Knowledge and Practices of Palliative Care Providers: An Interpretive Description of Sexual and Gender Diverse Patient Care and Their Influences

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Abstract

It is well documented that sexual and gender diverse (SGD) populations face discrimination in healthcare settings. Inquiry into this issue is important in all areas of healthcare, however palliative care is an excellent place to start this inquiry, as its underlying relational, person-centered, and holistic approaches theoretically offer a framework to support care delivery for SGD populations. This study explored care for SGD patients and families as described by multidisciplinary palliative care providers in community palliative care settings. Queer theory offered a lens for this study, supported by theorizations of relational inquiry and cultural safety. Interpretive description methodology with thematic analysis was applied to focus group data to generate three culminating themes: The effects of experience on care; "I'm scared I'm going to say the wrong thing"; and individually tailored approaches. The discussion speaks to the power of norms and how they affect ideas around provider discomfort and SGD disclosure. The discussion culminates with wondering how palliative care could be improved if some norms and structures of power are queered and reconceptualized. Recommendations from this research include increased and ongoing training that incorporates practice principles of cultural safety and relational inquiry, specifically understandings of power, safety, disclosure and provider discomfort. Additionally, policy makers and organizations are encouraged to engage with community SGD organizations, broaden their definitions of safety, and review if SOGI data collection can be done safely and effectively for SGD people.

Keywords: LGBT, LGBTQ+, 2SLGBTQIA+, Lesbian, Gay, Bisexual, Transgender, Sexual and Gender Diversity, Sexual and Gender Minority, Queer, Palliative Care,

Multidisciplinary Team, Nursing, Interpretive Description, Hospice, Relational Inquiry, Relational Practice, Cultural Safety, Queer Theory

Preface

It seemed like an ordinary evening at the National Art's Center (NAC) like any other that I'd been to before, except it was not quite the same. It is blatantly apparent that the audience was different. The conductor asked the audience a question: "how many of you are here because you love drag or Thorgy Thor?" People stand up and yell and cheer and clap. "And how many are here because they had season passes?" Some nervous laughter, and some clapping ensued. Looking around I could see those flamboyantly dressed, some dressed in leather, some in amazing sparkly costumes, and others in dress clothing as if attending a typical night out the NAC for a performance. The conductor continued "we may all look different and be here for different reasons, but we are all here to have a great time. I want to bring all the people in this room together to enjoy a night of music and drag." And we did.

The ensuing show seamlessly combined music, storytelling, queer history, and activism with dancing and sing-alongs and the traditional orchestra. The music was a mix of new and old, classical pieces by composers like Mozart, Bach, and Hayden with more contemporary Beyonce, Madona, and Lady Gaga (including a Bach style fugue using a Lady Gaga theme). Some history was shared with some of the pieces, such as an alternate version of a song that changed the lyrics from being about a heterosexual couple to those of a lesbian couple leading to the unlawful arrest of the signers at a karaoke night, or that of the first black composer to have a symphony played by a national orchestra. Other pieces shared evoked emotion and understanding, such as the sing-along to Girls Just Want to Have Fun and All is Full of Love by Bjork. Attention was brought to international persecution of LGBTQ+ people and work by charities helping this issue

were highlighted. It was a masterclass in combining traditional performance and methods with drag and queer culture which promoted an educational and a critical look at queer history while also celebrating the progress and joy of queer people and culture.

I attended this performance at a pivotal point in my thesis, part way through analysis. It reminded me that my research does not have to be only one thing, and most importantly, does not have to contribute to the doom and gloom paradigm of research regarding queer people. It reminded me that I can incorporate a multiplicity of views, both traditional and contemporary, to understand my research findings and guide my analysis. Most of all, it allowed me to imagine a future where palliative care, and all of healthcare, could acknowledge and reflect on their past while striving for a brighter, more cheerfully queer, more equitable future that queer and non-queer people could benefit from.

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Chapter 1. Introduction and Background

Introduction

The moment I realized that palliative care would not be safe for my queer friends was devastating to me. It was after I had talked to a patient's family member, and asked which pronouns they used, to which she replied, "no one has asked me that yet, thank you." This family member had visited every day for the last week, yet had never been asked? Worse, she had been misgendered the whole time. Thinking that this could happen at a place I truly believed gave amazing care not just to patients but to their family, was very difficult. This moment, and many other small ones that I began to notice after this event, began to add up. I didn't understand how my colleagues, who genuinely cared so deeply, did not appear to understand the importance of affirming gender identity and sexuality. Being a palliative care nurse and being queer, I realized I was in a good location to begin to answer the questions I had regarding how care providers in palliative care approached care for sexual and gender diverse people.

In this thesis I explore the knowledge and practices of interdisciplinary palliative care providers to better understand what influences their care of sexual and gender diverse patients and families. Palliative care is a great place to begin to examine how to improve care for sexual and gender diverse patients because its underlying relational, person-centered, and holistic approaches theoretically offer a framework to support care delivery for SGD populations.

The first chapter situates this study.by offering background to the study including a brief overview and introducing the including sexual and gender diverse populations and palliative care. The second chapter is a review of the literature, focusing on the

experiences of sexual and gender diverse people in palliative care. It ends with the research problem and questions that guided this thesis: what knowledge providers have and where they have developed this knowledge; what practices are used in caring for SGD populations and what guides providers in their practices; and how can providers improve care for SGD populations. The third chapter starts with locating me as a researcher and what theoretical foundations this thesis was built on, specifically Queer Theory, Relational Inquiry, and Cultural Safety. It continues with the details of the methodology used. Chapter four presents the findings from this thesis culminating in the three main themes of: the effects of experience on care, the fears of saying the wrong thing, and patient centered palliative care approaches. The final chapter is the discussion, which looks at how normalizing structures govern palliative care for sexual and gender diverse patients, as well as presents opportunities for queering aspects of palliative care.

Background

Around the world, homosexuality is criminalized in at least 67 countries, and at least 9 countries have laws criminalizing forms of gender expression (Human Rights Watch, n.d.; United Nations, 2015). In recent years sexual and gender diverse (SGD) populations[1] have been increasingly targeted and discriminated against. For example, in the United States, 533 anti-LGBTQ bills were created in 2024 (at various levels of government), and 597 bills have been put forward so far in 2025, showing an upward trend (American Civil Liberties Union, n.d.). These bills target all facets of life for sexual and gender diverse people, most prominently education and healthcare. Another example is the increase in anti-LGBTQ protests outside schools and hate motivated Pride flag

[1] Terminology to be discussed in background section entitled sexual an gender diverse populations

vandalism across Canada (Talati, 2023). In Canada, hate crimes targeting people for their sexual orientation have been increasing in recent years, they increased by 46% between 2020 and 2021 (438 total in 2021), and by 69% between 2022 and 2023 (860 total in 2023) (Government of Canada & Statistics Canada, 2024). Hate crimes committed against transgender and gender non-conforming people were not tracked, instead being lumped into the "other" category. These were only the reported hate crimes thus the true number is likely much higher.

Attacks on SGD people's rights and freedoms, safety and security, are happening despite both sexual orientation and gender expression being illegal grounds for discrimination, according to the Human Rights Act of Canada (Minister of Justice of Canada, 2021), and despite increasing rights such as same-sex marriage being legalized in 2005 (Minister of Justice of Canada, 2015). This increasing violence shows that although these protections have been legally guaranteed, it does not mean that SGD people are fully accepted in Canadian society.

Healthcare environments and associated care provision reflect societal norms and values. It is well documented that Canadian sexual and gender diverse people still experience discrimination and violence at significantly higher rates than their heteronormative and cisgendered counterparts (Statistics Canada, 2020) in the healthcare system (RNAO, 2021). Discriminatory practices and negative healthcare provider attitudes can lead to a reluctance of SGD patients to access healthcare services, causes poorer health outcomes, and leads to unsafe care practices (RNAO, 2021; The House of Commons Standing Committee on Health, 2019). These issues must be addressed across all care settings, as SGD patients have a right to safe care everywhere. However, this

examination needs to start somewhere; palliative care is a good place to start because the underlying principles discussed below support good quality SGD care.

Sexual and Gender Diverse Populations

Though I used the term queer above, and identify as such, the definition of queer is complicated. Originally, queer was a derogatory term used to refer to those labelled as gays and lesbians. It has since been reclaimed by activists and has been embraced in an academic sense to mean those that do not fit in the assumed heterosexual or gender normative roles. Some still may still find the term queer offensive to be referred to as, due to its history as a derogatory term. As such, I do not use it to refer to the population using the word queer in this thesis. Some argue that queer is ever changing and evolving and is not a stagnant definition (Moore, 2019; Sedgwick, 1994). Some push against the use of queer as an umbrella term for sexual and gender minorities, as it can cause an unwanted lumping of the categories together, removing their uniqueness. Originally in the proposal for this thesis, the term sexual and gender minority was used, in line with some other recent research (Cloyes & Candrian, 2021; Haviland et al., 2021; Maingi et al., 2018; Reich et al., 2022). However, I have chosen to pivot to the term sexual and gender diverse people/population/patients. My rationale for the choice to move away from sexual and gender minority is political. From my perspective, being referred to as a minority by those (e.g. researchers, healthcare workers) who have oppressed this population in the past and continue to dominate us is not empowering.

Sexually diverse people refers to those whose sexual orientation is not heterosexual and may include lesbian, gay, bisexual, asexual or other orientations (Statistics Canada, 2020). Gender diverse people refers to those whose personal and

social identity is different than that assigned at birth and may include transgendered persons, non-binary persons, gender fluid persons, genderqueer and other gendered persons (Statistics Canada, 2021). Sexually and gender diverse (SGD) people are constituted as a minority population based on numbers (approximately 1-2% of the Canadian population) but are also minoritized through dominant social relations of power and discursive practices. Issues regarding the invisibility of SGD patients are discussed in the literature review.

For the purposes of this thesis gender and sexuality are seen as socially constructed, and thus are not necessarily stable entities (Moore, 2019). We can see this continuing evolution in the literature, where SGD patients are described in many ways, including LGBTQ+, 2SLGBTQIA+, LGB, LGBQ, transgender and gender non-conforming, and others. For the purposes of this study, SGD is used. However, when referencing particular materials, the language from the source was used. Together, SGD people are those that differ in sexuality and gender than the majority heterosexual and cisgendered people. There may be an overlap of a person as both a sexual and gender diverse person (Registered Nurses Association of Ontario [RNAO], 2021; Schwab et al., 2022; Wilson et al., 2021).

Palliative Care

The World Health Organization (WHO) (2020) defines palliative care as an approach that improves the quality of life for patients and their families who are facing a life-limiting illness. Palliative care relieves suffering through person and family-centered, team-based, and holistic care, which are further explored below (Canadian Hospice Palliative Care Association, n.d.; World Health Organization, 2020). End-of-life care is

often a part of palliative care, however, is usually contained to the last weeks and days of a person's life (Canadian Hospice Palliative Care Association & Quality End-of-Life Care Coalition of Canada, 2015; Government of Canada, 2016). In Canada, the palliative approach to care can take place in any care setting, however end-of-life care typically takes place at home, in long term care homes, in hospitals, or in specialized hospice settings.

Person and Family Centered.

Person-and-family-centered care, according to the WHO (2007), is a healthcare design that places the person and family at the center of their healthcare, compared to a biomedical model, which emphasizes illness and disease. It emphasizes communication as it pertains to informed decision making for the patient and respect for those choices. Palliative care integrates person-and-family-centered care by viewing the family as the unit of care and by including family in decision making, care provision, and by ensuring that family members are supported through grief and bereavement (Canadian Hospice Palliative Care Association & Quality End-of-Life Care Coalition of Canada, 2015).

Within this claim of family centered care, however, the question arises: *who is considered family?* In Canada, legally who is family and who is not is defined by individual provinces, though most are similar. For example, in British Columbia, according to the Family Law Act (2011), a family member is considered a person's spouse or previous spouse, a person's child, a person who is living with or has lived with the person in a marriage-like situation (common law), a parent or guardian of the persons child, or a person that is living with and related to the person (in any of the previous

ways) (Family Law Act, 2011). By this definition, close friends or community members are not considered family.

Family is also defined legally in relation to substitute decision makers for an incapacitated patient. If no previous person is appointed by the patient or a court, it falls to the spouse or partner, then to a parent/guardian or child of the patient (if over the age of 16), then to the siblings and finally to any other relative of the incapacitated person (Health Care Consent Act, 2014). This definition means that if a patient has not assigned a substitute decision maker and becomes incapacitated, which is common in palliative care, a family member, even one that is estranged, has a legal claim on being their substitute decision maker over a close friend or community member.

This legal definition is less inclusive than palliative care conceptualizations of family. In their document *A Palliative Approach to Care in the Last 12 Months of Life,* the Registered Nurses Association of Ontario (2020) asserts that family are those closest to the patient in knowledge, care, and affection and is defined by the patient (RNAO, 2020). The document further states that this may include biological families, families of acquisition (by marriage for example), or families of choice (further discussed in the literature review section) which is more in line with the types of families sometimes seen in SGD patient lives. The legal definition does not account for this, and thus these two definitions are sometimes at odds in clinical practice.

Team-based.

Palliative care is delivered best when a multidisciplinary approach is taken according to the patients and families individual needs and helps ensure that care is holistic (Canadian Hospice Palliative Care Association & Quality End-of-Life Care

Coalition of Canada, 2015; World Health Organization, 2020). Common provider types in palliative care include nurses (nurse practitioners, registered nurses, registered/licensed practical nurses), personal support workers, physicians, social workers, family and social support, chaplains or other spiritual support workers, occupational therapists, physiotherapists, trainees, and volunteers.

In order to provide high quality palliative care, a trusting relationship must be created between providers and patients and their families so that care planning can incorporate care based on an individual's and families' goals and values (Canadian Hospice Palliative Care Association & Quality End-of-Life Care Coalition of Canada, 2015). Since palliative care providers have such an important role in palliative care, and the nature of the relationship between the provider, the patient and the family affect the quality of the care significantly, this thesis focused on the role of palliative care providers knowledge and practices for SGD patients and families.

Holistic.

The World Health Organization [WHO] (2020) states that palliative care prevents and relieves suffering beyond simply physical symptoms, of which they mention the domains of psychosocial, spiritual, as well as practical. The Canadian Hospice Palliative Care Association, the Association for Palliative Medicine of Great Britain and Ireland, and Palliative Care Australia all have similar definitions, mentioning some form of holistic care as an integral part of palliative care, including similar domains (Association for Palliative Medicine, 2023; Canadian Hospice Palliative Care Association, n.d.; Palliative Care Australia, n.d.). What these national palliative care associations fail to address in their holistic care definitions are the need for acceptance of both the patient

and their chosen family and the need for freedom of expression of both gender and sexuality.

In palliative care, the patient and family-centered approach combined with a focus on holistic care aligns with the needs of diverse situations of SGD people and their families. Patient and family-centered care situate the SGD patient and their needs as the focus of care. A holistic approach includes acknowledgement of all unique palliative care SGD needs. Palliative care is also unique in how it incorporates so many provider types and thus has the potential to improve care across professional silos.

Chapter 2. Review of Literature

Introduction

Review and synthesis of the literature was done to better understand the care that is provided to SGD patients as well as to understand the unique issues that SGD patients face in the palliative care context. Attention to interdisciplinary views by including research from interdisciplinary sources in the review was a consideration in this study, as palliative care is delivered by interdisciplinary teams. Thus, this literature review has included studies from multiple disciplines including social work, nursing, psychology, philosophy, public health, and medicine. This literature review was done in a very systematic manner, from a positivistic lens and does not fit well with my overall constructivist approach. It has been a learning experience, and if I were to do this literature review again, I would do it quite differently by including non-academic sources, first-hand accounts, as well as narratives, and grey literature. I would have emphasized the complexity and diversity of views and realities that these multiple sources would bring.

Synthesis of the literature resulted in identification of two key concepts: Discrimination and unique sexual and gender diverse culture. Discrimination encompassed five themes including assumptions, invisibility, environment, excluded groups, and lack of (care provider) education. Unique sexual and gender diverse culture included the two themes of intersectionality and families of choice.

Medline, PSYCHinfo, Embase, and CINAH were searched, see appendix A for PRISMA diagram. Searches of title and abstract were done using the following key words: LGBT or LGBTQ or GLBT or LGBTQIA+ or bisexual* or homosexual* or

"same sex" or two-spirit* or lesbian* or transsexual* or transgender* or “sexual and gender minorities” or “intersex persons” or “transgendered persons” or “gender identity” or “sexual orientation” or “gender non-conforming” combined with “palliative care” or “terminal care” or hospice or “palliative medicine” or “palliative therapy” or “palliative nursing”. Inclusion and exclusion criteria are shown in the chart below.

Inclusion Criteria	**Exclusion Criteria**
2SLGBTQIA+ population or any subset of this population	Studies focusing on a single diagnosis such as AIDS (okay if general condition such as cancer)
Palliative care, end of life, advanced care planning context	Published prior to 2013 (10 years)
Any type of discipline who provides healthcare directly	Single case studies, quality improvement projects, conference briefs
Any country	Not in palliative care context
English language	Languages other than English

Discrimination

In a US survey of over 800 multidisciplinary palliative care providers across multiple settings, Stein et al. (2020) showed that providers believed that LBGT patients were more likely than non-LGBT patients to experience discrimination (disrespectful, inadequate, or abusive care). They also found that many providers had witnessed discrimination of LGB patients (23.7%), and transgender patients (21.3%). This study validates a lack of safety for SGD patients in palliative care settings and a breakdown of trusting relationships between palliative care providers and SGD patients.

Assumptions

Cloyes and Candrian (2021) found many negative effects from individual and structural biases on SGD patient perceptions regarding non-acceptance and safety in palliative care settings. Assumptions regarding gender as binary, heteronormativity, and cisnormativity were cited as barriers to feeling accepted for SGD patients. Palliative care values person-centered care, thus patients should be asked and clarified based on individual preferences, and not assumptions. Braybrook et al. (2022) showed that there were better provider-patient relationships when providers used gender neutral terminology or mirrored the terminology that the patients used to describe their sexuality and gender identity. Using this mirrored language in addition to having positive body language during disclosures and sexuality and gender identity conversations improved communication and trust between patients and providers. Pecanac et al. (2021) found that LGBTQ+ patients valued providers that asked questions instead of making assumptions about sexuality and gender identity.

Invisibility

Heteronormative and cisgendered assumptions cause a type of invisibility for SGD patients, and make it more likely that needs of SGD populations will not be met (Harbin et al., 2012). One example of this invisibility is when providers state that they treat all their patients the same and deny that LGBTQ+ patients have unique needs because this diminishes and makes invisible the social realities that have a significant effect on marginalized communities health (Goldberg et al., 2018; Harbin et al., 2012). Wilson et al. (2018) cited a study participant who argued that by not asking about SGD status, institutions are projecting the image that these people do not exist in their

institutions, even though they most likely do, they are just closeted (meaning that their sexuality is hidden) (Wilson et al., 2018). Though many places provide specialized palliative care (institutions including hospitals, long term care homes (LTC), hospices, and community agencies), hospices being one of the most common, they do not routinely collect sexual orientation and gender identity data (SOGI) (Cloyes & Candrian 2021; Wilson et al., 2018) and thus SGD people are made invisible in these institutions and additionally in training, education, research, policy, and practices of healthcare systems because they are not being reflected in documentation (Braybrook et al., 2022; Cloyes & Candrian, 2021; Wilson et al., 2018). The Canadian Hospice Palliative Care Association of Canada (2015) states that palliative care should be holistic, encompassing the physical, psychosocial, emotional, and spiritual needs. Yet it fails to mention the needs for acceptance and freedom of expression of gender and sexuality as important parts of this wholistic care, which can be important to LGBT patients receiving palliative care (Wilson et al., 2018).

Environment

Discrimination is also seen in physical spaces for sexual and gender diverse people through the environment in which palliative care is provided. Braybrook et al. (2022) described that LGBT+ patients need to see themselves among staff and within organizational values, such as by having LGBT+ friendly images, badges in relevant colours, or some indication that relevant training had been completed. If SGD patients see that there is a person, or part of the organization that has these visual cues, they feel safer in disclosing their relevant care needs (Pecanac et al., 2021). Conversely, having visual signs with heteronormative assumptions or lacking SGD positivity can cause fear

of an unsafe and unwelcoming environment. Wilson et al. (2018) noted that many palliative care institutions are faith-based or have a faith-based history to them, which many Canadian LGBT patients feared their healthcare and end-of-life experiences being controlled by faith-based institutions. The relationship between faith-based institutions and SGD people, due to the history of and current persecution of LGBTQ+ persons and lack of acceptance in many of their communities, creates an unsafe environment for many SGD patients (Wilson et al., 2018).

Excluded Groups (Within SGD Populations)

Among SGD persons, there is evidence that transgendered and gender non-conforming (TGN) individuals are more likely to experience discrimination in palliative care settings than cisgendered patients (Pang et al., 2019; Stein et al., 2020). Additionally, TGN patients were more likely to live alone and be living with a disability than their cis-gendered counterparts (Witten, 2014). This increased vulnerability coupled with the fact that providers feel less comfortable treating TGN patients than LGB patients (Cloyes et al., 2023; Hughes & Cartwright, 2015) and the lack of TGN specific research (Maingi et al., 2018) means that less is known about the care needs of TGN patients, and their care is most likely less equitable than LGB patients. There is even less research concerning the unique palliative care needs for other subsets of SGD patients, which includes two-spirited, intersex, gender-fluid, asexual, aromantic, and those that identify as queer or define their sexuality or gender identity outside these recognized categories. This lack of research and information makes these patients and their needs less visible, and ways to address them less known.

Lack of (Care Provider) Education

A significant structural issue that affects the care of SGD patients is the lack of educational preparation for healthcare providers, both undergraduate and ongoing professional education, regarding the unique needs of SGD populations (Arthur, 2015; Sprik & Gentile, 2020). The effects of this lack of education manifests in lack of comfort treating SGD patients, lack of knowledge regarding SGD patients unique care needs, and attitudes that LGBTQ+ status is not an important consideration in palliative care provision (Arthur, 2015; Chidiac et al., 2021; Cloyes et al., 2023; Harbin et al., 2012). This lack of knowledge was shown by Chidiac et al. (2021) who did a pre-test post-test design with 145 health and social care workers at 4 hospices in the UK. The pre-test showed that 55% of participants rated themselves as "not knowledgeable" on LGBT+ issues and needs in palliative and end-of-life care.

Another negative effect from this lack of education was described by a transgendered patient in Pang et al. (2019):

> ... I said, I'm trans and I need a doctor or a GP [general practitioner], I'm post-op ... I just need a GP. And it took 42 doctors before I found one that would take me as a patient. And they were not, they were not, ah, they were very blunt and bold, you know, oh sorry we don't treat people like you, you know.

Lastly, Cloyes et al. (2023) found in their focus groups consisting of 48 health care team members in the US, that LGBTQ+ status was viewed as private and irrelevant to end-of-life care. The staff interviewed believed that the dying process was universal and thus they believed they treated everyone equally reflected their ethical duty to provide equal

care to all patients (Cloyes, 2023). Attitudes that deny the inherent differences of SGD patients, or any patients, may stem from a lack of education.

Discrimination against SGD patients has multiple effects on the population in palliative care. There is a mistrust of health care providers and institutions from SGD patients and families, and this leads to delay in accessing healthcare and in turn later diagnosis and referral to palliative care services (Higgins & Hynes, 2019; Lippe et al., 2021; Reich et al., 2022).

Unique Sexual and Gender Diverse Culture

It is important to understand that SGD patients, or LGBTQ+ are not a homogeneous group. They consist of distinct differences regarding sexuality and gender. Within each group there are many differences as well, like how a culture has many individual differences between people of the same culture. What brings LGBTQ+ groups together as a culture is a shared history of fighting for rights, shared experiences of discrimination and violence towards them, a knack for disrupting gender binaries and heteronormative notions in society, as well as shared moments of joy and celebration of uniqueness despite persecution and discrimination. Similar again to other cultures, LGBTQ+ culture is not stagnant and changes over time.

When talking about culture in this thesis, I draw from Cultural Safety and Relational Inquiry principles and an overall constructivist lens in understanding culture. Culture is not easily defined, but there are some points worth mentioning that guided my understanding of culture in this thesis. Firstly, culture could refer to those who share an ethnic background (though is not only shared by those with shared ethnic backgrounds), but also those who share a historical, political, linguistic, religious, economic,

geographic, or other similar backgrounds (Doane & Varcoe, 2021, pp. 233–236; Ramsden, 2002, pp. 87–88). For example, in this thesis, discussion of the culture of palliative care workers, those of healthcare workers, and those of SGD people and communities are conceptualized as having distinct cultures. Second, there are a lot of variances within a culture, people belong to multiple cultural groups that overlap and affect their overall experiences and there are many ways that culture can be expressed. Those belonging to similar cultures may express them completely differently or choose not to express them in ways altogether (Ramsden, 2002, pp. 108–113). Third, culture is relational, and power is embedded within cultural interactions and norms (Doane & Varcoe, 2021, pp. 233–270), with different cultural groups interacting (Ramsden, 2002, pp. 103–106). Lastly, from a constructivist view, culture is not stagnant but changes not just over time, but from person to person and from group to group (Ramsden, 2002, pp. 106–113).

Arthur (2015) and Barrett & Wholihan (2016) suggest that to serve people from this diverse culture, an understanding of its unique history, of stigma and its effects, and of the laws and policies surrounding these issues is what is needed to understand LGBT senior's views and preferences at end-of-life. Arthur (2015) also notes that there is significant historical context of certain generations of LGBT patients, such as seniors, that have lived through illegality, persecution, and trauma to the community from the AIDS epidemic which causes them to be less out and open than a younger generation who has experienced less persecution and even some celebration of LGBT identity. It is also important to note that not only seniors have lived through prosecution, illegality, and trauma for being SGD. For example, immigrants from other countries of all ages may

come from a place that still criminalizes or punishes SGD people and relationships, and they too interact with the palliative care system. Therefore, an understanding of the historical context of violence towards SGD people, of the culture of exclusion, and of the relationship each individual SGD patient has with this culture is important. This understanding is important because the relationship of individual SGD people with the historical context will be different for each person.

Intersectionality

An important thing to understand about being a sexual or gender diverse person is that it may intersect with other vulnerable statuses. For example, a person may be SGD but also might be unemployed, living in poverty, subject to ageism, be part of a non-dominant cultural or religious group, have varying levels of ability, or identify as a racialized person. Overlapping of discriminations produces vulnerabilities for patients, placing them at increased risk for further discrimination and poorer health outcomes (Arthur, 2015; Braybrook et al., 2022; Pang et al., 2019). Pang et al. (2019) found that the intersection of being institutionalized and being gender non-conforming led to a double vulnerability, especially if personal care was needed because it is an intimate care process where patients cannot hide if their gender is incongruent with their bodies (including the inability to hide scars from gender-confirming surgeries).

Families of Choice, Biological Relations, and Mixed Families

Sexual and gender diverse patients often experience rejections from their biological families, have less children than their straight and gender-normative counterparts, and are more likely to live alone, leading to increased isolation at end-of-life . Breaks in biological familial relationships mean that families of choice are often

cited as the support systems for SGD patients which consist of a mix of biological relations and non-biological close friends or community members (Stinchcombe et al., 2017).

There was some disagreement in the literature about whether families of choice were able to fully support SGD patients and their complex palliative care needs. Stinchcombe et al. (2017) found that families of choice were important to LGBT patients at end-of-life and relied on them to provide social support, love, caregiving duties, and advanced care planning support and decision making. While Wilson et al. (2018) found that many LGBT patients felt they could not ask their friends to help with caregiving at end of life, because it was too much to ask. Lower's (2017) found that LGBT patients families of choice were often the same age as the patients, elderly with their own health to worry about, and thus had less capacity to care for them when the time came. Maingi et al. (2018) noted that there was increased caregiver strain of partners of SGD patients because there were less of them to support the patient. With the increased chance for social isolation and limited caregivers available, there is increased chance that LGBT+ patients will need to enter an institution at end-of-life (Braybrook et al., 2022). With the thought of having to enter institutionalized care comes the fears of going back "into the closet" in order to ensure quality care (Wilson et al., 2018). Witten (2014) described that for some transgendered patients, the fear that their wishes would not be respected, fear of cruelty and abuse and of not being able to live their authentic selves was so severe that they wished death or suicide over institutional dependence.

Reich et al. (2022) described SGD patients' worries regarding their advanced care plans being ignored, and that providers would instead go to estranged family

members for decisions. This fear was validated by a survey done by Cartwright et al. (2018) which asked over 300 physicians to identify the correct substitute decision maker in a made-up car accident scenario and found that less than 1/3 of the respondents correctly identified the same-sex partner as the correct substitute decision maker.

Palliative care uses family as the unit of care, but in contrast to this value, Stein et al. (2020) found that 15% of palliative care providers had witnessed the spouse/partner or surrogate of a LGBT patient having treatment decisions disregarded, and more than 14% had witnessed a partner being treated disrespectfully. Having decisions disregarded or being treated disrespectfully creates barriers to good relationships between providers and families. This discrimination combined with biological family rejection increases SGD partner strain and opens the potential for disenfranchised grief, which is when a SGD's partner is denied the ability to grieve socially because of the seemingly illegitimate status of their relationship (Higgins & Hynes, 2019).

Summary

It is noteworthy to mention that this study took place in Canada, however only three studies identified in the literature review were of Canadian origin. This study helps fill the lack of research in the unique Canadian context. Many of the studies were in the United States (US) context, which has a significantly different healthcare system and political environment than Canada. SGD acceptance and equality is an issue that faces every country and must be addressed both globally and locally for things to improve. Canada, though it still has much work to do, is a good place to start, as the country was a relatively early adopter of marriage equality and legal protections for sexuality and gender expression.

In summary, there are many types of discrimination SGD patients and families face specifically within palliative care contexts. Assumptions are pervasive, invisibility of SGD people and needs are an issue, unsafe environments contribute to poor palliative care experiences, less is known or recognized regarding some subsets of SGD patients than others, and a lack of provider education is common. Additionally, SGD patients and communities have a unique culture, may have intersections that increase vulnerability, and have a different understanding of families. Understanding and consideration of these issues when planning and implementing palliative care are important.

Research Problem

Despite palliative care's core value of person and family-centered care and a focus on good provider-patient relationships, there is evidence that people who identify among SGD groups continue to experience discriminatory and inequitable palliative care (Stein et al., 2020). This issue highlights the need to develop an understanding of how palliative care provision is influenced, while taking into consideration the complex social, cultural, and political relationships that shape this care. These complex relationships occur at multiple levels within the institutional contexts, including between the patient and family, providers, and governance structures. This study aims to understand SGD care and what informs it from the palliative care providers' perspectives.

Research questions

1. What knowledge guides current palliative care providers in their care of SGD patients and their families? Where and when have they developed this knowledge?

2. What practices are currently utilized in caring for SGD patients and their families, and what influences their practices?

3. How can providers improve care for SGD patients? What resources do palliative care providers feel they need to provide safe palliative care and create safe environments for SGD patients and families?

Chapter 3. Methodology

Introduction

Interpretive Description (ID) was chosen for this study because of its theoretical and methodological flexibility and focus on iterative processes. It allows the researcher to select and integrate a variety of well-established qualitative research traditions, such as phenomenology, grounded theory, and ethnography. It uses different methods based on the research question at hand as well as logic that is justifiable and grounded in real world phenomena (Thorne, 2017, pp. 38–41).

In the ID tradition (Thorne, 2017), the theoretical scaffolding of a study clearly identifies what philosophical positioning the researcher is taking and what assumptions, values, and beliefs go with this. It also identifies what facts are being considered known and unknown about the research topic (Thorne, 2017, pp. 59–60). To accomplish this, the theoretical scaffolding consists of the theoretical forestructure (locating the research) and the literature review (what facts are considered). The literature review is in the previous section and the theoretical forestructure follows this introduction.

Interpretive Description requires research findings be grounded in data and is underpinned by the ideas of multiple constructed realities, where the researcher and the research participants influence each other to create knowledge (Thorne et al., 2004). ID's philosophical underpinnings are a good fit for this study's research questions in that they acknowledge the multiple realities of SGD patients and families, palliative care providers, and myself as the researcher trying to understand the complex nature of palliative care for SGD patients. To answer the research questions and in line with

multiple constructed realities, the decision was made to talk to the multidisciplinary healthcare teams, including volunteers.

Theoretical Forestructure

The theoretical forestructure consists of locating the theoretical allegiances the researcher has, locating the researcher within their discipline, and locating the relationship to the researcher's personal ideas and their proposed research (Thorne, 2017, p. 70). The constructivist paradigm is where this research study is situated. Constructivism acknowledges that knowledge is socially constructed, that multiple subjective realities exist, and that constructions reflect the context in which they are created (Lincoln & Guba, 2013, pp. 40–41). This paradigm fits with the study in that it acknowledges the context within which SGD care is administered, within health care institutions and within the culture of teams of healthcare providers. It also acknowledges the multiple realities inherent when caring for SGD patients and families, in which there is the patient reality, the family reality, as well as the provider and institutional realities.

Within the constructivist paradigm sits queer theory, which has been foundational to this research. Queer theory challenges that gender and sexuality are naturally or biologically based, instead offering that gender and sexuality are socially constructed and unstable entities (Moore, 2019). It challenges heteronormative and cisgendered notions as oppressive. Queer theory has strong roots in activism. Queer theory has allowed me to question how healthcare providers understand gender and sexuality and how they continue to discriminate and oppress patients and families through heteronormative and cisgendered assumptions, of which they may not even be aware. It has also allowed questioning of how practices and cultures within health care institutionalize dominant

discriminatory social beliefs and values. Identifying and analyzing the ways in which palliative care providers understand sexuality, gender, and relationships will help to better understand the influences on SGD palliative care practices. It will also allow a critique of how care providers re-create and resist conditions of marginality and oppression for SGD patients and families within the context of palliative care.

It may appear, at first glance, that the constructivist paradigm stated earlier may be in tension with the more critical theory orientation of queer theory. I believe, however, that this is not true, and that they work well together. In order to be critical of the ways that things are, knowledge of how something is constructed is needed. In this case, looking at the various constructions of healthcare providers knowledge and actions needs to be better in order to change what might be harmful practices. Constructivism also acknowledges that some constructions of these same healthcare providers may not be harmful, but helpful or even hopeful for a changed future. Overall, I believe that both constructivism and the more critical queer theory together will help understand the knowledge and practices of palliative care providers regarding care provision to SGD patients, as well as provide insight into improving the situation for all users of palliative care.

As discussed at the outset, my disciplinary background is nursing and palliative care, which I care about deeply. This study was designed to ask questions of clinical relevance for the purpose of improving clinical practice (Thorne, 2017, p. 74). Despite my nursing background, my aim was to understand the phenomena of SGD palliative care through an interdisciplinary lens, since palliative care is not only delivered by nurses, but multiple disciplines together, supported by volunteers (Canadian Hospice

Palliative Care Association, n.d.). In addition to theoretical models, my social position influenced my research questions and interests. I identify as queer; I have friends who identify as SGD people, and I am part of the SGD community. This identity has meant I have my own personal experiences of healthcare as an SGD person and have witnessed and learned about health care experiences of many SGD friends and chosen family. These experiences played a part in orienting me to the need for this research and influenced the creation of this study. In this thesis, I use queer theory supported by two practice-based theories: relational inquiry (Doane & Varcoe, 2021) and cultural safety (Ramsden, 2002). I choose relational inquiry because it acknowledges the multiple realities of SGD people and care providers and offers a way of seeing how those realities and relationships are affected by their context. I chose cultural safety for its understanding of how power and history shape care practices and interactions between providers and patients.

Relational inquiry describes an approach to nursing care that prioritizes the relational aspect of nursing work, constituting it as foundational to nursing practice (Doane & Varcoe, 2021). Relational inquiry asks nurses to critically reflect on all interactions on the intrapersonal and interpersonal relationships and the environmental factors that shape each situation (Doane & Varcoe, 2021). It consists of two parts, relational consciousness, and inquiry as a form of action. Relational consciousness requires a provider to look beyond the individual situation at hand and understand the relationships that are at play: interpersonal, intrapersonal, and context. The interpersonal looks at the relationships among and between providers, patients, and families. In this case, one significant consideration is the complex relationship between patients and their

chosen families. The intrapersonal aspect requires the providers to look within themselves, in this case, to examine their relationship with their beliefs regarding sexuality and gender and how it affects their care and treatment of patients. It also requires consideration of how a patient's relationship with their own sexuality and gender may affect their needs in palliative care. Lastly, an understanding of the context, in this case the complex social, historical, political, legal, and cultural environment in which palliative care is delivered to SGD patients, is also considered. Inquiry as action requires a provider to consider the relational aspects described previously with situational factors and knowledge to provide compassionate care.

Relational inquiry considers the multifaceted human experience within a complex healthcare environment. It fits well with the goals of this study in understanding how care is affected by relational aspects and the complex social, cultural, and political environments in which palliative care is delivered. The use of relational inquiry has allowed me to understand the relational influences on SGD care that affect palliative providers.

Cultural safety was originally developed by a nurse to foster safer environments for Indigenous persons using healthcare services in New Zealand (Ramsden, 2002). It is an outcome that is measured by the healthcare population being served. Appreciating the colonial history of Indigenous persons and how this history affects health and healthcare access is integral to creating culturally safer healthcare spaces (Health Council of Canada, 2013). Cultural safety principles include respectful engagement with patients, an understanding of the unequal power dynamics inherent in healthcare delivery and the need to fix these inequities through systemic change (Health Counsel of Canada, 2013).

It also requires providers to self-reflect regarding their values, attitudes, beliefs, and assumptions. Overlapping with the intrapersonal aspect of relational inquiry, participants in this research had the opportunity to self-reflect on their values, attitudes, and beliefs as well as the context of their work (e.g. organizational culture and societal values regarding sexuality and gender). More specifically, they were asked to self-reflect on their own practices with SGD patients and what influences their care. Cultural safety offers a practical guide placing the responsibility for upholding it in the hands of health care providers, while calling attention to institutional structures that support and undermine safe care.

Employment Considerations

I am currently employed by a hospice service in Canada and doing research at this location is considered insider research (Evered & Louis, 1981). In contrast, outsider research is where the researcher is not considered part of the group under study. Outsider research has strengths regarding the data collected are more objective and less prone to bias than insider research because the researcher is not as close to the participants (Dwyer & Buckle, 2009). Outsider research also has its own challenges, such as more difficulty gaining access to participants, participants seeing the researcher as being an outsider and thus not sharing as much intimate information, and questions of if an outsider can truly understand complex contexts to which they don't belong (Dwyer & Buckle, 2009).

Insider research requires the researcher to have direct contact with the organization under study, and a rich understanding of the context (Evered & Louis, 1981). This allows contextual understanding of the phenomena and generates knowledge

that is experiential and situationally relevant that sheds light on the human components of the phenomena (Evered & Louis, 1981). This type of research has the benefit that the researchers' closeness to the phenomenon and research participants allows an opportunity to have great insight into the research problem at hand (Lykkeslet & Gjengedal, 2007). There are, however, some potential issues to overcome when conducting insider research. Lykkeslet & Gjengedal (2007) cite risks related to preconceptions by the researcher and issues related to the closeness to and interactions with participants that could lead to cultural blindness and introduction of bias. For example, I might be inclined to cast my colleagues and organization in a disproportionally positive light. Lykkeslet & Gjengedal (2007) suggest that a strong focus on reflexivity allows the researcher to understand their preconceived notions and biases by critically examining them. During methodological decisions for this study, a focus on reflexivity was incorporated into the study design, in part, to help reduce this cultural blindness and attend to bias. Additionally, my thesis advisors were not insiders to any of the organizations, which allowed me to discuss with them when I felt I may have been seeing things in a biased way and allowed their outside perspectives on the data.

Methods

This section on methods is divided into sample and sampling, focus groups, study sites, data collection methods, data management strategy, and data analysis strategy. Each section contains the method used as well as the rationale for choosing that method. It ends with a quick summary of research ethics approval.

Sample and Sampling

As per Thorne (2017, pp. 98-100), sampling should be thoughtful, transparent, and follow a logic that is within the claims of the findings of the study. Purposeful sampling was chosen for this study because it aligned with the research questions as well as the intended audience for the findings of the study (multidisciplinary healthcare palliative providers, organizations, and policy makers). This audience includes palliative care providers (the context in which the study is framed), as well as interdisciplinary health care team members (as stated previously because palliative care is practiced in an interdisciplinary way).

Specific inclusion criteria included being: 18 years of age or older; an individual[2] who provides direct health care and/or supportive services to patients and/or caregivers; and is able to understand and clearly articulate oneself in English. Community palliative care settings (hospices and community agencies who do home visits) in a Canadian region were the study setting. Exclusion criteria included: not being an individual who provides direct care to patients (such as pharmacists or team leads); and not speaking English. Only individuals who directly support patients and/or caregivers were included in this study because I wanted to capture the direct influence of providers on SGD care. A separate study interviewing indirect providers would be interesting as they influence

[2] An individual who directly supports the delivery of health and supportive services to patients and/or caregivers and may include but is not limited to personal support workers, health care aids, nurses (nurse practitioners, registered nurses, registered practical nurses), physicians (and any trainees), physician assistants, social workers, allied health, trained palliative volunteers, and others.

the healthcare environment in terms of policy and administrative practices, however doing both was outside of the schope of this Master's thesis. Non-English speakers were not included for feasibility of this study because I do not speak other languages and there was no budget for translation. Including members from a variety of disciplines allowed a broader understanding of the complex social context in which palliative care is practiced.

Focus Groups

Data was collected by conducting three focus groups. Focus groups are a type of group interview where the primary aim is to promote interactions between the participants as opposed to having each participant answer each question (Pope & Mays, 2019, p. 58). The researcher facilitates or moderates instead of interviewing, in order to garner deep and nuanced understandings of the group's thoughts on a topic (Pope & Mays, 2019, p. 58). Focus groups were chosen so that the unique interactions of participants could be captured in the data. Understanding the relationship between providers can help to understand the relational influences that create organizational culture and affect the care of sexual and gender diverse patients. Focus groups are useful for creating meaningful interactions and can help participants clarify their values and opinions and allows the researcher to capture the extent of agreement and disagreement of participants on different complex issues (Jayasekara, 2012).

Focus groups were conducted with 3-5 participants per group, facilitated by myself and one of my thesis supervisors. One focus group was done in person and two were hybrid as per participant preference. A semi-structured approach to focus group interviews was used to allow the aims of the study to be met while providing room for developing themes and topics not initially anticipated. Focus groups allow data to be

situated within unique social circumstances, revealing group dynamics and shared knowledge (Thorne, 2017, pp. 89–91). Topics discussed included participant knowledge of unique palliative care needs of SGD patients and families and strategies used to support them, what resources and values underpinned the care that is given, how to improve care for this population and what is needed for this to happen (see Appendix B for full semi-structured interview guide and questions). Focus group discussion questions were printed in large print on individual cards. These cards were then shown in batches of 1 -3 questions for participants to discuss. These cards were read aloud for those using teleconferencing. Focus groups lasted between 60 and 120 minutes in length. The number of participants allowed adequate time for everyone to share while also ensuring enough participants to reveal group dynamics (Jayasekara, 2012).

Some limitations to focus groups include them becoming tangential, issues regarding power dynamics, and the chance only one or two people will contribute or dominate the discussion (Jayasekara, 2012). These issues were minimized during the focus groups in various ways. Firstly, tangentiality was anticipated but was preemptively minimized by the semi-structured nature of the questions and by keeping the questions in view of the participants at all times. Power dynamics were managed by requesting participant's respect each other's confidentiality at the outset and encouraging sharing of different opinions in a respectful manner. Lastly, some people in the focus groups were naturally quieter, or hesitant to share. We (myself and thesis supervisor) specifically sought to create opportunities to share from those we observed as less participative. This included directing questions and prompts to quieter participants directly, such as "what

do others think about X idea" or "does anyone have anything to add to this topic before we move on" towards the quieter participants.

Study Sites

One focus group per organization was completed. Two from hospices with hospice beds and one from a community palliative care agency without beds. One hospice focused on populations experiencing homelessness, another gave care primarily in a rural area, and the last was in an urban setting. The different settings increase credibility through triangulation and transferability of the results to multiple settings.

Data Collection

Data collection was iterative with analysis, as per interpretive descriptive design. Following each focus group, review and preliminary analysis of audio recorded text helped guide questions and topics for the future focus groups. This process allowed preliminary themes and ideas to be explored further in subsequent focus groups. Additionally, this iterative approach allowed a degree of member checking with subsequent focus group members confirming findings from the previous groups (Morse, 2015). An example of this happening was when the first focus group talked about discomfort and worry regarding misgendering patients/family. A question about if the second group also felt this way was asked based on this preliminary finding and further explored. Manual transcription was chosen and though it was rather labour intensive, the number of recordings allowed for manual transcriptions in the time constraints of the master's thesis (three recordings ranging from 1-2 hours). By transcribing the data myself, I was able to listen in depth to what every participant said, how they said it, and group reactions. Verbatim transcription was chosen to help capture group interactions. I

used Microsoft word to type out the transcripts. Each focus group was labelled FG1-FG3 in order of completion; whilst each participant was further labelled P1-P5 based on the order of first speaking (e.g. FG2P2).

Group demographics were collected via paper forms and included age, occupation, number of years working in palliative care, race/ethnicity, gender identity, and sexual orientation. See Appendix C for the demographics collection tool used. Race/Ethnicity data was collected with the purpose of describing the participants. However, since the number of participants in this study was small there was risk that a participant could be identified by their answers therefore, race/ethnicity, sexual orientation and gender identity, and occupation data are reported numerically, however are not included in qualitative quotes.

Data collection took place in conference rooms at the site's workplace, during non-working hours or via teleconferencing on Microsoft teams. Data collection was done through audio recordings of the in-person focus groups (on a physical audio recording device).

Data Management

Data requiring a management strategy consisted of demographic surveys (no names collected), consent forms, audio recordings, transcriptions of the audio recordings, and the researchers' notes. Hard copies of data (demographics, consent forms, and researcher notes) have been kept in a secure locked cabinet at the home of the researcher. Digital data (audio recordings, transcriptions, and researcher notes) are kept on a University of Ottawa OneDrive account and on a password protected computer. The original audio recordings were recorded on an audio recorder in the possession of the

researcher. They were then immediately uploaded to the University of Ottawa OneDrive account and the original audio data on these recorders was deleted. This data was only accessible to the researcher and the two supervisors. Any data shared with the thesis advisory committee, in presentations, and for publications was de-identified prior to sharing.

Data Analysis

Transcribing and Iterative Analysis.

After each focus group, I listened to audio data 2-3 times before the next focus group session. A journal entry was also written as soon as I arrived home regarding general thoughts about how the session went, things that stood out, and general ideas and concepts that I noticed during the session to begin to understand the data and track where ideas may have come from (Thorne, 2017, pp. 152–153). I also debriefed with the thesis supervisor who attended the focus groups directly after each focus group, and with both supervisors during weekly or biweekly meetings. Subsequent sessions listening to audio data allowed a general understanding of the breadth of the data in each recording. This general familiarization and journaling allowed reflection about data to be used in subsequent focus group sessions. For example, in focus group two, participants described feeling generally uncomfortable asking patients and family members about their pronouns. In the third focus group, participants were asked if they had similar feelings, and reasons they might be uncomfortable were explored. The research questions and theoretical frameworks queer theory, cultural safety, and relational inquiry were reflected upon when deciding which topics to discuss in subsequent focus groups. For the example above, discussing discomfort was deemed important to research question 2 (what

influenced practices with SGD patients), and intrapersonal reflection (from relational inquiry) was leveraged to help guide participants in answering the question.

Data was manually transcribed as suggested by Thorne (2017, p. 158) to help slow the pace of and allow attention and reflection to hear more deeply what is being said. Once a transcript was completed, I went back through and removed any names of participants or patients and further used the search function with participant names to ensure that none were missed. These transcripts were then uploaded to NVIVO software for further analysis, coding, and theme generation.

Coding the Data.

After each general section of the recording was transcribed (questions answered, or each discussion about one topic), as I reviewed the transcript sections and recorded ideas of potential themes, I used open coding. Open coding is a methodological approach of constant comparison that codes the data line by line with key concepts and phrases so that it can be examined and broken down into its conceptual components (Noble & Mitchell, 2016; Polit & Beck, 2017, pp. 766–769). Guiding me in the open coding process were my research questions and frameworks (Queer theory, cultural safety, and relational inquiry). I also realized that multiple codes could apply to the same set of data, thus some data had multiple codes attached to them at this time. In addition to potential codes, during initial readings of transcripts, I also commented on potential links to theory, flagged spots for further explorations, and highlighted any quotes that stood out to me (using Microsoft word comment function). I initially tried to begin coding in NVIVO once all data was transcribed, however I stopped using NVIVO because it required defining the themes/codes at a very early stage that did not fit well with the open

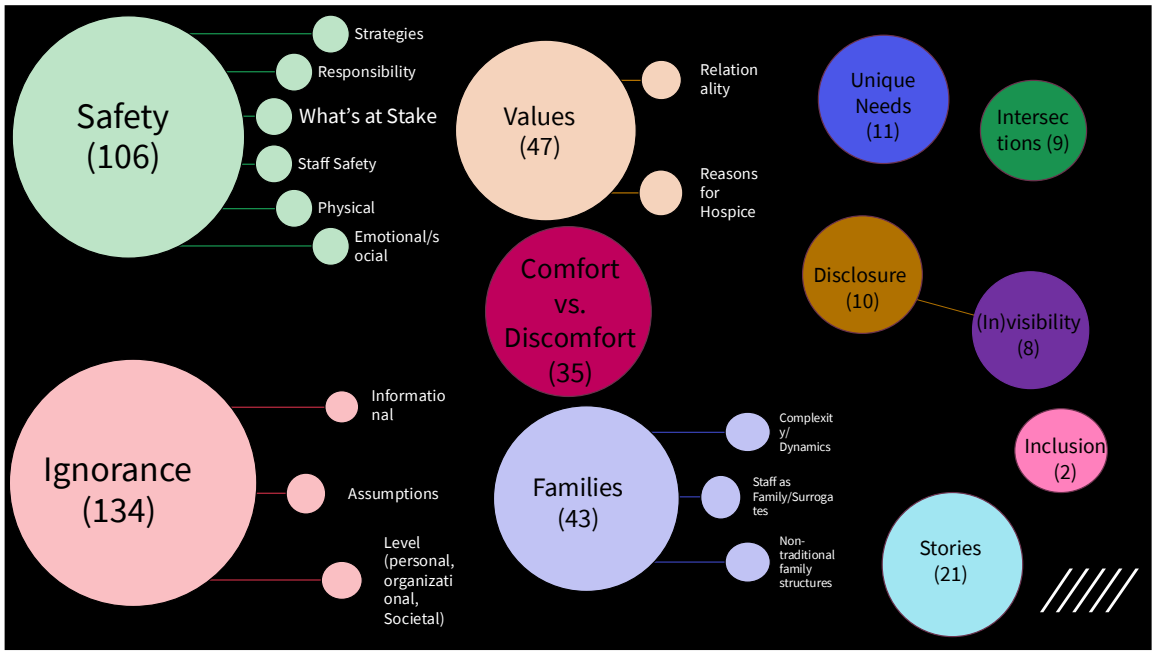
coding I had previously done. I was not ready to define themes in detail yet. I found Quirkos software supported more open and flexible coding. Quirkos was simple and flexible in developing codes, and I used it exclusively from this point on. The initially created open codes were moved to Quirkos for further analysis and development. These initial codes were reviewed and discussed with thesis advisors.

Generating Initial Themes.

Initial themes were generated using Quirkos to sort codes into meaningful groups. These initial 31 themes were further refined into 10 themes with sub themes which can be seen below in figure one. These initial themes were presented to the thesis committee for discussion and review with accompanying quotes as examples. The 10 initial themes (and subthemes) were: safety (strategies, responsibility, what's at stake, staff safety, physical, emotional) Ignorance (informational, assumptions, levels (personal, organization, societal)), Values (relationality, reasons for hospice), Families (complexity/dynamics, staff as family/surrogates, non-traditional family structures), comfort vs. discomfort, unique needs, intersections, disclosure/invisibility, inclusions, and stories.

Figure 1

Initial Themes and Subthemes



Reviewing and Developing Themes.

This study originally planned to use reflexive thematic analysis to analyze the data. Reflexive thematic analysis was initially chosen as the data analysis method because it acknowledged meaning as contextually and situationally based (Braun & Clarke, 2021), which fit well with the studies underlying constructivist roots. The assumption that the researcher cannot separate themselves from the research and analysis was what drew me to this method, as it acknowledged me (the researcher) as a reflexive and analytic tool, which also made sense as I was an insider doing the research (palliative care worker at one of the sites). This method also allowed a degree of flexibility during the inductive coding and analysis process, allowing for themes to be developed and not be predetermined (Braun & Clarke, 2021). I believed this flexibility would help with answering the research questions in exploring various aspects of group values by understanding the underlying themes that may have been implicit or have latent meaning.

I did not end up using reflexive thematic analysis, because the codes felt reductionist, compared to how I was understanding the data. Simply naming and explaining the codes did not convey the complexity of the data. Thus, after initial coding and developing the themes in the previous section, I moved away from using Reflexive Thematic Analysis. Instead, I decided to use my initial three research questions to ground my analysis, writing up points that answered the questions using the initially open coded themes (and other notes relating to underlying theories) as guidance.

In order to develop themes into findings and discussion I next wrote 9 short analytical stories (1-2 pages in length) each with my thoughts on a potential emerging theme or relationship from the data how they fit in with the theoretical groundings in queer theory, relational inquiry, and cultural safety. The titles of these writings along with some main points from each were then written in large font and taped to the wall underneath the three research questions. Using this approach allowed me to see a bigger picture and rearrange the themes in different ways to try and understand how they might relate to each other and to the research questions.

Crafting the findings.

At this point I was struggling with the findings because throughout analysis and open coding I focused on interpretation and description using theoretical perspectives, rather than a purely descriptive approach. I needed to take a step in the opposite direction to craft the findings from a descriptive perspective. I re-read all the transcripts and picked out quotes based on 3 sections: quotes that I feel passionate about sharing, quotes that I think are important, and quotes that might be important, but I can let go. I used myself as a research tool, grounded in the theoretical frameworks and research questions. I then

printed all of these quotes out, cut each into individual quotes, and sorted them based on the initial thing I believe the participants were portraying, primarily using the quotes that I felt passionate about. I chose final quotes to include based on how well they illustrated the points that participants were making with regards to the larger themes. Additionally, I included quotes that were central to my understanding or that had shifted my perspective. I was only able to put each quote under one idea, as they were physically printed on paper, in contrast to Quirkos where I could put multiple themes/ideas to the same quotes. I focused on the participants' statements as a descriptive value, limiting my interpretation in favor of what the participants were saying verbatim. Three main findings came of this, each with two sub-findings.

Producing the Report.

As per interpretive description methodology, an iterative approach was used not just in the focus group data collection, but also in analysis (Thorne, 2017, p. 197), specifically when it came to thinking through the analysis and writing the findings and discussion portions.

An iterative approach was used as a reflexive process to develop meaning, visiting and revising the data and connecting them with emerging insights and refining the focus of both sections (Srivastava & Hopwood, 2009). More specifically, while writing these sections I focused on what the participants were telling me, what I wanted to know and further discuss (as per my research questions and frameworks), and what the relationship between what the participants were telling me and what I wanted to know while thinking about how I wanted to present these to readers. As such, the discussion

and findings were crafted together at times, and while going back and forth between the two at other times.

Once the findings quotes were chosen, they were discussed with the thesis advisors, placed in logical order and groupings, then introduced and written up. These findings were used to create an outline for the discussion. Many of the discussion points previously written fit somewhat into these findings categories, however there were a couple of discussion points that did not exist that I saw needed to be included based on the findings. After placing the discussion points under each finding as they related, the main discussion points were written up.

There were still some discussion points that I felt were important but did not directly tie to the themes prioritized in the findings chapter. They were written in an additional document, and the main points were placed on a mind map and presented to the thesis advisors to discuss how these fit into the larger discussion.

Ethics Approvals

University of Ottawa Ethics Board Approval was received (Nov 2023). Recruitment was done via posters placed at each site as well as forwarded emails from each contact at each site and attending staff meetings to share about the study (See Appendix D for recruitment materials).

Credibility

In order to establish a study as credible, Thorne (2017) offers four criteria: epistemological integrity, representative credibility, analytic logic, and interpretive authority. A study may be judged for its theoretical, epistemological, and technical soundness with these criteria.

Epistemological Integrity

Epistemological Integrity refers to the demonstration that a study has a "defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological rules by which decisions about the research process are explained (Thorne, 2017, pp. 233–234)." The research questions must be epistemologically compatible with the knowledge they are generating, and the data sources must logically follow the research questions. For this study, the epistemological grounding is in constructivist theory, of which queer theory fits logically into (as it accepts multiple realities and social construction of gender and sexuality). The research questions were created with constructivism in mind, and decisional strategies to answer these questions and design the study were made on the same basis, such as the use of focus groups, who share and construct knowledge with the researcher. The analysis strategy used also acknowledged the multiple realities of participants through crafting the findings and themes. Thus, the research questions and methodological choices of this study are in line with the constructivist paradigm. Additionally, thesis supervisors with expert knowledge and practice in studies using constructivist theory were sought and oversaw this thesis.

Representative Credibility

Representative credibility refers to the ability of a study to show that the theoretical claims the study is making are consistent with the phenomena under study and the way the study is sampled (Thorne, 2017, p. 234). Generally some form of triangulation improves representative credibility, and researchers recognize that knowledge can be seen through other angles (Thorne, 2017, p. 234). This study's sample deliberately included participation of multiple provider types that interacted with the phenomena under study. It also included 3 different hospices, all in different geographical areas with different types of patient populations including a hospice focused on the population experiencing homelessness, one on rural palliative care, and the last in an urban setting. These two forms of triangulation (of participant diversity and of different areas and focuses) increased the credibility of this study's findings. Additionally, the research team consisting of myself (a frontline palliative care nurse and SGD person), and two supervisors (one with a background in equity research as well as research regarding violence, and the other with extensive palliative care knowledge as well as a background in research regarding organizational structure and working with health care providers), providing a diversity of professional backgrounds.

Analytic Logic

Analytic logic refers to the importance of making visible in the research report the reasoning and decision making from the inevitable forestructure through to the knowledge claims made on the basis of what was learned in the study (Thorne, 2017, pp. 234–235). Thorne (2017, p. 235) suggests that to achieve this, analytic logic has to be articulated well and that data and claims should be grounded in thick description with

context articulated. In this thesis, I did this by explicitly stating why methodological and analytic choices were made, by ensuring that findings were given within their contextual environment, and by choosing quotes with rich and thick descriptions.

Interpretive Authority

Interpretive authority refers to an assurance that the researcher's interpretations are grounded in the data, and not simply a product of the researcher's bias or experiences (Thorne, 2017, p. 235). In this study, data analysis was concurrent with data collection so that the findings of the first and second focus groups were checked with subsequent focus groups. This allowed a level of member checking and ensured that my interpretation was correct. For example, it was brought up in the second focus group that worry and discomfort was a barrier to effective care for SGD patients. A question asking about this phenomena was asked to the third focus group. Additionally, both thesis advisors had access to transcripts, my initial comments added to the transcripts, my interpretations, my open coding, and subsequent coding. This allowed them to refer to the original transcripts for clarity and accuracy of my interpretations.

As recommended by Thorne (2017) reflexivity was practiced throughout each major part of the study via a reflexive journal and through weekly/bi-weekly discussions with thesis advisors who challenged my thinking. Prior to and after each data collection and prior to and after analyzing each data set, a journal entry was created and included how I believed the interviews went, my thoughts and viewpoints regarding palliative care and sexual and gender diverse people/patients, as well as general thoughts and feelings regarding the process and content. Debriefing with one of the thesis supervisors (the one who attended the session) was also done after each focus group session. The reflexive

journal allowed me a safe space to be honest and to analyze the relationships between myself and the data being collected. It gave me an opportunity to reflect on the interview process involving the relationship between me as the researcher and the participants. This process allowed me to identify my biases and work through some of the emotions that came up in response to the data and discuss them with my thesis supervisors as needed.

Chapter 4. Findings

Introduction

Palliative care providers that participated in the focus groups for this study strongly valued person-centered and personalized care, and valued SGD patients as people. However, they described discomfort and fear of 'saying the wrong thing'. A key issue identified by participants was the lack of professional training opportunities and experiences. Discomfort and fear were identified as barriers to practicing in line with person-centered values. Participants described their lack of training and experience as affecting the safety of SGD patients. The first section of this chapter describes demographic data collected from the participants. The following sections are organized around analysis of the data using three main themes, with several subthemes. Theme 1. *The Effects on Experience on Care* includes the subthemes: a) *Invisibility of SGD palliative patients;* b) *Limited professional experience;* and c) *Drawing on personal experiences*. Theme 2. I *Can't Keep Up, and I'm Scared I'm going to Say the Wrong Thing* includes subthemes: a) *"We're always learning in this evolving world. LGBTQ – all these letters are brand new"*; and b) *"You feel scared you're going to put your foot in your mouth…"*. Theme 3. *Our approach centers on each person as an individual* includes subthemes: a) *"You're a person, what do you need, how can we give it to you?";* and b)*"It's not going to be quick and task oriented and it's going to be very individual, geared toward what their wishes would be and their priorities at end of life."*

Demographical Description of Participants

These findings are the product of three focus groups conducted at community hospices from December 2023 to February 2024 in Ontario, Canada. The focus groups

lasted between 60 and 120 minutes, with 3-5 participants each. Demographic information was collected from 11/12 participants. There was a total of 12 participants, with a mix of Registered Nurses [RN] (1), Registered Practical Nurse [RPN] (2), Personal support worker [PSW]/Unregulated Care Provider [UCP] (3), and volunteers (5 including some who were retired or non-practicing healthcare workers). There were a mix of ethnicities including: Black or African American (3), white/Caucasian (5), and those who preferred not to disclose (2). One participant identified their ethnicity as Francophone. The age ranges of participants were: 25-34 (1), 35-44 (3), 45-54 (3), 55-64 (1), 65+ (3). Participants identified their sexualities as: heterosexual/straight (7), lesbian (1), prefer not to disclose (3). Participants described their gender identities as female (9), male (1), prefer not to disclose (1). Educational levels ranged from high school diploma or equivalent (3), post-secondary diploma or degree (7), and Master degrees (1). Overall, though a small group, there was some diversity among participants regarding ethnicity, profession, and age range. Less diversity of participants was noted in sexual orientation and gender identity with most identifying as female and straight/heterosexual.

Theme 1: The Effects of Experience on Care

This theme describes participants' experiences with SGD patients and families as well as SGD people in their personal lives. It was interesting to hear how many participants had not (knowingly) or could not remember caring for SGD patients or family members in their professional care roles. They also described little to no training regarding SGD patients in palliative care settings. Instead, nearly all the study participants cared for SGD people in their personal lives. Participants shared many

moving stories about the SGD people in their personal lives and believed that these interactions shaped the way they saw and cared for SGD patients and families.

Theme 1a: Invisibility of SGD Palliative Patients

Participants in all focus groups had trouble identifying SGD patients or family members in their care, and the ones that did, often admitted to having very limited firsthand experience with these patients. Participants in all groups, both with many years of experiences and those with less admitted to having little first-hand experience with LGBTQ+ patients in the palliative or professional setting.

A long-time volunteer remarked on the lack of SGD clients in their practice:

> I haven't had a client, I'm trying to think back to a patient in the community, because that was one thing I did think of while coming here, [...] I've been here for quite a long time, and certainly my in-home clients, or even clients at the day hospice when I was there. It has changed a lot in the last 5 years but there was a very small, or very minority client base here that I'm aware of, I haven't had a client to my knowledge that was LGBTQ. (FG3P3)

Another participant shared that "in my personal life I had worked with some transgendered people and people transition[ing], but not in [a] professional [context], not here at the hospice." A volunteer with 10 years of experience was asked if they could describe care of a patient that was LGBTQ+:

> Can I tell you about a time you cared for a patient in this community? I can't. I think you and I exchanged a bit of that information in an email. I did not knowingly take care of someone from this community, so I don't feel I can really answer that question. (FG2P2)

A different participant reflected on how having limited experience affected how they interacted with a SGD patient:

> Certainly, when I first encountered somebody from the LGB community as a client I felt, I didn't feel empowered as to how to best address a patient. I felt I was stumbling over my words; I felt nervous, I didn't want to say the wrong thing. (FG2P1)

Theme 1b: Limited Professional Experience

Most participants had few experiences directly with SGD patients or family members. Participants also reflected that their training did not include SGD care or specific issues relating to SGD people. They did, however, recognize that the lack of training affected their care and practices. Participants wanted training that incorporated more than informational models such as videos and speakers with lived experiences. A long-time volunteer commented:

> As a volunteer I remember the only education that we received was, let's see, I graduated in November from the program, I think in January or February we had a presentation by some members, seniors, members of the seniors LGBTQ community and that was it. That was 10 years ago. I think things have changed a lot in that time and I think we really need an upgrade. Now perhaps the last class of volunteers, maybe there was some discussion about it. But I feel that we need more education as volunteers, and we haven't received it. (FG2P2)

Overall, staff and volunteers identified that they both had extensive training to support their transition to palliative care and to the organization, but that SGD information was

not discussed. The nature of the training was flexible, and they could do "as many shifts needed to be comfortable doing the role on your own (FG2P2)":

> We definitely had training in family issues, dealing with families, the medical side of things, infection control, body mechanics, relating to patients, having discussions with patients, we would do simulations. We'd present, someone would present something and then one of us would be a patient, one of us would be a volunteer, how would you handle that. I mean, it was very, very good training, it's the most intensive training for any volunteer position I've ever had. But there are things, I would say that [LGBTQ+ care] was an area that was lacking for sure. And then we had our [on the floor] training here, with [...] as many shadow shifts you felt you needed to feel comfortable doing the role on your own. (FG2P2)

Participants in this focus group talked about some of the online training modules they had to do as part of their training, and how it is quite lacking in SGD care topics and SGD specific issues:

> P4: I'm just thinking of the online training, I know it talks at a surface level about parking your beliefs at the door and being open to whatever beliefs or whatever being practiced in that household and [it] talked a lot about spiritual diversity and stuff. But maybe, I think that that could be totally beefed up, that training.
>
> Group: yeah, uh-huh, that's a good point [...]
>
> P3: [...] how long does it take, like an extra few minutes to specifically identity, groups, just so that people are aware that, like if you just say diversity, or to name anything

P2: Well, we do that, at least I do when I talk, yeah, but it is, gets to those…

P3: LGBTQ and that kind of pronoun use?

P2: Now we didn't talk about pronouns I don't think, I can't remember now. But it is to get to those deeper conversations and around what do we really mean when we say "leave your baggage at the door, what is your baggage?" Does anybody, are we even aware of that? And those are, we could certainly do more I think.

P4: [We could do more to] understand the specific issues that might come up, to know when, and what are the barriers that this population and, we could talk about a lot of diverse populations, but what are the barriers to entry to service that this population may experience. (FG3P1,3,4)

Another participant talks about the lack of foundational knowledge, and how a lack of information, guidance from leadership, and lack of tools has contributed to their feeling that they do not feel equipped to care well for LGBTQ+ clients:

Personally, I don't think this is an issue I've really delved into much in [organization name]. I think it's, there's an awareness of it, because we do have people sometimes choose it [to display pronouns] on their name tags, they choose it on their email signatures, their gender identity, they have the rainbow at the doors and things to see people are welcome. And I definitely do believe that's the culture we have here, I just don't think there's a lot of information available on the ground floor, at the bedside, for us to feel empowered to give the best care possible. I haven't really ever felt that it's been as an organization pushed to teach that. You have to go learn on your own private time and then bring it to the

> bedside. So, I feel that's definitely changing and it's definitely something that wants to be part of the care, because it's a very individual thing. But I'm just not always sure whether I'm always given the tools to do that. I'm not sure whether, with us being less educated, it may seem to our clients that we are not giving them a safe space because we're not really going in there, going in there with a knowledge base that feels secure. (FG2P1)

The same participant talked about some of the challenges regarding training from a personal level, and from the organization. They suggested that education needs to be mandated to be completed, as relying on individual staff and volunteers to do their own research would not be effective:

> I've probably let those patients down because I haven't taken the time to do my education on my own. But sometimes I just feel it's not just in that area [of SGD care], but all different areas [of healthcare education]. When I go home at night I fall into bed and I'm up the next day trying to just keep each day going. And then a year has passed, two years have passed and then I haven't realized. And then if [SGD education] was more of formal education training that we could go through. We have this new software program that we go onto to have training. If it was part of the training for [organization name], it would be something that we could go to rather than us trying to then try and find reliable information on the web that we can inform ourselves on our own time because a lot of the time, we don't have a lot. We have to prioritize what we're learning about because we don't have infinite time. And until you're faced with a [SGD] patient, you're like "oh yeah, I meant to look that up and I forgot." And then now we're faced with

> another patient in this community, and what am I supposed to do? So [education] almost needs to be forced upon us, and it's got [to be] more of a proactive thing than a reactive education. (FG2P1)

There were a multitude of ideas coming from staff and volunteers across focus groups wanting many types and forms of training, but all agreed that more training should be prioritized:

> I think [if employer] can provide us some videos to show us some different clients, how they are, and how to take care for them. This would give us more experience to see on videos, to show us different cases, and how they are taking care of them. This could help us practice [these skills and care]. (FG1P1)

Another participant noted that although information availability was important, it would not completely meet their learning needs:

> I think having the module [on SGD care] is important but I think we also need to have an actual person from the community coming in and talking about [SGD care]. Because seeing something on paper, you can read it and how you process it is how you process it, but actually having somebody there and answering your very specific niche questions would be way more helpful than words on a website. But both are definitely needed because [time between training] can be sometimes 3 months, 6 months between, even longer sometimes. (FG2P3)

Theme 1c: Drawing on Personal Experiences: "All My Training is Very Informal…"

Though participants did not have many professional experiences in their palliative practices with SGD people, almost all people in the focus groups shared that they had some form of informal or lived experience. This experience was often in their personal

lives with a family member such as a child or sibling, a friend or member of their community, or they identified as SGD themselves. Only one participant identified that their experience with SGD people was in the context of palliative care. Participants shared their experiences in the form of rich narratives, describing how they had seen the SGD person face struggles in their life, be marginalized, or even rejected at school or by family members. In their stories, they described witnessing the discrimination against a loved one (often family) who identifies as an SGD person, which spurred them to do their own research regarding LGBTQ+ culture and identity and seek out information and resources. Some participants made the connection between their personal relationships informing their palliative practice with SGD clients. For instance, a participant offers a narrative description of their experience with a family member and its significance in shaping their approach to caring for LGBTQ+ people in their practice:

> All my training is very informal. It's just through experience. For me, my cousin came out as gay when I was, I don't know how old. Let me see, I was probably like 18 or 19 and he told me first. Nobody else. And, my cultural background is that [being gay is] an abomination, and we are church kids, we grew up in church, for anyone to know would be um… It was very hard. My uncle had it set that my cousin was going to get a girlfriend and my cousin would skate around all those things. And I just kind of watched him struggle to navigate that because he had two lives. When he was with me, I would just try to figure him out. Like, okay, why do you feel like you're like this, okay, what drew you to this. And then let's meet your friends, let's go to these parties where you like to hang out, let's try to get immersed in this culture where you feel seen. Because we know when you're

> with us and the rest of our family you definitely don't feel seen, that's a whole other person that you have to be. And I think navigating that with him, and how even other people in his community that I got to know, just to see the way [being SGD] affected them personally, and just how they had to go through that. And even when he did get, he got outted, because he did not get to come out. He got outted, and just the stormfire that came through and how he was treated for a really long time and the support he needed to go through all that. It really formed my personality and how I treat people. Because at the end of the day nobody wants to be judged for anything, it doesn't matter what you are. I feel like because of that one [experience], I see other LGBTQ or trans or whoever outside and I come from that space, of knowing that they probably already had it hard, wherever they came from, whatever their background is they don't need that from me as well. And a lot of them are just looking for safe spaces and just people to let them be who they want to be in that moment that they're trying to be that. So yeah, it's just very informal. It's not something that they teach you in school. It's just life experience. And I like to sit with them and talk to them and get an understanding of how life has been for them. So that you don't trigger them or jump on these landmines that make it worse for them. But if you can offer them anything that makes it a little bit easier than that's what I try to do. (FG1P4)

Another example of how family experience with LGBTQ+ population has shaped participants awareness and approach to a potential unique LGBTQ+ need in palliative care was provided:

P4: I wonder about the family dynamics with extended family members, and I can tell you a story. It's not from my role in palliative care but just from a story from my own extended family. My mom's cousin is gay and maybe would prefer to identify as a man and that amongst the parents and my grandparents, among that older generation, wasn't always respected and certainty this individual wanted to be called [male name], and birth name was [female name], and the father would always refer to their child as [female name] for example. And then the father passed and at the funeral, [family member] got up to give the Eulogy and the amount of unresolved pain that was shared at that funeral was overwhelming to say the least and turned out to be like a 45 minute, hour long eulogy of just unprocessed pain and trauma from not being recognized as who he, they felt they were. And if I was facing the end of my life and I had unresolved issues with friends or family who didn't accept me, I would think that would be a really big part of my journey to the end of my life, would be those unresolved issues, like core issues, and pain. I just feel that would be a really unique part of supporting someone from the LGBTQ community though their death.

P2: yeah, when you were speaking, I just thought of the complicated grief

P3: that could accompany not having valid, respected, and heard, and be able to be acknowledged for who they want to be. (FG3P4,2,3)

In a third example, a participant shares their experiences with a neighbor, and how the school system provided guidance and resources in transitioning:

For me it's mostly personal. My neighbor's kid came out around 5 years old to start to transition in his school and in his community. It was really nice to see him

> evolve. And also, the parents to see how they brought him up and now she identifies as a female and also doing the whole process of changing and hormone therapy and big questions and it's a huge thing and it changed the family dynamic. But it was nice to see also around how when she initially started to realize that she felt more like a they, it was in school and it's really interesting because in French we invented the "iel." We don't have the "they" as in with English. They have he or she or they but in French they have il or elle, that's it. We invented the iel. I-E-L for the they. It's cool that she said "no, I'm a they." And then the teacher said "oh interesting" and actually they brought resources to the school so the school kids and teachers could be reminded about how can we approach and what pronouns and what does this mean, and can we support her because we want to make sure that she feels safe at school because we know there's a lot of bullying in school unfortunately. So very interesting and now to see where she's at in her life, and everything that's around it and also to take those big decisions before puberty and all those things, it's something that maybe, unfortunately, our older clients maybe are doing at a different age. But then making those decisions also when you're a teenager and struggling with your identity, it's big. So it's nice to see that there's resources. (FG1P3)

Though participants did not have very much formal education (from training session, professional interactions, workshops, organizational training) relating to caring for SGD people or their unique care needs, almost all the participants had some kind of lived experience. These lived experiences were very personal, and participants were able to articulate how these lived experiences have influenced their professional care practices

and interactions. Many of these experiences shaped the providers understanding of SGD marginalization and discriminatory experiences and caused providers to not want SGD people in their care to experience the same things. However, the lack of professional palliative care experiences but desire to ensure good care contributed to the next theme, where participants shared their worries regarding saying the wrong thing.

Theme 2: "I Can't Keep Up, and I'm Scared I'm going to Say the Wrong Thing"

Theme two captures many of the participants' worries regarding their abilities to keep up with information regarding SGD people and culture. Many participants linked their inability to keep up with changing culture with fears that they were going to say the wrong thing to SGD people. Their fears were often not regarding speaking to or interacting with the SGD person themselves, but regarding looking ignorant and or not affirming their patients as people. Some expressed concerns regarding confrontation and recognized that their practices are affected by their fears and worries regarding SGD knowledge.

Theme 2a: "We're Always Learning in this Evolving World. LGBTQ – All these letters are brand new."

Many participants believed that LGBTQ+ culture was rapidly evolving. Some equated this dynamic nature to the difficulty in keeping current in terms of knowledge and practices. Some participants believed that the older age of workers and volunteers played a part in their general lack of knowledge, believing that younger generations had more education and more lived experiences regarding SGD people because their friends were more diverse. A participant noted:

> People need training, and I think there's never enough training. As in, we're always learning and we're in this evolving world. LGBTQ, like all those letters are brand new, and when you look about it and the history. Same thing for the medical issues and addiction and trauma, these are also new subjects. So, I think we're always trying to evolve. (FG1P3)

There is a long history of LGBTQ+ populations relationship with healthcare and palliative care especially. One participant commented on the history of mistreatment, and another commented about how they sometimes forget, with all the new changes that are happening, that there is also a lot of history to know regarding SGD people:

> P2: For the LGBTQ community the obstacles that have existed over the years in healthcare, the prejudice that they've run up against is a real barrier for people to be even accessing hospice services because … there's been a lot over the years, and people very badly treated. Talking about even going back for years of course, [education session speaker] talked about even all the experiences he had [as an SGD individual] were just horrendous and then, obviously, through the AIDS epidemic how people were treated was absolutely appalling. And some of those people that survived during that are aging, they are going to be reluctant [to come to hospices].
>
> P4: Some of the headway, some of the pieces of legislation [regarding transgendered issues] that have come into play are so recent, and I don't know, I'm still young and I forget that there's all that history. (FG3P2,4)

Other participants commented on their perceptions regarding how changes regarding LGBTQ+ culture are difficult to keep up with and how the younger generation may find it easier:

> When you said, "I'm older," I'm older than you are. (group laughter). I have 2 children who are members of this community, and I try to be educated through them often. But I find it quite complex and sometimes I'm constantly asking for repetition of the information so that I can really get it in my brain. And it seems every year it gets more complicated, the terms, there are more terms, more ways to refer to people and [it makes knowing and using the right language] very complicated but in the end, I as a volunteer want to make the person in that bed feel like they are part of a community here. (FG2P2)

Another participant commented on their lack of knowledge about LGBTQ+ populations because it was less common, less spoken about, and not taught:

> Marriage, common-law relationships, partners, second marriages have all become so common that now we know the questions to ask about. Like [do you have a] common law partner? Do you have a blended family? Do you have children? Who's going to be your POA [power of attorney]? And that plays into the whole family dynamics thing about how families operate but I don't feel like we have the same knowledge base to go on for the LGBTQ community because it's not spoken about as much, so therefore we have more of a general view but we're not really getting taught [about LGBTQ families] either so we're not really getting a general base to go from to then go forward and be more individual. (FG2P1)

This participant shared their beliefs that younger generations were more educated on the subject and had more “tolerance”:

> I think because we have different age ranges of staff more information would be better. Because the younger staff, they’re more into pop culture, and they get [more exposed to SGD people and culture]. Or even when you’re going through school, my kids will probably be way more educated on things vs. me … because the level of expression now or even the way that they teach things in school is much different than my experience. And so even just with kids being allowed to wear whatever the hell they want to school vs. back in the day I don’t care what you identify as you better wear boy clothes if you’re a boy and girl clothes if you’re a girl. It’s not really like that now, so [the younger generation are] going to have a different tolerance level. If there were more resources, so you could be able to bridge that gap, that would be great too. (FG1P4)

This participant commented on how they believed the LGBTQ+ community is becoming more complex and believes that in general the healthcare world is not adequately prepared to care for them safely:

> When you think about this, feeling safe or unsafe our whole … I’m thinking about my generation and my kid's generation that it’s become much more of a norm, to have people in the LGBTQ community. I know it’s gotten more complex than that, in our culture we’ll probably all know someone who’s in that group. Those are going be the nursing home patients of 20, 30, 40 years and I don’t think the system as a whole is ready for that. I don’t know whether there’s enough of a part, an education and I think in general, I can’t speak for people but,

> I suspect there [has] been a lot of a lot of insecurity through the health care system, at various levels throughout the health care system [for SGD people] that I don't think hospice would feel like a safer place until we could prove it to [SGD people], and show it to them. But I don't think we could do that fully without more education for us as a workforce. (FG2P1)

Overall, many participants believed that SGD culture was rapidly changing or evolving, and this is part of the reason they have difficulty keeping up with the new information and language. Some participants knew that their struggle to keep up with changes in culture and language could affect the care of their patients.

Theme 2b: "You Feel Scared You're Going to Put Your Foot in Your Mouth…"

A very common thread among participants was this idea that they could say the *wrong* thing to SGD patients or family members. Participants stated that their intentions were not to be cruel, exclusionary, or ignorant, however they were afraid of being perceived this way. They worried about offending someone or making them feel discriminated against. These fears, at times, led to avoiding perceived confrontations, use of pronouns, and conversations regarding sexuality and gender identity. This included conversations not just with patients and families, but with colleagues as well.

One participant talked about being nervous regarding gender and sexuality conversations, and how they approach patients because of it:

> I'm also a little nervous about confrontation. I don't know when to even start the conversation because a lot of the generation that we look after are the older generation, 65-70+. So, I don't know when to ask and when not to ask those questions [regarding gender identity or sexuality]. I just look at the person, and I

> don't see factoring that in as part of my [care]. I even just avoid trying to use pronouns for the most part, just to avoid the conversation in general. (FG2P3)

Participants talked about the fear of hurting or insulting people as a big factor in their discomfort, for example this participant said:

> My age being what it is, I thought my time at school, the only word I can think of in our observation, thinking back, memories, because it was never discussed, is almost oblivious to people's needs. And it didn't bother me then, I guess I was oblivious too. Now I think how dreadful those high school years must have been for individuals who were feeling very different and extremely isolated. So, in a sense we've come a long way, but in conversation the biases are still there and many of us are not sure just how to handle these situations. I'm not saying we don't want to, but again that fear of saying the wrong thing, hurting somebody. (FG3P1)

It is important to note that though the participants spoke of fears and worries, it was not always regarding caring for the patients themselves, but an intense fear that they were going to offend or hurt the patient by saying the wrong thing, as this participant noted:

> I think sometimes I worry that I'll be, it'll be offensive to the person if I say "what pronouns would you like me to use" because am I going to offend them by asking? I'm assuming they'll probably be quite pleased to be asked but I'm scared to be hurtful or overstep my boundaries. And I'm happy, I'm completely happy to ask I just - sometimes worry that I'm going to hurt them in some way. Because some of this should be obvious, I don't know, I'm scared of

> confrontation. I'm scared that it would be more confrontational than helpful sometimes. (FG2P1)

This participant talks about how they grew up in an unaccepting culture (regarding religious, racial, sexuality, or gender diversity) that made them uncomfortable and how they now worry that those ideas may show themselves in an unintentional and offensive way:

> I think something I've always struggled with was the messages I received in my home growing up. Not so much in the school but just the comments my dad would make about anybody that was not conservative or white or Christian or white or heterosexual. And it was very much the same, but it always felt very uncomfortable -very, very uncomfortable, but it was also a place that I couldn't speak back, for fear of the anger or just what the fallout, the fallout we'll say. So, you just, you didn't [speak back]. So, then it wasn't until we left home, went on to university … there's been so many other things going down the road. But I do worry that [education I am currently taking], and we did a whole course on cultural diversity, but I do worry because of that early childhood programing, and I try to be as open, as self-aware as I can and really look at my biases, but I almost feel like is it somehow stuck in me in a way, like will I be making a microaggression with a client in some way, whether it be based on their sexual orientation, their gender, whatever it is, or their spirituality or their race. So I'm aware of that and have to be like, okay I'm human, that kind of thing, and try not to, almost put too much pressure on myself in a way, because I'm almost overly worried that I'm going to hurt someone. (FG3P3)

This participant talks about how they want to be a "complete positive force" in their patients' lives and feels there is a lot of pressure to do so. They link this pressure to the discomfort and fear they feel regarding saying the wrong thing because they do not feel they have knowledge of SGD culture:

> And I think to work in palliative care most of us, the majority of people who work in palliative care are there for the right reasons and they're there because they want to preserve dignity and respect they want to give quality end of life care, they want to support their clients and their families, they want to be a complete positive force through that journey. For that reason, everybody feels the ante going up and it just creates a bit more of a pressure. Because we're very much more comfortable with he and she because that's what we've grown up with, but I don't feel immersed in knowledge about the LGBTQ community enough that I would feel comfortable just starting random conversations because I just don't feel, you just feel scared you're going to put your foot in your mouth. That happens to me regularly (group: laughs). Like on a regular basis. (FG2P1)

These feelings of fear and discomfort and avoidance applied across settings, including in hospice, in homecare, in group settings (such as day hospice programs or bereavement groups) and across professional backgrounds. For example, this home support and bereavement group volunteer spoke about their worry regarding creating uncomfortable conversations with their clients':

> I think there's also a feeling there … A feeling there of "can we talk about this" or is it going to make people within this [bereavement] group feel uncomfortable. Maybe we prejudge some people, and we know that person might have a hard

> time with this, accepting this person into the [bereavement] group. And we do hold ourselves back from having an open discussion because we're worried about making certain people within the [bereavement] group feel uncomfortable or ourselves feeling uncomfortable with facilitating that kind of a discussion. (FG3P4)

This participant talked about discomfort not just with a patient themselves, but with a family member, and believed that having disclosure regarding SGD status ahead of time may have decreased the participant's discomfort:

> I recall, we had a lady at the far end of the hallway here, and her brother was transitioning. I wish that I had known that before I opened the door the first time. The first time I encountered (pause) her was when they rang the bell to come in, and I was taken aback because I didn't know, and had I known I would have been prepared and maybe I wouldn't have been stumbling over my words, and how I greeted them. I felt, I thought "have I insulted them, have I hurt them, have I upset them?" And if I go to apologize later, am I going to make it even worse. And I think that's all part of being safe. (FG2P2)

Overall, this subtheme showed the general fears and discomfort that participants felt regarding communicating with SGD people and families. The participants felt as though making mistakes or accidentally offending someone and not being adequately prepared for interactions with SGD people contributed to their care practices, leading to avoidance of perceived confrontation.

Theme two showed that participants in the focus groups struggled with keeping up with SGD culture and language. They attributed this, in part, to their perceptions that

SGD culture and terminology were changing quickly, and that there was knowledge they lacked. These feelings of lack of knowledge contributed to discomfort when caring for SGD clients and family members. The main fear in talking to SGD people, however, was in that they were afraid of offending SGD people or looking ignorant. The fear experienced was not of SGD people themselves. Participants were honest and self-reflective regarding their shortcomings and genuinely desired to create safe and accepting environments for their SGD patients but felt there were barriers to doing so (i.e. their lack of knowledge and fears talking about SGD issues).

Theme 3: Our Approach Centers on Each Person as an Individual

The final theme was regarding patient-centered care approaches and seeing each individual patient as a unique person. Participants spoke to their practices as being highly tailored to each individual patient, noting that customizing care to their patients' wants and needs required them to get to know their patients and genuinely accept them for who they were as people.

Theme 3a: "You're a Person, What do You Need, How Can We Give it to You?"

Participants had very deep and passionate ideas surrounding the importance of affirming a person as a person. Specifically, they placed emphasis on the importance of the process of figuring out who their patients were as people and a desire to make them feel at home (as opposed to at an institution). Participants did this by acknowledging that their clients needed to feel heard/listened to, feel seen and represented, and feel acknowledged for who they are. They showed deep respect through a few practices, including confidentiality rules in group settings (to ensure comfort to share who they were), supporting any cultural needs (religious, spiritual, LGBTQ+ or otherwise), and by

teaching staff and volunteers the importance of understanding their own biases. An extension of this specific to SGD patients was the recognition that LGBTQ+ relationships were valued just as other relationships are, and that their grief over loss of partners/family/friends was of equal value regardless of the LGBTQ+ nature of the relationship. One participant talked about how quality of life was very individual and important in their care practices:

> P3: Palliative care is just centered on quality of life, so what's their quality of life? Everybody has a personal understanding of that, and we're all different so if for them right now is "YOLO I want to eat chips and go smoke crack and come back and then chill…
>
> P4: and then die in peace, that's how that goes
>
> P3: and die in peace" lets do this, lets put all the things together. Quality of life I think is very important. (FG1P3,4)

This participant talked about how she viewed patients as people first:

> I think in terms of minorities and sexuality, it's just like [colleague] said, I think it's just more client centered. It's not really a white/black/orange/pink/green type thing, it's just like "person." Like, you're a person, what do you need? How can we give it to you? Kind of thing. And with minority groups, I've seen even with our First Nations people [our organization] really tries to get some kind of diversification, so they feel seen. They're [organization] always trying to find more ways to be more inclusive. So that people feel heard… they're always trying to open more doors and take down more walls so that people actually feel more represented and seen in these programs, which is nice. (FG1P4)

This participant talked about how the importance of genuine acceptance and effort go a long way in validating people and their grief:

> I think if you're genuine about your desire to be present with that person and in your acceptance. We all acknowledge that none of us are perfect, and we all screw up from time to time and we all say things we wish that we could put back in our mouth. But I think people recognize somebody who is genuinely trying to understand as opposed to somebody who's just paying lip service. So if you're genuine in trying to understand and in being accepting, then even if you screw up from time to time, people aren't, I mean maybe some people, but most people, they just want, especially in palliative care, at the end of their life, people just want somebody there who cares about them, who wants to be with them while they die. It doesn't matter who you are, everybody has that same need. So, if you're genuine about that I don't think people, like [the gay man] in [the] bereavement [group], he just wants to be heard. Same as everybody else, he just wants to be heard, and he wants his grief acknowledged. And yeah, he was in a relationship with that man for 30 years. His partner in life has died, the same as everybody else at that table. (FG3P2)

Participants form this same focus group reflected upon the idea of good intentions and if they are enough to provide safe care:

> P4: I think when we look at the hospice and the volunteers and the staff here all of us are just so well intentioned, we just so want this [hospice] to be wide open. And that's the feeling I get when I get here... But it takes more than good intentions to remove the barriers to care

P3: It takes action and constant awareness

P1: And a certain amount of time. We have to let time settle a bit, and then we just progress another step, but it has to be a conscious progression

P3: [We have to try] to put ourselves in their [SGD peoples] shoes

P2: But also know that we have no idea what people have been through. We don't know what trauma and pain and what they've heard and listened to and be told and made to feel. (FG3P4,3,1,2)

The group further noted the consequences of not being able to show that a palliative care space was safe. As the people in the focus group said before, good intentions are not enough. If trust is not established, the opportunity for care provision may not even happen:

… if you don't know that you're going to be accepted, you just don't, you don't reach out. What happens is, you find those supports withing your own community. (FG3P2)

All groups of participants spoke to the importance of getting to know and accept each patient as a person. Participants also noted that although their intentions were good and they valued patients as individuals, sometimes this was not enough to ensure safe care because each individual had different experiences, and their history may influence how safe they feel at institutions such as at a hospice.

Theme 3b: "It's Not Going to be Quick and Task Oriented and it's Going to be Very Individual, Geared Toward What Their Wishes Would be and Their Priorities at End of Life."

Participants agreed that palliative care is centered on individual people and their needs, wishes, and preferences. This meant that care, in practice, was constantly adjusted and reevaluated on a per person basis. Participants described a non-judgmental attitude as a part of person-centered care, as they were not to judge what a person wanted in palliative care based on their own wishes and values, but on the those of the patient they were caring for. They described not using scripts and task-oriented care philosophies as they recognized that they were not affirming individual patients' care needs. They treated information about wants/needs/wishes as very important information to have and share with the care team to deliver high quality coordinated person-centered care. They believed that this focus on individual needs and wishes ensured personalized care and comfort and acknowledged that safety and comfort for patients was a prerequisite to disclose this type of, at times, sensitive information.

One participant spoke about the importance of having non-judgement attitudes:

> No judgement when it comes to drug use, so we always ask that they tell us everything so that we can take care of them in the best way possible because we're also a harm reduction organization. (FG1P2)

Further, the same participant talked about how care practices are not different among patients, but based on how the patient wants to be taken care of:

> We've had a few other clients from the LGBTQ community and they're just another client. But we work to make sure that they always feel safe here, so no,

> other than tailoring care to their needs and making sure that they didn't feel discriminated against by anybody, there was no real difference in how we treat any of our clients based on their gender, minority anything. It's just as if they had a different religion and we make sure that they have their different denominations or different pastor or an Imam or Rabbi. It's just, there's no difference between them, okay this is who you are, okay how do we take care of you the best way you want? And then we go from there. (FG1P2)

Safety was a central discussion point during focus groups. Palliative care workers in the study had a very diverse theoretical understanding of what safety was. For example, when asked what safety meant in the context of their practice, a participants stated:

> Physical safety, number one. Emotional safety. And safety, I think, similar to what [Par3] said, safety to be who they are and not what somebody else thinks they should be. (FG2P2)

This is an interesting quote, as it gives insight into how palliative care providers understand what safety is and means in the context of their work. Firstly, different types of safety were noted as separate types of safety (not just by the participant in this quote, but others as well). Other groups described physical safety aspects that included things such as meeting physical needs of patients, having a roof over their heads or permanent housing, having 3 meals a day, to be free from violence, and to have physical care that made them comfortable.

Emotional safety included space to be heard, to be themselves/their authentic self, keeping confidential information confidential, having non-judgmental spaces and healthcare workers, to feel included and not othered and use of inclusive language

(including on materials), that their questions would be taken seriously and answered, that their care will be kind, compassionate, and personalized and not simply task oriented.

Another kind of safety was not explicitly articulated, but I believe was brought up – safety in relationships and personal trust. This included things such as having consistency and building trust from having consistent and familiar staff available, advocating in group settings for belonging, and understanding and being able to attend to individualized needs of patients (person centered). An example of having consistency in staffing is described by this participant:

> I think that level of consistency is really good for the clients. Because in other units sometimes when they don't have [the same staff] it creates some kind of tension but here they [clients] always know that she's [staff member] always going to be here. So, it's a kind of peace for [the patients]. "She's going be here, it's okay we'll get our stuff dealt with." (FG1P4)

Another participant talks about how safety for their patients is related to person centered care:

> Safety is a high priority for our patients. They have to know it's a safe place so they can be themselves without judgment. I want them to feel that they can broach any subject anytime and I would feel able to either answer the question or find somebody who can. They are entitled to physical care that would be kind, compassionate, just to honour them in their journey, that it's not going to be quick and task oriented, it's going to be very individual, geared to what their wishes would be and their priorities at end of life. (FG2P1)

These participants talked about their approach to care also being patient centered, regardless of their differences, and another talked about caring for patients to the same standard they would want a family member cared for:

> P3: Yeah, and that's my overall approach for anybody who comes through the doors, I tailor care specific to the person, this political [orientation], that political [orientation], this culture, that culture, this sex, that sex, it doesn't matter I try to just be the person to support them through their journey regardless of whatever it is they might be. [I'm] trying to get a bit of a better sense of what I need to do for transgendered people just by listening to this [focus group] or anybody a part of the [SGD] community.
>
> P1: Yeah, I agree completely with [last speaker]. It's very patient-centered. From a physical aspect I try to think to myself how do I like to lie in bed, if my shoulder is lying there is it uncomfortable if it's like this, I try to put myself in that person's position. And then I think, from a physical aspect what would be more comfortable than others. But then from a psychological, social, emotional point of view it tends to be very much patient driven. What do they want? What have we found out over the course of their care that we can adjust. And so I'm very much like [last speaker] in that: respect, privacy, dignity. And how would I want my - one of my one family members - to be treated, because I don't expect anything less of myself for my clients. (FG2P3,1)

The last participant also talked about how patient center care was patient driven, implying that one's own values are not the focus. This focus group brought up self-reflection/self-awareness as important in creating safety:

> P4: I think when dealing with the LGBTQ population specifically that there needs to be an active part on our part as care providers to uncover our own unconscious bias. And maybe it's uncovering it within a group setting. There's such an uncomfortableness, I think, as a population, that we face in terms of talking about bias and discrimination and I think the responsibility on our part is, as care providers, is to dig deep, and say "what am I really holding here subconsciously that could prevent me from creating a safe environment for this individual."
>
> P3: And I think weather it's LGBTQ or religion or spirituality or race or ethnicity, in any of those, we look at our biases and have self-awareness to ensure that it does feel safe for those clients all coming together. (FG3P4,3)

Another participant talked about how they had a hard time knowing or thinking of specific care needs for SGD patients, and their belief that maybe a patient centered approach should be enough to ensure good care:

> I don't think I've ever thought about specific palliative care needs [for SGD patients]. My first thought was "is there any"? If you're treating the person as a whole holistic person individual care, should they not be getting the care anyway? But then when you delve deeper, sometimes it's more difficult to get there, to find out their needs. But from a practical point of view, I generally come from that point of, um, what's the word, I don't know enough about it to say actually is there any palliative care needs that we have to think about, I genuinely don't know. (FG2P1)

Similarly, a participant in a different focus group talked about their palliative approach for LGBTQ+ patients being similar to other patients and how their patients are good at "directing and teaching" them how they want to be cared for:

> Working here specifically, I don't think there's been any care specifically to someone's sexual orientation or group. I've seen it a lot downtown, but that's more in the shelter system, and they don't have a specific care that's different from everybody else's care. You just support them like you support anybody else. I don't have any specific experience that was different. Other than when we have clients come in and sometimes they're trans or they're non-binary and then if one staff knows they'll tell you in advanced, "Hey, this is what their pronouns are," and you go with that when you're going to go introduce yourself to them or help them do something. If you don't know, a lot of our clients are very good at redirecting or teaching and educating. So that's helpful as well, and you just go with that. They're just regular people. They're just like everybody else in our system. (FG1P4)

Conversely, this participant talked about how having to constantly educate and teach health care workers may take a toll on SGD patients:

> Here we go again, a new nurse today. Oh, here we go again. At every point in their healthcare journey, the healthcare system, they're explaining to their GP [general practitioner], they're explaining when they go into emergency, they're explaining it when they're in the hospital, they're explaining at hospice. I wonder if there's a way that we could make it obvious, because we're not sharing information between all the systems, but is that something we could do? The

> admissions coordinator could then be more of a question for them to find out the information and then can we have more information upfront as part of the admission profile, so that we're really getting to the bottom of who is this individual that's coming in our doors, and how we can support them as best we can. Rather than the patient themselves, it's their responsibility to share that information again with the health care providers. (FG2P1)

The last quote also talked about information, and sharing of information, showing that some palliative care providers believed that information sharing may be helpful to create more person-centered and supportive care. In contrast to the attitude that as much information as possible should be shared in charts, one participant acknowledged that sometimes patients may not want to share information:

> There are opportunities where people can talk… sometimes [there is] information they don't necessarily want to share at the beginning. When I see people are getting less and less verbal sometimes, I really try to tie knots [ensure wishes and preferences for end-of-life/palliative care are documented] but sometimes they're not ready and they don't want to tie those knots. It's alright, we try. It's getting better every time… Maybe some people are at peace and they don't want to share [this] information. And what are you going to do, stir up some old crap just before they are dying, honestly? (FG1P3)

Person-centered care that was individual was engrained in the way these palliative care providers cared for patients. They recognize that two things are true at the same time that appear to be odds, but are actually both affirming of SGD people; that SGD people are the same as other people and deserve the same treatment as every other patient; and that

every patient (SGD or not) is treated differently based on who they are what their individual needs are. The providers understood safety as ensuring physical, psychological, and relational needs are met, and that patients are comfortable, and part of being safe is doing person-centered care. There were some different views of information and disclosure sharing, with some groups believing it would be better to have as much information as possible in the chart ahead of time so the burden of constantly having to repeat their story to healthcare providers was minimized, with other groups more following the lead of the patients and allowing the patients to guide their care by educating the staff about themselves and their care preferences.

Summary/Conclusion

Overall, many participant's knowledge and practices were guided by informal experiences from their personal lives (often not in palliative care contexts), and not by direct experiences with SGD patients or professional educational experiences as shown in theme one, the effect of experience on care. Theme two showed some of the difficulties providers believed were affecting their care of SGD patients, including the perception that SGD culture and language was changing quickly and they could not keep up, as well as the fear and discomfort regarding saying the wrong thing or being perceived as offensive towards SGD people. Theme three showed that participants understood the importance of SGD status to their patients' palliative care journeys and earnestly were trying their best to create safe and comfortable spaces for their patients. They used the tools that they had available to them, which was a deep understanding of SGD people as people and person-centered care approaches. Participants also recognized their own lack of professional experience and discomfort as barriers to providing safe

care and wanted more training in SGD topics to improve their care practices, in line with their valuing of SGD people's lives and deaths.

Chapter 5. Discussion

The Power of Normal: Discomfort and Disclosure

Norms and normative structures that govern nursing practice are often difficult to see but are important because they affect every interpersonal interaction. “Norms may not only have a way of disappearing from view, but may also be that which we do not consciously feel (Ahmed, 2014, p. 148).” Relational inquiry acknowledges that “the normative structures and practices within health care settings explicitly and implicitly shape the way nurses practice interpersonally in all settings” (Doane & Varcoe, 2021, p. 75). This section discusses analysis of norms and normative structures that affect SGD people in palliative care. First, how participants described their discomfort in providing care for SGD patients and families is explored and then contrasted with the familiar practices of working within discomfort in caring for people who are dying and engaging in conversations about death. Second, disclosure is discussed, specifically using Foucault’s conceptualization of pastoral power to consider how disclosure is related to patient-centered care. Third, ways in which palliative care could benefit from queering are imagined, including ideas surrounding reciprocal community engagement and education. Finaly, ideas surrounding the reconceptualization of safety are explored.

Discomfort

One of the most prominent findings from this study was the discomfort that providers often felt regarding discussing SGD topics. Ahmed (2014) describes discomfort as a feeling of disorientation where one’s body feels out of place, estranged, unsettled, awkward. I found the participants’ discomfort surprising, because palliative care providers are experts with having hard conversations, being uncomfortable, and

discussing difficult subjects. They regularly talk about death, dying, grief, and bereavement (Reitinger et al., 2018). A study found that recent experiences with death or knowledge of palliative care in general was linked to less discomfort discussing death and suffering (Quintiens et al., 2023). Though an uncomfortable or difficult topic in general, topics relating to death did not seem to be uncomfortable for the participants in this study at all, which led me to wonder if comfort talking about death was perhaps a product of specific palliative care norms, culture, and training. However, it seemed clear that this comfort did not translate to comfort with other difficult and uncomfortable topics, specifically SGD issues.

Education and training offer learning opportunities that operate as a potential mediator of comfort. Exposure to ideas and socialization normalizes practices that become accepted. Culture is produced through education, practice experiences, and role-modeling, whether explicitly part of the education or not. Engagement with certain aspects of care and refusal of other aspects of care within education and training experiences influence practice and delineates what is acceptable to do, discuss, or ignore.

While participants in this study believed that more formal training was required to improve care and safety for SGD patients, they also identified how current education practices continue to produce discrimination. Durocher & Caxaj (2022) showed that gender binaries have been and continue to be pervasive in nursing education. Because teaching, theory, and research form the basis of clinical practice, harmful discourses regarding heteronormativity and gender binaries can be transferred from the classroom to practice, challenging safety for LGBT patients (Durocher & Caxaj, 2022; Kellett & Fitton, 2017).

What is taught is not the only thing that influences clinical practices; what is not taught, or deliberately avoided, also affects discomfort and practices. Lim et al. (2015) reported on the many barriers to increasing LGBT content in nursing undergraduate programs from the perspective of over 1200 faculty members in the United States. Barriers included limited time/space in curriculum, discomfort in teaching LGBT curriculum, lack of knowledge, social pressures (e.g. from religious institutions), and not requiring LGBT topics for accreditation or for the national licensing examination (Lim et al., 2015). Because faculty hold authority over what knowledge future nurses gain, these perceived barriers are worrying. Perron and Rudge (2016) aptly describe how "in healthcare organizations, where care is increasingly monitored and standardized, certain kinds of knowledge enjoy particular authority and legitimacy (Perron & Rudge, 2016, p. 20)." In this way, Lim et al.'s findings that faculty members do not have enough time/space in the curriculum to teach LGBT care can be justified by concerns about time and curriculum space, but nevertheless points to educational priorities, and signals devaluing of and deliberate omittance of LGBT topics (and people). Barriers to faculty teaching LGBT topics because of the knowledge priorities set by governing bodies, some knowledges are legitimized, while others are not. By not requiring LGBT topics for accreditation, practice is shaped. In some cases, norms are led by institutions directly pressuring faculty to not teach SGD care. In this way, education reproduces heteronormative and gender normative assumptions. Thus, important knowledge to support safer care of SGD people is excluded from health care provider education. This omission underpins norms of specialized palliative care organizational training.

One example of how normalization through organizational training happens is through one of the standard training programs in Canada for palliative care providers: Learning Essential Approaches to Palliative Care (LEAP), provided by Pallium Canada. This course has whole sections dedicated to self-reflection (regarding its importance, regarding past experiences, attitudes, beliefs, values, fears, and biases and how they affect palliative care, and include practical self-awareness activities), advanced care planning (how to start the hard conversation), grief (how to approach conversations), and essential conversations (how to have challenging conversations) (Pallium Canada, 2021). Learning strategies include engaging the learner with many case scenarios, videos of those with lived experiences, role playing, group discussions, and self-reflective activities. Interestingly, LEAP courses do not explicitly discuss SGD care, or care of those from different cultures or minoritized populations. LEAP has specialized courses in individual disease systems (such as renal or lung) and in different settings (such as for long term care workers) but their curriculum does not attend to the specialized issues that SGD populations may face ("LEAP Core | Award-Winning Palliative Care Course," n.d.). As an influential educational program in palliative care, this omission can be understood as participating in the production of discomfort and contributing to silence surrounding SGD people's needs in palliative care.

Normalization alongside institutional values regarding death and dying, as well as the everyday work and practice regarding difficult discussions with patients facing death, are what may create comfort in discussing the difficult topics of death. Though participants across all focus groups identified that their organizations had some form of anti-discrimination statement on their websites, only one of the three organizations had

any recent training. Even in this case, the training was minimal, including a single presentation from an SGD community organization. Thus, in the context of limited practice experience, a culture that does not regularly talk about SGD people, care, and issues was created. Therefore, it is less surprising how providers in this study described feeling uncomfortable and unprepared to care for, or at times even talk to, SGD patients. Discomfort then becomes of special interest because those who took the time to participate in this study all described their motivation as connected to their desire to provide better palliative care for SGD people.

Cloyes (2024) found that even if they are well-intentioned, when palliative providers are uncomfortable with SGD patients, topics, and care, SGD people in palliative care notice their discomfort. This means that an undue burden on SGD people and caregivers exists, where the SGD person is positioned in a role where, to receive safe care, they are responsible for disrupting the usual practice of ignoring needs related to their sexuality or gender. Additionally, they are positioned in an awkward and demanding role where they are required to teach providers. They may even feel pressure to ensure provider comfort at a time when they are stressed and grieving, and may lack capacity to educate or address their care provider's discomfort (Cloyes et al., 2024). In this study, providers' discomfort, especially with transgendered patients, led to avoidance of conversations regarding gender and pronoun use. This was similar to what Braybrooke et al. (2023) found where clinicians, though they realized the importance of LGBTQ+ identity to holistic care, considered topics of gender and sexuality to be sensitive topics and sometimes avoided initiating them.

While discomfort entrenches and reproduces discriminatory practices, it also can be helpful. Instead of trying to avoid discomfort, it could be reconceptualized as an opportunity to reflect that something needs to be assessed further, in the same way that discomfort with dying, death, and grief have been used to develop palliative care as a specialty practice. Discomfort points us towards where we need to direct our attention, weigh decisions more carefully, and reflect on the source. I saw this happen within the focus group dialogue, where participants were given an opportunity to honestly and openly discuss their fears, worries, and thoughts regarding care for SGD people. Participants were encouraged to reflect on their discomfort and collaborate with their colleagues and the researchers to consider ways to overcome discomforts and co-create safer care. Participants were also able to brainstorm ways to change their individual practices, but perhaps more importantly, ways in which their organizations could improve relationships with SGD patients as well as the SGD community. For example, the participants of one focus group reflected that they had not cared for many SGD people, and wondered why. They traced historical issues related to palliative care, especially in the 1980's and 1990's with significant discriminatory practices around care of people with acquired immunodeficiency syndrome. From here, participants realized that their hospice could do more to ameliorate the exclusionary practices by reaching out to the community and demonstrating their intentions to recreate their hospice as an inclusive place. They began making plans to contact organizers of the Pride Parade in their community, and to make a point of participating this year for the first time. In this way, this focus group became not just a data collection method, but a means for social change.

Disclosure

Disclosure is a complex phenomenon which has been discussed from multiple healthcare perspectives in the literature (Chinn & Eliason, 2018; Venetis et al., 2017). This study offers a discussion of disclosure in the context of safety within palliative care. Cultural Safety and Relational Inquiry both speak to the importance of power in the healthcare setting, particularly the importance of understanding the power healthcare providers as well as healthcare systems have over their patients. Both these frameworks help to understand power from a historical, political, and cultural perspective, while simultaneously advocating for the need to challenge traditional power dynamics and find ways to share or equalize power in the healthcare setting. Though these perspectives are very helpful, I found myself wanting to go deeper in my understanding of how power imbalances are created and how they operate regarding disclosure of SGD status and health and social information in general. Though not part of the initial theoretical forestructure, I believe that Foucault's (1983) concept of pastoral power provides this discussion on disclosure an important view on how power is operating within palliative SGD care.

Pastoral power in the modern sense (no longer in the catholic sense) is a type of power that: a) has the mission of salvation for individuals (in this case salvation is equated with safety and good quality care); b) is both a type of power and a type of responsibility; c) is concerned both with the individual and the population as a whole; and d) requires intimate knowledge of the individuals in order to work (Foucault, 1983). Pastoral power comes from both caring and being responsible for the outcomes of that care. In this way it resembles the palliative nurse's role: to care for the patient as best as

possible, but with the responsibility to ensure safety and quality care. To do this, intimate knowledge of patients is gained (or is a necessity) to provide salvation (such as the very thorough initial assessments done for palliative care services). Power is gained through this exchange of intimate information and is to be used to guide the patient in making decisions for the good of themselves and the community at large (Howley & Hartnett, 1992; Oppedisano & Dillard-Wright, 2024). Pastoral power also governs what is normal and asserts its legitimacy and power through codes of what is normal (Oppedisano & Dillard-Wright, 2024). These codes include trajectories towards death and disease, what is constituted as safe, what treatments are acceptable, and what is normalized in palliative care institutions. These codes require careful management to ensure optimal palliative care goals are met (both individual and collective), and thus collection of personal information is not just wanted, but necessary in the management of the palliative patient.

Pastoral power is helpful in interpreting the findings. Each focus group discussed a deep-seated belief that ensuring good patient-centered care requires intimate details of patients and their families. In fact, patient-centered care was overwhelmingly cited as the central/guiding force in participants' palliative care work (see Theme 3). This collections of intimate information was justified by the implied promise that palliative care providers would use this information (including sexuality and gender identity information) for the purpose of individualizing care, as this was considered good patient-centered care.

SGD status disclosure is debated in the palliative care literature as both potentially helpful and harmful. Interviewing clinicians, LGBT+ patients facing serious illness, and their partners, Braybrooke et al. (2022) found that discussions of sexuality and gender identity improved patient-centered care practices. Specifically, for patients

who were comfortable sharing their LGBT+ status, standardized recording was helpful for reducing repetition, assumptions, and mistakes (Braybrook et al., 2022). Similarly, Schmidt et al. (2025) interviewed both patients and staff and found that the process of collecting SOGI data helped patients feel like they were a whole and authentic person when entering care. Disclosure allowed SGD patients to focus on their health instead of fearing that their identity would not be acknowledged. Further, disclosure produced increased visibility for SGD people in healthcare. Similar to the participants in this study, staff participants in Schmidt et al.'s study (2025) believed that SOGI data was important to improve the care of SGD people in general as it could play a significant role in knowledge generation and justify targeting resources towards health inequalities (Schmidt et al., 2025). Multiple studies argued similarly for the population benefits of collecting SOGI data for its potential use to better understand palliative care access, risks to the population, and identify and dimmish inequalities (Candrian & Cloyes, 2021; Toze et al., 2020).

On the other hand, potential risks were identified in disclosing SGD status, especially at the interpersonal level. Historical and current homophobia and transphobia, with mistreatment, discrimination, or substandard health care, translates to real and perceived dangers of disclosing SGD status (Bristowe et al., 2023; Cloyes et al., 2024; Rosa et al., 2023; Toze et al., 2020). Additionally, multiple studies reported that the disclosure process itself could cause harm and stress at a time when health status is already producing vulnerability (Cloyes et al., 2023; Varcoe et al., 2009). Because of these significant risks, many SGD people decide not to disclose their identity in palliative care contexts (Bristowe et al., 2023; Cloyes et al., 2024; Rosa et al., 2023). Disclosure is

a highly personal, relational and contextual decision for SGD people to make, with safety being a large factor in disclosing to providers (Chinn & Eliason, 2018, pp. 25–28; Rosa et al., 2023).

In this analysis, and through the lens of pastoral power, patient-centered care involving collection of detailed information, especially including SOGI data, can be understood as operating rhetorically. While patient-centered care principles require care providers to pursue details of patients' sexuality and gender, within the current discriminatory social context it also produces vulnerability, and opens people up to forms of discrimination. The formation of intimate knowledge as required narrative allows an opportunity to exert control over the palliative patient (i.e. being cared for well can only happen on the condition that information is disclosed). Volker et al. (2004) found that patients desired control over their palliative care in a multitude of ways including: protection of dignity; control of pain and other symptoms associated with disease; management of treatment; management of how remaining time is spent; management of impact on family; and control over the dying process. Palliative care providers can exercise influence and control many of the things patients' listed as important to control in their own palliative care journeys. Pastoral power operates through various techniques and practices including: provider's position as expert and knowledge holder (power derived from the position that they hold as nurses including having specialized knowledge from occupational/educational training, knowledge of palliative care and dying process, and knowledge of how the system works), power over resource allocation, power to make decisions regarding the care of their patients, power over information once collected (such as accessing charts or ability to go to family members for

information), and power over management of clients (such as how much time they choose to spend or not spend with clients) (Oudshoorn et al., 2007). Palliative care patients who are also SGD, in addition to being vulnerable to the power that providers wield over the palliative process, are vulnerablized in additional ways. Healthcare providers also have normalizing power by being of the majority and the power to define what is *normal* in their institution, and this may enroll them in reproducing heteronormative and gender normative care practices (such as assumptions regarding gender and sexuality, discrimination, and stigma) (Logie et al., 2019). SGD patients are affected by power imbalances in various ways due to compounding marginality and depending on their intersecting sociocultural positionings, such as socio-economic status or being a racialized (Arthur, 2015; Braybrook et al., 2022; Pang et al., 2019; Wilson et al., 2018).

As Ramsden (2002) recommends, safety should be informed from the patient's perspective, and not from the care providers' perspectives. Varcoe et al.'s (2009) argument regarding the collection of race and ethnicity data has many similarities to the collection of SGD data. Varcoe et al. (2009) states that if collection of such sensitive data is to happen, there should be solid evidence that it actually improves access and equity for the population having the data collected. If the benefits are only theoretical, but the harms are real, there is clear work to be done within the institution prior to the implementation of data collection. This caution in implementing SOGI data collection is backed by Schmidt et al.'s (2025) study which questioned if SOGI data collection was more harmful than helpful if staff were unaware of SGD cultural and clinical issues and unaware of the risks and benefits of collecting SOGI data itself. This lack of awareness

was true of the participants in this study, who were largely unaware of cultural and clinical issues and associated care needs specific to SGD patients. Varcoe et al. (2009) reinforces that if sensitive data is to be collected, it needs to be clear what that data is being used for, who has access to that data, and most importantly, there should be a commitment by the organization to action related to the stated reasons they are collecting the data.

The hospices in this study were small not for profit, not fully government funded, organizations. Given austerity measures and challenges of palliative care not being high priority for Ministry of Health funding, it is challenging for administrators and directors of these organizations to prioritize resources for the kind of data review process that would support equity. In this way, we can trace the discriminatory practices that health care providers and administrators are enrolled in, further up to the funding structures of these organizations. These structures allow us to identify priorities of governments, in ways that (re)produce certain priorities within healthcare practices. The prioritization of curative rather than palliative care, and the orientation of care towards the needs of heterosexual and cis or gender conforming people then becomes clear. Dominant social ordering is reproduced, as care providers and administrators are enrolled in governing practices that maintain, rather than disrupt, ideologies of neoliberal governance.

Ramsden's (2002) cultural safety framework speaks to ideas regarding sharing or giving power back to patients and thus made me wonder how identifying and disrupting pastoral forms of power could do for palliative care. I began to wonder if disclosure is necessary for good care, especially if it is not safe for all. Disclosure of information is central to how pastoral power operates and thus challenging or disrupting this

constructed need (legitimized by patient-centered care) for information might reduce the power of the health care providers over SGD people. From the literature, we see that one of the important things SGD people ask of their healthcare providers is to not make assumptions regarding gender and sexuality (Cloyes et al., 2023; Cloyes K.G. et al., 2022; Pecanac et al., 2021; Rosa et al., 2023). If these assumptions were addressed and practices and language changed accordingly and built into standard practices, this would affirm SGD people as existing and normal, all without needing to know if patient was SGD. For example, make it standard to introduce oneself with pronouns all the time, not just when someone uses different pronouns than expected. Or always use the words partner or partners when referring to significant others, affirming and normalizing partners of all genders, numbers, and marital statuses. Even further, ask questions about "who helps care for you and helps make decisions" normalizing not having a partner at all, or being widowed, or having friends, community members, or others not romantically involved as normal in care situations. Because in the end, are assumptions really being questioned if they are only applied to SGD encounters?

Insights and Opportunities for Meaning, Connection, and Growth

Engaging Relational Inquiry, Cultural Safety, and Queer theory together supports a critical understanding of pastoral power relations that permeate palliative care. From here, I want to consider how queerness could be beneficial in palliative care for all people, not just SGD people. Notably, queering palliative care can contribute to the philosophy of palliative care, and queering palliative care can an opportunity for creating meaning, improving connections, and growth as a discipline (Nagington & Lipscomb, 2024).

This analysis has demonstrated a link between excellent palliative care and safer SGD care. Participants in this study resist socializations to fear surrounding dying and negative associations we are taught regarding death. When participants shared their reasons for entering palliative care, they described wanting to build deep connections and meaning with patients, working with not just patients but whole family units, a different more embodied way of holistically caring that transcends physical care and includes care that is highly personal and attuned to a person's needs beyond the physical body. They described a type of care that reaches into being with people as they are, at a deeply vulnerable time in their life, without judgement and without trying to fix them, to bear witness to their journeys during perhaps one of the most important transitions of their patients' lives. Participants spoke about the palliative work they do as a privilege, and as creating deep and meaningful impacts on people's lives. Palliative care can be and is often difficult and sad yet is simultaneously meaningful. It is an act of resistance that focuses on connections and relationships, instead of biomedical fixing.

Similarly, providing safer healthcare for SGD people can be very meaningful. It too can be understood as an act of resistance, and a practice deeply rooted in connection and relationships. To be SGD offers a resistance of narrow understandings and normalizations that order all people. SGD people offer leadership and freedom from governance, and in so doing there is a lot of joy that comes from being SGD. For example, Shuster and Westbrook (2024) found that transgendered people had no trouble talking about the joy they experienced in being trans and actually preferred being part of this marginalized group, that embracing being transgendered improved their quality of life by improving self-confidence, body positivity and a sense of peace, and that being

from this marginalized population actually fostered deep and meaningful connections with others because their identity and experiences made them more open and understanding to others. Both groups, palliative care providers, and SGD people are constituted socially as negative or to be feared. Within these spaces of being oneself and engaging with the death in ways that resist fear and make meaning, both SGD people and palliative providers are focused on living and dying authentically and have found meaning and connection as a result of being SGD and as part of doing palliative care work. Thus, there is opportunity in queering palliative care.

Queering Palliative Care

Queering palliative care would build on the strengths of the resistance of palliative care providers. By *queering* (as a verb, not as a way of referring to queer people) I am referring to the questioning of the status quo, challenging notions of normalcy and relations of power or as Nagington & Lipscomb, (2024) posit, what can the radically different subculture, history, and experiences of SGD people and communities teach us about care. Working with SGD people in palliative care offers an opportunity for fostering connection, learning about found and chosen family and relationship structures that exist outside of heteronormativity; broadening the definition of family; and opportunities to see the diversity of authentically loving and caring. During focus group discussions, at no point did any healthcare provider say something regarding how we can learn from the SGD population, that they have something to teach us and that if we are open to their different and similar ways of understanding death, authenticity, relationships, family, and caring, then we could better understand ourselves and others in their dying process. Questioning our own heteronormative and gender normative ways of

palliative caring is a profound opportunity for growth, and could be a way to meet nurses' social justice mandate. Because interpersonal relationships between care provider and patients are not one sided (Doane & Varcoe, 2021).

I would like to present an example of how queering advanced care planning may have benefits for SGD and non-SGD people alike by reimagining an interaction that one of the participants in the study shared:

> Though not LGBTQ, we had the woman recently that actually removed her husband as [Power of attorney] POA because he was not advocating on her behalf. And she actually removed him as her POA and made her friend her POA … because, she said "I've already told you this is what I want, and you told them something different. You're not my POA anymore." And that was a difficult situation because he was coming up every day and sitting with her, but we couldn't, he did not, he was not her POA, which is a little bit different dynamic than we are used to. But she was courageous enough to say "mmm you're not doing this right so you're out." (FG2P1)

Queering advanced care planning might include not assuming spouses or significant others are the automatic POA. In this example above, perhaps if it was not expected (legality dictates POA as spouse first on that list, and because of this it is often assumed) the patient may have avoided having her husband make a decision not in line with her wishes if the option was given at the start that a good friend could be a POA. And in general, thought really needs to be given to the magnitude of such decisions, and that a good friend may make better decisions for you, as is common in the SGD community (Arthur, 2015). Underlying this example is unexamined heteronormative

practices of spouses as assumed POA and that a romantic partner must occupy this central decision-making role. However, what if a single partner were not expected to take this burden on alone, but felt they could confer with the other people that matter to the patient when making hard decisions and planning care. It might help decrease burnout (a common occurrence among caregivers of palliative care patients that can involve feelings of exhaustion, frustration, and being overwhelmed as well as symptoms such as fatigue, trouble sleeping, elevated blood pressure or increased substance use and has generally negative effects on health (Brazil et al., 2003; Hospice Palliative Care Ontario (HPCO), n.d.)). It might increase their ability to spend quality time with the person because some other things are taken care of.

Community Engagement.

In the discussion section entitled discomfort, it was suggested in one of the focus groups that due to the history of discrimination of SGD people, it was important for the hospice to demonstrate that they were trying to make their hospice an inclusive space. One of the ways this focus group thought to do this was through reaching out to community organizations such as those who run the Pride parade in their community. This community engagement is important, because it can create societal change that reaches beyond palliative care, but also in how societal changes can reach back and change palliative care in a reciprocal manner. In this section, I imagine how reciprocal community engagement might happen between local hospices and local SGD organizations.

I can imagine an ongoing relationship between local hospices and local SGD community organizations that work together to achieve mutual goals. For example, cultural safety and relational inquiry both speak to the importance of understanding

context, including history. This study showed a gap in knowledge regarding SGD context and history, but participants also wanted information from people with lived experience. Training and history presentations could be given by SGD organizations. This alone would be a good step, but I think it could go further. Relational inquiry also speaks to the inherent two-sided nature of relationships. I believe that on top of learning from the community, it is important as an organization to also give back to the community. In this case, in a reciprocal offer, for example, a workshop/planning day/ presentation or something could be given regarding advanced care planning for SGD people. Advanced care planning is something many hospices have expertise on and is important to address because the literature notes that SGD people have less advanced care planning than other groups (Hughes & Cartwright, 2014; Lawton et al., 2014; Reich et al., 2022). This relationship could also reduce the minority tax (those not in dominant positions having to bear the brunt of educating others) and create a mutually beneficial relationship.

Beyond the transaction of workshops, there are other less obvious benefits. For the hospices, those who run the workshop would gain an increased understanding of SGD relationships. Firsthand stories of SGD people and their relationships (not just romantic but all relations) might surface when discussion power of attorneys and care wishes. They would start to understand and practically see how non-traditional relationships affect and can affect decisions, expanding their thinking and understanding and normalizing these relationships. In hearing these narratives of people and their relationships, they could also begin to understand some of the issues and barriers to quality palliative care for SGD people and bring this back to their hospices to enact changes. Practically, they would contribute to increased advanced care planning which

promotes autonomy and choice and help fill this gap for SGD people, contributing to palliative education for this group. They would also form connections with local organizations and leaders which could lead to other opportunities to join together or provide mutually beneficial services for both organizations.

For the SGD community, these relationships could increase understanding of available community resources, such as some of the programs run by hospices such as day hospices and grief and bereavement programs. The presence of hospices and workshops regarding advanced care planning gives an opportunity to normalize planning and talking about death, dying, grief, and bereavement, and could improve grief literacy among SGD people. SGD people would also have the opportunity to have their voices heard and respected through increased understanding of advanced care planning and ensuring the legal forms are filled out regarding power of attorneys. They would also have an opportunity to talk to the hospice staff regarding their concerns, drawing attention to things perhaps the hospice has not considered.

Queering Nursing Education.

Queering nursing education does not just mean content, but also ways in which learning is happening. For example, art has always been a large part of queer expression, whether it be visual, musical, video or media based, or experiential. What could learning look like if we took out traditional forms of nursing education (lecture and presentations) – what would a workshop or module look like if instead of reading about the lived experiences of queer people, they listened to some queer music from different time periods to understand the queer lived experience this way? With reflective questions, sharing opportunities and prompts, this could be one way to make training more interesting and also get lived experience into education. This could also be done with

visual art from SGD artists depicting or not depicting SGD subjects and ideas. These could be ones tied to social justice initiatives or public messages to show how SGD people do advocacy or could just be art by a SGD artist, normalizing and appreciating them as people. Learners could seek out and find a piece of art or a song that speaks to them by an SGD artist and share about the themes they found and what they enjoyed. These methods are not just fun and innovative, but could help reframe SGD people and lives away from deficits, show the range of complexity of SGD lives, showing strength and joy among many other experiences of being SGD, and enrich health care providers care practices and lives. These methods could be used beyond education for SGD topics, but also for increasing engagement and understanding of topics related to any topics (i.e. lived experiences of racism, those that have created memorial artwork as increasing understanding of grief and bereavement).

Another opportunity to engage with art and queerness might also be a form of advocacy and resistance to the invisibilization of SGD people. Hospices often have visual artwork in the halls, and sometimes even in the rooms. What if hospices showed their support for SGD people by supporting local queer artists, either by purchasing artwork from them or by displaying them for sale at their locations. These pieces are functional ways of creating comforting spaces, and could foster conversations, increase visibility and value of queer people, and show support and valuing of queer community members.

Reconceptualizing Safety.

Theoretically, at first it may be easier to understand and learn about safety as separate physical/emotional/social/practical issues. However practically, addressing safety is rarely so unidimensional. This section speaks to the ways the participants and

nursing/healthcare in general conceptualize safety as separatable pieces and how this may limit understanding of how safety is an integrated issue that affects a whole person and the people around them. A reconceptualization of safety as a holistic concept that is not divisible into physical and other domains is considered, as it may be a way forward that helps palliative care providers provide safer care to patients.

Participants in this study had a broad understanding of safety (see finding theme 3b), similar to a recent concept analysis that found that patient safety (in home care settings, as there were no concept analyses of safety in palliative care settings) was "a multifaceted concept, which encompasses physical, mental, social and practical dimensions" (Shahrestanaki et al., 2022). Participants in this study often separated out safety as physical or not (emotional, trust, environmental). This splitting of safety follows the artificial mind/body dualism theorized by Descartes' mind and body, which continues in dominant social understandings (Descartes et al., 1996). This partitioning of safety into seemingly unrelated parts allows for hierarchies to be created and safety to be viewed as a disjointed issue. A participant described physical safety as "number one (FG2P2)" indicating that it was the most important type of safety for palliative care providers. In the literature, this divide is seen as a difference in patient versus provider perspectives or as a difference in prioritization and hierarchies of safety. For example, Barrow et al. (2022) found that patients conceptualized safety as what made them *feel safe* where staff and academic conceptualizations often were about *being* physically safe, showing physical safety was prioritized by providers but not necessarily by patients. They also found that patients' feelings of safety were strongly influenced by patient-provider interactions and relational aspects of care (Barrow et al., 2022). This artificial

separation and prioritizing of safety is limiting and may lead to issues of providers making decisions prioritizing physical safety over other aspects of safety for their patients or not recognizing non-physical safety issues as safety issues at all. For example, since the provider has the power in the relationship, they often get to determine what safety is and how it is measured (in tension with cultural safety principles regarding patients as the determiners of safety), potentially ignoring or downplaying the important ways patients measured safety in favour of physical safety definitions by staff (Lyndon et al., 2023). Lyndon et al. (2023) further asserts that not classifying sexism, racism, homophobia, and other types of discrimination as part of safety measures is a problematic systematic exclusion of patient experiences of care. However, perhaps the issue is not that safety is prioritized incorrectly, but that safety is separated and prioritized in a hierarchical way in the first place. Cultural safety (Ramsden, 2002) does not make a distinction between types of safety but sees safety issues such as racism, assumptions, stereotypes, physical harms, discriminations, ignoring of cultural practices, and ignoring of patient's stated needs all as equally important to address. By not separating out the facets of safety artificially, no hierarchy can be created. Instead, value is placed on safety issues based on what patients' state is safety for them and places the power of determining if care is safe in the hands of patients. Cultural safety "investigates setting up systems which enable the less powerful to genuinely monitor the attitudes and services of the powerful to comment with safety, and ultimately, to create useful and positive change which can only be of benefit to nursing, and to all the people whom nurses and midwives serve (Ramsden, 2002, p. 121)."

The creations of hierarchies of safety are not the only issues this classificational divide in types of safety creates. It also shapes and limits the ways in which health care providers understand safety as separate issues instead of holistic problems, which Cultural Safety practices would challenge. For example, if a staff member has expressed homophobic or transphobic opinions, trust and emotional safety may not be there, and a patient may not feel comfortable exposing their body to this staff member for fear or anticipation of judgement and poor care. This lack of emotional safety and trust could lead to worsening or development of a new pressure sore or wound, especially in sensitive or private areas (physical safety issue). There is risk in a provider seeing the main safety issue here as the development of the pressure ulcer, but in reality, the safety issue is much deeper and more complex than the pressure sore development. Typical interventions for this type of safety issue might be increased repositioning, decrease of moisture or other physical interventions. However, conceptualizing this problem as only a physical issue limits interventions because the true causes may not be considered. Homophobia and transphobia may not be considered since this disjointed conceptualization of safety does not place physical issues like pressure sores in the same box as staff attitudes and discrimination, despite them being clearly related in this example.

Broadening the concept of safety within palliative care to one that is not separable into domains may be helpful with ensuring that a hierarchy is not created and that safety understandings and interventions are not limited and disjoined. Issues such as racism, sexism, homophobia, transphobia could be taken as seriously as a fall or medication error

and resources for prevention and mitigation strategies could be allocated according to this equally valuing conceptualization.

This study has offered a window into how, despite intentions for safe care for SGD people, health care providers are enrolled in dominant discriminatory practices of social ordering. Participants described the tensions they felt in their care and desire for change. From this dialogue it becomes evident that these tensions point to misalignment between their values, and how they are covertly enrolled in reproducing dominant social values of heterosexism and gender normativity, enact governance, and maintain the status quo.

This thesis provides a meaningful opportunity to reconsider the power relations that recreate violent norms in palliative care. At the same time, this analysis provides improved understanding that support opportunities for resisting this violence and opens opportunities for not just SGD eople but also palliative care providers to engage in more fulfilling relations of care. Incorporating queer perspectives and narratives will aid in reducing stereotypes and assumptions regarding SGD people and palliative care, notably narratives that leverage principles of cultural safety and relational inquiry.

Recommendations

More training is needed for palliative care workers regarding SGD care. This training should incorporate understanding of power relations, self-reflection, contextual understanding, and engagement with provider discomfort and should be delivered in a way that includes meaningful and ongoing partnership with community SGD members and organizations. Care needs to be taken to create safe learning experiences that focus on meaning, connection, and growth, without diminishing the history of violence towards the SGD population.

Organizations and policy developers need to engage with and center the voices of SGD people and community at every step of development. Adding requirements for SOGI data needs to be done with care and nuanced understanding of what benefits and risks are present for both SGD people, their families and the larger community, with follow through of stated goals of SOGI collection. Definitions and measurements of safety need to be rethought, with particular attention to patient measures of safety, hierarchies of safety, and safety as a holistic concept.

Limitations

The limitations in this study include: that the participants that volunteered for the focus groups may have been drawn to participate because they represented a group already interested in SGD care and topics, and thus may have a more positive or invested view of SGD people and issues; that a small sample size of 12 participants and 3 groups was used, limiting generalizability; and that the three study sites though all serving different populations, were in close geographical proximity.

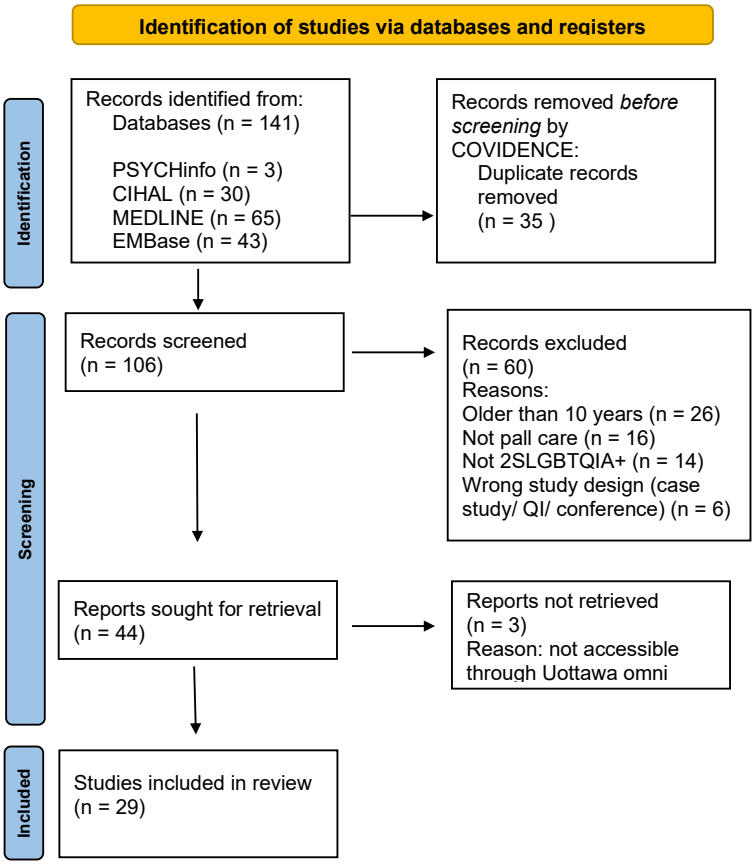
Conclusion

Engaging Relational Inquiry, Cultural Safety, and Queer theory in this thesis has allowed me to question, grow, and explore myself and my nursing practice, and improve my palliative care understanding. In turning into the discomfort articulated by our participants and by the challenges they identified with disclosure for SGD people, this study has found that that we still have a ways to go in terms of creating safer care for SGD people, their families, and for all people and families we care for in palliative care. In reflection, what I really want the reader to take away from this thesis are the ideas surrounding queering palliative care and the ways that palliative care can benefit everyone by questioning some of our taken for granted assumptions and practices. Though I have discussed advanced care planning, community engagement, education, and safety, there are so many more opportunities to improve palliative care. SGD people, their existence, their experiences, their resistance, and their ideas can help guide the way to form stronger connections, find and co-create meaning, and grow as a specialty, if we are willing to listen and learn.

Appendices

Appendix A

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix B

Demographics Questions

What is your age group?

- 18-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65 years and older

Please select your occupation.

- Personal support worker or unregulated care provider
- Registered Practical Nurse
- Registered Nurse
- Social worker
- Counsellor
- Chaplain
- Physician (including residents)
- Trained Volunteer
- Other

What is your highest level of education attained?

- Less than secondary (high) school graduation
- Secondary (high) school diploma or equivalent
- Some postsecondary education

- Postsecondary certificate, diploma or degree
- Master's or equivalent
- Doctorate or equivalent
- Other

How many years have you worked in palliative care?

In relation to race/ethnicity, how do you identify? May list more than one identity or 'prefer not to say.'

In relation to gender, how do you identify? May list more than one identity or 'prefer not to say.'

In relation to sexual orientation, how do you identify? May list more than one identity or 'prefer not to say.'

Appendix C

Semi-Structured Interview Guide

This Preamble will be read verbatim:

Hello, thank you all for coming today. My name is Amalissa, my pronouns are she/her or they/them and with me I have my supervisor Dr. (Einboden or McMillan) to help guide the focus group process. Before we start, I'm going to revisit the aim of the study; describe expectations for participation with each other; and describe how we will proceed if someone becomes distressed during our discussion.

Aim and voluntary nature of study:

- The purpose of this study is to understand what knowledge palliative care providers have regarding sexual and gender diverse patient (often referred to as the LGBTQ+ community) care and what practices are used by these providers. We aim to understand where and how this knowledge is gained, and what influences these practices. Another purpose of this study is to explore the concept of safety in palliative care for this community.
- This study is completely voluntary. This means that you can leave at any time that you wish with absolutely no consequences from me, the research team, or your employer.

Rules for engagement:

- Your identity and what you say here will be kept strictly confidential by the research team. I ask that all participants here show respect to their colleagues by not sharing participant identities or what is said with anyone outside of here.

In person: I will be taking audio recordings that will only be accessible to me and my two supervisors. Transcripts will have identifying data removed prior to sharing with the

thesis committee, and the final publication will not have any names or identifying information.

OR

If online: I will be taking audio recordings and video recording which will only be accessible to myself and my two supervisors. The video will be deleted ASAP after the session is complete. I ask that you keep your cameras on to facilitate better discussion. Transcripts will have identifying data removed prior to sharing with the thesis committee, and the final publication will not have any names or identifying information.

What will happen if someone shows signs of distress (or you become distressed):

- Some of the subject matter we will be discussing is sensitive. I ask that everyone remain respectful of their colleagues, and if there is disagreement on anything, to please constructively critique the idea and not the person. If I notice anyone showing signs of distress, or if I feel distressed myself, I will call for a break in the session, where the recording will be turned off and everyone can take a break or walk as needed. Anyone here also has that same power, if you are feeling distressed, please call for a break. After the break, we can decide as a group how to move forward.
- If there is something you would like to discuss once this session is over, please feel free to contact myself or my supervisors at the email addresses provided on the consent form I have sent you. Does everybody understand and is okay with starting?

Interview guide: The following questions are simply a guide. Each question may or may not be used in the focus groups.

Sexual and gender minorities, often referred to as the LGBTQ+ community, are a community that is made up of those who do not identify as heterosexual or do not

identify with their assigned gender at birth. There is a lot of diversity within this community of people, and likewise the care of this community can be as varied as the community itself. As we go through the questions laid out in front of you, I would like you to focus on how you, your practice, and your organization care for those in this community.

1. Warm up questions

   a) How long have you worked in palliative care and what brought you to palliative care? What are some of the core values that underly your palliative care work?

   b) For many in our field, supporting people in feeling safe before they die is an important part of our work. What does safety mean to you, in the context of your work (prompt: think not just physical safety, but psychological and social)

   c) What guides your practice in caring for SGM patients? Did you bring with you a policy, a book, a lived experience, podcast/media, workshop you attended, school presentation, etc?

   (Prompts: How has this resource influenced and/or supported your care patients and families in this community, how did you come across this resource)

2. a) How is this community supported (or not supported) in your organization? Are there any palliative care resources specifically for these patients and families that you are aware of? (Prompt: safe respite, SGM grief support group, online resources)

   b) How does your organization support you when caring for this population? (Prompt: SOGI data, resources, policies, education days, open managers)

3. a) What kinds of things do you think make an organization feel safe or unsafe for sexual and gender diverse patients?

   b) How do you create safety for patients and families in this community, and do you feel supported to implement them (why or why not and how would you like to be supported)?

4. a) Can you tell me about preparation or education you have received, formal or informal, regarding care of this community? (Prompt: in school, from work, on your own time, at community event, in the news?

5. b) What kind of training do you think would be beneficial for providers to have/ what training do you want in the future?

6. Is there anything you would like to add? Or anything you feel is important to discuss that we didn't have the opportunity to talk about?

Appendix D

Recruitment Poster

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