult and becomes disenfranchised grief. The experience of disenfranchised grief is a great hardship for the bereaved since it is such a challenging and isolating experience. Over time, this lack of recognition and support can evolve into complicated grief. Complicated grief, characterized by persistent and intense feelings of sadness and despair, has been found to have profoundly negative effects on one's mental health. This is particularly concerning when considering the prevalence of mental health issues within the LGBT community (Yarns et al.,

2016). Preexisting mental health issues may be exacerbated through the experience of complicated grief, leaving individuals with unimaginable pain. This pain can be especially isolating when looking at the limited access to supportive networks and services.

A lack of LGBT-specific grief support groups was also identified as an issue. This lack of culturally competent support groups exemplifies the lack of representation that exists for the LGBT community in death care systems. Since heteronormativity is centered within American culture, the experiences of those outside of this structure are discarded and rarely catered to. Due to this discarding of identities, the LGBT community and individual identities within the community are not recognized as needing different care than their heterosexual counterparts, and in turn, are either subjected to support groups where they face potential exclusion and discrimination by both members of the group and the leader or avoid these support groups entirely. The LGBT community is deserving of more culturally competent support groups, and this should not end with groups aimed at the Queer community as a whole. As previously discussed, different identities within the community have different experiences. Being Queer is not a monolithic experience, and because of these different experiences within the community, different support should be offered.

Implications for future research

One of the largest issues that was prevalent throughout all research was the lack of representation of Queer identities within studies. There is an overall lack of acknowledgment of the LGBT community within research concerning death care, but research concerning specific identities is especially lacking. As stated previously, being Queer is not a singular experience, and the specific identity of an individual can affect the care they receive. Future research concerning the LGBT community and deathcare systems should consider individual identities

when seeking to understand how treatment is impacted. Future research should also consider the ways that other confounding traits of an individual may impact care as well. For instance, ageism is rampant throughout American culture and is considered by the APA to be “one of the last socially acceptable prejudices” (Weir, 2023). Ageism, being not just a highly prevalent issue but one that is widely accepted, indicates that older people are likely to face poor treatment at the hands of others. Because of this, the age of subjects must also be considered when attempting to understand identity and its impact on care. Similarly, age is not the only factor influencing treatment, as race and socioeconomic factors are also huge contributors. Those who belong to various marginalized identities lack important social capital, and it is important to understand how this influences their treatment.

Understanding how being marginalized in various aspects is important in research and trying to create better systems of care. Culturally competent care stems from “the ability to collaborate effectively with individuals from different cultures” (Nair, 2019), and compassionate care stems from cultural competence. This idea is especially important when examining medical care. When providers are culturally competent, they can treat individuals with far more compassion, and thus, “competence improves health care experiences and outcomes” (Nair, 2019). Efforts must be made to increase this competency amongst professionals to decrease the existing disparities in care between the LGBT community and their heterosexual counterparts.

Furthermore, it is equally important these efforts are not put off until tragedy occurs: crucial research regarding deathcare and the Queer experience was not conducted until after the AIDS epidemic. Not only should it *not* take atrocities to recognize the importance of a community, it is important to have this research prior to avoid potential harm or to know how to

take action when harm does occur effectively. Without this knowledge, communities are isolated and left to fend for themselves when handling tragedy, which further harms in a cycle of trauma.

Regarding the trauma that has occurred from the AIDS epidemic, it is also important that future research assesses how this experience has impacted the LGBT community. The AIDS epidemic taught the LGBT community that the government, many healthcare institutions, and many of the general public did not care for their wellbeing. This created a lack of trust within the community that may have generational implications, with even those who were born after the AIDS epidemic having a distrust surrounding these systems. The generational impact of the AIDS epidemic may be another source of fear and anxiety for Queer folks attempting to interact with deathcare systems. To better understand the effects of this trauma, future research must take the AIDS epidemic into consideration when conducting studies.

The harm inflicted upon the LGBT community within deathcare is trauma that stems from systemic issues, which in turn have stemmed from social issues. Future research must acknowledge both the systemic and social roots of the challenges that face Queer people in order to create systems that can compassionately treat this community. Research should also be proactive to prevent future harm and better support this population. While all of these points should be considered when considering future studies, because of the overall lack of representation currently, merely beginning to include the LGBT community within this work will be monumental.

Conclusion

Throughout this work, I have continually argued that the LGBT community lacks important representation in deathcare systems. This lack of representation poses significant risks and, as a result, compromises the safety and well-being of Queer individuals. Additionally, in

being disregarded by research, we lack a comprehensive understanding of how this population interacts with deathcare systems and how these systems impact them. Since we do not understand the needs of the LGBT community, we, therefore, lack knowledge of how to treat these individuals properly. This further perpetuates harm, and the community is repeatedly put at risk. This is seen in the ways that barriers to achieving adequate medical care, end-of-life planning, and grief support all cause deep amounts of pain. With these barriers in place, the LGBT community is isolated from general communities as well, which further exacerbates the harm of these issues.

While no community's safety should be disregarded, this dismissal is especially relevant when examining an aging and growing population. By 2030, it is estimated that there will be more than 3 million LGBT individuals in America who are over the age of 65 (Movement Advancement Project and SAGE, 2010). The care for this community can not be ignored. As this community ages and grows, the demand for inclusive and respectful deathcare services will only continue to become more and more necessary. This need can not be ignored without ignoring fundamental aspects of equality and social justice.

In conclusion, in this present moment, Queer lives are put at risk through the representation they lack within deathcare systems. Addressing this gap requires *intentional* inclusion of Queer identities in research, culturally competent education that trains providers to serve the community in more respectful ways, and policies that ensure equitable treatment for LGBT populations. By doing so, we can move towards a model of end-of-life care that is more inclusive as well as more compassionate.

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