2SLGBTQ+ CARER-EMPLOYEES IN CANADA

“THERE’S JUST NOTHING OUT THERE FOR PEOPLE LIKE US”: THE EXPERIENCES OF 2SLGBTQ+ CARER-EMPLOYEES IN CANADA

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Lay Abstract

This thesis examines and explores the experiences of Two-Spirit, lesbian, gay, bisexual, transgender, and queer (2SLGBTQ+) carer-employees in Canada. These caregivers balance their unpaid care work with their paid employment, and face barriers when navigating care and work that are related to their 2SLGBTQ+ identity.

Building on research that has identified that LGBT caregivers have unique needs and characteristics, and on research that highlights that individuals attempting to balance unpaid care work with paid employment face significant challenges when attempting to do so, this research brings these two fields together to examine how 2SLGBTQ+ identity impacts these experiences. In particular, it highlights that these caregivers experience poorer quality of life and worklife, that type of work and non-traditional caregiving dynamics may leave these caregivers more vulnerable to negative consequences associated with work-care conflicts, and that experiences of discrimination and concerns regarding confidentiality and anonymity for rural and northern 2SLGBTQ+ caregivers shape their ability to successfully navigate healthcare systems.

Abstract

This thesis extends prior research on LGBT caregivers and carer-employees by employing a mixed-methods approach to investigate the intersecting factors of identity, employment type, and geographical location on the experiences of Two-Spirit, lesbian, gay, bisexual, transgender, and queer (2SLGBTQ+) caregivers in Canada. These caregivers are broadly absent from both the carer-employee and LGBT caregiving literature, and this dissertation offers an initial attempt to correct this.

It begins with a quantitative study involving 2SLGBTQ+ carer-employees, assessing how their identity and experiences of discrimination influence their quality of life, work life, and willingness to seek workplace accommodations for caregiving responsibilities.

Subsequently, a qualitative component delves into how employment type shapes these experiences, with a particular focus on how insecure customer service workers and those employed in unionized pink-collar work navigate work-care conflicts. This section also examines the impact of non-traditional caregiving dynamics on the ability of these caregivers to navigate such conflicts.

Lastly, it explores how past and current experiences of discrimination, non-conventional relationships, and geographical location affect the capacity of 2SLGBTQ+ carer-employees to interact with healthcare providers and advocate for their care recipients.

This research offers a substantial contribution by bringing to the forefront a hitherto unaddressed population. The existing body of literature on carer-employees has overlooked the specific challenges faced by 2SLGBTQ+ carer-employees, and the LGBT caregiving literature has similarly overlooked the role of employment in shaping the experiences of these caregivers. Furthermore, it underscores the significance of geographical location for 2SLGBTQ+ caregivers in rural and remote areas and highlights the experiences of midlife and younger caregivers, particularly those providing care for individuals experiencing severe mental illness. It concludes with discussions of the policy implications of this research.

Acknowledgements

I would like to begin by acknowledging the contributions of co-supervisors Dr. Suzanne Mills and Dr. Robert Wilson, whose role in shaping this thesis has been invaluable. Their willingness to take on the roles of co-supervisors for a research project that was already in progress was a great kindness, and this work would not exist without their support.

I would also like to thank committee member Dr. Niko Yiannakoulias for his insight and contributions, particularly regarding the second chapter.

Dr Allison Williams, who initially supervised this research project, and who provided support and feedback regarding the research which shaped Chapter 2, is also gratefully acknowledged for her support in that process.

On a personal note, I would like to thank my mother, Susan Suter, for her consistent willingness to listen and support me throughout this process. While the dissertation may well have been completed without her assistance, it would have been completed with a significantly increased number of tears and a significantly decreased amount of clean laundry.

I would like to thank each and every participant who willingly shared their stories with me. Many of your stories will stay with me for the rest of my life, and I thank you for your trust in me and your willingness to provide intensely personal and often very emotionally heavy narratives of strength, survival, and vulnerability. Very literally, this could not have been completed without you.

Finally – and appropriately enough, given the subject matter of this dissertation – I would like to thank my chosen family. Talia Kollek, Shayla Notman, Alex Wilson, Daniela Giulietti, Rand Clayton, among too many others to name – I couldn’t have done this without you. I am grateful every day that I live alongside a strong chosen family of people keenly concerned with justice, wellbeing, and building a better world for each and every person who lives here.

Table of Contents

List of Figures and Tables

Chapter 2

Appendix A

Statement of Academic Achievement

As a manuscript thesis, each substantive chapter takes the form of papers intended for publication. Chapter 2 was co-authored by Li Wang with comments and assistance from committee member Dr Niko Yiannakoulias. Dr Wang aided with survey design, while Dr. Yiannakoulias provided input on the paper in its initial draft stages. All data collection, writing, and analysis was completed by myself.

Chapters 3 and 4 were produced with the assistance and feedback from co-supervisors Dr Suzanne Mills and Dr Robert Wilton. Both parties provided feedback on drafts, analytical approaches, and phrasing throughout the writing process. All data collection, analysis, and writing were completed by myself.

Chapter 1. Introduction

The population of informal caregivers in Canada has increased significantly over the past twenty years. As of 2018, 1 in 4 Canadians were informal caregivers, defined as individuals who provide unpaid care for people with physical or mental health conditions. This increase has been driven by several factors. The first is the rise in the number of individuals who require care: an aging population (Statistics Canada, 2022), an increase in the rates of chronic illness (Casey, 2015), and an increased focus on the importance of aging-in-place for older adults(Chappell & Funk, 2011) have combined to produce increased demand for care supports in the home, including in the form of in-home nursing and personal care assistance. This increased demand, however, has coincided with a period in which jurisdictions across the country have systematically reduced access to publicly funded health and social care supports in the community (Guyon & Perreault, 2016).

The gap between the increased *demand for* and the decreased *provisio*n *of* state-funded services has been filled by informal caregivers. Until very recently, the most common profile of an informal caregiver was that of a woman, in her 40s or 50s, balancing paid work with unpaid care for an aging parent and dependent children (Canadian Institute for Health Information, 2010; Neufeld et al., 2008; Statistics Canada, 2012). However, recent research suggests that the gendered dynamics of care have somewhat shifted, and men are now equally as likely to provide informal care as women (Wu et al., 2023). Women continue to be more likely to provide physical care when compared to men, and in general, tend to provide care for longer durations and at higher intensities (Wu et al., 2023). The average age of these carers means that they are typically at the height of their earning potential (G. Joseph & Joseph, 2019; G. M. Joseph et al., n.d.), and they face significant barriers to successfully navigating the worlds of work and care (Henz, 2006; A. Williams et al., 2019a). These caregivers, called "carer-employees", face unique challenges in engaging in both care and work, and many ultimately leave the paid workforce entirely (Lilly et al., 2010).

The number of individuals who identify as being members of the Two-Spirit, lesbian, gay, bisexual, transgender, and queer (2SLGBTQ+) community has also grown (Statistics Canada, 2022). Results from the 2018 *Survey of Safety and Privacy in Public Spaces* indicate that about 4% of Canadians identify as being lesbian, gay, or bisexual, and about .33% of Canadians identify as transgender or nonbinary. These numbers are likely to increase: almost 1% of Canadians between 18 and 24 identify as being transgender or nonbinary, and youth aged 15 to 24 make up nearly 30% of the total population of self-identified 2SLGBTQ+ people in Canada (Statistics Canada, 2022).

Although research from the United States indicates that LGBT people are more likely to engage in informal caregiving when compared to the general population, little attention has been paid to their experiences in Canada. The research that exists has typically focused on their experiences in the context of care for LGBT older adults (Kortes-Miller et al., 2018a; Mulé, 2020; Stern, 2019). Although the research on LGBT caregivers seems to indicate that they, too, are likely to balance their unpaid care work with paid employment(Fredriksen-Goldsen, 2023), there has been no attention paid to the experiences of 2SLGBTQ+ carer-employees. Given that there is a well-established body of literature which highlights that carer-employees face significant barriers in their paid employment, this is an unacceptable oversight. It is this oversight which this dissertation aims to correct: 2SLGBTQ+ people are completely absent from the carer-employee literature, and the role of work is completely absent from the already small body of work on 2SLGBTQ+ caregivers.

This dissertation takes a mixed-methods approach to examining the needs and experiences of 2SLGBTQ+ carer-employees in two Canadian provinces, Ontario and British Columbia. It begins by providing an outline of the background issues which influenced the experiences of carer-employees and 2SLGBTQ+ caregivers. It then presents the results of an online survey that sought to identity how workplace-level experiences of discrimination, individual identity, and caregiving intersect to influence the quality of life and worklife for this population. Chapter 3 then uses the lenses of work and place to examine how economic precarity and geography intersect to produce increased vulnerability to negative economic impacts associated with caregiving and work. Chapter 4 then highlights how interactions with health systems for these carers are affected by identity, experiences of discrimination and stigma, and increased structural burden for 2SLGBTQ+ caregivers. The dissertation concludes with a discussion of the broader implications of this research with regards to the ways in which 2SLGBTQ+ caregivers experience health and employment systems, and potential areas for improvement.

As a manuscript thesis, each substantive chapter was produced as a manuscript for publication. As such, there may be some repetition between the chapters, particularly regarding the literature reviews. Chapter 2 was produced with the co-authorship of Li Wang from the McMaster Institute for Research on Aging and with the assistance of committee member Dr Niko Yiannakoulias. The research for Chapter 2 was funded by CIHR/SSHRC Partnership Grant *Mobilizing a Caregiver Inclusive and Accommodating Workplace Organizations Standard: A Partnership Approac*h, led by Dr. Allison Williams. Co-supervisors Dr. Robert Wilton and Dr. Suzanne Mills provided feedback and assistance on Chapters 3 and 4.

2SLGBTQ+ carer-employees are a vulnerable population. These caregivers are asked to balance their work, their care, and their identity in often challenging or even hostile environments. Participants in this research were located in different places, from downtown Toronto to small towns in Northern British Columbia. They ranged in age from 18 to 73 and reflected a vast multitude of identities and experiences. Throughout this dissertation, I will highlight the experiences of individuals who are not currently reflected in the literature – in *any* of the literature. The experiences of transgender caregivers working in insecure customer service jobs in Northern Ontario are not reflected in the caregiving literature, but the interplay between their care and work roles are also not reflected in the literature on queer workers. The experiences of a closeted gay education worker providing care for someone with serious mental illness in small town British Columbia are not reflected in the literature. Nor is that of the 65-year-old educator in downtown Toronto who cannot retire as planned because his partner relies upon his work-provided insurance in order to obtain necessary medication. More than presenting a store of repeated vulnerability, this dissertation will also highlight the ways in which 2SLGBTQ+ identity can serve as a protective factor: throughout this dissertation, the role and importance of informal supports and the presence of extensive non-kin care networks formed of 2SLGBTQ+ community members will be highlighted.

Background

1.1.1: Carer-Employees

Carer-employees, defined as individuals who balance paid employment with unpaid care work, face distinct challenges when engaging in both work and care. Throughout this dissertation, care work will be defined broadly to include direct care tasks such as nursing, wound, and personal care; instrumental care tasks such as engaging in housework, cooking, or administrative tasks, and care management tasks such as accompanying care recipients to medical appointments, advocating on their behalf to healthcare providers, and coordinating formal and informal care resources.

Unpaid care work has been consistently associated with poorer mental and physical health outcomes for caregivers when compared to the general population (O'Reilly et al., 2008; Robison et al., 2009). This includes increased rates of stress-related health conditions such as anxiety, depression, insomnia, and cardiovascular illness (Wange et al., 2018). The extent to which caregivers experience negative mental or physical health outcomes is strongly mediated by the availability of formal and informal supports, with friend and family support having been highlighted as a key mediator of care strain (Gouin et al., 2016; Chappel & Funk, 2011). Recognition of carer status also appears to reduce the likelihood of care strain (Broom, Parker, & Kenny, 2019; Larkin & Milne, 2013) as it is a key driver of positive caregiver identity, something which mediates the extent to which carers internalize negative stress responses (Chattoo & Ahmad, 2008).

The overwhelming majority of informal caregivers in Canada balance their paid employment with unpaid care work, and there have been some recent shifts in the typical profile of the carer-employee. Previous work had identified that the most common profile of a carer-employee in Canada was that of a woman, in her 40s or 50s, balancing eldercare and childcare with paid work (Williams et al., 2017), but recent research suggests that this may no longer be the case. Between 2012 and 2018, the proportion of male carer-employees grew significantly, and it is now equally common for men to be defined as carer-employees as it is for women(Wu, Williams, Wang, & Kitchen, 2023). However, at the same time, the intensity of care taken on by women increased significantly when compared to that of their male counterparts. For carer-employees of all genders, general health and life satisfaction significantly worsened in 2018 when compared to 2012 (Wu et al., 2023).

These shifts regarding the gendered dynamics of care and the extent of caregiving effects on health have coincided with a general increase in the number of informal caregivers in Canada. Duxbury (2014) identified that out of a 25,021 sample of employees in Canada, approximately 25% of surveyed employees were engaged in some form of caregiving, while the 2018 General Social Survey identified that nearly 31% of employed respondents were also caregivers (Wu et al., 2023). Worldwide, both the number of caregivers and the hours of informal care provided increased significantly during the COVID-19 pandemic (Bergmann & Wagner, 2021; Cohen et al., 2021; Wu, Williams, Wang, Henningsen, et al., 2023), suggesting that these numbers are now likely even higher.

State-funded and regulated supports for caregivers in Canada are limited. Federal caregiving benefits provide access to Employment Insurance for individuals caring for people who are critically ill or at the end of life (Government of Canada, 2023). Carers of critically ill children may receive payments for up to 35 weeks, while carers of critically ill adults may receive payments for just 15 weeks. If the individual who is being cared for is at the end of life, their carer may be eligible for the Compassionate Care Benefit, which allows carers to receive payments for 35 weeks. These benefits are restricted to family caregivers, a definition which includes those who are considered to be “like family”. However, if the caregiver is not legally or biologically related to the care recipient, they must submit a notarized document to the government stating that their care recipient considers them to be like a family member (Government of Canada, 2023), something which may place a significant administrative burden on non-kin caregivers.

The other form of state support comes in the form of publicly funded in-home nursing and personal care. These supports are provincially regulated in Canada and differ significantly between provinces. In Ontario, there is a strict cap on the number of hours of publicly funded care which individuals are eligible to receive, amounting to 120 hours in the first 30 days of care and 30 hours for every 30-day period afterward (Adlin et al., 2020). Although it has previously been possible to receive government-funded support for assistance with instrumental tasks of daily living (iADLs), such as housework, cleaning, and cooking, this is no longer available through the publicly funded system in Ontario(Marani et al., 2023). Further, while there has been a marked increase in the number of individuals seeking access to in-home care supports through the government (Canadian Home Care Association, 2014), the proportion of provincial health funding which is dedicated to home health care has remained at the same level for the last 25 years (Adlin et al., 2020).

In British Columbia, care supports are divided into two categories: home care, which refers to medical support such as wound care and medication administration, which is provided by registered nurses, and home support services, which are provided by home support workers and provide assistance with IADLs(Chiu, 2016; Mcbride & Mcnutt, 2007). In recent years, these services have undergone substantial reconstruction: home support workers no longer provide assistance with meals or transportation (Sharman et al., 2010). It is important to note that unlike Ontario, there is no cap on the number of available hours: however, British Columbia requires that those in receipt of home support pay a portion of the costs out of pocket. Across jurisdictions, there is a general understanding that the amount of publicly-funded care support provided by the state is insufficient(Aronson et al., 2004; Canadian Institute for Health Information, 2010; Lilly et al., 2007; Sharman et al., 2008), and a 2018 survey by the Canadian Carers Alliance indicated that just 2% of individuals receiving state-funded home care had all of their care needs met via the state.

Given that state-funded supports, in both the financial and care realms, have been broadly understood to be insufficient, it is unsurprising that carer-employees dedicate so much of their time trying to maintain their ability to engage fully in both work and care. Carer-employees frequently experience work-care conflicts, which can have significant effects on their physical, mental, and financial wellbeing.(Rajanala et al., 2020). These conflicts occur when work or care responsibilities prevent carer-employees from wholly fulfilling the expectations placed on them in either sphere(Henz, 2006; Lilly et al., 2010; Phillips & O'Loughlin, 2017). Work interference with care may take the form of carer-employees being unable to attend medical appointments or provide personal care to their care recipient as they are required to be at their worksite during the times in which these tasks would take place. Care interference with work refers to the opposite phenomenon, wherein carer-employees miss work or are unable to meet the expectations of their employer due to the mental or physical strains associated with caregiving.

Carer-employees experiencing work-care conflicts are faced with two options: to fail to wholly meet their caregiving responsibilities, or to modify their work arrangements, including by leaving the workforce entirely. Work interruptions are thus more common for carer-employees when compared to their non-caregiving peers. These interruptions can take the form of taking paid or unpaid leaves, reducing work hours, seeking alternate work arrangements, or leaving their current position (Andersson et al., 2019). Once carers leave the workforce, they are unlikely to return: leaving the workforce temporarily to care for a spouse was found to reduce the probability of returning to work by 78% (Gonzales et al, 2019) when compared to leaving the workforce for other reasons.

However, the negative consequences associated with work-care conflicts for carer-employees are not limited to those who leave the workforce. For individuals who maintain their employment status, care-work conflicts are associated with negative physical and mental health outcomes (McNall et al., 2009; Willis, 2010). Work intrusion on care is particularly associated with these outcomes, with these carer-employees often experiencing feelings of guilt, shame, and anxiety (Wu, Williams, Wang, & Kitchen, 2023).

Navigating work-care conflicts is an inherently challenging endeavour, and one which is highly contingent on the work and care environments in which the conflict is occurring. Researchers have identified that caregiver-friendly workplace policies, such as work-from-home, job-sharing, paid leaves, and access to respite supports are associated with carer-employees maintaining their paid employment successfully(Ding et al., 2020; Ireson et al., 2018a; Mofidi et al., 2019; A. M. Williams et al., 2017). Similarly, access to caregiving supports – and in particular, supports from friends and family – are associated with the ability to maintain caregiving duties and paid employment(G. M. Joseph et al., n.d.) .

However, access to both forms of supports is contingent on particular forms of both work and family arrangements that do not necessarily reflect the experiences of all caregivers. While research has repeatedly identified the specific supports mentioned above as being key to maintaining paid employment, they are also supports which are almost exclusively located within the realm of white collar, professional-class work. It is not hard to see why it would be difficult, if not impossible, for a precariously employed customer service worker to access work-from-home or flexwork arrangements. Similarly, the presence of supportive family and friends does not always reflect the reality of caregivers who may have strained relationships with their families of origin or who have relocated far away from their support systems, both of which may be particularly relevant for 2SLGBTQ+ caregivers.

1.1.2: 2SLGBTQ+ Caregivers

Research on 2SLGBTQ+ caregivers in Canada is limited, and mostly confined to the caregivers of LGBT[1] older adults (Wardecker & Johnston, 2018), who may or may not be LGBT older adults themselves (Knauer, 2016). International research, particularly from the United

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[1] A note on terminology. Throughout this dissertation, care has been taken to use precise terminology where accurate and appropriate. Studies which focus on the experiences of lesbian, gay, bisexual, and transgender populations are referred to as focusing on LGBT people, while those excluding transgender populations are referred to as focusing on LGB populations. When appropriate, the terms "sexual and gender minorities" may be used to refer to research which includes people who do not identify as transgender or as lesbian/gay/bisexual, but who do identify with a non-heterosexual or cisgender identity such as individuals who identify as gender nonconforming.

States, has identified that there are several areas in which LGBT caregivers may differ from the general caregiving population. There does not appear to be any current research which focuses on the experiences of Two-Spirit caregivers, and thus it is difficult to say with any degree of certainty how their experiences may differ from the broader population.

Research on LGB caregivers seems to indicate that lesbian, gay, and bisexual caregivers are younger than the general caregiver population (Coon, 2007; Valenti & Katz, 2014a) and that the gendered dynamics of care may not apply. Drawing on a large, US-based population sample, Anderson and Flatt (2018) argue that gay and bisexual men appear to provide care at equivalent rates and intensities when compared to lesbian and bisexual women (Anderson & Flatt, 2018a). In 2011, Muraco & Fredriksen-Goldsen identified the same phenomenon when examining the experiences of small population of low-income midlife and older lesbian, gay, and bisexual adults in San Francisco(Muraco & Fredriksen-Goldsen, 2011). Muraco & Fredriksen-Goldsen also highlighted the role of friend-care, intergenerational care, and inter-gender care, something which was echoed in research by Hash & Mankowski (2017), who noted that caregiving relationships between individuals who did not have a biological or legal kin tie, and between caregivers and care recipients of different ages and genders, appeared to be more common when compared to the general population (Hash & Mankowski, 2017).It is possible that these dynamics are more common only among unmarried lesbian, gay, and bisexual caregivers, as other research has indicated that health-seeking and caregiving behaviours among married gays and lesbians mirrors that of individuals in heterosexual marriages (Peak et al., 2020). Despite the indications that LGB caregivers tend to be younger than the general caregiver population, much of the research on the experiences of LGBT caregivers has been situated within the realm of social gerontology, and little is known about young LGBT caregivers or LGBT caregivers in their early adulthood.

Demographically, LGBT caregivers appear to differ significantly from the general caregiver population. There have recently been two large, population-based US studies which have included LGBT caregivers as a subject of interest. The results indicate that at least 55% of LGBT caregivers are men (Fredriksen-Goldsen et al., 2022), with some studies indicating that percentage may be as high as 60% (Anderson, 2021). They are generally highly educated, with just 9% of LGBT caregivers surveyed in the US National Aging, Health, and Sexuality Survey reporting that their highest level of education was high school or less. However, the relatively high levels of education in this population do not appear to indicate higher levels of income: over a third of respondents indicated that their income was less than 200% of the US Federal Poverty Line, meaning that they earned less than $27,000USD per year for an individual. However, as both of these studies used data gathered from the National Aging, Health, and Sexuality Survey, they included only LGBT caregivers who were 55 and older, leaving a large proportion of the potential population of LGBT caregivers outside of the scope of these studies.

A scoping review on the experiences of LGBT caregivers of individuals with dementia identified that these caregivers may face a loss of LGBT identify, that past experiences with health systems and broader historical events may influence willingness to seek care, and that family and friend support networks may be constituted differently (Di Lorito et al., 2022).The loss of LGBT identity was identified as being related in part to the extent to which identity is relational, and the strains of caregiving may separate individuals from the broader LGBT community. The finding that willingness to seek care and support for their caregiving responsibilities was linked to past experiences of discrimination both within and outside the health system has been echoed in other studies and is not solely a concern within the context of dementia care. Finally, the differences in constituted social networks, with a greater involvement of unrelated friends and fictive kin, and a lesser reliance on biological family, has also been well-established outside of the realm of dementia care. As these studies focused on the experiences of caregivers of individuals with dementia, the study populations were again focused on midlife and older LGBT people and their caregivers.

In a large, cross-sectional study of palliative care providers in the United States, participants were asked about the treatment of LGBT patients and caregivers within their palliative care and hospice systems (Stein et al., 2020). Of the 860 healthcare providers who were surveyed, 53.6% stated that they had seen discriminatory behaviour directed at LGB patients, and 63.4% stated that they had witnessed these behaviours directed at transgender patients. However, discriminatory actions and behaviours were not limited to interactions with LGBT patients. Providers were also asked if they had ever witnessed the spouse, partner, or caregiver of LGBT patients have their visiting hours limited, being denied or limited access to their care recipient in the ICU or emergency department, having their treatment decisions denied or minimized, being denied private time with their care recipient, or being treated discriminatorily or abusively. 43 % of the respondent care providers indicated that they had, on more than one occasion, witnessed LGBT caregivers being treated in a discriminatory manner related to their LGBT identity. When asked if they believed that LGBT caregivers were more likely to be treated in a negative or discriminatory manner when compared to heterosexual, cisgender caregivers, 64% of the surveyed healthcare providers answered in the affirmative. This is, to date, the only study which has examined the perspective of healthcare providers on discrimination towards LGBT caregivers, and it is consistent with the findings of other research discussed below which examined these experiences from the perspective of the caregivers.

It is also important to note that there appear to be differences in the health status of 2SLGBTQ+ caregivers when compared to the general caregiver population. As a group, LGBTQ+ people generally report poorer mental and physical health when compared to their demographically similar heterosexual, cisgender peers(Mccrone, 2018) This also appears to hold true for experiences of care strain and the physical and mental health consequences of caregiving. The results of a large population-based study conducted by Fredriksen-Goldsen et al (2022) indicated that LGBTQ caregivers were more likely to live in poverty when compared to the general caregiver population, despite comparatively higher levels of education. It was further identified that these caregivers appeared to report higher degrees of care strain, lower quality of life, and higher rates of physical and mental health issues.

Higher rates of physical and mental health issues, and greater experiences of care strain, appear to be linked to experiences or expectations of discrimination among LGBTQ caregivers. Caregivers who reported having experienced discriminatory attitudes or actions at the hands of healthcare providers were more likely to report lower quality of life, and both day-to-day discrimination and the anticipation of potential stigma were negatively correlated with quality of life (Fredriksen-Goldsen et al., 2023). Further, these experiences were also directly correlated with care strain. One potential explanation for this relationship is that acting as a caregiver, and interfacing with a variety of health systems and health care providers, may expose LGBTQ caregivers to greater experiences of identity stigma and discriminatory attitudes.

The relationship between experiences of discrimination and increased care strain is not necessarily solely associated with contemporary experiences of discrimination while engaging with healthcare providers. While some research has suggested that gender or sexual minority identity itself may be associated with higher experiences of care strain (Kittle et al., 2021; Stevens et al., 2018), it appears that the strongest driver for identity-associated care strain is lifetime experiences of discrimination (Emlet et al., 2021). Caregivers whose life histories include experiences of identity-based discrimination, trauma, or violence are at a much higher risk of negative health outcomes associated with care strain. It is likely that for these caregivers, interfacing with potentially unsupportive systems, and the anticipation of potential discrimination, has the result of increasing stress levels and care strain (Fredriksen-Goldsen et al., 2023).

In addition to experiences of identity stigma and discrimination, higher degrees of care strain among LGBT caregivers appears to be linked both to the personal circumstances of the caregiver and their relationship to their care recipient. Analysis of the US-based National Health, Aging, and Sexuality survey, which included a sample of 746 sexual and gender minority caregivers, showed that care strain appears to be negatively correlated with increased age, meaning that younger LGBT caregivers appear to show higher rates of care strain than those who are older. It is important to note here that the National Health, Aging, and Sexuality Survey included only midlife and older adults, as participation was limited to those who were 55 or older. Other factors which contributed to increased care strain were lower income, higher education, physical care provision, and providing care to a spouse or partner (Fredriksen-Goldsen, Schuman, & Yung, 2023).

However, there are a number of protective factors which have been identified as serving to mitigate the negative impacts on quality of life and psychological well-being associated with care strain. Strong community ties within the LGBT community appears to be associated with reduced care strain and negative mental health effects are strongly mitigated (Emlet et al, 2021). Social support for caregivers has been well-established as serving to mitigate the negative consequences associated with caregiving (Chappell et al., 2011; Parmar et al., 2021). However, it is important to note that the presence of specifically LGBT communal support has the strongest effect on care strain, rather than the presence of family or other supports (Fredriksen-Goldsen et al, 2023). While this is a positive factor for LGBT carers in large metropolitan areas with strong LGBT communities, it also suggests that those who are living in isolated areas, away from large LGBT communities, or who are closeted may not have access to these protective factors.

If little attention has been paid to the experiences of lesbian, gay, and bisexual caregivers, even less has been paid to the experiences of transgender, gender diverse, and gender nonconforming caregivers. At the time of writing, there is no research focusing wholly on the experiences of transgender caregivers, as all publicly available research that includes transgender caregivers as a population of study includes them alongside lesbian, gay, and bisexual caregivers. This is perhaps an inevitable result of the bulk of the research on LGBT caregivers coming from the gerontological literature: as was mentioned above, the percentage of individuals who identify as transgender or nonbinary is nearly 3 times higher for LGBT adults between 18 and 24 when compared to the general population (Statistics Canada, 2022).

In their work on the health and wellbeing of LGBT caregivers, Boehmer at al. (2019) found that although LGBT caregivers as a whole reported poorer mental and physical health when compared to heterosexual caregivers, the association between transgender caregivers and poorer health was not found to be statistically significant (Boehmer et al., 2019a). This was complicated by the fact that in order to obtain statistical power, transgender women, transgender men, and non-binary/gender-variant trans people were all compiled into one statistical category. Further, the transgender respondent pool was significantly younger than the cisgender respondent pool. As such, they were unable to determine if transgender caregivers truly do report significantly poorer health when compared to non-transgender caregivers. However, given that transgender people report higher rates of discrimination from healthcare providers and that experiences of identity stigma and discrimination are strongly correlated with poorer health outcomes for caregivers, it seems likely that transgender caregivers may be more vulnerable to negative health outcomes when compared to their heterosexual peers.

Because the body of research on LGBT caregivers has been primarily approached from the perspective of health and aging research, there are some key gaps that remain unfilled.

LGBT caregiving research has looked at caregivers of individuals with dementia (Andersen et al., 2021; DiLorito et al., 2021; Candrian et al., 2021), caregivers of individuals with cancer (Cloyes, Hull, & Davis, 2018; Thompson et al., 2021) and on interactions between caregivers and long-term care facilities (Cacares et al., 2020; Dickson, Heine, & Bunting, 2021). However, despite the higher rates of chronic illness, disability, and serious mental illness within the LGBT community, the experiences of LGBT caregivers of people with serious mental illness and the caregivers of individuals with chronic, non-life limiting illness have been broadly absent from the literature. The other result of the focus on LGBT caregiving coming broadly from the perspective of researchers concerned with aging is that the literature has yet to take up work, and the interplay between work, care, and identity, as a serious focus.

It is this gap that this dissertation aims to fill, with an additional focus on how place impacts the multifaceted experiences of 2SLGBTQ+ carer-employees. The study population included in this dissertation were broadly midlife and younger 2SLGBTQ adults, with a median age of 37. As a result, navigating care and work was an active concern for them. Further, although many participants were providing care for individuals with life-limiting conditions like cancer, over a third were providing care to individuals with serious mental illness. The remainder broadly cared for people with chronic illnesses that were not necessarily terminal, which is another population that has not been included in the broader LGBT caregiving literature. Given that both chronic illness and serious mental illness are more common within the 2SLGBTQ+ community and given that midlife and younger 2SLGBTQ+ caregivers are much more likely to be balancing care and work than older adult caregivers, the lack of consideration for these particularities is unconscionable. It is this lack of consideration that this research aims to begin to rectify.

The substantive chapters of this dissertations (Chapters 2-4) take the form of 3 research papers, each of which contribute to the overarching goal of this research project to fill the gaps in both the carer-employee literature and the LGBT caregiving literature to include the experiences of 2SLGBTQ+ carer-employees, and to reflect on how identity, place, and work shape these experiences.

1.2 Chapter Objectives

The research presented in Chapter 2 uses the results of an online quantitative survey to examine how quality of life and worklife for 2SLGBTQ+ carers is affected by experiences of identity stigma and workplace-level experiences of discrimination. Using the World Health Organizations Quality of Life (Brief) testing instrument (WHO-QOL-BREF) and the US National Institute of Occupational Health and Safety's Quality of Worklife testing instrument, participants self-assessed their overall health and quality of worklife. As quality of life and worklife for 2SLGBTQ+ caregivers may be affected by workplace-level experiences or anticipations of experiences of discrimination, participants also indicated if they had experienced or witnessed workplace-level experiences of homophobia or transphobia. Findings indicated that although the health of the care recipient was the most substantial driver of changes to quality of life and worklife, both sexual orientation and gender identity played a role. In particular, bisexual respondents and non-binary respondents reported poorer quality of life and worklife when compared to the rest of the sample, even after controlling for the health of the care recipient. Workplace-level experiences of homophobia and transphobia were also correlated with decreased quality of worklife and a decreased willingness to seek accommodations for their caregiving responsibilities: individuals who had witnessed or experienced discrimination on the basis of sexual orientation or gender identity in their workplace were less willing to seek accommodations. Given that workplace accommodations for caregiving are a key support to allow carer-employees to remain in the workforce, this finding has important implications regarding the retention of 2SLGBTQ+ carer-employees.

Chapter 3 uses the results of qualitative interview data collected across four locations to explore how 2SLGBTQ+ caregivers navigate work-care conflicts, and how identity, work, and place interact to make some 2SLGBTQ+ caregivers more vulnerable to negative health and economic consequences associated with caregiving. These locations were: Thunder Bay, Ontario; the Greater Toronto Area, Ontario; Prince Rupert, British Columbia; and the Greater Vancouver Area, British Columbia. Interviews were conducted remotely over Zoom between March 2022 and September 2022. Eligible participants were individuals who self-identified as members of the 2SLGBTQ+ community who were providing informal care and who worked in either insecure customer service roles or in health care, education, or social services. This paper focuses on how type of work and place interact to shape the experiences of 2SLGBTQ+ caregivers navigating care and work, and in particular, the consequences on employment, financial stability, and the health and wellbeing of these carers. Findings indicated that the ways in which 2SLGBTQ+ caregivers experience work-care conflicts were strongly shaped by type of work, as well as contextual, place-based factors regarding identity and community. Results highlighted that insecure customer service workers face additional barriers when navigating work-care conflicts, and that for the public sector workers in the sample, concerns regarding identity disclosure and the presence or absence of non-traditional caregiving relationships mediated their ability to access extended health benefits that could have been used to help support their caregiving.

Chapter 4 uses the same interview data to look at how identity shapes the experiences of 2SLGBTQ+ carers navigating health systems, and how non-traditional care structures as well as anticipated or experienced instances of discrimination combined to place a greater strain on these carers as they interacted with healthcare providers. Using the frameworks of misrecognition and structural burden, it focuses on how identity and experiences of misrecognition combine to place a greater structural burden on these carers as they navigate health systems. This highlights that although significant improvements have been made regarding the experiences of cisgender lesbian and gay couples in major metropolitan regions as they navigate healthcare systems, the same cannot be said for transgender caregivers, caregivers living in rural or remote northern regions, and individuals engaged in non-traditional caregiving relationships.

Chapter 5, the conclusion, uses the results of the research discussed in the previous chapters to consider how 2SLGBTQ+ working carers are – and are not – served by the present health, employment, and governmental structures. It concludes with some opportunities for further research, as well as sketching the implications that the research discussed in the previous chapters has for policy approaches to support 2SLGBTQ+ working carers.

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Chapter 2. Coming Out to Care: A Quantitative Approach to the Experiences of 2SLGBTQ+ Carer-Employees in Canada

Geffros, S & Wang, L. (2023) Coming Out to Care: A Quantitative Approach to the Experiences of 2SLGBTQ+ Carer-Employees in Canada. *Journal of Gay and Lesbian Social Services* (Revised and Resubmitted)

Abstract

Drawing on data from a national, online, quantitative survey, this paper aims to explore the experiences of 2SLGBTQ+ carer-employees and the relationship between identity, quality of life, quality of worklife, and workplace-level experiences of discrimination. Significant relationships were identified between sexual orientation, gender identity, and quality of life and worklife, as well as between workplace-level experiences of discrimination and willingness to access accommodations for caregiving. We highlight how sexual orientation and gender identity are correlated with differences in quality of life and worklife, and the potential implications for interventions supporting 2SLGBTQ+ caregivers.

Background

As of 2018, over 7.8 million Canadian adults were engaged in informal caregiving – over 25% of the population (Statistics Canada, 2020). These numbers have increased significantly over the last twenty years (Duxbury, Higgins & Schroeder 2009) and are expected to continue to increase as a result of the aging Baby Boomer cohort (Ryan et al., 2012), cuts to publicly funded care at the hands of neoliberal governments (Power & Hall, 2018) and the growing movement to age in place rather than access residential aged care (Kwon, Lee & Kim, 2015). The prototypical informal caregiver in Canada is a cisgender, heterosexual woman, in her forties or fifties, who balances unpaid eldercare duties with childcare and paid employment (Williams et al., 2017). These caregivers, referred to as 'carer-employees', experience significant barriers in the workforce and are more likely than non-carers to reduce their hours of work or leave the labour force entirely (Bittman, Hill & Thomson, 2007), which is particularly problematic as many carer-employees are at the height of their earning potential (Bittman, Hill & Thomson 2007).

Employees may not disclose that they are engaging in informal caregiving to their employers, and many managers may erroneously believe that they do not have informal caregivers amongst their employees (Calvano, 2013). These unsupported carer-employees experience significant barriers to engaging in work and may be more likely to engage in absenteeism and presenteeism, disrupting their work function and potentially costing employers significant amounts of money (Calvano, 2013). It is generally accepted that engaging in informal caregiving has the potential to effect work performance (Zacher & Winter, 2011), stress levels and experiences of caregiver burden (Rubin & White-Means, 2009), hours worked, job satisfaction and organizational commitment (Shoptaugh, Phelps & Visio, 2004), and the physical and mental health of carer-employees (Kayaalp, Page & Rospenda, 2021). As caregiving remains a highly gendered activity, these penalties disproportionately effect women (Williams et al., 2017).

In a large, US-based population study, LGBT caregivers were generally significantly younger, more racially and ethnically diverse, less likely to be married, and more likely to be of low socioeconomic status compared to the general population (Anderson & Flatt, 2018). As a result, they often report higher degrees of financial strain, poor health, and emotional stress(Boehmer et al., 2019a). They are also generally more likely to be providing care, with 32% of a US-based national sample reporting caregiving duties, and more likely to be providing care for unrelated friends or fictive kin (Shiu, Muraco, Fredriksen-Goldsen, 2016) something which is correlated with lower levels of social support, elevating the risk of caregiver strain and its associated poor health outcomes(Anderson et al., 2021). This may be a factor in the significantly higher levels of stress, poor access to respite and transportation services, high levels of caregiver stigma, and higher scores on self-reported distress indicators(Anderson et al., 2021). However, it is possible that these norms of friend-care are less strong for married LGBT people, whose caregiving patterns typically closely mirror those of married heterosexual caregivers(Peak et al., 2020).

The gendered dynamics of care identified by Williams et al. (2017), among others, may also not apply to the 2SLGBTQ+ community (Hash & Mankowski, 2017). Studies of LGBT caregivers tend to report gay and bisexual men providing care at rates which are equivalent to those of lesbian and bisexual women, and the care type, duration, and intensity do not seem to differ by gender (Croghan, Moone & Oldon, 2014). How these gendered dynamics of care may affect transgender, nonbinary, and genderqueer caregivers have not been well-established. Literature on Indigenous experiences of caregiving may be applicable to the experiences of Two-Spirit caregivers. This literature tends to indicate that Indigenous caregivers provide care at a higher rate and intensity than non-Indigenous caregivers (Hokanson et al., 2017), and that caregiving is similarly gendered within Indigenous communities as it is in non-Indigenous communities, with Indigenous women providing more care than Indigenous men (Webkamigad et al., 2020).

Despite a growing body of literature on gay and lesbian caregivers, particularly in the context of older adult caregivers, there is no extant research on the experiences of Two-Spirit, lesbian, gay, bisexual, transgender, or queer (2SLGBTQ+) carer-employees, and research on 2SLGBTQ+ caregivers in the Canadian context is difficult to come by. Research is very limited with regard to the experiences of Two-Spirit or other third gender identifying caregivers, and research on LGBT caregivers has not, to this date, typically focused on the specific intersection of caregiving and paid employment. This study aims to fill this gap by addressing, at a high level, how caregiving, paid employment, and experiences of identity stigma and discrimination impact the lives of 2SLGBTQ+ caregivers in Canada.

Current Study

This study aims to address the gap in the literature regarding the experiences of 2SLGBTQ+ carer-employees, and to consider how workplace-level experiences of homophobia or transphobia may impact the quality of life and worklife of 2SLGBTQ+ carer-employees.

A total of 4 hypotheses were tested. The first two hypothesis proposed a non-directional relationship between identity variables, quality of life, quality of worklife, and ability to balance care and work.

> H1: There will be a relationship between 2SLGBTQ+ carer-employees self-reported quality of life, quality of worklife and 2SLGBTQ+ identity.
>
> Null H1: There will be no significant relationship between identity variables and quality of life or quality of worklife.
>
> H2: There will be a relationship between 2SLGBTQ+ carer-employees' self-reported ability to balance care and work and 2SLGBTQ+ identity.
>
> Null H2: There will be no significant relationship between the ability to balance care and work, and 2SLGBTQ+ identity.

The second two hypotheses proposed a relationship between workplace-level experiences of homophobia or transphobia and quality of life, quality of worklife, and willingness to access accommodations for caregiving.

> H3: Self-reported quality of life and worklife will be correlated with workplace-level experiences of homophobia or transphobia.
>
> Null H3: There will be no significant relationship between workplace-level experiences of homophobia or transphobia, quality of life, and quality of worklife.
>
> H4: 2SLGBTQ+ carer-employees willingness to seek accommodations for caregiving in the workplace will be correlated with workplace-level experiences of homophobia or transphobia.
>
> Null H4: There will be no significant relationship between willingness to seek accommodations for caregiving in the workplace and workplace-level experiences of homophobia or transphobia.

Methods

Ethics approval was obtained from the University Research Ethics Board. Participants were recruited by contacting 2SLGBTQ+ community organizations in Canada, who then provided information on the study to their members and, if applicable, promoted the study on their social media accounts. Service organizations were identified through personal networks from one of the authors and by online searches. The online searches took the form of using a search engine with the terms "City name + LGBT", "City name + queer", "City name + Two-Spirit", and "City name + transgender" for the top 100 most populous cities in Canada. With the sole exception of Montreal, cities in Quebec were excluded from this search, as all recruitment and survey provision were solely available in English. The final list of 38 organizations included 15 LGBTQ or Queer Community Centres, 8 identity-specific groups or centres such as those targeting transgender or Two-Spirit populations, 13 organizations which organized local Pride events or other resources, and 5 online-only groups for 2SLGBTQ+ people in the area. The community centres and Pride committees were contacted via email, while the online-only groups were contacted via social media messages. Of the organizations who were contacted, 21 responded and agreed to share information regarding the study with their members. Organizations with physical locations were provided with an email message to share with their membership and digital files of recruitment posters. Social media graphics and information were also provided upon their request. Organizations who were primarily online were provided with information to share with their group members or granted permission to the researchers to directly share recruitment information within the social media groups.

An anonymous, national, online survey was run for a period of 2 months, from April 2021 to June 2021. Eligible participants were currently providing care for someone with a physical or mental health condition, not including regular child-rearing duties, were over the age of 18, were Canadian residents at the time of the survey, were currently employed, and self-identified as a member of the 2SLGBTQ+ community. Prior to commencing the survey, participants affirmed that they met the ethics criteria by selecting "Yes" under each eligibility criterion. If they selected "No" to any of the eligibility criteria, they were redirected to a page indicating that they were not eligible to participate in the survey at this time, and their session was closed.

Participants (n=199) affirmed they met all eligibility criteria, and the completion rate was 80.4%, with 160 eligible respondents answering all of the questions for which they were eligible. Respondents who indicated that they were cisgender were not eligible to answer any of the questions which dealt directly with transgender identity.

The survey included 39 questions which were grouped into five sections: demographic and identity variables, caregiving variables, workplace-level experiences of homophobia or transphobia, quality of life, and quality of worklife. Demographic and identity variables were collected using an expansive approach to self-identification, with participants indicating their sexual orientation, gender identity, and sex. The included options for sexual orientation were lesbian, gay, bisexual, pansexual, queer, asexual, Two-Spirit, straight, or other orientation not specified. Gender identity options included cisgender man, cisgender woman, transgender man, transgender women, nonbinary, genderqueer, Two-Spirit, or other gender not specified. A two-step approach was taken to sex, with participants first identifying as male, female, intersex, or other sex not specified, and then asked if the sex they indicated was the same as that listed on their birth certificate.

Caregiver status was assessed using a combination of categorical variables where participants indicated their relationship to their care recipient, how long they had been a caregiver, the health of their care recipient, and what kinds of care they provided, and 5-point Likert scales assessing how supportive they found their friends and family to be of their carer status, their ability to balance care and work, and their willingness to access workplace accommodations for their caregiving responsibilities if doing so would result in the disclosure of their 2SLGBTQ+ identity.

Workplace-level experiences of homophobia or transphobia were assessed using a combination of questions that asked participants to indicate if they had ever seen or experienced behaviour in the workplace that they believed to constitute harassment on the basis of sexual orientation or gender identity and the degree to which they have disclosed their 2SLGBTQ+ identity within the workplace and 5-point Likert scales assessing their willingness to bring a partner of the same gender to a work event, their belief that their workplace had policies in place that protected workers from harassment on the basis of sexual orientation or gender identity, and their willingness to disclose their identity to their coworkers or manager. The Likert responses to all questions related to workplace-level experiences of homophobia were summed and averaged, to produce true Likert scale data.

Quality of life was assessed using the World Health Organization's Quality of Life – BREF testing instrument (WHOQOL-BREF), which assesses self-reported quality of life over the past two weeks across four domains: physical health, psychological health, social relationships, and environment. Scores were calculated out of a possible 100 points.

Quality of worklife was assessed using a modified version of the National Institute for Occupational Health's Quality of Worklife survey, which uses 5-point Likert scales to assess worklife across the domains of job level, culture and climate, health outcomes, other outcomes, hours of work, work/family conflict, supervision, benefits, and union status. A mean score out of 5 was calculated for each domain, and a final mean score across all domains was calculated.

Results were analyzed in R, where for the purposes of analysis some categorical variables were combined, in order to have no category with fewer than 5 observations. Genderqueer, nonbinary, and other gender not specified were combined into the category of "Genderqueer, nonbinary, or other transgender identity", while bisexuality and pansexuality were combined into the category of bisexuality. The variables of other sexual orientation not specified, and queer were combined into a single category.

The first three hypotheses were initially tested using two-way ANOVA tables to identify significant relationships. As this study did not include anyone who identified as cisgender and heterosexual, which would have been the appropriate reference group, ANOVA tests were used rather than linear regression models. Interaction effects for the interaction of gender identity and sexual orientation were identified using F tests. The final hypothesis was tested using a linear regression model, as both the dependent and independent variables were Likert-scale data which, although ordinal, could be treated as intervals. For the first three hypotheses, Akaike Information Criterion tests were conducted to identify the model of best fit. As both sexual orientation and gender identity were treated as categorical variables with different classes, Hypotheses 1 and 2 then underwent post-hoc testing using Tukey's Highly-Significant Difference test to identify which classes were associated with significant differences from each other.

ANOVA tests for H1 included Sexual Orientation and Gender Identity as independent variables, and Quality of Life and Worklife were treated as dependent continuous variables. Health of Care Recipient was treated as a potential confounder.

ANOVA tests for H2 included Sexual Orientation and Gender Identity as independent variables and Ability to Balance Care and Work and Friend Support of Caregiving as dependent ordinal variables. Health of Care Recipient was treated as a potential confounding variable.

ANOVA tests for H3 included Workplace-Level Experiences of Homophobia or Transphobia as independent variables and Quality of Life and Worklife as dependent continuous variables. Gender Identity and Sexual Orientation were treated as potential confounding variables.

A linear model for H4 included Workplace-Level Experiences of Homophobia or Transphobia as independent variables and Willingness to Seek Accommodation for Caregiving as a dependent interval variable. Gender Identity and Sexual orientation were treated as potential confounding variables. An Akaike Information Criterion test was conducted on the models to determine the model of best fit.

Results

Descriptive Statistics

In total, 160 eligible respondents completed the survey, answering more than 80% of the questions. As respondents were permitted to indicate more than one identity variable (e.g., indicating that they were both Two-Spirit and a transgender man), the totals across all gender categories may be higher than the eligible response pool. The responses were similar across all genders, with cisgender men (n=33), cisgender women (n=33), transgender men, (n=35) and transgender women (n=31) being nearly evenly represented. In descending order, the remaining respondents identified as Two-Spirit (n=19), nonbinary, genderqueer, or other gender not specified (n=11). Significantly more respondents indicated that their sex was female (n=87) than they did male (n=58), intersex (n=7), or other sex not specified (n=8). With regard to sexual orientation, significantly more respondents identified as lesbian (n=51) than bisexual or pansexual (n=46), gay (n=37), queer or other orientation not specified (n=28), heterosexual or straight (n=18), or asexual (n=3).

Participants also indicated their age, province of residence, and the industry in which they were employed. Participants ranged in age from 18 to 74, with n=15 aged 18-24, n=75 aged 25-34, n=32 aged 35-44, n=19 aged 45-54, n=14 aged 55-64, and n=3 aged 65-75. The most common province of residence was Ontario (n=47), followed by British Columbia (n=38), Alberta (n=23), Saskatchewan (n=17), Manitoba (n=15), New Brunswick (n=7), Newfoundland (n=6), Nova Scotia (n=4), and Quebec (n=2). Participants were able to select their industry of employment according to Statistics Canada's employment categories used on the Census and were able to select multiple industries if they were applicable. The most common industry was mining, quarrying, oil and gas extraction (n=24), followed by construction (n=18), utilities (n=18), information and cultural industries (n=18), manufacturing (n=17), wholesale trade (n=17), health care and social services (n=15), real estate (m=10), professional, scientific, or technical services (n=10), finance (n=7), retail trade (n=6), waste management (n=6), educational services (n=6), agriculture (n=5), arts and entertainment (n=5), management (n=4), transportation and warehousing (n=3), accommodation and hospitality (n=3), and other services (n=3).

Descriptive statistics indicated that cisgender men reported the highest quality of life, followed by cisgender women, transgender men, transgender women, non-binary or genderqueer people, and Two-Spirit individuals (Figure 1).

Figure 1. Gender Identity and Quality of Life

Gender Identity	Minimum WQB Score	Median WQB Score	Maximum WQB Score	Mean WQB Score	Standard Deviation	95% Confidence Interval
Cisgender Man	42.48	62.38	70.86	59.85	7.56	56.86, 62.84
Cisgender Woman	28.1	60.43	71.05	58.23	9.95	54.21, 62.25
Transgender Man	34.48	60.38	70.95	57.07	10.02	53.11, 61.03
Transgender Woman	40.72	54.67	71.62	56.62	9.32	52.93, 60.31
Two-Spirit	22	49.9	67.05	49.74	12.84	42.90, 56.58
Nonbinary or Genderqueer	29.33	54	60	49.98	10.07	43.21, 56.75

Individuals identifying as gay reported the highest mean quality of life scores, followed by those identifying as queer, lesbian, heterosexual and bisexual (Figure 2)

Figure 2. Sexual Orientation and Quality of Life

Sexual Orientation	Minimum WQB Score	Median WQB Score	Maximum WQB Score	Mean WQB Score	Standard Deviation	95% Confidence Interval
Gay	42.28	59.76	70.86	58.54	7.645	55.87, 61.21
Queer	22	59.28	71.05	57.68	11.83	53.55, 61.81
Lesbian	40.76	57.01	71.62	56.81	8.45	53.71, 59.91
Bisexual	28.1	49.18	70.4	51.73	11.67	47.52, 55.94

Cisgender men reported the highest mean quality of worklife (Figure 3), followed by cisgender women, transgender women, transgender men, Two-Spirit people, and nonbinary and genderqueer people.

Figure 3. Gender Identity and Quality of Worklife

Gender Identity	Minimum NIOSH Score	Median NIOSH Score	Maximum NIOSH Score	Mean NIOSH Score	Standard Deviation	95% Confidence Interval
Cisgender Man	2.575	3.925	4.513	3.845	0.46	3.687, 4.013
Cisgender Woman	2.737	3.684	4.421	3.665	0.49	3.499,3.841
Transgender Woman	2.75	3.775	4.45	3.586	0.52	3.399, 3.781
Transgender Man	2.6	3.775	4.55	3.574	0.54	3.365,3.755
Two-Spirit	2.625	3.200	4.097	3.386	0.13	3.139, 3.641
Nonbinary or Genderqueer	1.925	3.455	4.2	3.258	0.2	2.85,3.75

Individuals identifying as queer reported the highest mean quality of worklife (Figure 4) followed by those identifying as gay, lesbian, straight, and bisexual.

Figure 4. Sexual Orientation and Quality of Worklife

Sexual Orientation	Minimum NIOSH Score	Median NIOSH Score	Maximum NIOSH Score	Mean NIOSH Score	Standard Deviation	95% Confidence Interval
Queer	2.62	3.79	4.51	3.701	0.55	3.509, 3.893
Gay	2.58	3.84	4.55	3.72	0.47	3.556, 3.884
Lesbian	2.83	3.65	4.42	3.53	0.42	3.376, 3.684
Bisexual	1.93	3.32	4.45	3.42	0.66	3.182, 3.658

Hypothesis Testing

H1: There will be a relationship between gender identity, sexual orientation, quality of life, and quality of worklife.

This hypothesis was then broken down into two sub-hypotheses for ease of testing.

H1A: There will be a relationship between gender identity, quality of life, and quality of worklife.

H1B: There will be a relationship between sexual orientation, quality of life, and quality of worklife.

Given that the health of the care recipient is likely to have an impact on caregiver quality of life and worklife, it was included in the initial two-way ANOVA analyses as a potential confounder.

Two-way ANOVA analyses were run first using gender identity, sexual orientation, and quality of life (Figure 5), then using gender identity, sexual orientation, health of care recipient, and quality of life (Figure 6).

Figure 5. Gender Identity, Sexual Orientation, Quality of Life

Model 1: Two-Way ANOVA, Gender Identity, Sexual Orientation, and Quality of Life	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	**8**	**1721**	**215.15**	**2.247**	**0.0286**
Sexual Orientation	8	1031	128.91	1.347	0.2275
Residuals	117	11200	95.73		

Figure 6. Gender Identity, Sexual Orientation, Health of Care Recipient Quality of Life

Model 2: Two-Way ANOVA, Gender Identity, Sexual Orientation, Health of Care Recipient, and Quality of Life.	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	**8**	**1245**	**215.15**	**2.247**	**0.01098**
Sexual Orientation	**8**	**1397**	**174.6**	**2.96000**	**0.00486**
Health of Care Recipient	**1**	**2319**	**39.309**	**7.11e-09**	
Residuals	111	6549	59		

A third two-way ANOVA was run using these categories, testing for potential interaction effects between the three categories (Figure 7). Significant results were found in all three analyses, requiring additional tests to identify the model of best fit.

Figure 7. Interactions of Gender Identity, Sexual Orientation, Health of Care Recipient on Quality of Life

Model 3: Interaction Effects	D	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	**8**	**1245**	**155.7**	**3.592**	**0.001592**
Sexual Orientation	**8**	**1397**	**174.6**	**4.030**	**0.000592**
Health of Care Recipient	**1**	**2319**	**2319.1**	**53.514**	**4.12e-10**
GI:SO	**25**	**1859.5**	**74.4**	**1.716**	**0.041729**
GI: HoCR	**5**	**558.1**	**111.6**	**2.576**	**0.034284**
SO: HoCR	**5**	**544.0**	**108.8**	**2.511**	**0.038267**
GI:SO: HoCR	9	683.5	75.9	1.752	0.094264
Residuals:	67	29003.5	43.3		

An AIC Test (Figure 9) was run using the 3 models identified in Figures 5, 6, and 7.

Figure 9. AIC Test of Models 1, 2, and 3

Figure 9. AIC Test of Models 1, 2, and 3	K	AICc	Delta_AICc	AICcWt	Cum.Wt	Lower Limit
Model 1	18	1015.29	97.62	0	1	-486.67
Model 2	**19**	**917.67**	**0.00**	**1**	**1**	**-436.35**
Model 3	63	1017.84	100.17	0	1	-383.89

Model 2, which included the Health of Care recipient as a potential cofounder, but which did not include potential interaction effects, was identified as the model of best fit.

Model 2 (Figure 6) identified significant relationships between the independent variables of gender identity, sexual orientation, and health of care recipient and the dependent variable of quality of life. Although the F value indicated that the greatest effect size comes from the health of the care recipient, it also indicates that there are additional smaller effects that result from sexual orientation and gender identity.

In order to identify which classes within the categorical variables of sexual orientation and gender identity produced a significant effect, the post-hoc Tukey's Test of Highly Significant Differences were run using sexual orientation, gender identity, and quality of life. All Tukey's Highly Significant Difference tables can be found in the appendix.

The THSD test identified a significant difference between gay and bisexual respondents, with bisexual respondents reporting poorer quality of life when compared to gay respondents. No other results were statistically significant.

The second THSD test examined the relationship between gender identity and quality of life.

These results indicated significant differences in quality of life between cisgender men and Two-Spirit people and between non-binary people and cisgender men: in both cases, Two-Spirit and non-binary participants reported poorer quality of life when compared to cisgender men.

H1A: The null hypothesis was rejected. Although the greatest effect size was associated with the health of the care recipient, both sexual orientation and gender identity had significant relationships with quality of life. The post-hoc THSD tests identified that bisexual respondents reported lower quality of life when compared to respondents who identified as gay, and these results were statistically significant. They also identified that Two-Spirit people reported lower quality of life than cisgender men, as did non-binary people. All other differences were not statistically significant.

H1B:

The relationship between quality of worklife, gender identity, and sexual orientation was modelled using MANOVA tests, including health of care recipient as potential confounder. This was assessed by running 3 tests: Model 1a (Figure 10) was a two-way MANOVA test using gender identity, sexual orientation, and quality of worklife. Model 2 (Figure 11) included the health of the care recipient as a potential confounder. Model 3 (Figure 11) included gender identity, sexual orientation, and quality of worklife in order to test for interaction effects.

Figure 10. Gender Identity, Sexual Orientation, Quality of Life

Model 1a	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	8	3.557	0.4446	1.659	0.166
Sexual Orientation	8	3.204	0.4005	1.495	0.168
Residuals	117	31.348	0.2679		

Figure 11. Gender Identity, Sexual Orientation, Health of Care Recipient, Quality of Worklife

Model 2A	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	**8**	**3.105**	**0.388**	**2.083**	**0.04331**
Sexual Orientation	**8**	**4.105**	**0.513**	**2.754**	**0.00821**
Health of Care Recipient	**1**	**8.382**	**8.382**	**44.73**	**8.72e-10**
Residuals	111	20.687	0.186		

Figure 12. Interactions of Gender Identity, Sexual Orientation, Health of Care Recipient on Quality of Worklife

Model 3A	D	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	**8**	**3.105**	**0.388**	**2.442**	**0.02212**
Sexual Orientation	**8**	**4.105**	**0.513**	**3.228**	**0.00365**
Health of Care Recipient	**1**	**8.382**	**8.382**	**52.724**	**515e-10**
GI:SO	**25**	**7.020**	**0.281**	**1.766**	**0.03414**
GI: HoCR	5	1.238	0.248	1.557	0.18431
SO: HoCR	5	1.055	0.211	1.327	0.26358
GI:SO: HoCR	9	0.724	0.080	0.506	0.86510
Residuals:	67	10.651	0.159		

Model 3A identified some potentially significant interactions effects. An AIC test (Figure 13) was again conducted, and it identified Model 2 as the model of best fit.

Figure 13. AIC Test of Models 1a, 2a, and 3a

	K	AICc	Delta_AICc	AICcWt	Cum.Wt	Lower Limit
Model 1a	18	227.56	52.61	0	1	-92.81
Model 2a	**19**	**174.95**	**0.00**	**1**	**1**	**-64.99**
Model 3a	63	294.40	119.45	0	1	-22.17

Model 2a (Figure 11) demonstrated that although the bulk of the effects came from the health of the care recipient, gender identity and sexual orientation also played a role. Two Tukey's HSD tests were conducted to determine which classes within the categories of sexual orientation and gender identity showed significant effects.

The significant effects from the Tukey's HSD tests identified that bisexual respondents reported lower quality of worklife when compared to queer respondents, and the results were statistically significant. They also showed that nonbinary and genderqueer respondents showed lower quality of worklife, and the results were statistically significant.

Null Hypothesis H1 was rejected. There is a significant relationship between sexual orientation, gender identity, quality of life, and quality of worklife. While the biggest driver of differences in quality of life and worklife is that of the health of the care recipient, sexual orientation and gender identity both play a role.

H2. *That there is a relationship between sexual orientation, gender identity, and difficulty balancing care and work.*

Null H2: *That there is no relationship.*

For H2, Difficulty Balancing Care and Work is treated as a dependent interval variable, while sexual orientation and gender identity are treated as categorical independent variables. Health of care recipient is again a potential confounder.

To test H2, three models were again constructed. Model 1c (Figure 14) shows a two-way ANOVA of sexual orientation, gender identity, and difficulty balancing care and work.

Figure 14. Gender Identity, Sexual Orientation, Balancing Care and Work

Model 1C	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	8	8.74	1.093	0.913	0.50845
Sexual Orientation	**8**	**27.80**	**3.475**	**2.904**	**0.00566**
Residuals	109	130.45	1.197		

Model 2C (Figure 15) includes the health of the care recipient as a potential confounder.

Figure 15. Gender Identity, Sexual Orientation, Health of Care Recipient, Quality of Worklife

Model 2C	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	8	9.09	1.136	1.089	0.37667
Sexual Orientation	**8**	**27.94**	**3.493**	**3.348**	**0.00186**
Health of Care Recipient	**1**	**8.382**	**8.382**	**44.73**	**8.72e-10**
Residuals	106	110.59	1.043		

Model 3C (Figure 16) checks for interaction effects between the independent variables.

Figure 16. Interactions of Gender Identity, Sexual Orientation, Health of Care Recipient on Quality of Worklife

Model 3C	D	Sum Sq	Mean Sq	F Value	Pr(>F)
Gender Identity	8	9.09	1.136	1.425	0.20423
Sexual Orientation	**8**	**27.94**	**3.493**	**4.380**	**0.0031**
Health of Care Recipient	**1**	**18.87**	**18.867**	**23.661**	**8.22E-06**
GI:SO	**25**	**40.29**	**1.612**	**2.021**	**0.01310**
GI: HoCR	5	5.25	1.050	1.316	0.12047

SO: HoCR	5	7.29	1.457	1.828	0.12047
GI:SO: HoCR	9	8.32	0.925	1.160	0.33633
Residuals:	62	49.44	0.797		

As all models produced significant results, an ACI test was conducted to determine the model of best fit.

Figure 17. AIC Test of Models 1C, 2C, and 3C

	K	AICc	Delta_AICc	AICcWt	Cum.Wt	Lower Limit
Model 1C	18	404.33	21.32	0	1	-180.97
Model 2C	**19**	**383.01**	**0.00**	**1**	**1**	**-168.85**
Model 3C	63	498.27	115.26	0	1	-118.91

The best fit is the model which includes the health of the care recipient (Figure 15). As this model identified sexual orientation as having potentially significant effects, although with a smaller effect size than that of the health of the care recipient, a Tukey's HSD test was conducted on the relationship between sexual orientation and the ability to balance care and work. This test revealed that Bisexual respondents reported reduced ability to balance care and work when compared to gay and queer respondents.

Null H2 was rejected: there is a significant relationship between sexual orientation and the ability to balance care and work, although the effect size is smaller when compared to the health of the care recipient.

H3: That there will be a relationship between work-place level experiences of homophobia or transphobia, and poor quality of worklife and quality of life.

Null H3: That there will be no such significant relationship.

Two one-way ANOVA tests were conducted (Figure 18 and 19), with workplace-level experiences of homophobia or transphobia as an independent interval variable and quality of life and worklife. Likert scale data for workplace level experiences of homophobia or transphobia using 5 different Likert items, including "Would you feel comfortable bringing a partner of the same gender to an event to which partners were invited?", "Would you feel comfortable disclosing your gender identity?” “Would you feel comfortable reporting harassment on the basis of your sexual orientation or gender identity?” “Have you ever witnessed or experiences actions within the workplace which you believed to be homophobic or transphobic?” Participants who answered “Yes” to the final question were then asked if this had been directed at (a) the participant (b) a coworker (c) a member of the public or (d)Someone else. Each item was assigned a point value of 1, resulting in a total score out of 5, with 1 indicating that they had never seen or experienced discriminatory actions and 5 indicating that they had witnessed all of the above. These Likert items were summed and averaged to produce the Likert scale data related to workplace-level experiences of homophobia or transphobia.

Figure 18. Domain-level Experiences of Discrimination and Quality of Life

	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Experiences of Discrimination	1	329	329.2	3.189	0.0764
Residuals	132	13624	103.2		

Figure 19. Domain-level Experiences of Discrimination and Quality of Worklife

	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Experiences of Discrimination	**1**	**1.28**	**1.278**	**4.58**	**0.0342**
Residuals	132	36.83	0.279		

There was a statistically significant relationship identified between quality of worklife and workplace-level experiences of discrimination. Because sexual orientation and gender identity could potentially act as confounders, another ANOVA test was run including them as independent variables (Figure 20).

Figure 20. Domain-level Experiences of Discrimination and Quality of Worklife

	Df	Sum Sq	Mean Sq	F Value	Pr(>F)
Experiences of Discrimination	**1**	**19.297**	**19.297**	**139.211**	**<2e-16**
Gender Identity	8	1.291	0.161	1.164	0.327

Sexual Orientation	8	1.441	0.180	1.299	0.251
Residuals	116	16.080	0.`39		

Neither gender identity nor sexual orientation were statistically significant.

Null hypothesis 3 was rejected.

H4: There will be a relationship between workplace experiences of homophobia or transphobia and willingness to seek accommodations for caregiving.

Null H4: There will be no such relationship.

A linear model was constructed (Figure 21) as both the workplace-level experiences of homophobia or transphobia and the willingness to seek accommodations were true Likert scale data and could be treated as continuous variables.

Figure 21 . Domain-level Experiences of Discrimination and Willingness to Seek Accommodations

	Estimate	Std. Error	T value	Pr(>t)
Intercept	5.129219	0.20047	25.900	<2e-16
Experiences of Discrimination	-0.48696	0.07518	-6.477	3.86e-09

A significant relationship between workplace experiences of homophobia and transphobia and willingness to seek accommodations was identified, showing that with increased experiences of homophobia or transphobia there was a decrease in the willingness of participants to seek accommodation. Null hypothesis 4 was rejected.

Discussion

Quality of Life, Worklife, and Identity

Previous work on 2SLGBTQ+ caregivers has indicated that the gendered dynamics of care often seen in heterosexual populations of caregiver doesn't apply to queer caregivers: cisgender gay and bisexual men care at equivalent rates and intensities to cisgender lesbian and bisexual women (Hash & Mankowski, 2016). These results initially seem to support this position: response rates were relatively evenly divided between cisgender men, cisgender woman, and transgender people, and the type of care provided by respondents did not seem to be significantly affected by gender.

However, further analysis shows that the effects of caregiving are not felt equally, and that there is a significant gendered difference in the effect of caregiving on quality of life and worklife for 2SLGBTQ+ caregivers. Cisgender men consistently reported the highest quality of life and worklife, and cisgender women reported higher quality of life and worklife when compared to transgender respondents of all genders. Transgender men and women reported higher quality of life when compared to nonbinary and genderqueer people, who in turn reported higher quality of life than Two-Spirit individuals. This was true across the descriptive statistics; however, when investigated further for statistically significant results, things became slightly more complicated.

H1 was rejected: although the health of the care recipient was the primary driver of differences in quality of life and worklife, there were differences within the sample that showed that bisexual respondents reported poorer quality of life when compared to gay respondents, and these results were statistically significant. This may not be related to carer status – bisexual people often score poorly on quality of life and health indices when compared to the general population, but it is noteworthy that it continues to hold true for bisexual caregivers when compared to gay caregivers. Two-Spirit and nonbinary people scored poorly when compared to cisgender men, and these results were statistically significant.

Regarding worklife, bisexual respondents reported lower quality of worklife when compared to queer respondents, and the results were statistically significant. It was also demonstrated that nonbinary and genderqueer respondents showed lower quality of worklife when compared to all other respondents, and their lower quality of worklife compared to cisgender men was statistically significant.

This relationship may not be the direct result of their carer status – in general, transgender populations typically report poorer health and quality of life when compared to cisgender populations, and the low quality of life reported by Two-Spirit, nonbinary, and genderqueer individuals could reasonably be attributed to the impacts of multiple marginalization. However, it is worth noting that in general, Two-Spirit, nonbinary, and genderqueer respondents were significantly younger than the other transgender respondents. Self-reported health typically declines with age, and that younger Two-Spirit, genderqueer, and nonbinary carers report poorer quality of life than the rest of the sample suggests that, at the very least, the relationship between these identities and poorer quality of life and worklife is sufficiently large so as not to be outweighed by their relative youth. For Two-Spirit participants, an explanation may be that, by virtue of being an inherently Indigenous identity, participants experience significant barriers related to racial or ethnic discrimination and settler-colonialism. Whilst this is a plausible explanation for the patterns demonstrated in the data, we do not at present have sufficient data to confirm this etiology, and more research is needed.

The same pattern held true for quality of worklife, possibly for similar reasons. Of note here is that although the associations found between quality of life and identity were statistically significant only for Two-Spirit, genderqueer, and nonbinary people, here the relationship is statistically significant for transgender men as well. Again, cisgender men reported the highest quality of worklife, followed by cisgender women, transgender women, transgender men, Two-Spirit people, and genderqueer and nonbinary people.

The relationship between sexual orientation and quality of life and worklife, on the other hand, was highly consistent with what has been established in the literature. First, it is important to note that as all participants in this study self-identified as being members of the 2SLGBTQ+ community, and all responses that indicated a cisgender, heterosexual identity were excluded from analysis. As such, the data from straight respondents included in this and subsequent sections should be understood as representing respondents who were both heterosexual and transgender or gender diverse.

Individuals identifying as queer reported the highest quality of life (although this was not statistically significant), followed by those identifying as gay, lesbian, straight, Two-Spirit, and bisexual. Only the bisexual results, which included bisexuals of all genders, were considered statistically significant: these individuals scored, on average, 7.239 points less on the WHO-QOL-BREF 100-point scale when compared to those who identified as gay. This is consistent with the literature: bisexual people report poorer mental health status (Taggart et al., 2018), higher rates of substance use disorders (Feinstein & Dyar, 2017), and poorer overall health status when compared to other members of the 2SLGBTQ+ community (Feinstein et al., 209). Bisexual people are also more likely to be closeted, both at work and in their social lives (Barringer, Sumerau & Gay, 2017). Given that bisexual people typically score lower on most measures of health and well-being, it is difficult to make any causal assertions in the case of bisexual caregivers and quality of life, but minority stress is a plausible factor. Bisexuals also reported the lowest mean quality of worklife, although it is once again difficult to suggest a causal relationship.

Minority Stress, Multiple Marginalization, and 2SLGBTQ+ Caregivers

It is worth noting that in the results discussed above, the lowest self-reported quality of life and worklife scores were consistently associated with Two-Spirit identity, non-binary or genderqueer identity, and bisexuality. As noted above, a plausible explanation for the poor quality of life and worklife for Two-Spirit caregivers is that as an inherently Indigenous identity, Two-Spirit people experience the simultaneous effects of discrimination on the basis of sexual orientation or gender identity, racism, and settler-colonialism. In addition to the material effects of discrimination in employment, housing, and healthcare, these intersecting oppressions may also make it difficult for them to access respite or support. Two-Spirit people often report experiencing racism in white colonial LGBT spaces, homophobia or transphobia in some Indigenous spaces, and the intersecting effects of both in formal spaces such as healthcare and education (Greensmith, 2016).

The minority stress model discussed above also posits a theory of minority coping: that the negative physical and mental health effects of stigma, experiences of discrimination, and homophobia can be countered via the protective factors of communal resilience, opportunities for social support, and communal values. Thus, while all sexual and gender minorities may potentially experience the effects of minority stress, its effects may be lessened among those with a strong connection to a supportive community and a kinship with other members of this community. This is not a protective factor that is equally accessible for all 2SLGBTQ+ people: as mentioned above, Two-Spirit people may not have access to any community that is truly supportive of all aspects of their identity, and the same often holds true for other multiply marginalized LGBTQ+ people. Further, this may explain the low scores associated with genderqueer and nonbinary identity and with bisexual identity. Genderqueer and nonbinary people often experience difficulties accessing support both within and outside of the 2SLGBTQ+ community (Cosgrove, Bozlak & Reid, 2021). Similarly, bisexual people often experience biphobia both within and outside of the 2SLGBTQ+ community, and a such they may not have access to the same communal relationships which serve as a protective factor (Lewis, Kholodkov & Derlega, 2012).

Workplace-Level Experiences of Discrimination, Quality of Life, and Worklife

While it is unsurprising that increased experiences of workplace-level homophobia or transphobia are associated with poorer quality of life and worklife, it does suggest that addressing quality of life and worklife for 2SLGBTQ+ caregivers will be necessarily insufficient unless there is a corresponding effort to address equity and harassment in the workplace. Given that research on carer-employees identifies the worksite as being a site of respite for the general carer-employee population (Greenfield et al., 2018; Kim & Park, 2017), it is worth noting that this data suggests the worksite may not be able to serve the same purpose for 2SLGBTQ+ carer-employees, and thus interventions to support their wellbeing may need to first address the ways in which workplace-level experiences of discrimination can affect the wellbeing of 2SLGBTQ+ workers. This correlation held true even when controlling for gender identity and sexual orientation, suggesting that workplace-level experiences of discrimination continue to effect individuals across the spectrum of 2SLGBTQ+ identity, and that this impacts quality of life and worklife.

Workplace-Level Experiences of Discrimination and Willingness to Access Accommodations for Caregiving

It is unsurprising that individuals who reported higher levels of workplace-level experiences of homophobia or transphobia also indicated that they were less likely to access accommodations for caregiving, but it is troubling. Given that the worksite is considered the most promising site of intervention for working carers, and that rates of workplace-level discrimination remain unfortunately high – In 2023 a study by the Canadian Labour Congress found that 73% of transgender workers have experiences harassment in the workplace (Canadian Labour Congress, 2023), it is deeply concerning that 2SLGBTQ+ caregivers are less likely to access accommodations if they believe their workplace to be hostile towards 2SLGBTQ+ identity. In addition to raising concerns regarding the extent of workplace discrimination, it also raises questions of how best to intervene to support 2SLGBTQ+ caregivers at work. At present, there are some forms of support available to carer-employees which are administered outside of the workplace – some jurisdictions in Canada have introduced state-administered financial support for caregivers, and the federal government administers the Compassionate Care Benefit, which allows caregivers of individuals with terminal illnesses to access unemployment benefits while on leave from their jobs (Government of Canada, 2023). However, other supports – modifications to the type or modality of work, changes in worksites, work-from-home or flex-time arrangements – are administered solely by employers. The result of this research suggests that this may not meet the needs of 2SLGBTQ+ caregivers and may indicate that other approaches are necessary.

Limitations and Next Steps

Due to restrictions in place as the result of the COVID-19 pandemic, it was not possible to recruit participants in person or to provide physical copies of the survey for potential participants who lacked access to an at-home internet connection. It is also important to note that for the duration of the survey, most regions of Canada remained under stay-at-home orders, meaning that it was not possible for potential participants to complete the survey using a public computer at a library or community center, which further limited the participant pool to individuals with a reliable, in-home internet connection and personal computer, tablet, or smartphone. This may have resulted in a data set which skewed younger than the general population of 2SLGBTQ+ caregivers, and this in turn may have impacted the self-reported quality of life and worklife as both are often associated with age. Further, the effect sizes in all models were quite small, meaning that identity is insufficient to fully explain the variance in quality of life, worklife, and willingness to access accommodations. The total survey population was also small and the result of a convenience sample, limiting its generalizability. There were also several potential confounding variables, which were accounted for in post-hoc tests to the degree that was possible: however, there are many aspects of caregiving that exist outside of the bounds of a Likert scale and given that this data collection took place in Spring-Summer of 2020, caregivers in Canada were under high degrees of overall stress.

A further limitation is the relative youth of the sample. This is a common issue in research that focuses on the experiences of 2SLGBTQ+ people; however, given that informal caregiving is more common among midlife and older adult populations, further research is needed to examine the needs of midlife and older 2SLGBTQ+ carers in the research.

In the absence of population-level statistical research on this population, this analysis represents an initial intervention on the subject of 2SLGBTQ+ carer-employees in Canada. The results are being used to inform qualitative work on the same subject. It raises important questions about how to best support 2SLGBTQ+ carer-employees, and potential avenues for implementing improved policies and approaches to meet the needs of this population.

Appendix

Figure 22. Tukey's HSD Test, Sexual Orientation and Quality of Life

	Difference	Lower Limit	Upper Limit	P adjusted
Asexual – Two-Spirit	9.1428571	-20.7612178	39.046932	0.969398
Bisexual – Two Spirit	-2.4139881	-24.2101409	19.382165	0.9998891
Gay- Two Spirit	4.878789	-16.8979301	26.655506	0.9939283
Lesbian – Two Spirit	2.2181648	-19.5779980	24.014308	0.9999325
Queer – Two Spirit	5.5571429	-16.6203127	27.734598	0.99889511
Straight – Two Spirit	0.1882784	-22.52549791	22.902054	1.000000
Bisexual – Asexual	-11.5568452	-33.3529980	10.239308	0.6898008
Gay – Asexual	-4.2640693	-26.040782	17.512649	0.9970993
Lesbian -- Asexual	-6.9247024	-28.7208552	14.871450	0.9630559
Queer – Asexual	-3.5857143	-25.7631698	18.591741	0.9990120
Straight – Asexual	-8.9545788	-31.6683542	13.759197	0.9000284
Gay – Bisexual	**7.2927760**	**-0.1263901**	**14.711942**	**0.0373693**
Lesbian – Bisexual	4.6321429	-2.8438759	12.108162	0.5129320
Queer – Bisexual	7.9711310	-0.5528419	12.108162	0.0831254
Straight – Bisexual	2.6022665	-7.2330868	12.437620	0.9853102
Lesbian – Gay	-2.606331	-10.0797992	4.758533	0.9344646
Queer – Gay	0.6783550	-7.795798	9.152509	0.9999836
Straight – Gay	-4.6905095	-14.4827178	5.101699	0.7817273
Queer – Lesbian	3.3389881	-5.1849847	11.862961	0.9027676
Straight – Lesbian	-2.0298764	-11.8652296	7.805477	0.9961209
Straight – Queer	-5.2688645	-16.0225695	5.24841	0.7384532

Figure 23. Tukey's HSD Test, Gender Identity and Quality of Life

	Difference	Lower Limit	Upper Limit	P adjusted
Cis Man – Two Spirit	**10.11825397**	**1.1619068**	**19.07460117**	**0.01706494**
Cis Woman – Two Spirit	8.49761905	-0.522588	17.51782693	0.07711551
Nonbinary – Two Spirit	-0.07337662	-11.1923353	11.0455802	1.000000
Trans Man – Two Spirit	7.33447972	-1.6218675	16.29086292	0.1749633
Trans Woman – Two Spirit	6.88192240	-2.0744248	15.8382690	0.2344506
Cis Woman – Cis Man	-1.62063492	-9.4208746	6.17960472	0.9907864
Nonbinary – Cis Man	**-10.19163059**	**-20.3459809**	**-0.03728032**	**0.0443959**
Trans Man – Cis Man	-2.78377425	-10.5100762	4.94252780	0.907863
Trans Woman – Cis Man	-3.23633157	-10.9626336	4.48997048	0.8303381
Nonbinary – Cis Woman	-8.57099567	-18.7817167	1.63972539	0.1542363
Trans Man – Cis Woman	-1.16313933	-8.9633790	6.63710031	0.9980631
Trans Woman – Cis Woman	-1.61569665	-9.4159363	6.1845299	0.9909147
Trans Man – Nonbinary	7.40785634	-2.7464939	17.56220661	0.2883782
Trans Woman – Nonbinary	6.95529902	-3.1990513	17.1096430	0.3584623
Trans Woman - Trans Man	-0.45255732	-8.1788594	7.27374473	0.9999802

Figure 24. Tukey's HSD, Sexual Orientation and Quality of Worklife

	Difference	Lower Limit	Upper Limit	P adjusted
Asexual – Two-Spirit	0.1625000	-1.386261136	1.7112611	0.999992
Bisexual – Two Spirit	-0.39167519	-1.520519147	0.7371688	0.94937
Gay- Two Spirit	-0.05369972	-1.181537134	1.0741377	0.999993
Lesbian – Two Spirit	-0.31340721	-1.442251167	0.8154368	0.9811679

Queer – Two Spirit	0.04257265	-1.106019349	1.1911646	0.9999998
Straight – Two Spirit	-0.36896636	-1.545334887	0.8074022	0.9653008
Bisexual – Asexual	-0.55417519	-1.683019147	0.5746688	0.7614435
Gay – Asexual	-0.21619972	-1.3344037134	0.9116377	0.997423
Lesbian -- Asexual	-0.47590721	-1.604751167	0.6529368	0.8672861
Queer – Asexual	-0.11992735	-1.268519429	1.0286646	0.9999215
Straight – Asexual	-0.53146636	-1707834887	0.6449022	0.8249647
Gay – Bisexual	0.33797546	-0.046270364	0.7222213	0.1242300
Lesbian – Bisexual	0.07826798	-0.308922304	0.4654583	0.996503
Queer – Bisexual	**0.43424784**	**-0.007217009**	**0.8757127**	**0.0370549**
Straight – Bisexual	0.02270883	-0.486673686	0.5320913	0.9999995
Lesbian – Gay	-0.25970748	-0.643953313	0.1245383	0.4042196
Queer – Gay	0.0962737	-0.342612295	0.531570	0.9945845
Straight – Gay	-0.315426664	-0.822414629	0.198814	0.5088647
Queer – Lesbian	0.35597986	-0.085484990	0.7974447	0.2005782
Straight – Lesbian	-0.0555915	-0.564941666	0.4536234	0.9998986
Straight – Queer	-0.41153901	-0.963304757	0.14002267	0.2846759

Figure 25. Tukey's HSD Test, Gender Identity and Quality of Worklife

	Difference	Lower Limit	Upper Limit	P adjusted
Cis Man – Two Spirit	0.45875978	-0.01601529	0.93353485	0.0646008
Cis Woman – Two Spirit	0.27906249	-0.19909783	0.75722281	0.0646008
Nonbinary – Two Spirit	-0.08774763	-0.67716162	0.50166815	0.9980783
Trans Man – Two Spirit	0.18808701	-0.28668805	0.66286208	0.8609695
Trans Woman – Two Spirit	0.19990952	-0.2748655	0.67468459	0.8272194

Cis Woman – Cis Man	-0.17969729	-0.59318721	0.23379263	0.8073396
Nonbinary – Cis Man	**-0.54650651**	**-1.08478760**	**-0.00822542**	**0.0443761**
Trans Man – Cis Man	-0.27067276	-0.68024326	0.13889773	0.3995658
Trans Woman – Cis Man	-0.25885026	-0.66842076	0.15072024	0.4512384
Nonbinary – Cis Woman	-0.36680922	-0.90807852	0.17446008	0.3706576
Trans Man – Cis Woman	-0.09097548	-0.50446540	0.32251444	0.9880276
Trans Woman – Cis Woman	-0.07915297	-0.49264289	0.33433695	0.9936923
Trans Man – Nonbinary	0.27583375	-0.26244734	0.81411484	0.6759606
Trans Woman – Nonbinary	0.28765625	-0.25062484	0.82593734	0.6351757
Trans Woman - Trans Man	0.01182250	-0.39774799	0.4213900	0.9999994

Figure 26. Tukey's HSD Test, Sexual Orientation and Balancing Care and Work

	Difference	Lower Limit	Upper Limit	P adjusted
Asexual – Two-Spirit	-7.105426e-15	-3.26278316	1.2819179	1.0000000
Bisexual – Two Spirit	-1.103448e+00	-3.48881449	1.8965257	0.8074744
Gay- Two Spirit	-2.187500e-01	-2.59689146	2.7652683	0.9999624
Lesbian – Two Spirit	-4.838710e-01	-2.86427676	1.9086585	0.9922471
Queer – Two Spirit	3.333333e-01	-2.09860165	1.2819179	0.8074744
Straight – Two Spirit	-5.833333e-01	-3.07532514	2.1593915	0.9999624
Bisexual – Asexual	-1.103448e+00	-3.48881449	1.2819179	0.9964023
Gay – Asexual	-2.187500e-01	-2.59689146	2.1593915	0.9996134
Lesbian -- Asexual	-4.838710e-01	-2.86426766	1.8965257	0.9964023
Queer – Asexual	3.3333333e-01	-2.09860165	2.7652683	0.9996134
Straight – Asexual	-5.833333e-01	-3.0753214	1.9086585	0.9922471

Gay – Bisexual	8.846983e-01	0.04817286	1.7212237	0.03080330
Lesbian – Bisexual	6.195773e-01	-0.2233810	1.4624927	0.3009255
Queer – Bisexual	1.436782e-01	0.4577833	2.4158249	0.0004617
Straight – Bisexual	5.201149e-01	-0.59981413	1.640040	0.8045839
Lesbian – Gay	-2.651210e-01	-1.0873864	0.5571267	0.9600401
Queer – Gay	5.520833e-01	-0.40922338	1.5133900	0.6024236
Straight – Gay	-3.645833e-01	-1.46904066	0.7398740	0.9552624
Queer – Lesbian	8.172043e-01	-0.146904066	1.7840767	0.1563637
Straight – Lesbian	-9.946237e-02	-1.20876737	1.0098426	0.9999677
Straight – Queer	-9.16667e-01	-2.13263416	0.2993008	0.2717678

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Chapter 3: "It's like you're burning the candle at both ends": Canadian 2SLGBTQ+ Working Carers Navigating Work-Care Conflicts

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What We Know

- Informal caregiving is on the rise worldwide, and most caregivers balance unpaid care work with paid employment.
- Work-care conflicts are associated with significant negative health and economic consequences for caregivers.
- Two-Spirit, lesbian, gay, bisexual, transgender, and queer (2SLGBTQ+) caregivers likely differ in some key ways when compared to the general caregiver population.
- 2SLGBTQ+ caregivers face unique challenges that are often poorly accommodated by health and employment systems.

Contributions

- This paper highlights how 2SLGBTQ+ caregivers navigate work-care conflicts.
- It also examines how work, place, and identity interact to further expose some 2SLGBTQ+ caregivers to negative health and economic consequences associated with caregiving.
- It concludes with a discussion of how the experiences of 2SLGBTQ+ caregivers relate to those of the general caregiving population.

Introduction

Informal caregiving is on the rise worldwide, with the United Nations Department of Economic and Social Affairs highlighting that nearly 80% of all long-term care is currently being provided by unpaid caregivers, who are overwhelmingly women (UNDESA, 2022). The majority of carers are defined as working carers – those who balance their unpaid care work with paid employment (Carers Canada, 2019). Worldwide, care work is associated with significant health and economic consequences: unpaid caregivers experience higher rates of stress-related health conditions (Geruso et al., 2022; Pinquart & Sörensen, 2006; Schulz & Beach, 1999)and leave the labour force early at higher rates when compared to non-caregivers(Geruso et al., 2022; Ireson et al., 2018b).Further contributing to these impacts are conflicts between work and care, which arise when there are physical, emotional, or temporal intrusions between the two spheres – such as an individual needing to leave work early to take their care recipient to a medical appointment, or the emotional strain of caring leading to absenteeism or presenteeism (Beauchamp et al., 2023).

Balancing paid and unpaid work successfully, with minimal consequences for the health and well-being of caregivers, often requires supports both within and outside of the workplace. Within the workplace, work-from-home, flex-work, job-sharing, and paid and unpaid leaves have been identified as key supports that facilitate the retention of working carers in their chosen careers (Lilly et al., 2007; Williams et al., 2019a). Outside of the workplace, caregiving supports have been highlighted as factors which mitigate the negative health and economic impacts associated with care work: chiefly, the presence of family care networks and the use of paid healthcare workers to ensure that the needs of care recipients are being adequately met (Joseph et al., n.d.).

Supports outside of the workplace are somewhat easier to come by – government-funded community nursing supports and privately paid care workers are relatively common figures in Canadian caregiving relationships. Access to state-funded care is highly geographically specific (Wilson et al., 2010) with systemic issues in accessing home health care in rural and remote communities (Kuluski et al., 2012)). Further, of the 6.4% of Canadian households who receive some form of paid in-home healthcare, just over half (54%) received solely government-funded care (Statistics Canada, 2018), meaning that the remaining 46% of households were also paying out of pocket for private care workers. This is the result of decades of underfunding of public community care, which has led to significant gaps between the amount of care supports which are needed and the amount which governments are willing to fund (Canadian Carers Alliance, 2018).

Given that research on working caregivers indicates that unsupported caregivers often struggle to maintain their paid employment(Lilly et al., 2010), it is likely that the same holds true for 2SLGBTQ+ caregivers, although this can only be assumed as there is no extant data on these experiences. Research from the United States has indicated that the bulk of 2SLGBTQ+ unpaid caregivers are also employed full-time and balance their caregiving responsibilities with paid work(Hash & Mankowski, 2017). It is likely that the same supports which have been identified as being crucial for the retention of working carers in general would also provide the same relief for 2SLGBTQ+ workers. There are also some factors specific to the population that may make balancing paid and unpaid work more challenging when compared to the general population: as stated above, many 2SLGBTQ+ carers provide care for an individual to whom they are not biologically or legally related, which may exclude them from many federal or provincial programs designed to support unpaid caregivers (Boehmer et al., 2018).

There are other aspects of the working carer experience which may be affected by 2SLGBTQ+ identity. Accommodations such as job sharing, flex work, and telework, are rarely found in many areas of public sector work, and are generally completely absent from the blue collar, pink collar, and customer service sectors which combine to form the bulk of the workforce in post-industrial service economies such as Canada and the United States (Crouch, 2021). Although this is the case for all working carers employed in these sectors, it is particularly relevant for the 2SLGBTQ+ community, who are overrepresented in insecure customer service work and within the realms of health care, education, and social services (Tilscik et al., 2015).

Employment discrimination continues to shape the experiences of queer workers, and transgender workers in particular, who are overrepresented in customer service work and the gig economy (Waite, Ecker, & Ross, 2019). This means that many 2SLGBTQ+ working carers are unlikely to be able to access the workplace supports which have been identified as being most impactful in assisting with navigating work-care conflicts, and that they may be more vulnerable to negative outcomes as a result. While unionized public sector workers in Canada typically have access to some degree of paid leaves for caregiving, these systems also often fail to meet the needs of 2SLGBTQ+ workers as they are often structured on the basis of heteronormative understandings of care: many state and private benefits in Canada restrict access to those who are caring for first-degree relatives (Charlesworth et al, 2016), such as a spouse, child, or parent. This is simply not reflective of the experiences and relationships of many 2SLGBTQ+ working carers.

This paper examines the experiences of 2SLGBTQ+ working carers as they navigate work-care conflicts, with a focus on how identity, type of work, and place intersect to shape the choices available to them and outcomes which they experience as they negotiate work and care. Building on research which shows that balancing care and work remains extremely challenging for unpaid caregivers (Bittman et al., 2007; Williams et al., 2019b)and research which highlights that 2SLGBTQ+ caregivers have unique experiences which are often poorly-recognized by the health system(Anderson et al., 2021; Coon, 2007; Valenti & Katz, 2014a; Wardecker & Johnston, 2018), I aim to show how 2SLGBTQ+ caregivers in Canada navigate the challenges created by a system which often fails to meet the needs of diverse caregivers(Brotman et al., 2007; Rajanala et al., 2020). These experiences were strongly tied to their employment, individual identity, and place, as well as the intersections thereof. These interactions resulted in a landscape of care-work interactions in which some 2SLGBTQ+ workers were made further vulnerable to negative health and employment outcomes.

Methods

This work forms a portion of a larger research project aimed at identifying how identity, work, and place effect the experiences of 2SLGBTQ+ caregivers in Canada. Semi-structured virtual interviews were conducted over Zoom between March 2022 and September 2022 of a total sample of n=40 individuals who self-identified as a member of the Two-Spirit, Lesbian, Gay, Bisexual, Transgender, and Queer (2SLGBTQ+) community and who were located in or around the four data collection sites of Toronto, Ontario; Thunder Bay, Ontario; Vancouver, British Columbia; and Prince Rupert, British Columbia.

All participants affirmed that they were presently, or had within the previous six months, providing care for an individual with a physical or mental health issue. Individuals who provided care to a dependent child were not included, unless the children also had a disability. Although childcare is certainly a form of unpaid care work, the experiences of LGBT parents are well-studied and not the focus on this paper. However, caregivers of children with disabilities were included, as their care involves a significant amount of interaction with formal health and social care systems, which was a primary focus of this project.

Participants were employed in one of the following: customer service or retail work, healthcare, education, and/or social services. These segments of the labour market were selected in order to capture a large population of 2SLGBTQ+ workers, who are overrepresented in customer service work and the social services sector (Tilczek, Antiby & Knight, 2015). Further, as one of the concerns of this project is the effect of precarious work on the experiences of 2SLGBTQ+ caregivers, the experiences of customer service workers were key. These workers are also poorly represented in the bulk of the carer-worker literature. Workers in public sector jobs in healthcare, education, and social work are comparatively less likely to experience precarity, and trade union density in these sectors remains high in Canada. As such, their presence in the sample also highlights how working conditions and access to benefits effect the experiences of 2SLGBTQ+ caregivers.

Participants indicated that they currently resided in one of the Greater Toronto and Hamilton Area, an urban region in Southern Ontario, Thunder Bay, Ontario or its surrounding environs, a mid-sized city in Northern Ontario, the Greater Vancouver Area, a metropolitan region in southern British Columbia, or Prince Rupert or its surrounding environs, a small city in Northern British Columbia. As experiences with care and queer identity are highly location-specific, these regions were chosen to provide a point of comparison across two vectors: between provinces, and between Canada's urban south and rural and ex-urban northern regions. Recruitment took place over several months, with the aim of identifying 10 participants from each region of concern, with half of each regional sample employed in insecure customer service work and half employed in healthcare, education, or social services.

Participants were recruited via 2SLGBTQ+ community groups, caregiver support groups, region-specific Facebook groups, and via snowball sampling. Interview questions focused on the nature of their care relationships, how long they had been engaging in caregiving, how they interacted with formal health care systems and informal care networks, and how they navigated caregiving from a practical, physical, and emotional perspective. Financial security and precarity were assessed through questions such as “Do you typically have enough money at the end of the month to pay your bills?” “Do you feel able to cover an emergency expense, if necessary?” and “Do you ever worry about not being able to cover your essential needs?” and “Does your wage at your primary job provide you with enough to pay your bills every month?” Work-care conflicts were assessed through questions such as “Would you be able to change your schedule unexpectedly in order to engage in caregiving?” and “Have there been times where you have needed to call in sick or otherwise modify your job duties to engage in caregiving?” Interviews ranged in time from 45 minutes to 2.5 hours.

Sample Characteristics

Participants in this study were evenly split between customer service workers (n=20) and those employed in healthcare, education, and social services (n=20)

There was a relatively even split in geographic location, 12 participants from the Greater Toronto and Hamilton Area, 9 from Thunder Bay and Northern Ontario, 10 from the Greater Vancouver Area, and 9 from Prince Rupert and Northern British Columbia. The two northern locations included small cities and their associated rural and ex-urban communities, while the two southern regions represented greater metropolitan areas.

The sexual orientation of participants slightly overrepresented gay and lesbian participants (n=24), with queer (n=9), bisexual or pansexual (n=5), heterosexual or straight (n=2), and Two-Spirit (n=1) participants forming the remainder of the sample. Of note, all participants in this study who indicated a sexual orientation of heterosexual or straight were transgender, as no cisgender heterosexual participants were recruited for this project.

Cisgender women (n=13) were slightly overrepresented when compared to cisgender men (n=12), with transgender women (n=6), transgender men (n=5), non-binary or genderqueer (n=3), and Two-Spirit people (n=1) forming the remainder of the sample.

With regards to age, the highest proportion of interviewees were between 25 and 34 (n=15). This was followed by participants aged 35-44 (n=10), 45-54 (n=6), and 55-64, (n=5). Participants aged 18-24 were equally represented when compared to participants over the age of 65 (n=2). The median age at the time of interview was 37.1.

The bulk of participants (n=16) were providing care to a spouse or long-term partner: they were categorized as such if they were either married to their care recipient or had been in a committed relationship for a period of more than 6 months. This does not**,** necessarily**,** mean that they were legally considered to be in a common-law relationship with their partner, and broadly indicated a committed emotional relationship rather than necessarily a legal one. This was followed by participants who provided care for a friend (n=9), which included individuals who were described as a friend by the care provider but with whom they may have also been in occasional, short-term, or non-exclusive romantic or sexual relationships. In the case of at least 4 participants, this also included care recipients with whom the caregiver had at some point been in a committed romantic relationship. This was followed by individuals providing care to a dependent child with a disability (n=7). Of the remaining participants, slightly more were providing care to an aging parent or parents (n=5) than those providing care to other relatives (n=3), of which two were providing care to a sibling and one to a grandparent.

Regarding the condition for which the caregiver was providing care, participants were more likely to be providing care for a physical health condition or developmental disability (n=28) than for an individual experiencing serious mental illness or substance use disorder (n=12). Of those providing care for a physical health condition, a plurality (n=12) provided care to someone experiencing a chronic and potentially life-limiting condition such as multiple sclerosis, cancer, or chronic kidney disease, followed by those providing care to individuals with chronic but non-life-limiting conditions (n=8_such as systemic lupus erythematosus, myalgic encephalomyelitis, or rheumatoid arthritis, developmental disabilities such as Autism Spectrum Disorder or Downs Syndrome (n=5), and ageing-associated conditions such as Alzheimer's Disease and dementia (n=3).

Interviews were video and audio recorded and transcribed. Transcriptions were analysed in QDAMiner, where they were analyzed using inductive thematic analysis. Inductive thematic analysis requires that the researcher approach the data without pre-existing codes, themes, or directions in mind, and is most useful in areas in which there has been a limited amount of pre-existing research or in which the ways in which the participants make sense of their own experiences are considered to be important. As the act of care and caring is an inherently individual act to which people attach their own meaning, inductive analysis was considered to be most appropriate.

Through this process, transcripts were first read through in the entirety at least twice, before any thematic coding occurred. Researcher thoughts, experiences, and ideas were bracketed, to the degree that was possible, by noting them in a separate research notebook. After having been read through twice, transcripts were then initially analyzed by coding for initial impressions based on the data.

After the initial round of coding, the codebooks were organized into themes. The second round of analysis used the themes generated from the initial codebook in order to examine the transcript as a whole with a closer eye for potential responses which may also be appropriately coded under the initial themes and subthemes. The final round of analysis, which took place after all interviews had concluded and all transcripts analyzed twice, allowed for further validation of the themes identified and ensured that transcripts were consistently analyzed according to the identified themes.

Results

Work-care conflicts are, to some degree, inevitable: they are also associated with a heightened risk for negative health and employment outcomes for caregivers (Williams et al., 2019c). All participants provided examples of times when their work and caregiving responsibilities conflicted. The precise shape and scope of the conflicts were dictated by several factors, chiefly type of work and the extent of their caregiving responsibilities. In particular, precarious work, restrictions placed on access to caregiving benefits for individuals with professional-class jobs, and the presence or absence of family and friend support all contributed to the experiences of work-care conflicts for participants in this study. In addition, place, and the place-based nature of both identity and work, further shapes these experiences.

Type of Work

Negative outcomes were not experienced equally across the sample. Carers who were employed in low-wage service work were more likely to report difficulty in maintaining their paid employment, while those employed in public sector work were more likely to report seeking alternative employment or modifications to their current roles. Type of work also shaped their motivations for maintaining their current employment and the ways in which they prioritized their worklife: those who were employed in public sector roles frequently mentioned the importance of continuing to be able to access extended health benefits. As these two sectors, broadly construed, employ the bulk of 2SLGBTQ+ workers in Canada (Waite, Pajovic, & Dernier, 2020), it is worth examining the role of work more broadly in the experiences of 2SLGBTQ+ working caregivers.

Low-Wage Service Workers

Employment discrimination and precarious employment remains a significant factor in the lives of 2SLGBTQ+ people in Canada, something which was demonstrated by the experiences of participants employed in customer service work, many of whom were young trans people. These participants often described real and persistent fears of losing their jobs, and many relied on multiple low-wage service jobs to support themselves and their care recipients. They expressed significant anxiety over being seen as a poor or unreliable worker and recounted how working in the gig economy added to their anxieties. The work-care conflicts which shaped the experiences of all participants held significantly higher-stakes for these individuals: they were far more likely to report histories of relying on social assistance, of navigating housing and food insecurity, and of high levels of care strain as they attempted to maintain their work and care responsibilities.

Customer service work is inherently precarious: no service worker who was interviewed was a member of a union, and few had any form of extended health benefits. They were highly aware of the precarity of their existence, and the limited choices available to them. Several had experienced periods of repeated unemployment, often as a result of their caring responsibilities.

Participants engaged in customer service work often faced heightened negative consequences as a result of work-care conflicts. Mike, a customer service worker located in Northern Ontario, was one of few participants who provided care for a sibling. His younger sister had a significant developmental disability, and his parents were unable to provide the care that she needed. Mike had grown up providing care for his sister, and his experiences were strongly shaped by the interaction between the care role he viewed as essential and the demands of customer service work. He emphasized that he had always been hired in roles where his immediate coworkers were aware of his caregiving responsibilities, but that, ultimately, this had not resulted in him experiencing any degree of grace or empathy on the part of his immediate supervisors. Instead, his failure to perform the role of a good or reliable worker resulted in a loss of employment:

> "…Yeah, it definitely has [impacted my career] … My manager just stopped scheduling me. I didn't last long after that."
>
> (Mike, Gay Cisgender Man, Customer Service Worker, Northern Ontario).

In Mike's case, his loss of employment had come after he had requested to switch shifts with a coworker in order to accommodate his caregiving responsibilities, something which he had initially done with ease but which, as time went on, came to mark him as an unreliable – and thus, disposable – worker.

Beth, a customer service worker in Northern British Columbia, had a similar experience. Her partner had experienced a long period of hospitalization that had culminated in her receiving a life-limiting diagnosis. Despite Beth's attempts to find outside supports to help care for her partner so that she could work, she had been unable to do so.

> "… you'd think there'd be something out there, right, something that could help us, or would pay for someone to like, come and be at the apartment or whatever. There's nothing as far as I can tell. Somehow, it's all on me."

Lacking access to family or other supports, Beth had initially taken time off to help care for her partner when she came home from the hospital. She had done so with the assumption that there would be work waiting for her when she returned: however, this was not the case.

> "… and then, like, I tried to go back, and [my manager] basically just laughed at me. Told me not to come back. Like, fuck me, I guess."
>
> (Beth, Cisgender Lesbian, Customer Service Worker, Northern British Columbia)

At the time of interview, Beth and her partner were relying on her partner's disability benefits and selling handicrafts online to make ends meet: it was clear that this was a constant struggle, and that the financial strain weighed heavily on her.

Further underlying the experiences of low-wage customer service workers was the experience of disposability: they frequently expressed sentiments that indicated that their employers had made it clear that they could be replaced at any moment. Many lacked access to any form of financial safety net and did not have family supports which they could fall back on.

Mo, a young nonbinary food service worker in the Greater Vancouver Area, described providing care to their friend and occasional romantic partner who experienced serious mental illness that impeded her ability to work. Neither they nor their care recipient had relationships with their families-of-origin, and as such, were unable to access supports from their family to help them deal with the high cost of living in the GVA. Mo's family was not supportive of their trans identity, and the withdrawal of family financial support had resulted in them leaving post-secondary education without a degree. At the time of interview, they were attempting to return to higher education, but expressed that in both their family relationships and at work, they felt as though they were disposable.

> 'Everything feels, like, you're replaceable, you know? At work, and just, anywhere. And there isn't anything you can do about it. Sometimes I think, like, for a lot of people my age, like, you get sick like she did, you'd go home, yeah? But I don't have that, and a lot of us don't. It's the same thing with the job, or with money. It's like … nothing is there to catch you when you fall."
>
> (Mo, Nonbinary Queer Person, Customer Service Worker, Greater Vancouver Area).

For Mo, and working carers like them, societal expectations – both in the form of the levels of family support caregivers are assumed to have, and in the form of workplace expectations which make no allowances for outside forces such as caregiving responsibilities impacting the ability of low-wage workers – have completely failed to account for their needs. The mention of their family, both in the context of care work and financial support, feels telling: there is no social safety net for Mo. Neither the state, nor their family of origin, is there to, as they put it, "catch [them] when [they] fall".

An additional aspect shaping the experiences of low-wage customer service workers in the sample was the role of the gig economy for workers for whom all or part of their income came from app-based gig work. This was the case for 5 participants in total, of which all but one were transgender or gender non-conforming. Although all low-wage customer service workers were at risk of losing employment if they needed to change their employment arrangements to accommodate their caregiving relationships, gig workers face the additional barriers that these decisions were made by an algorithm without a human face – they were not able to advocate for themselves.

Ella, a young transgender woman in the Greater Vancouver Area, had been caring for her chronically ill partner for over a year at the time of interview. Both women worked in the customer service sector, and even prior to her partner's illness, the pair had barely been able to make rent payments on their studio apartment: afterwards, it was a constant struggle. Ella took on additional work, adding regular shifts as a gig worker for a popular food delivery app to her full-time job at a restaurant. Although her caregiving responsibilities remained extensive, she related several examples of times in which she had needed to prioritize her paid employment, including a time when her partner had been released from hospital after an outpatient procedure that required her to be monitored for several days at home.

> "They told us, like, she needs to have someone with her for the next three days, to watch out for any complications. But I'd already taken time off work [to accompany her to the procedure] and I didn't want to piss of my boss. Plus, like, the thing with [the food delivery app] is that if you don't work enough, it hurts your rankings. And it's like -- rent is still due, no matter what. It's not like your landlord cares."
>
> (Ella, Transgender Lesbian, Customer Service Worker, Greater Vancouver Area).

As someone who worked both at a restaurant and for a food delivery app, Ella had initially been able to take off some work from the former without angering her employer. In contrast, her gig work made no such exceptions – missing work for any reason reduced her ranking on the app, something which meant she could have lost out on additional work.

For transgender workers who are overrepresented in the customer service industry, concerns like those expressed by Mo and Ella are relatively common. This was also the case for Dani, a customer service worker in Northern Ontario, worked night shifts at a gas station to better allow her to care for her partner. As a trans woman, Dani was keenly aware that her ability to maintain her employment was contingent on her ability to be a "good worker" and avoid drawing attention to herself.

> "You don't want to give them any excuse, right? Cuz like, they're looking for one, if they're looking for one, they'll find it. We talk about moving sometimes but where would we go? I couldn't afford to live in Toronto or whatever. So, like, yeah. Sometimes

> there will be an emergency and I'm not there, because I have to be at work. I can't give them an excuse. I've had to make my peace with that."
>
> (Dani, Straight Transgender Woman, Customer Service Worker, Northern Ontario)

The concerns Dani and Ella outlined regarding angering their employers were echoed by other customer service workers, some of whom feared that they would be let go if they were perceived as not prioritizing their workplace responsibilities. These fears are not unreasonable: as reported above, several participants reported losing employment or being scheduled for fewer shifts as a result of needing to take time off work for their caregiving responsibilities. Even those who had yet to experience negative employment consequences personally nevertheless lived in fear that they could occur. Jerome, a customer service worker from the Greater Toronto Area, highlighted the importance of being perceived as a good and reliable worker, stating "I have a reputation for being reliable. It's important to me. I don't want to ruin that." (Jerome, Cisgender Gay Man, Customer Service Worker, Greater Toronto Area)

The experiences described above are not inherently unique to queer and trans workers: disposability and insecurity shape the working conditions of all customer service and gig workers. However, participants were also aware that their identity meant that every move was highly scrutinized, and that their ability to make mistakes or otherwise fail to fulfill the role of ideal worker was limited when compared to cisgender heterosexual workers. They were also aware that their ability to obtain alternative forms of employment were limited when compared to cisgender heterosexual workers, leaving them further vulnerable to serious economic impacts.

Public Sector Work

The public sector workers in the sample worked in healthcare, education, and social services. The majority of these workers were protected by a union contract and had access to some degree of extended health benefits: a privilege of which many of them were keenly aware. This does not mean that these workers did not experience negative consequences as a result of work-care conflicts, but it does mean that they were typically better-situated to navigate these consequences without experiencing immediate fallout in their personal and professional lives.

In theory, these workers were faced with the same choices and challenges as the customer service workers, however, the options available to them – and the consequences thereof – were greater. Many workers were typically highly educated and in demand: it was significantly easier for them to seek alternative employment should this become necessary. In most cases, this meant seeking out different positions within the public sector, but sometimes meant turning to self-employment. Public sector workers typically had access to extended health benefits – however, the nature of their caregiving relationships sometimes meant that they were not able to fully utilize these benefits in the same way as their straight cisgendered colleagues.

Janine, a not-for-profit worker in the GTA had initially sought employment at her current workplace because they promised her the ability to work from home, something which ultimately turned out to be false. However, her relative economic privilege and higher level of education meant that the need to seek alternate employment, while inconvenient, was not a financial emergency.

> "I'm looking for a new job right now, because they hired me knowing I had a daughter with a disability, and that I took the job specifically because it was a way of applying the skills I have to sort of, make a difference, but the position was supposed to be partially remote. And during COVID, I was fully remote. Well, we're still during COVID, and now they want me in there all day, every day, and I just can't do that and take care of my daughter."
>
> (Janine, Cisgender Lesbian, Social Services Worker, Greater Toronto Area)

Fortunately for Janine, her education and relative economic privilege meant that she was able to seek different employment without risking significant negative consequences, and, moreover, that she was able to engage in her search for new employment while remaining secure in her current role. This was the case for many of the public sector workers interviewed when they discussed changing roles.

Steve, a school social worker in Northern British Columbia, had previously been employed in child protection in the Lower Mainland of British Columbia. When he was offered a position in a school in Northern BC, he took it. Although he noted that this change came with significant consequences to his social networks and his finances, he found that the new role allowed him the opportunity to enforce more rigid boundaries between his work and personal life, leaving him time to engage in caregiving.

> "We moved a bit before COVID for [another job] … I guess technically it counted as a pay cut, because taking the job meant that we had to move and suddenly we were paying way more for everything. But honestly, it was the difference between a really sort of inconsistent schedule with a lot of expectations about what you would be doing when you were technically off the clock, and more of a 9-to-5, embedded within the school system."
>
> (Steve, Cisgender Gay Man, Social Worker, Northern British Columbia)

Although moving to a region of Northern British Columbia with a higher cost of living constituted, as he put it "technically a pay cut", he judged that the associated flexibility was worth it. This was a theme that repeatedly arose in the narratives of participants who were pink collar workers who sought alternate employment: the changes may have been frustrating or inconvenient, but the potential negative consequences did not outweigh the positive aspects associated with their new employment.

Sometimes, seeking alternative employment came in the form of self-employment, which came with its own challenges. Although public sector workers broadly had access to extended health benefits, this was not necessarily the case for caregivers who turned to self-employment. This was often the source of significant financial pressures, but these participants viewed these pressures as an understandable trade-off provided it allowed them with sufficient control over their working conditions to best accommodate their caregiving duties.

Deborah, a clinical social worker in the Greater Toronto area, had been employed as a social worker for over 35 years, working at various points for hospital systems, in schools, and in child protection. Having lived in the United States for several years, she moved back to Canada when her father had a serious fall and entered long-term care. Upon return, she set up a private practice as this allowed her a greater degree of flexibility to care for her parents. However, this came at a significant financial cost to her:

> "I've been self-employed since I got back to Canada, because I needed the flexibility [to accommodate care as a result of] my parents aging ... so my employment has really been – this is an area I think really needs to be looked at, self-employed caregivers, because I've been financially devastated by this. Since 2019 there are periods from like a day to a month that I've been off work and not had any revenue and no social net that I'm aware of, I'm not able to find one."
>
> (Deborah, Cisgender Lesbian, Clinical Social Worker, Greater Toronto Area)

Despite having completed several years of post-graduate education and training and having had a long career in the public sector in both Canada and the United States, Deborah's turn to self-employment placed her at a significant financial disadvantage. She also indicated that she was paying out of pocket for extended health benefits, and as such, chose to purchase a plan with very limited coverage. The flexibility she required to fulfill her caregiving responsibilities thus required her to forgo many of the benefits that the public sector workers in the sample experienced.

For public sector workers, access to extended health benefits were key. Their employer-provided plans were typically quite good and covered much of the costs incurred during their care recipient's medical care which were not covered by the public health system. As these benefits are inextricably tied to employment, maintaining access to extended health benefits became a key motivator for participants remaining in their current employment arrangements.

This was the case even when the participants in question expressed a desire to change their employment circumstances or retire, as the extended health benefits provided to retired public employees are typically both more expensive and less extensive than those provided to current workers.

David, a 65-year-old teacher from the Greater Toronto Area, had been teaching for over 30 years and had intended on retiring with a full pension in his early 60s. His partner's diagnosis with a degenerative chronic condition in his 50s caused him to change these plans: his pension would not be sufficient to cover their living expenses alongside the expensive therapies and medications which his partner required and which were not covered by government insurance. When asked how his care responsibilities effected his working life, his frustration was obvious:

> "I should have been retired by now. I planned to be, but it wasn't in the cards. You'd think that we're in Canada, we've got this great healthcare system, right? But the thing you learn when you're sick, or a loved one is sick, is that there are these huge holes [in the system], and it's so expensive."
>
> (David, Cisgender Gay Man, Education Worker, Greater Toronto Area)

It is unsurprising that David was frustrated: on paper, his position was relatively privileged, at least when compared to other participants. He had been employed in a unionized profession for over three decades, and the extended health benefits associated with his union contract were robust. He was married to his care recipient, and belonged to a union – indeed, as a member of the Ontario Secondary School Teacher's Federation, he belonged to a union which was the first in the country to extend full benefits to same-sex partners. However, despite all of this, he was still facing the prospect of having to delay his retirement. The benefits offered to retirees were significantly less robust than those offered to working teachers, and as such, he found himself remaining in the profession. Given that much of the narrative of working 2SLGBTQ+ carers in this study have revolved around the ability to access extended health benefits, his story is an important note demonstrating that even when everything goes according to plan, it can still be insufficient to meet the needs of many.

For Lisa, a healthcare worker in Northern Ontario, access to extended health benefits were also a key driver in maintaining her current employment. Her partner's condition required expensive treatments and supports which were not covered by government benefits, but which Lisa's employer-provided healthcare insurance did cover. This meant that when she struggled to her partner's care needs conflicted with her employment responsibilities, she focused on maintaining her employment.

> "My thing was just, we're going to need to figure something out, because the other option is that I leave my job, and that would mean losing my insurance, and we have really good insurance. So, I need to keep that job."
>
> (Lisa, Cisgender Lesbian, Healthcare Worker, Northern Ontario)

Lisa and her partner, like David and his husband, were relatively fortunate – in both cases, the care recipient was the legal spouse of the caregiver, and as such, there was no question that they would be covered by their benefits. This was not the case for many participants.

The coverage of extended health benefits often extends only to the employed worker and their first-degree relatives, something which became problematic for participants who provided care to someone who did not fall into that category.

Graham, a cisgender gay man in the Greater Vancouver Area, provided care to a friend and former romantic partner who was experiencing a potentially life-limiting illness. He expressed frustration at the limitations of the benefit programs he paid into, stating: "There's just nothing out there for people like us" (Graham, Cisgender Gay Man, Education Worker Greater Vancouver Area)

Jessica, a bisexual cis woman in the Greater Toronto Area, expressed similar frustrations. She had been caring for a friend who was experiencing serious mental illness for nearly two years and was beginning to feel the effects of care strain. She knew that accessing some form of caregiving leave would have been beneficial to her, stating: "I'd go on leave if I could, but I can't." (Jessica, Cisgender Bisexual Woman, Social Worker, Greater Toronto Area). Her contract included paid caregiving leave for workers who required it but, as is typical, this was only the case for caregivers who cared for first degree relatives. As such, she instead found herself attempting to navigate work-care conflicts with no relief in sight.

These participants often expressed very high degrees of care strain, sentiments which are best described in the words of Anna, a teacher in the Greater Toronto Area who provided care for a queer young adult whom she considered to be her de facto child, but to whom she was not legally related:

> "I looked into getting a leave, but it wouldn't have worked, the rules didn't fit for us ... and so I guess I'm just burning the candles at both ends."
>
> (Anna, Cisgender Lesbian, Greater Toronto Area, Education Worker).

Like Jessica, Anna was yet another case of somebody who would have had access to paid caregiving leave if the person she was providing care to was a legal relative. Because this was not the case, she was left with nothing. It is here that we see identity playing the most significant role in the experiences of the public sector workers in the sample: their caregiving relationships were not treated with equal weight when compared to those who cared for spouses or biological or adoptive children.

All participants had experienced some form of work-care conflicts, and all were able to identify times when these conflicts led to their need to maintain one role over another. These conflicts resulted in challenges in both their work and care roles, but the shape and scope of these challenges were strongly shaped by industry.

Identity, Place, and Community

As both identity and community are strongly place-based, it is important to understand that the ways in which work-care conflicts were affected by identity and community were highly impacted by place. Participants who were located in the large metropolitan southern regions of study were more likely to have access to a larger 2SLGBTQ+ community: as such, their care arrangements were more likely to involve friend and fictive kin care. Participants in the rural and northern regions were less likely to be out at work, had smaller local 2SLGBTQ+ communities, and the conditions in their local labour markets often meant that they faced additional challenges when seeking alternate employment.

Participants in larger metropolitan regions were more likely to be caring for friends, former or occasional romantic partners, and others with whom they did not share a legal or biological kin tie. This meant that even those who had access to extended health benefits or caregiver supports within their workplace sometimes struggled to access the benefits to which they were entitled, as was discussed above. It also sometimes operated as a positive factor in facilitating caregivers' ability to navigate work-care conflicts. These non-kin care networks are more common in the 2SLGBTQ+ community, and many participants reported that they found these networks to be vital. Often, these non-kin care networks formed around care recipients and care providers who did not have relationships with their biological family, either due to distance – the bulk of these networks were found in major metropolitan areas, and both caregivers and care recipients often lived at a considerable geographic distance from their biological family – or as a result of their identity.

This was the case for Chris and his care recipient. A gay trans man in his thirties, both he and his care recipient were from other areas of the country and did not have significant relationships with their families of origin. An artist and retail worker in the Greater Toronto Area, Chris was one member of a 4-person care network who provided care to a close friend and occasional romantic partner.

> "It's difficult but it works for us… because I'm not the only one. We are really fortunate to have this incredibly close-knit group of friends, some of whom can take things on when they need us to. If it was just one of us, I don't think I could make it work."

> (Chris, Transgender Gay Man, Greater Toronto Area, Customer Service Worker)

These participants experienced their care networks as being essential to their ability to balance care and work, and to maintain a high degree of care for their care recipient. The benefits of multi-member care networks were obvious to those who engaged in them: participants frequently endorsed sentiments like "I don't think it would work if it was just me," (Ryan, Cisgender Gay man, Greater Vancouver Area, Customer Service Worker) and "I can't imagine doing this any other way" (Sam, Queer Nonbinary Person, Greater Toronto Area, Social Service Worker).

For these carers, this relatively uncommon way of providing care was viewed not as an aberration but as a necessity, even if it was one which formal systems sometimes failed to recognize or accommodate.

However, this, too, was not without its caveats. Aditya, a social worker in the Greater Vancouver Area, expressed that they worried that some members of their care network failed to prioritize their carer roles because they lacked a kin tie to the care recipient. At the time of interview, Aditya was working in what they characterized as a "physically and emotionally intens[ive]" job as a harm reduction worker, and they were struggling to balance the two without experiencing burnout. They felt that the best way to resolve this work-care conflict was to briefly step back from their care responsibilities and to focus on employment, however, they expressed worry that they were signaling that their care recipient's needs were less important.

> "… I believe that everyone has a responsibility to each other, and it felt like I wasn't doing mine by stepping back. And people, like, through no fault of their own, but sometimes I felt like – and I think that [care recipient] feels like that too, he's sort of said as much – that some people think that, because the person you're helping isn't related to you by blood, it's easier to step back or fall through on commitments. And you can't do that if you've committed to trying to help someone, as far as I'm concerned."
>
> (Aditya, Nonbinary Queer Person, Social Services Worker, Greater Vancouver Area)

Despite these caveats, all of the participants who took part in large non-kin caregiving networks – who were located almost exclusively within the large southern metropolitan regions in the sample – expressed that they played a vital role in allowing them to manage work-care conflicts without reducing the amount of care that their care recipient received. However, this was not necessarily an option for those located in the northern samples.

Rural and northern participants were less likely to report the presence of robust non-kin caregiving networks, and more likely to describe their experiences as being shaped by isolation – that is, as one participant phrased it, "It feels like it's just the two of us against the world" (Laura, Queer Cisgender Woman, Social Services Worker, Northern British Columbia). As a result, Northern participants' ability to navigate negative work-care were further curtailed: simultaneously lacking access to formal supports and informal queer kin networks, they instead ended up attempting to navigate these conflicts independently, leading to feelings of isolation and care strain.

Place-based aspects of 2SLGBTQ+ identity, and the ability to navigate work-care conflicts, were further complicated by concerns regarding identity disclosure. While all but three participants located in the southern metropolitan areas of the study were out in all aspects of their lives – two of the three were out in all areas of life with the exception of their biological family, while the remainder was out to friends but not at work or to family members – there were 3 participants in the northern samples who were out only to LGBT friends or online, and an additional 4 who were out to friends and some family members but not at work. This was particularly common for participants who were transgender or who worked in education.

This impacted their ability to navigate care-work interactions, as was the case for Grant, a teacher in Northern British Columbia who chose not to include his common-law spouse on his benefit applications and who therefore was unable to access paid caregiving leave to support him as he struggled with a chronic life-limiting condition:

> "I wouldn't say I'm closeted, exactly, but I'm very private [at work]. And in a smaller place, where everyone knows everyone, it's harder, for sure. You can take sick leave if you're caring for your partner, but the same thing doesn't really exist if you're taking care of a roommate. And like, they can say that stuff's confidential, but it doesn't really work that way. I don't believe it would be, anyway."
>
> (Grant, Cisgender Gay Man, Education Worker, Northern British Columbia)

Grant's story highlights a concern that participants in smaller communities frequently shared: namely, that they did not trust that the regulations which technically required their information to be treated confidentially would hold in their small communities. As such, these participants lost out on key tools which could have assisted them in navigating work-care conflicts.

Nina, a closeted healthcare worker in Northern Ontario, was out to a small group of friends, but was not out at work or to the bulk of her family members. As a result, when her long-term – though unmarried – partner was diagnosed with cancer, she chose not to access caregivers supports that she did not believe were truly confidential.

> "When [partner] was diagnosed, they gave us a list of support groups, things like that… but it's a small community, and I know there are rules about confidentiality and things, but I also know that people gossip."

(Nina, Cisgender Lesbian, Healthcare Worker, Northern Ontario)

Caregiver support groups are often key tools that assist caregivers in navigating work-care conflicts and their caregiving duties in general: this is particularly true for potentially life-limiting conditions like cancer, which is associated with a high degree of care strain.

Nina's experience highlights how concerns regarding identity disclosure left closeted participants without access to important supports that can help mitigate the often-stressful experiences associated with caregiving. Workplace supports such as paid leaves have been identified as important factors that facilitate caregivers' ability to maintain employment, while community supports such as caregiver support groups are associated with lower degrees of care strain. When 2SLGBTQ+ carers in rural or remote communities fail to access supports due to concerns regarding identity disclosure, they are thus further exposed to potential negative health consequences.

Discussion

Working Carers: What's Different?

It has been well-established that working carers often face significant mental, physical, and financial costs when they attempt to navigate work-care interactions. This work is best understood as being in conversation with recent work highlighting the importance of workplace supports to prevent working carers leaving the labour market (Williams et al. 2019, Sethi et al. 2022), as well as the work of Fredriksen-Goldsen et al. (2018) that highlights the unique care structures that are present within the community of LGBT caregivers. As such, it asks the question: what happens when working carers, as a result of identity, type of work, or place, attempt to navigate care-work conflicts? Are there any meaningful differences in the experiences of 2SLGBTQ+ working carers that make their experiences worthy of study?

The overarching experiences of working carers is one in which structural factors within and outside of the workplace leave people vulnerable to negative health and employment outcomes, something which has been well-established. Given that this is true for even the most economically and socially privileged working carers, it is important that we understand how identity, work, and place may interact to produce an increased vulnerability to negative outcomes.

The experiences of 2SLGBTQ+ carers are not necessarily unique –with the exception of concerns specific to identity disclosure, many of the experiences described above could apply to many caregivers. This is true. Any caregiver who cares for someone who is not a first-degree relative faces significant barriers in navigating bureaucratic systems which reify the nuclear family as the site of care. It is also true that any caregiver who is employed in insecure customer service work is vulnerable to negative economic consequences as a result of their caregiving.

However, it is also true that these experiences are simply less common outside of the 2SGBGTQ+ community. With the exception of some Indigenous (Jacklin et al, 2015) and newcomer communities (Li & Yee, 2018) relatively few individuals outside of the 2SLGBTQ+ community find themselves in the situation of providing intensive care for someone who is not a first degree relative. 2SLGBTQ+ workers, and transgender workers in particular, are more likely to be engaged in customer service and gig work when compared to the general population(Kinitz et al., 2022). Rural and Northern caregivers of all kinds face more barriers than those who are providing care in metropolitan areas, but 2SLGBTQ+ caregivers do it while navigating additional concerns regarding identity disclosure and employment discrimination.

The results of this study are not universally negative. While 2SLGBTQ+ identity makes working carers more vulnerable to some negative health and economic impacts, there are also aspects which may constitute protective factors. The relative frequency of non-kin caregiving seems to indicate the potential presence of communal values around caregiving and an understanding of the importance of care work. Given that research on racial and ethnic minority communities who place a positive value on caregiving indicates that this outlook can serve as a protective factor against care strain, it is possible that the same may be true in the case of the 2SLGBTQ+ community. Non-kin care networks can also be an advantage when compared to traditional familial care dyads – if a higher number of individuals are involved in care, the consequences associated with care-work conflicts can be shared among a greater number of people.

Interactions Between Identity, Work, and Place

It was sometimes difficult to separate the experiences of participants in this study according to strict lines of identity, work, and place. Indeed, these factors all interacted in meaningful ways which produced the outcomes described above. A cisgender gay male teacher who provided care to a spouse or common-law partner located in the Greater Toronto Area might report that there were significant economic factors which prevented them from retiring, while a cisgender gay male teacher in Northern British Columbia might report the same concerns, with the addition of fears of loss of employment due to identity disclosure. A young transgender customer service worker might speak of thinking of returning home to an unaccepting rural community but decide that they prized the presence of the queer community they had found in the city over the economic security they might find in their hometown. A transgender customer service worker in Northern Ontario might talk of moving South with their care recipient to have greater access to resources but decide that this is not possible because they could not afford housing prices in the metropolitan South. This is to say that although identity, work, and place, were all factors which impacted the experiences described above, they were not experienced as discrete factors, but as interactions: identity-place, place-work, work-identity, and many other permutations thereof.

How, then, do these factors interact to shape the outcomes to which it has been established that working carers are vulnerable? Repeated narratives of simultaneous disposability and hyper-scrutiny, of forming kin structures outside of the heteronormative nuclear family and being punished for them by bureaucratic systems, and of place-based concerns regarding identity disclosure combine to produce a population of working carers who are simultaneously more vulnerable to certain negative consequences associated with navigating work-care conflicts, -- particularly economic consequences – and who are, to some degree, and in some locations, protected against some of the social and emotional consequences associated with caregiving. It must be emphasized that these protective factors are strongly place-based: participants with access to robust queer communities, with embedded norms regarding community and non-kin care, were able to navigate work-care conflicts by relying upon extended care networks of non-kin carers, while those located in rural and more isolated regions experienced both the increased vulnerability to negative economic consequences associated with work-care interactions and lacked access to the protective factors associate with strong non-kin care networks.

Conclusions, Limitations, and Next Steps

The findings of this study are not necessarily surprising: participants who are dealing with forms of marginalization understandably sometimes struggle to deal with work-care conflicts. What is important, however, is that even the most economically privileged members of the 2SLGBTQ+ community – individuals with well-paying, unionized, public sector jobs – nevertheless found their experiences being shaped by identity and place, and their ability to successfully navigate work-care conflicts were contingent on a number of factors. For a public sector worker to access the extended health benefits, which often included paid caregiving leave, to which they were entitled, they had to be in a legal marriage or common-law relationship with their recipient and be willing to deal with the potential consequences associated with identity disclosure in the workplace. At a time when heightened scrutiny is being placed on LGBT public sector workers – and LGBT teachers in particular – it is possible that concerns regarding identity disclosure for public sector educators may come to serve a larger role in the experiences of 2SLGBTQ+ caregivers employed in public sector work, even for those who are located in large metropolitan areas.

On the other end of the spectrum were the insecure customer service workers, and transgender workers in particular, who were employed in the gig economy. That these participants did not have access to paid leave was something of a given, but that even accessing unpaid leave could potentially put their jobs in jeopardy is an important consideration. The point raised by gig workers that in low-wage customer service work in traditional employment arrangements there is at least the possibility for working carers to negotiate with their managers or their co-workers to try and accommodate their caregiving duties is important. You cannot negotiate with an algorithm, and these workers had no choice but to prioritize their app-based gig work or face real financial penalties and limited future opportunities for work.

Identity, type of work, and place all shaped the choices participants made when faced with care-work conflicts. Non-traditional caregiving relationships were poorly recognized by workplace benefit agreements, and employment discrimination remains a factor in shaping the experiences of queer and trans workers in Canada. When faced with work-care conflicts, type of work and economic precarity strongly impacted the choices available to caregivers – and the consequences of those choices – when workers were employed in insecure customer service work versus unionized pink-collar professions.

The final note is the role of place: outside of the workplace, many participants in the southern samples were protected from some negative consequences associated with caregiving due to their engagement in informal care networks. These networks appear to form more easily in communities with larger and more visible 2SLGBTQ+ communities; however, it is not impossible that they exist in rural and remote communities as well. Given the increased concerns that Northern participants expressed regarding identity disclosure, if such networks exist, it is difficult to see how a researcher could gain access to them.

A key limitation of this work is that participants were recruited via 2SLGBTQ+ community organizations and snowball sampling: they were, to some degree, inherently connected with the local queer community, and their ability to access informal resources was likely significantly higher when compared to isolated members of the 2SLGBTQ+ community. This is also relevant when considering the degree to which participants were out at work – although several participants indicated that they were not, these were a minority of overall participants and not reflective of the research which indicates that more than 50% of Canadian 2SLGBGTQ+ workers are not out at work (Pride at Work, 2021). As such, identity disclosure may be of higher salience to this population than participants indicated, and further research is needed to consider how isolation and identity disclosure may intersect and impact the experiences of 2SLGBTQ+ working carers. Given that the personal narratives of individuals who, in some respects, represent a group of 2SLGBTQ+ carers with significant cultural capital and the ability to access community supports, it is likely that these more isolated carers are even more vulnerable to the impacts of work-care conflicts, and that their available choices are further curtailed.

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Chapter 4. Misrecognition and Structural Burden’s Role in 2SLGBTQ+ caregiver interactions with health systems.

Abstract

Objectives

The experiences of 2SLGBTQ+ caregivers navigating health systems are poorly studied, with the bulk of the literature focusing on the experiences of carers of 2SLGBTQ+ older adults and that of 2SLGBTQ+ patients. This study highlights how identity affects the ability of 2SLGBTQ+ caregivers to effectively navigate health systems, including how non-traditional care relationships, experiences or perceptions of discrimination, and place interact to increase structural burden for 2SLGBTQ+ caregivers.

Design

This paper compares the experiences of 2SLGBTQ+ caregivers in Canada drawing on 40 interviews with 2SLGBTQ+ informal caregivers in 4 locations in Canada. Interviews were audio and video recorded and transcribed before undergoing inductive thematic analysis.

Results

Participants highlighted how their ability to successfully navigate health systems were influenced by identity and place. Lack of recognition of non-traditional care-relationships, concerns or perceptions of discrimination directed at themselves or their care recipient, and geographic barriers were all identified as ways in which identity effected the ability of 2SLGBTQ+ carers to interface with health systems.

Conclusion

The findings underscore the need for a greater understanding of the experiences of 2SLGBTQ+ carers in Canada, particularly those from rural and Northern communities. They also highlight ways in which lack of provider education or understanding, as well as legal and social barriers, contributed to increased structural burden for 2SLGBTQ+ caregivers.

Introduction

The experiences of 2SLGBTQ+ caregivers in Canada are poorly documented, with the bulk of the available literature focusing on the experiences of LGB older adults and their caregivers. Given that improving health outcomes for 2SLGBTQ+ patient populations is an expressed priority of the Government of Canada and that the 2SLGBTQ+ patient and caregiver population is likely to rise in the near future, it is important to understand how 2SLGBTQ+ caregivers in Canada experience the act of seeking healthcare with and for their care recipient, and what barriers exist regarding their interaction with health systems.

Background

Despite an established body of research which demonstrates that 2SLGBTQ+ individuals are significantly more likely to experience physical or mental health issues than heterosexual and/or cisgender populations (MacApagal et al., 2016; Mccrone, 2018; Stevens et al., 2018) the population of 2SLGBTQ+ patients remain poorly served by health systems (Cahill, 2017; Mulé, 2020; Rossman et al., 2017). Studies have demonstrated that 2SLGBTQ+ patient experience is extremely variable based on location and individual identity, with rural LGBTQ patients reporting higher rates of negative health systems interactions (Colpitts & Gahagan, 2016a) and transgender patients reporting significant difficulties associated with receiving adequate health care (Bauer et al., 2014). These negative experiences have been attributed to a lack of provider education(Eliason et al., 2011; Kelly, 2017; Kortes-Miller et al., 2018b), as well as broader societal levels of homophobia, heterosexism, transphobia and cissexism(Harding & Peel, 2007). While there have been attempts to address the lack of education among providers (Röndahl, 2011; Searle, 2019)these efforts have been piecemeal and largely left up to individual medical schools to design and implement, despite a 2019 Standing Committee of the House of Commons report recommending that the federal government work with the provinces to develop a standard level of LGBT health education for use in medical and nursing education across the country.

The experiences of 2SLGBTQ+ caregivers interacting with health systems has been given comparatively less attention. Research from the United States indicates that LGBT caregivers are, as a population, different from the general caregiver population in several ways. LGBT caregivers are typically younger than the general caregiver population (Valenti & Katz, 2014a) are more likely to provide care to a friend or unmarried partner (Wardecker & Johnston, 2018) and more likely to report negative physical or mental health outcomes as a result of their caregiving (Anderson et al., 2021). Gay, bisexual, and transgender men are also significantly more likely to act as informal caregivers than heterosexual and cisgender men. Research on Canadian caregivers has typically focused on the experiences of the caregivers of LGBT older adults, who may or may not be LGBT older adults themselves However, some research has shown differential experiences in accessing home care (Furlotte et al., 2016) and in interacting with healthcare providers (Butler, 2018).

Discrimination on the basis of sexual orientation and gender identity remains a reality for 2SLGBTQ+ people navigating healthcare systems. Transgender and gender diverse patients, in particular, frequently report negative interactions with healthcare providers (Kcomt, 2019; Mccrone, 2018; Oswald & Culton, 2003; Reisner et al., 2014; Seelman et al., 2017). Discrimination in health systems is associated with poorer care, diminished willingness to seek help for health conditions (McKay et al., 2023; Romanelli & Hudson, 2017), and LGBT patients presenting with more advanced stages of chronic disease as a result of this diminished willingness (Burgess et al., 2008). Discriminatory experiences are also highly likely to be internalized in a way in which negative health outcomes may be produced. Meyer's (1999, 2007, 2013) minority stress framework elucidates how the mental health and well-being of gender and sexual minorities are affected by societal prejudice. Within this framework, Meyer identifies three categories of stressors: (a) external, objective stressors or conditions, which encompass experiences like homophobia or transphobia; (b) expectations and concerns regarding future occurrences, often leading to hypervigilance; and (c) the internalization of prevailing social attitudes. It is crucial to note that this model is cumulative, indicating that prior encounters with external stressors shape individuals' responses to future events.

Gender and sexual minority experiences with health systems are often contingent on geography. The small body of literature on the experiences of LGBT patients in rural areas of Canada indicates that these patients often express concerns about anonymity, provider prejudice (Colpitts & Gahagan, 2016b; Logie BA et al., 2019), lack of education (Gardner et al., 2014), and lack of resources, particularly for trans and gender nonconforming patients (Blodgett et al., 2017). This is compounded by the general differences in healthcare access in rural areas of Canada when compared to urban centres: in general, rural health care users experience longer waits, lack of access to specialized providers and difficulty receiving some forms of care without travel (Wilson et al., 2020). This means that rural LGBT populations often do not have the luxury of attempting to see a different provider if they experience a negative interaction: instead, many simply aim to avoid utilizing the healthcare system all together (Kuluski et al., 2012).

This paper uses the frameworks of misrecognition, minority stress, and structural burden to help shed a light on how 2SLGBTQ+ caregivers experience interactions with the healthcare system. Misrecognition, as defined by Fraser (1999, 2014), describes a social dynamic in which one party in a social relation is denied the status of full participant, which may then result in experiences of maldistribution(Fraser, 2006). This is not a purely social or discursive phenomenon: writing in 2006, Fraser highlights that misrecognition, as applied to the experiences of gays and lesbians, had been used to deny them access to the recognition of their marriages as legally valid, with associated negative legal and financial consequences. Denying LGBT people, the ability to be recognized as equal parties in social relations such as the relationship between a health care provider, a patient, and their caregiver, is thus not merely a matter of interpersonal rudeness and its consequences are not merely emotional: they are in fact material, which the experiences of 2SLGBTQ+ caregivers will make clear.

Minority stress, as defined by Meyer (1999, 2007, 2013) describes the process through which gender and sexual minorities internalize experiences or perceptions of discrimination and identity stigma, resulting in negative physical and mental health consequences. Gender and sexual minorities who have experienced discrimination on the basis of their identity, or who understand that such events are a possibility due to identity stigma, may internalize these stressors. As a result, they may come to anticipate experiences of discrimination, which is also experienced as a stressor, and may attempt to take actions that can ameliorate the possibility of experiencing these actions, such as concealing their gender or sexual identity. However, concealment is also experienced as a stressor, and is associated with negative health outcomes.

Within the realm of 2SLGBTQ+ caregivers, then, the minority stress model suggests that these caregivers may, as a result of past experiences or general levels of identity stigma, enter into interactions with healthcare providers anticipating experiences of discrimination, and may take actions to try and ameliorate this. In the case of caregivers, there is an additional stressor – caregivers may fear that their care recipient will experience the negative consequences of discriminatory actions or attitudes and may enter into interactions with health systems with this in mind.

The framework of structural burden is a relatively new one, which aims to understand the unique forms of care burden that result when informal caregivers are required to act as case managers(Taylor & Quesnel-Vallée, 2017). Case management refers to the form of care in which caregivers must advocate on behalf of care recipients to healthcare providers, coordinate formal and informal care providers to ensure coverage of their care recipient’s needs, and liaise with healthcare providers to ensure that the expressed wishes of their care recipient are given due consideration with respect to their care. This form of care is vital to the wellbeing of chronically ill and disabled care recipients, and it is also an increasingly common form of care that caregivers are expected to provide as individuals live longer, and with more intensive health conditions (Funk et al., 2019).

Methods

This study was conducted as a component of a broader project exploring the experiences of 2SLGBTQ+ caregivers in Canada. The research aimed to investigate how factors such as identity, work, and location influence their caregiving experiences and workplace dynamics.

Semi-structured virtual interviews were carried out via Zoom from March 2022 to September 2022. The study involved 40 participants who self-identified as members of the 2SLGBTQ+ community and were situated in or near four specific data collection sites: Toronto, Ontario; Thunder Bay, Ontario; Vancouver, British Columbia; and Prince Rupert, British Columbia. All participants confirmed that they were presently providing care to individuals dealing with physical or mental health issues. It is important to note that traditional child-rearing responsibilities were not considered unless the child also had a disability.

The interview questions delved into various aspects of their caregiving experiences. Participants were asked about the nature of their care relationships, the duration of their caregiving roles, their interactions with formal healthcare systems and informal care networks, and how they managed caregiving from practical, physical, and emotional standpoints. Some of the questions aimed to gauge their caregiving experiences included inquiries like, "Do you believe your race, gender, or orientation has affected your experiences as a caregiver?" and "Can you share your interactions with doctors, nurses, and other healthcare providers? Were they positive, negative, or mixed? Are there any notable experiences you'd like to mention?" Participants were also encouraged to describe their relationship with the care recipient, the types of care they provided, any improvements they believed would enhance their caregiving experiences, and whether there were other individuals involved in caring for the same recipient.

Sample Characteristics

Of the 40 total participants in this study, half were customer service workers (n=20), and the other half worked in healthcare, education, or social services. Geographic distribution was relatively even, with 12 participants from the Greater Toronto and Hamilton Area, 9 from Thunder Bay and Northern Ontario, 10 from the Greater Vancouver Area, and 9 from Prince Rupert and Northern British Columbia. The northern locations included small cities and their surrounding rural and ex-urban communities, while the southern regions represented larger metropolitan areas.

In terms of sexual orientation, the sample slightly overrepresented gay and lesbian participants (n=24), with queer (n=9), bisexual or pansexual (n=5), heterosexual or straight (n=2), and Two-Spirit (n=1) participants making up the rest. Notably, all participants who identified as heterosexual or straight were transgender, as no cisgender heterosexual participants were recruited.

Cisgender women (n=13) were slightly overrepresented compared to cisgender men (n=12), with transgender women (n=6), transgender men (n=5), non-binary or genderqueer (n=3), and Two-Spirit people (n=1) comprising the remaining participants.

Regarding age, the largest group of interviewees fell between the ages of 25 and 34 (n=15), followed by participants aged 35-44 (n=10), 45-54 (n=6), and 55-64 (n=5). Participants aged 18-24 were equally represented compared to those over the age of 65 (n=2). The median age at the time of the interview was 37.1.

The majority of participants (n=16) were providing care to a spouse or long-term partner, which meant being married to their care recipient or in a committed relationship for more than 6 months. This didn't necessarily imply a legal common-law relationship but signified a committed emotional bond. Following this group, participants provided care for a friend (n=9), which included individuals described as friends but who may have also had occasional, short-term, or non-exclusive romantic or sexual relationships with the caregiver. In some cases, the care recipient had been in a committed romantic relationship with the caregiver at some point. Additionally, seven participants provided care to a dependent child with a disability, and five cared for aging parents, while three cared for other relatives, including two siblings and one grandparent.

Regarding the care recipients' conditions, most participants provided care for physical health conditions or developmental disabilities (n=28). Among those providing care for physical health conditions, the majority (n=12) cared for individuals with chronic and potentially life-limiting conditions like multiple sclerosis, cancer, or chronic kidney disease. Others provided care to individuals with chronic but non-life-limiting conditions (n=8), developmental disabilities (n=5), and aging-associated conditions (n=3) such as Alzheimer's Disease and dementia.

Analysis

Interviews were video and audio recorded and transcribed using QDAMiner. Inductive thematic analysis was used, which is considered to be most appropriate for research which focuses on individual experiences and in which there is limited previous research. As part of that process, interviews were transcribed and then read through twice before thematic coding began. Each transcript underwent three rounds of thematic coding. The first focused on generating codes based on initial readings of participant responses, without a view to the development of larger themes or subthemes. After this was complete, larger themes were developed using the codes generated in the first round of analysis. The second round of analysis consisted of using the generated themes to re-examine the transcripts and identify any additional data which was best categorized using the larger themes and subthemes. The final round of analysis took place after all interviews had been transcribed and analyzed twice, to ensure consistency of coding across transcripts and to ensure that all themes were properly identified and accounted for.

Results

Barriers to full interaction with healthcare providers were influenced by the relationship between care providers and care recipients, including the number of non-kin caregivers present and their relationship to each other, and by concerns related to identity stigma or discriminatory treatment, something which was particularly pertinent for transgender and gender nonconforming participant. Among care dyads, a common theme was that of misrecognition, with individuals engaging in spouse or partner care being instead identified as friends, sisters, or other relatives. This specific pattern of misrecognition was the sole domain of care dyads in which both parties identified as or were commonly perceived to be women. Another theme which arose for care dyads was the inclusion of secondary or tertiary caregivers to provide respite or instrumental care, and the limitations thereof. For individuals engaged in care networks, common themes arose around the challenges associated with interacting with formal healthcare systems as members of large, non-kin caregiving networks.

Concerns about discrimination and identity disclosure were two themes that arose consistently within the realm of transgender and gender nonconforming participants. These themes were associated with significant fear and anxiety for participants, and some of these participants expressed concerns that their cisgender care recipients would receive worse care due to their association with the transgender or gender non-conforming caregiver.

While all of these themes were strongly associated with place, as the existence of the large non-kin caregiving networks discussed above was generally contingent on the presence of a large 2SLGBTQ+ community, some themes arose that were specific to the concerns of rural and northern participants. For these participants, themes relating to anonymity, confidentiality, and the inability to seek alternative care providers after negative or discriminatory experiences were particularly pertinent.

Care Relationships

The relationships between carers and their care recipient significantly influenced the ways in which carers interacted with formal healthcare providers. As the specific breakdown of care relationships (e.g. spousal care, friend care, etc.) was discussed in detail in the methods section, for the purposes of discussion it is important to understand the breakdown of care relationships into two categories: care dyads, and care networks. Care dyads, which took the form of a single individual providing the majority of care for a single care recipient, with some potential involvement of secondary caregivers for respite care or assistance with instrumental care tasks, took multiple forms: while the majority of care dyads were spousal/partner or parent-child caregiving relationships, some care dyads involved a primary caregiver providing care to a friend or former partner. In contrast, care networks were more likely to involve multiple non-kin caregivers, and the bulk of participants engaged in friend care were engaged in some form of care network.

While all forms of care relationships impacted the ways in which caregivers interacted with health systems, these impacts took different forms. Individuals caring for friends faced significant social and legal barriers when interacting with the formal healthcare system, particularly when they attempted to engage in advocacy or care management. Alternatively, some participants who were providing care to a long-term partner indicated that their relationship was mischaracterized as being that of friends when interacting with healthcare providers. This misrecognition also impacted their ability to engage in advocacy and care management, although the impacts were felt differently when compared to those who were engaging in friend care.

Care Dyads

The first form of care relationship which will be examined is that of the dyad. This is the most commonly recognized form of care relationship, and, in theory, should have been the most easily legible for healthcare and service providers. Unlike the relationships which will be discussed later in this analysis, care dyads are common in the dominant culture, and spousal or partner care should have been easily recognized as such by healthcare providers. This was not always the case.

Instead, it was common for participants who *were* engaged in committed caregiving dyads to have their relationship mischaracterized as that of friends or acquaintances. Notably, this experience was the exclusive domain of participants who either identified as or were generally perceived to be women. These carers reported being repeatedly misidentified as friends, sisters, or mother-daughter pairs.

Nora, a cisgender lesbian in the Greater Vancouver Area who provided care for her partner who was experiencing a chronic life-limiting illness, reported an experience of accessing care for an injury:

> "I remember once, we had to go to urgent care because she'd fallen and hit her head, and the nurse said "oh, you're such a good friend" and it wasn't a conversation I wanted to have at 3 in the morning, so I just said 'yep, that's me!'. She got a kick out of it, though."

Although she related the story as an example of an amusing experience to which she was accustomed, she also acknowledged that there were ways in which this could become problematic or an emotional burden.

> "… At the same time, it's like – even when you're in the notes as the caregiver, not everyone reads them, or looks for that, so when a new person comes on you have to sort of clarify who you are and why you're there, which is fine, but it's not something that --- it's just another thing."
>
> (Nora, Cisgender Lesbian, Greater Vancouver Area)

Other participants who had experiences like Nora's talked about them in a similar way – as a vaguely amusing anecdote, which was generally expected to occur. However, Daniella, a cisgender bisexual woman in the Greater Toronto Area, also noted that this mischaracterization could potentially lead to discriminatory actions.

> "It's not even – like I'm aware we're so fortunate, just in comparison to what it could be or what it has been, but like the legal aspect isn't in question, which is a relief. It's more the sort of immediate emotional thing, but it's also – when someone assumes that you're a friend, or a sister, or whatever, it's like – what happens if you correct them and they're a raging bigot?"
>
> (Daniella, Cisgender Bisexual Woman, Greater Toronto Area)

This was, unfortunately, not a hypothetical concern. Although significant progress has been made regarding the acceptance of 2SLGBTQ+ identities within and outside of healthcare systems in Canada – something which Daniella notes even as she recounts feeling concerned about the possibility of discriminatory action – many participants reported concerns about or experiences of discrimination, as will be discussed in the following section.

However, it is worth noting that the presence of what has been categorized in this paper as a care dyad did not necessarily mean that the only individuals involved in the care were the primary caregiver and care recipient – indeed, this was true for just 3 participants. The three participants who reported being a sole caregiver were the spouses and adult daughter of their care recipient, and there were usually other factors at play that resulted in an isolated care dynamic. For these participants, geographic distance from other potential caregivers and difficult relationships with biological family resulted in isolated care dyads.

Instead, more common among care dyads were support systems which were analogous to those of the traditional family care network or system, in which a single individual provides the majority of care tasks (and, particularly, direct care tasks like personal care or wound care), with outside parties providing assistance with instrumental care tasks or providing respite care. These networks did not usually involve the participation of biological family.

This was the case for Gina, a cisgender lesbian in her 50s in Northern British Columbia who provided care for her long-term partner who was experiencing early-onset dementia.

> "There's just so much, and you can't do it on your own. It's one of the times when you sort of regret not having children, you know? [laughs] You sort of realize early on that this is just not something that's going to be tenable in the long term without help. I still work, so it's not a matter of wanting, I just can't always be there. We have a few very, very good friends who have helped out… I can't imagine doing this without them."
>
> (Gina, Cisgender Lesbian, Northern British Columbia)

Gina and her partner had moved to Northern British Columbia for work; she as a nurse and her partner as a civil servant. Both women were in their fifties when her partner received the diagnosis, and Gina explained that they did not have access to familial supports, due to both geographical distance and family histories of discomfort with the women's sexual orientation.

> "You know, people would – friends will ask me all the time, do you regret moving up there? …. And I didn't, really, until [my partner] was diagnosed. Then you miss things. Resources, yeah, but also just friends. We have a lot of people who want to help, but they're so far away."

There was also a limit to the kinds of care her friends were able to provide. As she explained,

> "You know, it's not like they can take her to the doctor, or, I mean, they can, but they don't know to ask the right questions necessarily, so it's challenging."

Here, Gina was highlighting an area in which reliance on friends as supplementary caregivers within a care network that mimicked that of a family care network was somewhat problematic. Unlike other participants, whose care networks involved extensive involvement of multiple non-kin care providers, Gina was her wife's primary caregiver, and as such, there were some questions only she would have known to ask. While it would certainly have been possible for her to provide the friends who were willing to accompany her wife to her medical appointments with detailed lists of questions that were necessary to ask, doing so would have contributed to her mental load – so instead, she simply chose to attend those appointments herself, and to rely on friends in other roles that did not involve directly liaising with healthcare providers.

Care Networks

In some cases, care networks took the form of a broader non-kin care network which engaged a number of unrelated participants. For several participants, care was shared in a more egalitarian way, across multiple caregivers who were neither first degree relatives nor spouses of the care recipient. These friend care networks sometimes involved a degree of specialization, with one individual taking on the bulk of direct care tasks and others taking on other aspects of care including case management, but this was not always the case. For participants who were associated with their care recipient through friendship and who were members of non-kin care networks, interactions with healthcare providers were often challenging.

Kai, a trans man in his early 30s in the Greater Vancouver Area, cared for a friend and occasional romantic partner who was experiencing a chronic life-limiting illness. In his case, there were several other individuals involved in the care, one of whom lived with the care recipient and took on the bulk of direct care tasks. The other members of the network attempted to take on the bulk of care management and interactions with medical professionals, but this was not always easy.

> "It's weird… Like it gets easier after a while, when you're dealing with the same doctors and shit, but initially… also like, I get that it's easier to have one person be the designated person for medical stuff, but it means you have to choose. Like, the system isn't set up for there to be more than one person, unless it's like your parents, I guess."
>
> (Kai, Transgender Gay Man, Greater Vancouver Area)

As Kai highlighted, there are systemic barriers at play for individuals who are engaged in non-kin caregiving networks. Fortunately, Kai's care recipient was legally competent to make their own care decisions, and the bulk of interactions between caregivers and medical providers came in the form of coordination of care and advocacy. It is also important to note that these interviews took place during the COVID-19 pandemic, and both Ontario and British Columbia had imposed restrictions on caregivers accessing healthcare facilities. In many cases, particularly during the early stages of the pandemic and resultant stay-at-home orders, healthcare facilities required that a single person be designated as a caregiver who was permitted to accompany the care recipient while they were in hospital. When Kai refers to "the designated person" in the above quote, he is referring to this process, rather than a formal medical Power of Attorney.

Kai was not the only participant to raise the example of how the COVID-19 pandemic response failed to meet the needs of care networks. Sam, a gay man in the Greater Toronto Area, was one member of a 6-person care network that provided care for a close friend and former romantic partner who was experiencing cancer. During the COVID-19 pandemic, they were asked to designate a single person who would be permitted to visit their care recipient in hospital – and, later, a single person who would receive priority access to the COVID-19 vaccine.

> "What was super-weird for us was during COVID, you had to pick one person as your, like, designated caregiver. And I just wanted to be like, guys, that's not how this works. That's not how it works for us at all. [laughs]"
>
> (Sam, Cisgender Gay Man, Greater Toronto Area)

Here, the failure of formal health systems to recognize non-traditional caregiving relationships had significant material consequences: during the initial roll-out of priority access to the COVID-19 vaccine, their multi-member care network had to essentially choose which of them would be prioritized, introducing a hierarchy into their care network which had not previously been present. Moreover, this was not just a matter of hurt feelings – those who had not yet received the vaccine were limited in their ability to provide care to their care recipient and in their ability to accompany him to medical appointments, introducing barriers to interactions with healthcare systems that had not previously existed.

It is important to note that the structural barriers faced by non-kin caregivers or those in non-traditional caregiving relationship are not merely attitudinal: for some participants, there were also significant legal considerations. Julia, a cisgender lesbian in the Greater Vancouver Area, was part of a polyamorous family unit with dependent children. Although she was legally married to one of her partners, there were two other additional partners with whom she shared the task of raising the children. Despite being raised in a household in which all adult partners were treated as parents, the reality remained that at the time of the children's birth, which took place prior to legal reforms in British Columbia that allowed for the inclusion of multiple parents on the same birth certificate, only two parents could be listed. At the time of the interview, they were looking into legal options to retroactively address this but believed that this would likely be challenging.

> "I do think there's judgment about families like mine, and there's also the legal aspect. Our legal frameworks aren't set up to acknowledge families with multiple parents, all of whom want to be part of the care or decision-making process. Legally speaking, we aren't [all considered parents], which means that in an emergency scenario or when you're dealing with healthcare providers, there's an automatic dismissal if you aren't [their legal parent]. Like, you basically have the same rights as a stepparent or a family friend at that point, which is to say, none."
>
> (Julia, Cisgender Lesbian, Greater Vancouver Area)

This was problematic for a number of reasons: two of the dependent children had significant disabilities, and it was challenging for the parents not listed on the children's' birth certificated to engage with healthcare providers. Although the family had made an effort to ensure that all parents were legally tied to the children to the extent that was possible, it meant that engaging with new healthcare providers was a consistent source of anxiety for the family.

Participants engaged in non-traditional care relationships were keenly aware that they faced significant legal and attitudinal barriers when engaging with formal care systems, and, like Julia, they had often pursued legal options to ensure that there was no question as to their ability to engage in care.

Lana, a cisgender lesbian in Northern Ontario, was one member of a 4-person care network that provided care for a friend who was experiencing cancer. It was important, she stated, to "Be really intentional about it", a realization that had been prompted by the discovery that control of her care recipient's medical care would have automatically passed to a sister with whom she did not have a relationship.

> "It was when she had her first long stay in the hospital, and we were sorting out power of attorney, things like that. And we realized that, first of all, we were going to have to pick a person for that and that's harder when it's not the automatic thing of, well, that's your spouse, of course they'll be your POA. And the second thing we realized was we were really lucky that nothing had happened beforehand, and that we were making these choices when she was able to express her own desires. Otherwise, it would have defaulted to, I think, her sister, who hated her and what she saw as her choices."
>
> (Lana, Cisgender Lesbian, Northern Ontario)

In both Lana’s and Julia’s cases, there were fewer legal barriers to their engaging in their caregiving roles than there would have been even ten years previously, but that these barriers were lessened did not mean they were eliminated. In both cases, they had to engage in legal and administrative processes which were challenging for them to navigate even as highly educated professionals. Language and educational barriers could have very easily made these processes more challenging, or even impossible, to navigate.

Overt Experiences of Homophobia and Transphobia

Despite significant improvements in attitudes towards 2SLGBTQ+ people both within and outside of the healthcare system, barriers to appropriate care continue. Many participants had experiences with what they believed to be discriminatory actions or attitudes; many more had narratives which included concerns of potential discrimination. These concerns frequently centred around transphobia or discrimination on the basis of gender identity: participants who highlighted discrimination as being a primary concern were often in caregiving relationships where either they or their care recipient were transgender or gender nonconforming. These concerns frequently centred on the wellbeing of their care recipient.

Sarah, a cisgender queer woman in the Greater Vancouver Area, provided care to her partner, a transgender woman. While hospitalized, her partner was repeatedly misgendered by healthcare providers, something which caused significant distress to both Sarah and her partner. However, she recounted that although her first instinct was to advocate on her partner’s behalf, she was also concerned that by doing so, her partner may have received worse care.

> “… when you’re the patient, it’s different, like, you can choose to sort of die on that hill if you want, you’re the one who’s going to take the consequences. But it’s different if you’re taking care of someone else, and honestly sometimes it’s just easier to let people make their assumptions.”
>
> (Sarah, Cisgender Queer Woman, Greater Vancouver Area)

Interestingly, Sarah was not the only cisgender partner of a trans person who reported experiences in which they felt the need to restrain themselves from advocating for their partner. Transgender patients often report negative interactions with healthcare systems, and that their advocacy is less likely to be taken seriously (Ding et al., 2020). It is interesting that in the case of both Sarah and the following participant, the transgender partners of cisgender caregivers asked their cis partners not to advocate on their behalf for fear of making things worse.

Mark, a cisgender gay man with a transgender partner, reported an experience in which his partner requested that he refrain from advocating on their behalf:

> "I remember the nurses at the one clinic just kept misgendering my partner, and I, being the kind of person that I am, wanted to go on the warpath, I had like, resources pulled up on my phone, I was going to educate them… and my partner just looked at me and was like "Babe, please don't." It was a really humbling moment. "
>
> (Mark, Cisgender Gay Man, Northern British Columbia).

In some cases, concerns about discrimination were expressed as fears that the identity of the caregiver, rather than that of the care recipient, could result in negative outcomes. Dani, a transgender woman in Northern Ontario, provided care for her partner, a cisgender man. She explained that while she wanted to accompany him to medical appointments – and particularly when he was admitted to hospital – she was concerned that her presence might negatively impact the ability of her partner to receive needed care.

> "I mean, I'm trans, and he's not, and at a certain point it felt like it was almost hurting the situation to have me involved. I avoid the hospital whenever possible, because it's just – you start to have some really bad experiences. And there's an emotional weight to that, too, because you want to help take care of someone… but you being there is actually harming their ability to get the care they need."
>
> (Dani, Transgender Straight Woman, Northern Ontario).

In this case, Dani was concerned that her partner, who would otherwise have been perceived by healthcare providers as a cisgender heterosexual man without any association with gender variance, would experience poorer care as a result of her presence. Thus, concerns about discrimination on the basis of her identity, rather than that of the care recipient, was a key barrier in preventing her from advocating on behalf of her partner.

Concerns that the identity of the care provider could reflect poorly on the care recipient were echoed by Deborah, a cisgender lesbian who provided care to her elderly father. In her case, she believed that healthcare providers failed to give her advocacy the same weight as interactions they had with her straight, cisgender brother.

> "I think in a lot of ways, I wasn't the most effective spokesperson, I guess. My brother was very minimally involved in Dad's care, and it did seem like they were much more willing to listen to him, but I do have a hard time pulling out how much of that was gender and how much of it was homophobia."
>
> (Deborah, Cisgender Lesbian, Greater Toronto Area).

While Deborah was cisgender, she was also gender non-conforming: that these concerns regarding queer identity impacting the ability of individuals to liaise with healthcare providers were broadly associated with individuals who were either transgender or gender nonconforming suggests that while significant progress has been made regarding the treatment of gay and lesbian people in the healthcare system, the same cannot be said for transgender and gender nonconforming people.

Given Deborah's statement that she was unsure if it was her queer identity that impacted her ability to advocate on behalf her father, it is important to note that fears or perceptions of discrimination have the potential to impact the experiences of 2SLGBTQ+ caregivers, regardless of whether discriminatory behaviour takes place. Participants were directly asked if they felt that their interactions with healthcare providers had been impacted by their identity, and although some were able to identify specific incidences of discrimination, others pointed to a general feeling or perception that they believed this to be the case. Jerome, a cisgender gay man in the Greater Toronto Area, expressed his experiences thusly:

> "I do feel that I am treated differently, but it's something I've never been able to pin down, exactly. It's just a feeling, you know?
>
> (Jerome, Cisgender Gay Man, Greater Toronto Area)

These experiences – whether they were the result of past experiences with healthcare providers or contemporaneous incidents that they either witnessed or experienced, had a chilling effect. As their stories indicate, fears or perceptions of discrimination significantly impacted the ability of caregivers to advocate on behalf of the patient.

The Role of Place and Health Systems

Several aspects discussed previously – the presence of care networks, and concerns regarding identity – were strongly place-based. Participants who were engaged in large, non-kin care networks were located almost exclusively within the two metropolitan southern samples. The sole exception, that of Lisa, was distinct in that her care network was both comparatively small and consisted of herself, her partner, and her two close friends, with Lisa taking on a significant amount of care herself. None of the individuals who reported providing care to a friend and doing so within the context of a large care network, were located outside of the southern metropolitan regions.

The second concern, that of discrimination on the basis of identity, is best discussed here in the context of the significant barriers associated with healthcare access in rural and remote regions of Canada. There are well-documented barriers faced by individuals accessing health and social care in rural and northern regions of Canada, but, in addition to these, participants also highlighted how identity shaped their experiences. Northern participants generally resided in small cities and rural and ex-urban regions in Northern Ontario and British Columbia, while the remainder were located in the large metropolitan regions of the Greater Toronto Area and the Greater Vancouver Area. Attitudes towards 2SLGBTQ+ people are strongly place-based: negative attitudes towards 2SLGBTQ+ people are less common, although certainly present, in the metropolitan South.

Identity and place also interacted with regards to concerns of anonymity and confidentiality while navigating health systems. This theme was particularly prominent in the experiences of participants who were not out in all areas of their lives or who were concerned about stigma related to mental illness.

Ben, a cisgender gay man in Northern British Columbia, provided care for a partner who experienced serious mental illness which had resulted in several cycles of hospitalization. He related an experience of putting off seeking emergency care for suicidal ideation until they knew that the emergency room would not be staffed by a personal acquaintance.

> "Yeah, I remember once… he'd been having a very hard time, and we were experienced enough at that point to go, ok, it's time to go to the hospital again. He knew he needed to go, too, but we decided to wait, because we knew that a friend of [his mother] was on shift at the ER that night. He didn't want her to see him like that, even though it wasn't a secret, everyone knew he had problems. I remember just staying up all night with him, because I didn't want to let him out of my sight, and just counting down the hours until shift change. It was… one of the hardest things I've done."
>
> (Ben, Cisgender Gay Man, Northern British Columbia)

Concerns regarding anonymity relating to a stigmatized condition led Ben and his partner to avoid seeking prompt care for an episode of serious suicidal ideation: there could have been disastrous consequences associated with this.

Anonymity also effected the ability of some participants to advocate on behalf of their care recipient. Beth, a cisgender lesbian in Northern British Columbia, had lived in her small northern city for her entire life, and described the tensions that arose when she felt that her partner wasn't being appropriately treated by their local healthcare providers.

> "I think I'd be more comfortable taking a more aggressive approach if I was somewhere else, like, in Vancouver or something. But we're small enough that it's sometimes a situation where like, I'm not going to argue with you, you know my mom."
>
> (Beth, Cisgender Lesbian, Northern British Columbia)

In another example, Nina, a closeted healthcare worker in Northern Ontario, chose not to access a caregiver support group she was referred to after her partner was diagnosed with cancer, stating that she did not trust that confidentiality requirements would be adhered to.

> "When [partner] was diagnosed, they gave us a list of support groups, things like that… but it's a small community, and I know there are rules about confidentiality and things, but I also know that people gossip."
>
> (Nina, Cisgender Lesbian, Healthcare Worker, Northern Ontario)

For participants who had lived in both northern regions and in the metropolitan south, the differences that geography imposed were obvious. Teddy, a queer trans man in Northern Ontario, had been born and raised in a small exurban Northern community before attending university in Toronto. Having returned to Northern Ontario for work, he highlighted that he had experienced a number of behaviours from healthcare providers that he felt were discriminatory towards himself or his partner.

> "Part of it's the area… there have definitely been interactions where I go, that wouldn't have happened in Toronto. Or if it did, there would have been consequences."

When asked if he had ever pursued a complaint against healthcare providers who he felt had behaved in a way which was discriminatory, he shrugged.

> "… You could do that, yeah. But you can't just go to a different hospital or something, there's just the one. So, you could complain to the patient advocate or something, they might even send you an apology, but at the end of the day you're still going to have to see the same doctor who said something fucked up. So no, I guess is the answer to that."
>
> (Teddy, Queer Trans Man, Northern Ontario)

It is easy to see, in Teddy's experiences, how concerns regarding anonymity and healthcare provider discrimination could potentially combine to produce poorer outcomes for care providers and their care recipients, something which was also repeated by other participants from Northern areas.

Mark, whose experiences providing care to his transgender partner in Northern British Columbia, were documented in the previous section, reported a similar experience. Although he refrained from engaging in advocacy on behalf of his partner when requested to do so, his frustration was obvious.

> "You always get the excuse, like, oh, sorry, we just aren't educated about that kind of thing. We don't know any better. We're not comfortable providing [gender affirming care]. It drives me nuts. It's their job to know."
>
> (Mark, Cisgender Gay Man, Northern British Columbia).

A common experience among participants located in the Northern sample was having to travel long distances for medical care: many participants reported having to travel for hours in order to access hospitals with specialists who could meet their care recipient's medical needs. While this is obviously an inherent barrier to adequate healthcare access, there was also a sense in which this was experienced as a positive by some participants. Indeed, Beth mentioned that she had on occasion needed to travel several hours to access care for her partner, who had a serious cardiological condition. Although this placed an administrative and financial burden on the couple, she also indicated that there was a degree of relief associated with accessing care in a city.

> "There are a lot of things we've had to travel for, and obviously that's not great, but in some ways, it was almost a relief to just be another face in the crowd."
>
> (Beth, Cisgender Lesbian, Northern British Columbia)

Discussion

The experiences of participants highlighted above are best understood in conversation with three broad frameworks: minority stress, misrecognition, and structural burden. In particular, these experiences show how misrecognition and minority stress interact to produce greater structural burden on caregivers when they interact with health systems and healthcare providers.

The minority stress framework as described by Meyer (1999, 2007) describes the process by which societal prejudice effects the mental health and well-being of gender and sexual minorities. The cumulative nature of the model, which describes how gender and sexual minorities internalize experiences of discrimination and identity stigma and come to anticipate discriminatory actions, thus increasing their stress levels and potential negative health consequences, makes it a key framework with which to understand the experiences of 2SLGBTQ+ caregivers. It is likely that all 2SLGBTQ+ people have experienced instances of behaviours which were driven by homophobia or transphobia, and discrimination at the hands of healthcare professionals remains sadly common. Thus, 2SLGBTQ+ carers – particularly those who have already experienced or witnessed discriminatory behaviour – enter interactions with the healthcare system with a degree of hypervigilance and concerns about future events effecting the experiences of the people they care for. Participants were sometimes unable to point to specific discriminatory events, instead highlighting attitudes or feelings they were being treated differently. This hypervigilance contributed to increased structural burden.

The second framework with which I make sense of the experiences of 2SLGBTQ+ carers navigating health systems is that of misrecognition. Misrecognition, as defined by Fraser (2006, 2014) refers to the social dynamics in which an individual is denied the status of full participant in a social interaction, something which can be associated with maldistribution and injustice – that is, misrecognition is not merely social or cultural, but has direct material consequences. Writing in 2006, Fraser argued that misrecognition of gays and lesbians led directly to the lack of marriage equality at the time – failing to recognize gay and lesbian relationships as full and equal participants in social interactions led to them being legally treated as invalid.

Failing to recognize 2SLGBTQ+ caregivers as such, particularly those in non-traditional caregiving relationships, has similarly negative material consequences. Recognition of carer status has been identified as a key protective factor in mitigating care strain (Jeyagurunathan et al., 2017; Neufeld et al., 2008; Ward-Griffin et al., 2015)and individuals who are recognized as being carers are more likely to receive support from friends and family. For individuals whose care role includes care management – that is, liaising with formal and informal care providers, advocating on behalf of the care recipient, and communicating with healthcare professionals– being recognized as a caregiver is not just psychologically beneficial, it is a logistical requirement. Participants who lacked legal recognition as carers struggled to fully engage in their care tasks, as they simply did not have a right to do so in the eyes of the health systems with which they interacted.

Misrecognizing women caring for their female partners and spouses as being individuals caring for family or friends is also problematic under this framework: it may be interpreted by those who experience it as indicating that the healthcare provider has some degree of prejudice against same-gender relationships and places the additional emotional burden of requiring the caregiver and recipient to decide whether to disclose their relationships.

Both frameworks help explain how 2SLGBTQ+ caregivers may experience increased challenges interacting with health systems as they engage in case management. Some researchers have highlighted that as the type and duration of care commonly provided by informal caregivers has shifted (Funk et al., 2019), carers are increasingly expected to engage in case management alongside providing direct care (Taylor & Quesnel-Vallée, 2017)This form of care is associated with a high degree of care strain, and the ability of care providers to do so successfully is strongly mediated by factors such as socioeconomic status. It is also the role in which caregivers most frequently find themselves in direct interaction with healthcare providers, and, as such, the role in which systemic barriers and discriminatory behaviours on the part of healthcare providers are most immediately felt.

It is also important to note that most participants who raised concerns about either misrecognition or potential discrimination were either transgender or gender nonconforming, caring for a trans or gender nonconforming partner, or were engaged in relationships which fell outside of spousal care. This suggests that significant improvements have been made regarding the treatments of gay and lesbian patients and their spouses, but that these changes have not extended to the treatment of individuals whose relationships fall outside of the heteronormative understandings of spousal care.

This form of care is highly associated with structural burden – something which is distinct from the forms of care burden or care strain associated with engaging in direct physical care. Taylor and Quesnell-Valee (2017) proposed the concept of structural burden as that which arises out of "managing complex interactions with the fragmented structures of formal health and social care systems". They also highlighted that this is a burden which may be experienced relatively early in the care-provision process: long before an individual needs intensive nursing care supports, they and their care recipients must navigate these complex systems in order to obtain adequate treatment.

Given that some 2SLGBTQ+ caregivers have experienced or are concerned about discriminatory treatment on the part of healthcare providers, and that some of these caregivers experience the injustice associated with misrecognition, it is important to consider how these actions may contribute to increased structural burden. A carer who fears that their care recipient may be mistreated as a result of the identity of either the carer or care recipient may enter interactions with healthcare providers with a high degree of anxiety: as was shown above, participants were often deeply concerned that their advocacy may result in their care recipient receiving poorer care. Participants who must first struggle to be recognized as someone with the status of carer – and thus, the ability to engage in care management in the first place – enter into the emotionally draining and time-consuming process of care management having already had to fight for recognition. This cannot help but increase the structural burden placed upon 2SLGBTQ+ carers.

The final context in which we should consider the experiences of 2SLGBTQ+ carers navigating health systems is that of place. Place strongly influenced the ways in which 2SLGBTQ+ carers formed care networks, with the large, non-kin caregiving networks being located almost exclusively within the metropolitan south. Researchers have highlighted that individuals in rural and Northern regions of Canada often struggle to access appropriate treatment from health systems. This is not an experience which is unique to 2LGBTQ+ carers by any means, but it is another way in which these carers may face increased structural burden. Participants in small Northern cities had concerns regarding anonymity and confidentiality that effected their ability to advocate on behalf of their care recipient; they were also generally more concerned about potential experiences of discrimination. Their options in managing this were limited by place – they could not simply access alternative healthcare providers, as those did not exist. As such, participants had to return to health systems in which they had experienced or witnessed discriminatory behaviours, and some chose to curtail their advocacy on behalf of their care recipients to try and limit the exposure of their care recipient to further negative experiences.

Conclusions, Limitations, Next Steps

This study is the first which focuses on the experiences of 2SLGBTQ+ caregivers navigating the healthcare system in Canada outside of the context of older adult care, and it highlights several ways in which the identity of caregivers and care recipients effects their ability to engage with health systems. While previous research has identified that that 2SLGBTQ+ patients face barriers to adequate and appropriate treatment, this is the first which highlights that the identity of caregivers also plays a role in the experiences of these patients. It also foregrounds the ways in which known issues in the Canadian healthcare system – particularly that of access in rural and Northern regions of the country – interact with identity to produce poorer outcomes for 2SLGBTQ+ caregivers and their care recipients.

Much has been recently written about the potential for caregiver-centric care (Kokorelias et al., 2019; Rosenthal, 2014; Feinberg, 2014), and the role of education for healthcare providers on the importance of integrating caregivers into the healthcare system (Adam et al., 2021; Sabo et al., 2022). The experiences of 2SLGBTQ+ patients have also been raised – it is known that these patients often experience worse outcomes, across the board, when accessing healthcare (Bovicini, 2017; McClain, Hawkins, & Yehia, 2016; Wilkerson et al., 2011). This paper highlights that these two areas, while important, do not go far enough in addressing the concerns of 2SLGBTQ+ caregivers and their care recipients. Integration of these areas of research is paramount if we hope to develop health care systems which adequately meet the needs of all users.

Health systems have a direct role to play in this: the structural burden placed on 2SLGBTQ+ carers is amplified by issues of misrecognition and discriminatory actions. If health systems aim to move towards a system which recognizes the role of carers and one in which patients of all identities are treated equally, it must do so with an eye towards how minoritized caregivers are treated both socially and legally during interactions with health systems.

There are a number of important limitations to this study. As a qualitative study, it is inherently non-generalizable, and follow-up research with larger patient and caregiver cohorts is necessary to ensure that these experiences are being adequately captured. Further, this research was conducted using snowball sampling and in partnership with 2SLGBTQ+ community groups – a necessity to ensure that rural and Northern regions were adequately represented, but something which means that participants were inherently connected with the 2SLGBTQ+

community. As care networks are driven by social networks, this means that the participants in this study were more likely to have peers and friends who identified as members of the 2SLGBTQ+ community, and this may have influenced the degree to which they engaged in friend and non-kin caregiving. It is also important to note that this means that participants were definitionally out in at least some portions of their lives, as they voluntarily accessed services via these groups. The experiences of wholly closeted and isolated members of the 2SLGBTQ+ community are thus not reflected here.

Although an effort was made to recruit a sample which was racially diverse and which represented a wide range of ages, neither of these aspects of identity were a key focus of this research. Indeed, participants broadly skewed younger when compared to the general caregiving population – something which is a common issue with 2SLGBTQ+ research, but which makes it difficult to know if the general 2SLGBTQ+ caregiver population is in and of itself younger than the general caregiving population or if this is simply the result of sampling issues. Given that both race and age strongly effect the experiences of members of the 2SLGBTQ+ community, further research is needed to examine how the needs of racial and ethnic minority 2SLGBTQ+ caregivers may differ from those of the general population. Research on 2SLGBTQ+ older adults in Canada has typically focused on their experiences interacting with long-term care systems, and further research is also needed on how 2SLGBTQ+ older adult caregivers interact with health systems as a whole.

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Chapter 5. Conclusion

The primary goals of this dissertation were to examine the experiences of 2SLGBTQ+ working caregivers in Canada, and to consider how identity, type of work, and place effect these experiences. A secondary goal was to consider how these factors influenced the ways in which these carers experience work and interactions with healthcare systems, and to consider how these carers could be best supported. As a result, this conclusion will, in addition to highlighting the research contributions of each chapter, discuss some of the potential implications for further research and policy work that may result in improved experiences for 2SLGBTQ+ working caregivers in Canada.

This research constitutes an initial intervention into the experiences of Canadian 2SLGBTQ+ carer-employees and is the first to consider how LGBTQ+ identity can affect the experiences of caregivers both at work and in their caregiving duties. It brings together the research on the experiences of carer-employees and that of LGBTQ caregivers to consider how identity, work, and place effect the overall quality of life and wellbeing for LGBTQ caregivers.

By sharing the experiences of a diverse group of 2SLGBTQ+ carer-employees from multiple regions of Canada, I aim not just to highlight the ways in which this population is made vulnerable to negative health and economic consequences of care, but to share their resilience. Participants shared personal narratives which ranged in length from just 45 minutes to well over 3 hours, and which highlighted how the diversity of experiences within the 2SLGBTQ+ communities are not reflected well in the existing literature.

At present, this is a population whose voices are wholly absent from all the bodies of literature in which one may expect to find their experiences highlighted. The health equity literature, while keenly concerned with the experiences of LGBT patients, only rarely considers the concerns of 2SLGBTQ+ caregivers. The small body of 2SLGBTQ+ caregiver literature has typically been both US-based and focused on the experiences of midlife and older caregivers of older adults, whereas the participants in this research had a median age of just 35. Perhaps because of its focus on the experiences of older adults, and its general roots in the gerontological literature, the LGBT caregiving literature has not, as yet, focused on how these caregivers navigate paid employment. From the perspective of the carer-employee literature, participants in this research were doubly invisible: the voices of both precarious workers and 2SLGBTQ+ people are broadly absent from this body of literature.

Age is another factor which sets this research apart from other work on LGBT caregivers, and which highlights another way in which this population has, until now, been excluded from broader narratives on care and caregiving research. Many younger participants provided care for individuals experiencing serious mental illness. However, previous work on interventions for LGBT caregivers have focused on supporting midlife and older LGBT adults engaged in care for individuals with dementia or aging-related health conditions. The research on mental health caregiving similarly has not taken up 2SLGBTQ+ caregivers as a population of concern – these caregivers have been repeatedly ignored by the bodies of work in which one would expect to find their experiences and concerns represented.

This research also highlights the experience of rural and remote 2SLGBTQ+ caregivers in a way which is, again, broadly absent from the LGBT caregiving literature. Participants in the northern samples were often dealing with compounding and intersecting health and economic issues which made them more vulnerable to potential negative consequences associated with caregiving. It is also worth noting that the experiences of rural and remote caregivers, in general, are not well attended to by the carer-employee literature.

Again and again and again, in a multitude of ways, across multiple disciplines and fields of study, the participants in this work have been ignored and not given due attention. By bringing these experiences together to form a holistic picture of the experiences of 2SLGBTQ+ caregivers in Canada, I was better able to highlight how the particularities of their life experiences, the place-based nature of their identity and community relationships, and the interactions between multiple systems produced results which make a large and growing population of caregivers doubly vulnerable to the well-established potential negative consequences associated with caregiving.

Throughout the substantive chapters of this dissertation, the objectives were first to examine the overall quality of life and worklife experienced by 2SLGBTQ+ caregivers in Canada and consider how identity and experiences of discrimination could potentially affect those experiences.

In Chapter 2, the first substantive chapter, I took a quantitative approach to gather data on the quality of life and worklife of 2SLGBTQ+ caregivers in Canada. Using the data gathered for this chapter to inform the further studies, and in particular, to inform the questions that were asked of the participants in the qualitative studies, this was followed by Chapter 3, in which I focused on how type of work, place, and community effected the experiences of these caregivers navigating work-care conflicts. Chapter 4 examined the role of health systems in the experiences of 2SLGBTQ+ caregivers, and how identity, caregiving relationships, and concerns regarding potential discrimination effected experiences of minority stress and contributed to structural burden. I will now discuss the contributions of each chapter in detail.

5.1 Research Contributions

5.1.1 The Role of Work

Although identity shaped the experiences of participants in many ways, one of the primary drivers of outcomes in both Chapter 2 and 3 was that of work and workplace experiences. In Chapter 2, workplace experiences of discrimination and a lower quality of worklife were correlated with lower quality of life in general, and a greater degree of care strain. Given that most informal caregivers work full time, it is important to consider the role of work in this landscape.

In Chapter 2, type of work was not examined as a key driver of experiences, and instead the overall quality of worklife and workplace experiences were focused on. The results showed that, at least for the participants, poorer quality of worklife and increased domain-level experiences of homophobia or transphobia were correlated with higher degrees of care strain and lower quality of life on self-reported indices. It is important to note that although many participants in Chapter 2 reported workplace experiences of discrimination, this was much more common for participants who were transgender, gender diverse, or who otherwise did not identify with the gender they were assigned at birth. -Employment discrimination against LGBT people continues to strongly effect the experiences of 2SLGBTQ+ workers in Canada(Pizer et al., n.d.), and it has been established that this particularly effects transgender workers (Mccrone, 2018). It is here that it is important to note how the samples in both Chapter 2 and 3 deviated from the general 2SLGBTQ+ population. Research has shown that nearly 50% of LGBT workers in Canada are not out at work (Pride at Work, 2018) something which was not reflected in either sample. Most participants, across both samples, were out at work: those who were not were often clustered in rural or Northern communities or were transgender. Transgender workers face higher rates of workplace scrutiny (Galupo & Resnick, 2016), and it is not surprising that they often reported experiences of or anticipations of discrimination.

Further impacting the experiences of these carers was type of work and it is here that the contributions of this dissertation become particularly important. Much of the carer-worker literature focuses on the experiences of white-collar professionals and the experiences of low-wage service workers are not well-reflected in the literature. Additionally, much of the carer-worker literature focuses on workplace accommodations which are highly contextual and rarely found outside of the context of white-collar professional class work.

Given that the bulk of Canadian 2SLGBTQ+ workers are clustered in low-wage customer service work and “pink collar” public sector work in healthcare, education, and social services(Kinitz et al., 2022), it was important to examine how type of work effected the experiences of these carers. What was found was unsurprising: both groups were constrained in their ability to navigate work and care, but the consequences were very different. The pink-collar workers in the sample were sometimes concerned about the potential consequences of identity disclosure – several participants who were employed in public sector roles and who lived in rural or northern communities were not out at work – and were often constrained in their ability to access workplace benefits. For instance, participants who were providing care to someone who was not a first degree relative, which is more common within the 2SLGBTQ+ community (Boehmer et al., 2019b), were unable to access paid leaves or other benefits which could help them accommodate their care responsibilities. Further, these participants were often concerned with retaining their paid employment as it was often the case that their extended health benefits were a key support for their care recipients.

Low-wage service workers, on the other hand, rarely had access to extended health benefits. None of the low-wage service workers were unionized, and many of these participants had personal narratives which included periods of unemployment and housing instability: some relied on work in the informal economy, gig economy, and government assistance in order to maintain some degree of financial stability. Caregiving had the potential to disrupt their ability to do so, and in some cases, this resulted in loss of housing.

Employment discrimination against transgender people, in particular, was a common concern for low-wage service workers. Their ability to maintain employment was contingent on them maintaining an ongoing role as a “good worker” who did not disrupt the status quo. This meant that when caregiving responsibilities had the potential to intrude on their work roles, these participants had justified concerns that doing so could result in a loss of employment. This is also an area in which low-wage service workers in the southern metropolitan centres experienced challenges that were distinct from their counterparts in northern communities: high costs of housing in both of the southern locations meant that these participants’ experiences of precarity were shaped by the potential for the loss of housing. This does not mean that this was not a concern for the rural and northern participants, but their experiences were largely shaped by a depressed local labour market which also effected the public sector workers in the study, rather than being located solely in the experiences of customer service workers.

Overall, workplace experiences had a strong effect on the ability of these carers to meet their caregiving responsibilities: concerns about discrimination and overall quality of worklife effected the quality of life and care strain experienced by these caregivers. Type of work further effected these experiences, with low-wage service workers experiencing significant precarity. Workplace-level experiences of discrimination were correlated with an unwillingness to access caregiving accommodations in Chapter 2, and they framed the concerns for participants in Chapter 3 starkly.

5.1.2 The Role of Place

2SLGBTQ+ experiences are highly place-based: available resources, the presence or absence of a local 2SLGBTQ+ community, and general attitudes towards 2SLGBTQ+ people are all contextual. In general, rural and northern communities tend to report lower positive attitudes towards LGBT people e(Carlson, 2012)and resources are significantly less available when compared to large metropolitan areas (Mulé, 2020). Further complicating the place-based experiences of 2SLGBGQ+ caregivers is the way in which geography effects the local labour markets and the provision of healthcare services. Many northern communities in Canada have high unemployment rates and it may not be easy for people to seek alternate employment. Health care resources are similarly curtailed(Bosco & Oandasan, n.d.; Wilson et al., 2020): it has been well-established that rural and northern areas of Canada have fewer resources available within their healthcare system.

All of the above factors highly effected the experiences of participants. In Chapter 3, it was noted that rural and northern participants had smaller 2SLGBTQ+ communities available to them, and this shaped the choices they made in the face of work-care conflicts.

Chapter 4 highlighted how health system navigation was also strongly place-based, and that this was particularly true for participants who were concerned they or their care recipient may experience discrimination on the basis of their sexual orientation of gender identity. Smaller communities made maintaining anonymity challenging, and participants who had experienced negative interactions with healthcare providers did not feel as though they were able to raise formal complaints. With few healthcare providers to choose from, some participants opted to forgo objecting to discriminatory treatment in order to maintain a relationship with the healthcare providers responsible for their care recipient.

5.2 Policy Implications

There are several important policy implications raised by this research: the first is that which arose in Chapter 2, which highlighted that workplace experiences of discrimination had the potential to affect the willingness of 2SLGBQ+ carer-employees to access accommodations for their caregiving responsibilities. This suggests that there may be a greater role for interventions for carer-employees located outside the workplace: perhaps in the form of more extensive government supports, or accommodations which are provided and regulated by government or nongovernmental bodies. It also highlights the importance associated with workplaces rigorously enforcing already existing antiharassment and anti-discrimination laws.

The impacts of discrimination carried over into the experiences of participants highlighted in Chapter 3 and 4, where concerns regarding anonymity and identity disclosure were highlighted as potential barriers to care. While there have been recent shifts towards the inclusion of 2SLGBTQ+ cultural competency in medical school curricula (Beagan et al., 2015;

White et al., 2015) it is clear that this has not been sufficient to meet the needs of 2SLGBTQ+ caregivers. This is an area in which further education of healthcare providers could have an obvious impact on the experiences of 2SLGBTQ+ caregivers as they navigate the healthcare system. Here I would also highlight the repeated experiences of discrimination on the part of transgender and gender variant caregivers. It is noteworthy that all of the participants who reported experiencing obvious and clear discriminatory actions on the part of healthcare providers were transgender – it is heartbreaking that it caused one participant to stop providing care for her partner when he was hospitalized, because she realized her transgender identity was causing her cisgender partner to receive poorer care. That transgender participants from all surveyed regions, including the major metropolitan areas of the Greater Toronto Area and the Greater Vancouver Area, had concerns regarding discrimination from healthcare providers suggests that a significant, national culture shift is needed regarding the treatment of transgender and gender variant people within the healthcare system.

The repeatedly expressed concerns about anonymity and confidentiality for 2SLGBTQ+ caregivers in rural and remote regions should be a cause for great concern for health policymakers. In particular, I would draw their attention to two narratives which were shared in Chapter 4 – that of the individual who forewent emergency medical care for serious mental illness due to concerns regarding anonymity, and that of the individual who experienced explicit discrimination at the hands of a healthcare provider but did not feel empowered to file a complaint. This is alarming and suggests that significant efforts are needed to shift the culture of healthcare provision across these communities. A greater degree of investment in rural and remote health is another obvious solution – I note that in both cases, the participants were aware that the dearth of healthcare providers in their respective communities meant that they did not have the option to seek care in a different setting or from another qualified individual.

The second area in which policy interventions seem to be the most apparent is in the experiences of working caregivers highlighted in Chapter 3. Low-wage service workers consistently lacked access to any form of caregiving supports, something which is particularly problematic given that the service sector is the largest sector of the Canadian economy (Statistics Canada, 2023). It is highly unlikely that these sectors will change in the absence of government intervention – they have little incentive to. I would draw particular attention to the individuals featured in Chapter 3 whose narratives included repeated experiences of housing insecurity and reliance on social assistance, both of which were directly linked to their need to fulfill caregiving duties. In those cases, vulnerable workers were made more vulnerable by the dearth of state-funded supports and the lack of employment protections available to them. Gig and service sector workers urgently need secure work; moreover, they need to be able to engage in necessary caregiving tasks without losing their job. As the population of informal caregivers increases, there will be an increased need for workers in the service sector to access accommodations for their caregiving, something which will require interventions at the policy level to obtain. All workers need access to paid caregiving leave, and they must be guaranteed access to their jobs when they return.

I would also highlight the role that policymakers can play in regulating the provision of extended health benefits. Despite their comparatively high levels of income and job security, Chapter 3 also highlighted the experiences of several caregivers who were unable to access leaves and financial support as their care recipient was not a legal relative. Given that non-kin care structures are more common not just in the 2SLGBTQ+ community but also in Indigenous and some racialized communities, equitable access to paid leave is a clear social justice issue.

I will conclude my discussion of policy implications with a general comment on the importance of the inclusion of 2SLGBTQ+ caregivers in discussions of health and work policy across multiple levels of government. This research highlights that pre-existing issues of inequity in our healthcare and economic systems which effect people living in rural and remote regions of Canada and those working in precarious jobs are amplified for the many 2SLGBTQ+ people who live in these regions and work in these professions. It is common to think that 2SLGBTQ+ considerations are relevant only for policymakers in large, metropolitan areas, and this simply is not the case. It is common to think of 2SLGBTQ+ caregivers – if we do so at all – in the context of the growing population of 2SLGBTQ+ older adults and their caregivers, and so not account for the concerns of young and midlife 2SLGBTQ+ caregivers. We must, of course, consider the needs and concerns of 2SLGBTQ+ older adults and their caregivers – their stories are reflected in this work as well, and they have been the subject of repeated inequities at the hands of state bodies. However, this research, which includes the voices of young and midlife 2SLGBTQ+ caregivers in Canada for the first time, highlights that we are currently in the process of repeating our errors with current and future generations. In an economic and political climate in which the substantive progress made by 2SLGBTQ+ rights movements over the last century seem to be threated, it is all the more vital that we centre the experiences and voices of 2SLGBTQ+ caregivers.

5.3 Future Research Opportunities

This dissertation represents an initial intervention into the experiences of 2SLGBTQ+ carer-employees in Canada, which are not currently reflected in the literature. As such, more research is needed to fully explore these experiences. In particular, the experiences of midlife and older adult 2SLGBTQ+ carer-employees are not well-represented within this dissertation, as the participant pool was relatively young in comparison to the general population. This is a common problem in 2SLGBTQ+ research, but the voices and experiences of 2SLGBTQ+ midlife and older adults are particularly important for caregiving research, as the bulk of caregivers are typically midlife and older adults.

Other areas which require further research are the experiences of racial and ethnic minority 2SLGBTQ+ caregivers. While a strong effort was made to recruit a racially and ethnically diverse sample, the intersecting experiences of race and 2SLGBTQ+ identity was not a primary focus of this research. Given that multiple marginalization can have significant effects on the lives of 2SLGBTQ+ racial and ethnic minorities, it is important to understand how it may affect the experiences of caregivers. This is particularly true for 2SLGBTQ+ people who belong to racial and ethnic minority communities who may have different values regarding caregiving.

A final key factor which is worthy of further research, but which was not a primary focus of this dissertation, is the role of reciprocal caregiving and caregiving for people with serious mental illness. 2SLGBTQ+ people experience higher rates of physical and mental health issues when compared to the general population, and as such it is likely that many 2SLGBTQ+ caregivers are experiencing physical or mental health issues themselves while caring for their care recipient. Care dyads wherein both parties experience some form of physical or mental health issues often engage in some form of reciprocal caregiving, and this would likely be a point of interest for future research. Finally, although many participants in this study provided care for individuals experiencing serious mental illness, this was not a primary focus of this dissertation. Caregivers for individuals with serious mental illness often face unique barriers related to stigma and support access, and this is an important area in which more research is needed.

Appendix B

(1) Survey Instrument
(2) Interview Guide
(3) Ethics Approval