

COMING OUT AND COMING IN TO LIVING WITH DEMENTIA:

Enhancing Support for 2SLGBTQI
People Living with Dementia and
their Primary Unpaid Carers

May 2022

Egale

NIA NATIONAL
INSTITUTE
ON AGEING 

LAND ACKNOWLEDGEMENT

We would like to begin by acknowledging that Egale is based on the traditional shared territories of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples. The territory is protected by the Dish With One Spoon Wampum Belt Covenant, an agreement between the Haudenosaunee, Anishinaabe and allied nations to peaceably share and care for the resources around the Great Lakes. The concepts of gender, sexuality, and oppression that we often rely on in 2SLGBTQI advocacy work are largely based in White, Western, colonial systems of thought and do not represent the multitude of understandings of identity that exist outside of this viewpoint. Colonial violence created the foundations for the landscape of gender-based violence that we understand today. Indigenous communities and Two Spirit activists, scholars, writers, and artists have gifted us with ample tools to work with as we move toward the collective liberation of gender and sexuality minority people. We are grateful to carry these with us here and in our work beyond. The violence of colonialism is ongoing. So too are movements toward resisting this violence.

ACKNOWLEDGEMENTS

Egale is Canada's national 2SLGBTQI organization. Egale works to improve the lives of 2SLGBTQI people in Canada and to enhance the global response to 2SLGBTQI issues. Egale achieves this by informing public policy, inspiring cultural change, and promoting human rights and inclusion through research, education, awareness, and legal advocacy. Our vision is a Canada, and ultimately a world, without homophobia, biphobia, transphobia and all other forms of oppression so that every person can achieve their full potential, free from hatred and bias.

The **National Institute on Ageing (NIA)** is a public policy and research centre based at Toronto Metropolitan University (formerly Ryerson University). The NIA is dedicated to enhancing successful ageing across the life course. It is unique in its mandate to consider ageing issues from a broad range of perspectives, including those of financial, psychological, and social well-being. The NIA is focused on leading cross-disciplinary, evidence-based, and actionable research to provide a blueprint for better public policy and practices needed to address the multiple challenges and opportunities presented by Canada's ageing population. The NIA is committed to providing national leadership and public education to productively and collaboratively work with all levels of government, private and public sector partners, academic institutions, ageing related organizations, and Canadians.

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EXECUTIVE SUMMARY

What are the unique experiences and needs of Two Spirit, lesbian, gay, bisexual, transgender, queer, and intersex (2SLGBTQI) people living with dementia and those who care for them? What is the current state of unpaid care as experienced or perceived by 2SLGBTQI people living with dementia and their primary unpaid carers? And how can people, organizations, and institutions across sectors come together to enhance care provision and support?

In response to these clearly identified gaps in knowledge and a growing need for shared understanding, resources, and critical inquiry, in 2019 Egale Canada partnered with the National Institute on Ageing (NIA) to pursue primary research focused on better understanding the experiences and perspectives of 2SLGBTQI communities on living with dementia, and on providing unpaid care. Funded by a Public Health Agency of Canada (PHAC) Dementia Community Investment Grant, this research study is the first phase in a multi-phase research, education, and awareness project. With future project phases in mind, we designed the research with a primary focus to expand knowledge and understanding, spark critical conversations, and create collaborations towards better supporting 2SLGBTQI people living with dementia (PLWD) and their primary unpaid carers across Canada.

In this report, Egale and NIA share the findings from their national qualitative research study that engaged 2SLGBTQI community members living with dementia, primary unpaid carers of 2SLGBTQI PLWD, and community group representatives, and dementia care and service provider stakeholders. We situate our discussion of dementia and unpaid care in a current climate of growing and broad-based attention to the need to improve Canada's healthcare systems and structures especially for aging populations, amidst increased reliance on the labour of unpaid carers, and as part of re-emerging conversations about the dynamics and distribution of care work. We also situate this discussion as part of an ongoing recognition of the need to expand care and support services that can better meet the needs of 2SLGBTQI and other equity-deserving communities, with a particular focus on living and caring in the context of dementia.

KEY FINDINGS

Becoming Carers: People can become primary unpaid carers for 2SLGBTQI PLWD through a wide variety of pathways and from a range of prior positions, including close pre-existing relationships (e.g., as spouses, close family members, and close friends) and more distant prior relationships (e.g., acquaintance, fellow community members). Carer participants discussed their journeys into care in different ways, including from a strong sense of identity as a carer, pragmatic rationale, and circumstantial factors, and shared insights into how they brought previous experiences of providing care into their current caring practices and roles. There is a need to expand beyond a focus on spousal and children carers and improve carer supports if 2SLGBTQI PLWD and their carers are to be better supported, along with a need for increased recognition of the gendered dimensions of unpaid care labour and of the diverse experiences and expertise that carers bring to their practices and roles.

Coming Out and Coming in to Living with Dementia: Regarding the significance of gender and sexual identity in experiences of living with dementia and providing care, the concept of change emerged centrally as participants described their experiences of grappling with dementia diagnoses and the impact of dementia on their abilities, relationships, and how they were recognized and treated. Some participants drew parallels between the changes they experience while coming into living with dementia and the relationship changes that many 2SLGBTQI people have experienced in response to coming out about their sexual and/or gender identity. Enhancing supports for grappling with change in caring relationships, recognizing the multiplicity and fluidity of identities, and offering a spectrum of services (e.g., from aging in place to community living and long-term care options) would benefit 2SLGBTQI people living with dementia and carers alike.

The Power of Support Networks: 2SLGBTQI PLWD and carers participants sought support from a range of sources including family and friends, community members and groups, and healthcare and social services. These participants reflected on what was working well and where options for support fell short: including in the coming together of family and friends to the falling away of acquaintances and lack of support networks, and experiences of findings support and inclusion in formal care services and encountering barriers to access. Key next steps that emerged from these participants reflections, as well as observations by 2SLGBTQI community group representatives and dementia care and aging service providers, included breaking down silos between dementia-specific and 2SLGBTQI-focused support, enhancing the availability and accessibility of care and support resources, and increasing understanding and awareness of the unique needs of 2SLGBTQI PLWD among communities and care services.

RECOMMENDATIONS

Rooted in the findings of our study, we provide the following recommendations to better enable programming, policy, advocacy, and research:

- **Build 2SLGBTQI-inclusive dementia-related services and community spaces**, including integrating discussions about dementia into existing 2SLGBTQI support and social groups and creating more opportunities for 2SLGBTQI PLWD to come together in support and community.
- **Increase recognition and support for primary unpaid carers of 2SLGBTQI PLWD**, including through increasing recognition of diversely situated primary unpaid carers in workplace and government care policies and leaves, and creating dedicated spaces such as support groups for primary unpaid carers of 2SLGBTQI PLWD.
- **Enhance supports for 2SLGBTQI communities and carers through structural and systems-level change**, including by reducing barriers to accessing dementia-related care in rural and small-town communities, and integrating 2SLGBTQI histories and experiences into core course content for healthcare and social service provider training across a range of professions.
- **Broaden perspectives and deepen community engagement for future critical research**, including through building rapport, trust, and accountability in relationship with 2SLGBTQI communities and community members, examining the particularities of living in suburban, rural, and remote areas for access to services and networks of support, and intentionally welcoming and learning from Indigenous, Black, and racialized 2SLGBTQI people who are living with dementia.

While these recommendations are focused on 2SLGBTQI communities and carers, they also speak to broad social and structural issues including healthcare and social service gaps that, if addressed, could be of potential benefit to many groups.

GLOSSARY

- **2SLGBTQI:** Two Spirit, lesbian, gay, bisexual trans, queer, questioning, and intersex. The order of the acronym beginning with Two Spirit recognizes the presence of Two Spirit and Indigenous peoples across Turtle Island, and the historical erasure of Two Spirit people through settler colonialism and in mainstream queer organizing. For a full 2SLGBTQI glossary of terms, see: <https://egale.ca/awareness/glossary-of-terms/>
- **Dementia:** An umbrella term referring to a progressively debilitating disease that erodes cognitive and functional abilities of individuals. While the most common form of dementia is Alzheimer’s disease, there are numerous additional types of dementia including Vascular dementia, Frontotemporal dementia, and Lewy body dementia, among others (Sinha, 2012).
- **Person/people living with dementia (PLWD):** In line with person-first language, person/people living with dementia recognizes that living with dementia is one aspect of an individual’s experience, recognizing that a person is not reducible to their abilities, conditions, or diagnoses.
- **Primary unpaid carer:** According to The Change Foundation (2016), primary unpaid carers—or caregivers—are “the people—family, friends, neighbours—who provide critical and ongoing personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability of end-of-life circumstances” (p. 2). By pairing “carer” with “unpaid,” we are following current shifts away from the usage of “informal” towards more inclusive terminology that recognizes unpaid care provided beyond partners, family, and friends (Stall et al., 2019). Taking the lead from participants, this study uses the term “carer” instead of “caregiver” to better represent the reciprocity within the caring relationships of participants in this study.

INTRODUCTION

What are the unique experiences and needs of Two Spirit, lesbian, gay, bisexual, trans, queer, and intersex (2SLGBTQI) people living with dementia and those who care for them? What is the current state of unpaid care as experienced or perceived by 2SLGBTQI people living with dementia and their primary unpaid carers? And how can people, organizations, and institutions across sectors come together to enhance care provision and support?

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BACKGROUND

POPULATION AGING, DEMENTIA, AND UNPAID CARE

It is no secret that Canada's population is aging. Recent population projections estimate that the proportion of older adults living in Canada could increase from 18.5% in 2021 to 23% in 2031—gradually increasing to 24% of the population by 2051 (Government of Canada, 2014; Statistics Canada, 2021).

As the aging of the baby boom cohort continues to influence Canada's population distribution in the coming years, we will also see an increase in the number of people living with dementia (Canadian Institute for Health Information [CIHI], 2018). As of 2019, there were more than 419,000 people over the age of 65 who had been diagnosed with dementia, according to the Public Health Agency of Canada's National Dementia Strategy report (2019).

While it is estimated that approximately at least 78,600 older adults will be newly diagnosed each year in the coming years, it is important to note that these numbers are likely an underrepresentation as there are many people who have not received a diagnosis (Public Health Agency of Canada, 2019).

Furthermore, they do not account for dementia among people under the age of 65. Young onset dementia, also known as early onset dementia, accounts for 2 to 8% of all dementia cases in Canada and the most recent data shows that at least 16,000 Canadians are living with young onset dementia (Alzheimer Society of Canada, 2022). Worldwide, at least 55 million people live with dementia, a number projected to increase to 78 million by 2030 (Gauthier et al., 2021, p.29).

Alongside the projected increase in the number of people living with dementia, the number of Canadians providing unpaid care is also anticipated to increase (National Institute on Ageing [NIA], 2020). This rate of increase is especially significant considering that, nationally, unpaid carers provide up to 75% of care services to older adults living at home—estimated to equate to nearly \$25 billion of care annually (Health Council of Canada, 2012; Stall et al., 2019).

Beyond monetizing the contributions of unpaid care in Canada, the rise in both the number of people living with dementia and, subsequently, the number of people providing unpaid care highlights the need to direct attention, support, and resources towards better supporting those who are living and caring within the context of dementia.

Further, as people's situations and experiences differ based on a myriad of social dynamics, including geography, socio-economic status, race, gender, ability, and more, there is further need to tailor such support and resources to best support the distinct needs of 2SLGBTQI people living with dementia and those who care for them.

2SLGBTQI OLDER ADULTS' EXPERIENCES AND APPROACHES TO CARE

Despite advances in rights and freedoms for 2SLGBTQI individuals living in Canada, stigma and discrimination persist, and life experiences and past histories continue to be relevant within 2SLGBTQI older adults' expectations for the care they will receive as they age (Correro & Nielson, 2020; Fredriksen-Goldsen et al., 2015; Le Berre & Vedel, 2020; Wilson et al., 2018).

When it comes to accessing care and support from healthcare institutions and social services in Canada, documented barriers for 2SLGBTQI older adults include concerns about discrimination, including being refused care (e.g., Brotman et al., 2007; Grigorovich, 2015), being misgendered and a lack of gender affirmation (e.g., Bauer et al., 2015; Pang et al., 2019), and concerns about recognition (or lack thereof) of significant others (Furlotte et al., 2016). Analyses have identified needs for more inclusive policy development in support of more inclusive health and social care and systemic changes (e.g., Mulé et al., 2009), as well as identified gaps in education and training for healthcare professionals and service providers. Significantly, research has established both a need and desire for increased access to professional development opportunities to better serve 2SLGBTQI communities (Daley & MacDonnell, 2015; Gahagan & Subirana-Malaret, 2018; Kortés-Miller et al., 2019).

Negotiating care later in life can present unique challenges for 2SLGBTQI people, for myriad of social and structural reasons. At the same time, many 2SLGBTQI older adults have fostered creative practices to access desired care and continue to create vibrant lives and forge meaningful connections above and beyond health and care-related concerns. As it comes to care and caring, many 2SLGBTQI older adults have well-established chosen families who, in some cases, are also providing care and support in aging and old age (Barrett et al., 2015; Hafford-Letchfield et al., 2018; Mock et al., 2020; Moreno et al., 2017; Wilson et al., 2018).

For example, 2SLGBTQI people have historically come together to support fellow community members, friends, and others, and have created intentional networks of support in times of crisis and need. Communities who are excluded from or harmed by formal care systems have also come together to provide mutual aid and collective care, including 2SLGBTQI communities and people living with disabilities (Piepzna-Samarasinha, 2018; Spade, 2020).

Caring also happens within families of origin as LGBT older adults are more likely to be involved in the unpaid care of their aging parents and other biological family members, as well as to partners and friends (Kimmel, 2014; Moreno et al., 2017).

INTERSECTIONS OF 2SLGBTQI COMMUNITIES, CARE, AND LIVING WITH DEMENTIA

In exploring literature within the intersections of 2SLGBTQI experiences of aging and old age and dementia, we found a dearth of knowledge, policy, and practices that speak to the lived and living experiences of 2SLGBTQI PLWD and their primary unpaid carers.

In terms of prevalence, while the National Dementia Strategy (2019) calls for greater focus on 2SLGBTQI individuals, the prevalence of dementia among 2SLGBTQI communities is not known. It can be expected that prevalence will increase as the population ages (Le Berre & Vedel, 2020).

Recent research has posited that lifelong social inequity (e.g., due to systems of homophobia, transphobia, biphobia, racism) experienced by 2SLGBTQI older adults and their communities may place them at elevated risk of cognitive decline and/or developing dementia (Flatt et al., 2018; Fredriksen-Goldsen et al., 2018). Researchers have identified 12 modifiable risk factors (including less education, hypertension, smoking, physical inactivity, and infrequent social contact) that account for around 40% of dementia cases worldwide and suggested that because many risk factors cluster around inequalities both health promotion and societal action are needed as part of dementia prevention and delay (Livingston et al., 2020, p. 414).

While it is known that a wide range of risk factors and social determinants of health can impact health and co-morbidities for older people, there is currently no conclusive epidemiological evidence regarding the implications of such factors for 2SLGBTQI people, or sexual and gender minority communities, regarding dementia. Much of the research that does exist on the intersections of 2SLGBTQI aging and dementia originates from the United Kingdom, Australia, and the United States, and these findings are not necessarily

directly generalizable to Canadian contexts due to differences in national medical, legal, and social support systems (McGovern, 2014; Moreno et al., 2017; Wilson et al., 2018). Research examining the particularities of 2SLGBTQI community members' experiences of living with dementia and providing care are minimal, though there are emerging analyses in this area (e.g., see Baril & Silverman, 2019; Pang, 2022; Silverman & Baril, 2021).

Further, little is known about people's experiences of caring for 2SLGBTQI people living with dementia. This includes how unpaid carers come to and understand their roles, and their insights about supportive caring practices, gaps in support, and areas for systemic improvements. Given previous discussions of the intersections of dementia and unpaid care work, it is reasonable to assume that caring for a 2SLGBTQI person living with dementia—or caring as a 2SLGBTQI individual—continues to be demanding (e.g., physically, emotionally, financially). It can also be assumed that people bring creative practices and diverse networks of support towards their caring roles, and that better supporting carers lends in turn to supporting those they care for.

The current gaps in understanding of 2SLGBTQI older adults are a reflection of the compounding of long histories of cis-heteronormative stigmatization and discrimination (e.g., homophobia, transphobia, biphobia) with pervasive ageism in Canadian society (Egale Canada, 2020; Westwood, 2019; Wilson et al., 2018). It is also important to state that the "2SLGBTQI" acronym, used as a representation of queer and trans individuals and communities, is not a monolith, and people have distinct and varying experiences impacted by gender and gender expression, sexual orientation, as well as ability, age, race, and many other dynamic identities and social factors.

Without greater knowledge and understanding that centres the perspectives of 2SLGBTQI people living with dementia and their primary unpaid carers within Canada, the ability of government, healthcare professionals, and others to provide equitable and comprehensive support and care is severely compromised, as is the ability to advocate for change.

THE STUDY

With an identification of gaps and needs, this qualitative research study aimed to better understand the unique experiences and needs of 2SLGBTQI people living with dementia (PLWD) and their primary unpaid carers in Canada.

Research Questions

The study was guided by the following research questions:

- What is the current state of unpaid care as experienced—or perceived—by 2SLGBTQI people living with dementia (PLWD) and their primary unpaid carers who live in Canada?
- Based on these experiences and perceptions, what can we learn about the aspects of care that are beneficial, detrimental, ignored, unfilled, imagined?
 - From the perspective of 2SLGBTQI PLWD? (Phase I)
 - From the perspective of primary unpaid carers? (Phase I)
 - From the perspective of service providers and key stakeholders in aging and dementia care? (Phase II)
- What distinguishes the experiences of 2SLGBTQI PLWD—and their primary unpaid carers—from the general older adult population in Canada?
- What suggestions do 2SLGBTQI PLWD, their primary unpaid carers, and other key stakeholders have for enhancing care provision and support?

Two advisory committees were established to provide expertise and input on the study, including 2SLGBTQI identified older adults and community organization and service provider representatives.

METHODOLOGY AND CONCEPTUAL ORIENTATION

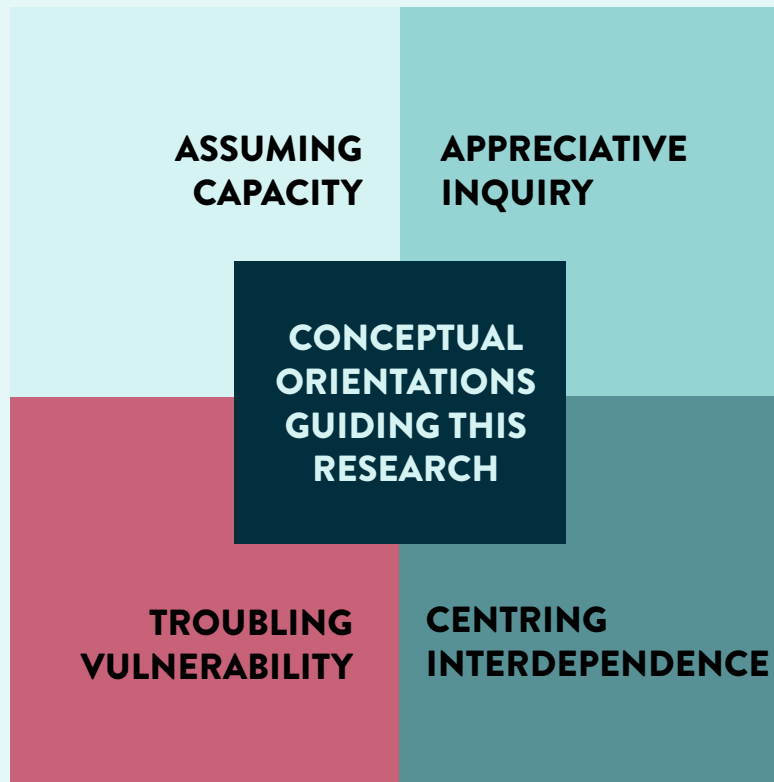
People living with dementia and 2SLGBTQI communities are often figured as unique and vulnerable populations, for whom existing healthcare and social services must be improved.

Breaking down barriers to accessing needed healthcare and social services and to expanding effective and affirming services is critical.

To achieve this, broader systems-level and social change are needed to enable people living with dementia and other cognitive disabilities and differences and people who are part of 2SLGBTQI communities to access desired healthcare and social services, to cultivate alternative models of support, and to thrive.

This research sought to better understand the experiences and situations of 2SLGBTQI people living with dementia in Canada, and of primary unpaid carers of 2SLGBTQI people living with dementia.

Overarchingly, we situate our inquiry into the experiences and situations of 2SLGBTQI PWLD and primary unpaid carers as a critical vantage point on social relations of care and support, as well as contemporary conditions experienced by a wide range 2SLGBTQI people in Canada today. In designing the study, we (the authors of this report) reached consensus on key conceptual and ethical orientations moving into the research. These orientations informed how we engaged with participants and community stakeholders, the questions we asked, and how we conducted our analysis.



The conceptual orientations guiding this research were:

Appreciative Inquiry: Stemming from organizational studies, appreciative inquiry was originally used as a way to initiate positive transformation of organizational culture (Whitney & Trosten-Bloom, 2010). According to Busche (1998), “the basic process of appreciative inquiry is to begin with a grounded observation of the ‘best of what is,’ then through vision and logic collaboratively articulate ‘what might be’ towards collectively experimenting with ‘what can be’” (p. 41). Appreciative Inquiry focuses on strengths (e.g., what is working), analyzing why it is working well, discussing hopes for future change, and then creating a plan for future action (Whitney & Trosten-Bloom, 2010).

For example, within the context of this project, appreciative inquiry informed how focus group and consultation event questions were formulated and how conversations were facilitated. We made clear throughout the research process that we were interested in understanding experiences of care/caring through life stories of what is and what could be. By engaging with 2SLGBTQI PLWD and primary unpaid carers of 2SLGBTQI PLWD in this way we were better able to understand past and current experiences of care alongside conversations that imagine forward to what care and caring could look like.

Centring interdependence: Interdependence is a concept developed in feminist care ethics research and across a broad range of feminist and critical disability studies analyses that recognizes the inherent co-constitution and inter-reliance of lives (e.g., see Kittay, 2020; Mingus, 2017). Analyses of interdependence and care relationships underscore the mutuality of giving and receiving care and challenge a singular and dichotomous understanding of dependence/independence and giver/receiver of care. In this understanding, care is not a one-way street, nor is it framed in terms of burden. All people are understood as existing in dynamic relationship with each other, relationships that include reciprocities, challenges, and creativity.

In this research, at a foundational level we recognize the mutuality of relationships among 2SLGBTQI people living with dementia and those—here, unpaid carers—involved in their lives. Analytically, recognition of interdependence also shifts the focus away from the “individual” towards how communities and people in relationship can best be supported and enabled. Centring interdependence led us to be interested in how people came to be involved in care relationships, how they understand their roles and interpersonal dynamics, and how they described their experiences of reciprocity and creative negotiations.

Troubling vulnerability and “assuming capacity”: Research with marginalized groups of people demands especially close attention to dynamics of power and efforts to reduce harm. It also demands attention to specific histories of exclusion from research and from desired social participation.

It is common in health-related research for 2SLGBTQI communities to be framed as “more vulnerable” and “at risk.” Counter to framing that instantiates risk discourses or focusing on individualized resiliency (e.g., see Lupton, 1999; Rose, 1999) our incoming orientation was a focus on strength, creativity, as well as challenges that people—rather than populations—face in their everyday lives.

Critical disability studies theorists working with people with a diverse range of cognitive abilities, disabilities, and identifications have advanced important concepts for more just and ethical research practices. This includes arguments against a blanket understanding of people with cognitive disabilities and differences as “vulnerable” and incapable. For example, Patterson and Block question this categorical assumption and the inherent infantilization of people with disabilities and argue instead for focus on “ability to consent” and “power to resist manipulation” (Patterson & Block, 2019, p. 73). Kohler suggests starting from a point of “assuming capacity,” an orientation that resists the categorical denial of research participation based on cognitive disability or difference, and that demands developing practices for more inclusive research (Kohler, 2019). Troubling vulnerability and “assuming capacity” are both orientations that we adopted in this research, from participant engagement to data analysis.

DATA COLLECTION

Putting our theoretical and methodological orientations into action, we engaged with 2SLGBTQI PLWD, their primary unpaid carers, and key community stakeholders in a multi-phased approach to data collection. In what follows, we describe our approach to data collection.

Phase I: Focus Groups and Individual Interviews

In Phase I, we led a series of focus groups with 2SLGBTQI PLWD and with primary unpaid carers of 2SLGBTQI PLWD. Focus groups were co-facilitated by an experienced facilitator in the field of dementia care, with co-facilitation used as a way to build trust and rapport among research participants and to address power dynamics that may arise between the researcher and participants (see ACT on Alzheimer's, 2016; Forrestal et al., 2015; Upadhyay & Lipkovich, 2020). Focus groups lasted an average of 2 ½ hours. We also conducted individual interviews—lasting 30 minutes—with select participants, at their request or because of significant scheduling conflicts.

The purpose of these focus groups and individual interviews was to learn more about the unique experiences, needs, and/or desires of 2SLGBTQI PLWD and primary unpaid carers of 2SLGBTQI PLWD from across Canada.

Recruitment Process

The recruitment process consisted of initial outreach by distributing our call for participants using a variety of strategies, including:

- Online study landing page to host the call for participants and recruitment form.
- Call for participants distributed through the Egale Canada and NIA subscription newsletters and dedicated outreach via each organization's social media platforms.
- Purposive sampling by direct outreach through advisory committee members and to organizations and service providers across Canada working within 2SLGBTQI, aging, and dementia support circles to distribute the call for participants and recruitment flyer.

Following initial outreach, potential participants who expressed interest were scheduled for an introductory meeting with a member of the research team. The purpose of this meeting was to provide a confidential space (outside the focus group setting) to discuss the study and consent process, familiarize focus group participants with the process (e.g., connecting to video conferencing system and utilizing features), provide space to address questions and concerns, and collect demographic information to ensure participants meet the inclusion criteria (Forrestal et al., 2015).

Focus Group and Interview Questions

During the focus group and interview sessions, Phase I participants were guided in discussion with the following questions:

- How would you describe your current experiences of [living as/caring for] a person with dementia?
- What do you feel has influenced or shaped your perceptions, experiences, and expectations of care and support?
- Tell me what you want to see change in order to ensure quality of life and equity for 2SLGBTQI people living with dementia and their primary unpaid carers moving forward?

In appreciation of their participation in this study, each Phase I participant received a \$50 gift card.

Demographic Profile of Phase I Participants

Our recruitment efforts resulted in a total of five focus groups and two individual interviews: one focus group with 2SLGBTQI PLWD ($n = 2$); four focus groups with primary unpaid carers ($n = 13$); and two individual interviews with primary unpaid carer participants who preferred this mode of engagement due to comfort levels and scheduling conflicts. In total, there were 17 participants in Phase I. The majority of participants ($n = 12$) lived in Central Canada (i.e., Ontario, Quebec), with one participant from Eastern Canada and four participants from Western Canada (see Figure 1). All participants were above the age of 30, and a significant portion ($n = 6$) were between 60 and 70 years of age (see Figure 2). In terms of their sexual identity, participants reported a range of sexual identities, including queer ($n = 3$), gay ($n = 3$), lesbian ($n = 5$), pansexual ($n = 1$), and straight ($n = 4$) (see Figure 3). All participants identified as cisgender with the majority ($n = 11$) being women/female-identified individuals (see Figure 4). Finally, in terms of racial identity, most participants were White ($n = 15$) and two were people of colour.

Figure 1. Phase I Participants: Geographic Location

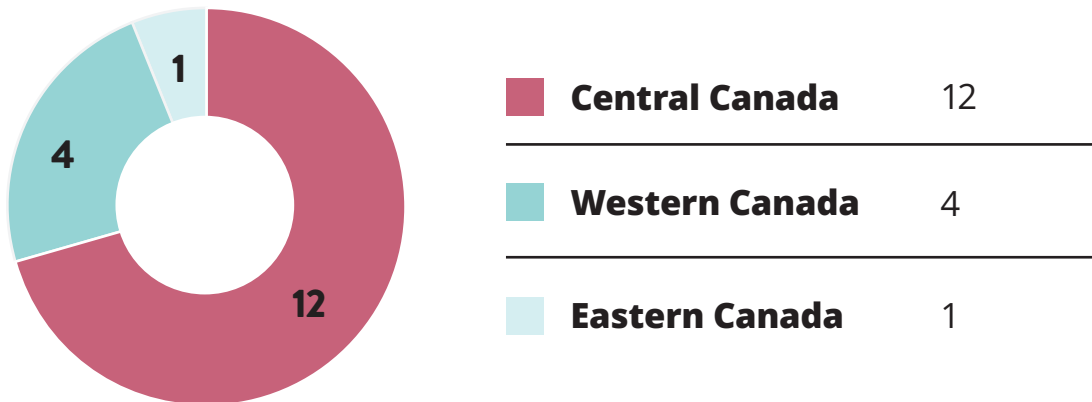


Figure 2. Phase I Participants: Age

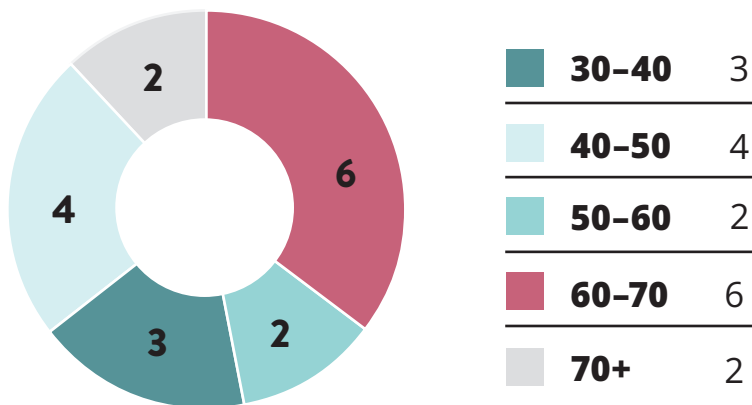


Figure 3. Phase I Participants: Sexual Identity

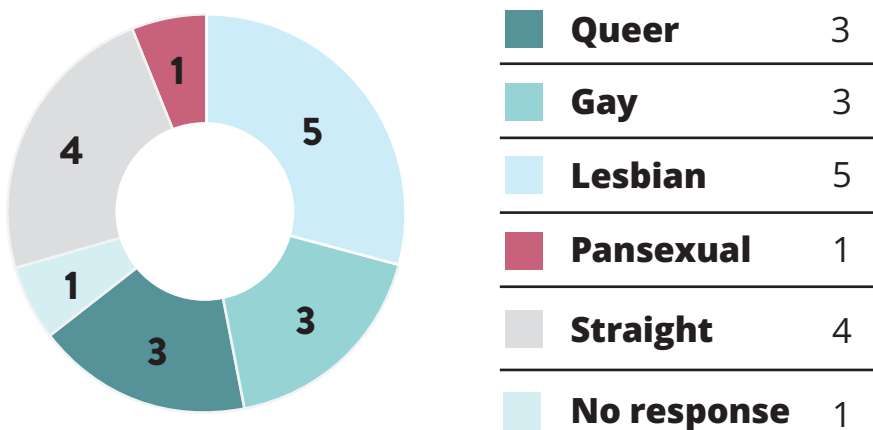
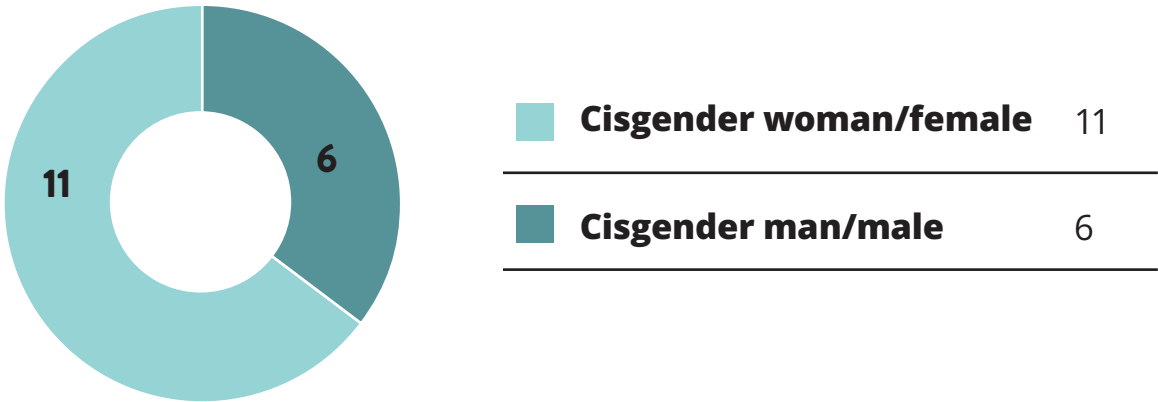


Figure 4. Phase I Participants: Gender Identity



Phase II: Consultation

In Phase II, we hosted a Virtual Community Consultation Event with key stakeholders in aging and dementia care. The purpose of Phase II was to share back preliminary findings, and to bring a larger group of involved parties together to share knowledge and identify recommendations for future collective action towards better supporting 2SLGBTQI PLWD and their primary unpaid carers.

We distributed targeted invitations to key stakeholders involved in 2SLGBTQI advocacy, care, and support services; and dementia-related and general aging care and support services. We also invited four panelists with expertise in promoting equity and inclusion in dementia care services to speak with event participants. Phase I participants and advisory committee members were also invited, with their understanding that their participation in Phase II may increase the possibility that they would be recognized as Phase I participants.

The Virtual Consultation Event

The consultation event consisted of a presentation of preliminary findings, an expert panel, and breakout discussion rooms.

Panelists were invited to share their perspectives on the opportunities and challenges presented by living and caring within the intersections of 2SLGBTQI identities and dementia. We intentionally selected and invited panelists who could speak to some of the gaps identified in Phase I data, such as experiences of dementia care among racialized and immigrant communities and perspectives on supporting trans older adults living with dementia.

Panel Presentations

The panel included presentations by:

- Dr. Alexandre Baril and Dr. Marjorie Silverman, Associate Professors in the School of Social Work at the University of Ottawa, on *Trans Older Adults Living with Dementia: Rethinking Intervention Strategies from Anti-Oppressive Perspectives*
- Jessica Bindra, M.A., Quality Improvement and Project Manager, Alzheimer Society of Ontario, on *Dementia Care Services Among Asians in Ontario*
- Vince Pietropaolo, M.A., General Manager, COSTI Family and Mental Health Services, on *COSTI's Innovative Program for People Living with Dementia and their Caregivers*

Breakout Room Discussion Prompts

Following the panel, Phase II participants engaged in breakout room discussions. The discussion prompts for these sessions were:

- Where does your existing knowledge of the situations of 2SLGBTQI people living with dementia and their primary unpaid carers come from?
- What is needed to better support primary unpaid carers for people living with dementia, and specifically for those who care for 2SLGBTQI PLWD?
- Within your current area of work, or activities related to 2SLGBTQI older adults, dementia, and/or caring, what is one thing that you think could be implemented to better support 2SLGBTQI people living with dementia?
- What coalitions and investments would you like to see made in order to better support 2SLGBTQI PLWD and primary unpaid carers of 2SLGBTQI PLWD?

Key insights from these discussions have informed our recommendations for future policy, programming, and research outlined below, as well as the ongoing development of educational e-modules and guidance documents to support the implementation of our recommendations.

Demographic Profile of Phase II Participants

In total, 25 people participated in Phase II. This included Phase I participants ($n = 5$), representatives from 2SLGBTQI-focused older adult groups ($n = 6$), dementia care service providers ($n = 7$), and general aging care providers ($n = 7$) (see Figure 5). Thirteen participants were from Central Canada, while ten were from Western and Northern Canada, and two were from Eastern Canada (see Figure 6).

Figure 5. Phase II Participants: Relation to Project

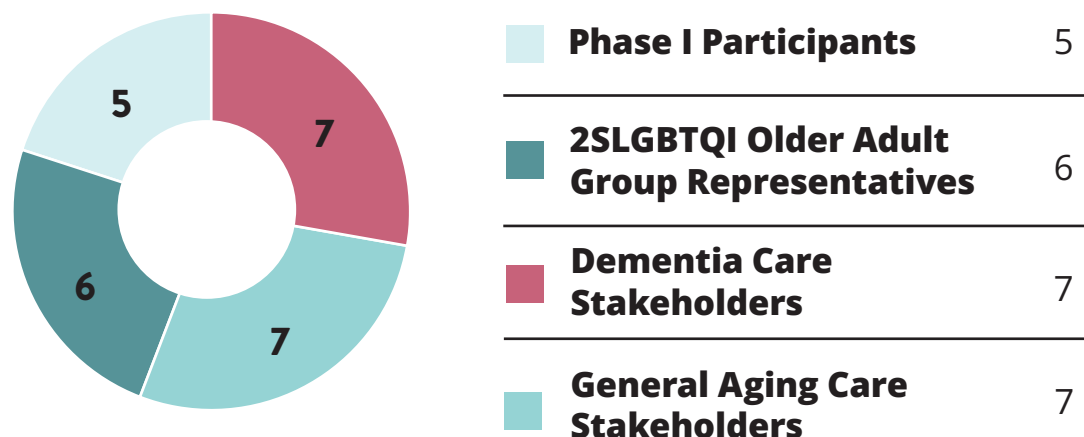
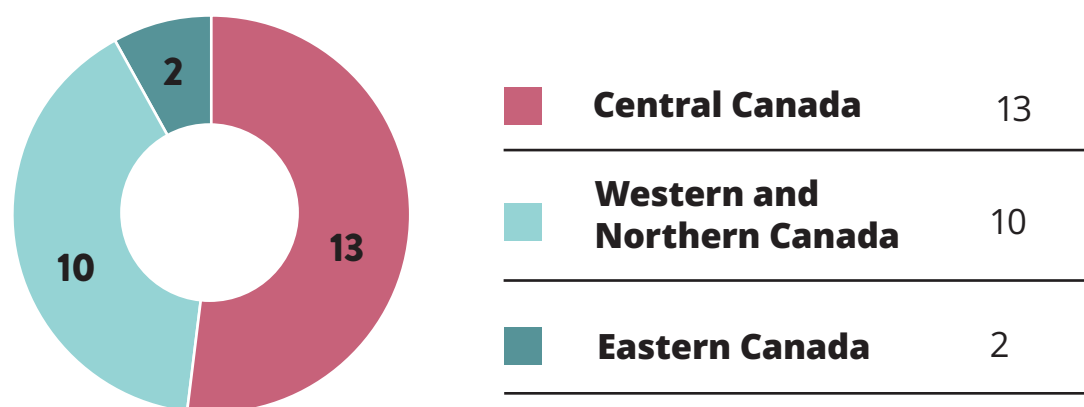


Figure 6. Phase II Participants: Geographic Location



LIMITATIONS AND GENERALIZABILITY

In our recruitment efforts we sought to reach and welcome in participants from across Canada with a wide range of identities and positionalities, including in terms of gender and sexuality, race, socio-economic status, and urban, rural, and remote dwelling. Despite our recruitment efforts, our participant group was not as diverse as we had hoped. Reflecting knowledge gaps that have been identified within existing literature (Fredriksen-Goldsen & Muraco, 2010; Kertzner et al., 2009; Peel et al., 2016; Wilson et al., 2018), our participant sample of 2SLGBTQI people living with dementia and primary unpaid carers who did not identify as heterosexual consisted of individuals who identified as lesbian and/or gay. There were no participants from the territories, representing a significant gap in findings, and most Phase I participants were from Ontario and Quebec. The majority of Phase I participants were White. In addition, while focus group and consultation event participants spoke of the need to expand supports and services in rural areas, the PLWD and carers we engaged were mainly living in urban settings.

Engaging broader communities of 2SLGBTQI people living with dementia and unpaid carers will be critical for future work in this area.

Given the dearth of research that has directly engaged 2SLGBTQI people living with dementia specifically, this study is part of important emerging conversations and research that is explicitly focused on, or intentionally invites in, 2SLGBTQI communities. As one of the few studies in this area, we hope that the insights shared especially with regards to lived experiences of dementia and unpaid care will be built upon in future research, policy making, and program planning, as well as spur further conversations and reduce stigma about dementia within our communities. While the results of this qualitative study are not generalizable (e.g., they do not speak to all 2SLGBTQI communities in Canada, or make a singular statement), they are transferable.

Study findings illuminate social dynamics and key factors shaping 2SLGBTQI communities' experiences living with and providing care in the context of dementia, and can be applied to understanding similar situations and individual circumstances.

In the Recommendations section we expand further on future directions for research.

VIRTUAL ENGAGEMENT

Virtual engagement presented both limitations and opportunities. Given health and safety concerns due to COVID-19 and ongoing changes to public health guidelines and regulations, all phases of engagement in this study occurred virtually via online communication platforms. Virtual engagement reduced barriers to travel to focus group sessions, and enabled participants from across the country to be in conversation with one another. This was especially significant given that Phase I participants were not necessarily connected to 2SLGBTQI communities or to other carers in their local areas. A key limitation of virtual engagement is access to stable internet, access to a computer or other device, and digital literacy. We found that holding an introductory meeting with participants worked well in developing comfort and familiarity with the online platform and focus group atmosphere. Online focus groups also meant that participants had to join from their homes or other places, potentially deterring people without access to private, quiet, and/or comfortable spaces to participate from. As qualitative researchers continue to use in-person and virtual methods, we encourage specific attention to ways to increase accessibility including for people living with dementia.

KEY FINDINGS

The following discussion presents key findings that emerged during our analysis of conversations during Phase I and II of this study. Specifically, our process of thematic analysis aimed to shine light on the unique aspects of experiences of living and caring within the intersection of dementia and 2SLGBTQI identities. We have included anonymized examples and direct quotes from participants that reflect the breadth of experiences shared and the depth of the conversations that took place. In so doing our aim is to amplify perspectives and experiences of study participants and to present potential points of connection to a general readership including people living with dementia and carers themselves. At the end of each subsection, we describe some direct implications of these findings for policy, programming, future research, and for efforts towards driving better health and social care and systemic change.

BECOMING CARERS

To begin our conversations with Phase I participants who identified as primary unpaid carers, we asked participants about the pathways that brought them into caring relationships and about their roles and how they understood them. The responses shared provided insight into the multiple and varied ways that people “become” carers for 2SLGBTQI people living with dementia.

Carer participants became primary unpaid carers through a wide variety of pathways. Some had been in close pre-existing relationships (i.e., before the onset of dementia), including as spouses, close family members, and close friends. Others came to care for people who were more distant in their social networks, including people in their communities and broader friend groups.

Carers described a range of what they did in their caring roles, from preparing and delivering meals, to attending medical appointments and navigating healthcare and social services, and continuing to be present as companions and significant others. They discussed their journeys into care in a variety of ways, including from a strong sense of identity as a carer, and pragmatic rationale and more circumstantial factors.

Embedded within many of the stories people shared were insights into how they brought previous experiences of providing care and navigating support networks and systems into their current caring practices and roles. This included past experiences as care professionals, and caring experience from relationships with other family and community members in old age and with disabilities and chronic illness.

For example, one woman spoke of the support she had provided to both her parents, including one with Alzheimer's, and to multiple other family members. She had been an ally and advocate in healthcare settings for her gay brother over their lives and continued to show up to support him (e.g., cooking him meals, handling finances) when he began to experience memory loss and other symptoms. Her journey into becoming a carer had started early in life and seemed to be a significant part of her life experience and sense of self. As she put it, "I believe I was born a caregiver." Significantly, while her brother had been "out" as a gay man and had had an active social life, he did not currently have a network of friends, and she described herself as his sole caregiver.

One older gay man made a connection between past caring experience during the height of the HIV/AIDS epidemic in Canada and his current caring role for his partner living with dementia. As he related:

“ Well, the biggest thing is that I've done a lot of [this since] the 80s, caretaking. Actually, dealing with dementia with much younger men, with HIV/AIDS. So... there's not a lot of surprises in how someone may act...I've volunteered, it's kind of been what I've done all my life. A lot of that because we were in [a big city] in that era. That's kind of what you did, your caretaking...So this isn't new to me.

Describing a key difference between the "teams" of people who came together in the 1980s and his caring experience today, this participant elaborated:

“ There would be teams of us in the 80s, because all of us were working as well. So we, as friends, we would break up, "well, I have Wednesday nights, I have Thursday morning, I can take [them] to the doctor sometime." Whereas now, it's exclusively myself. So that's a big difference. So I, I do talk to some relatives. But it's not like there's someone there to spell me [since they don't live close by]. There really isn't any...professional help unless you're... we're not in any income bracket where I can bring a [personal support worker] on our own.

This participant also spoke about caring for a previous partner who had passed away. Of the 15 carer participants, seven were partners or spouses to the person they were providing care to. This included people who had been with their spouses and partners for more than two decades, including with significant differences in age. One person described nuances in how she became a carer to her partner with young onset dementia, in part due to the absence of family and friends as well as useful additional support services.

While family members lived several hours away and were dispersed around the country, friends who lived nearer were also not very present. As this participant described:

“ So I was living [with] my partner. So that’s the first part, that we’ve lived together for over ten years. And I think the reason it fell on me... well, partly because you’re living with the person, you know, you’re there, you’re the one that’s there. The other part is that there is nobody, like, we’ve got a few friends. But they work. My partner is [in her late 50s]. So being younger, all of our friends work... So there’s nobody in our circle that would be able to step in, to sort of take over. And when we have had the odd person who would pop in and say, well, I’ll just, I’ll just, we’ll just go for coffee. So they take the person for coffee, they come back and they’re like, “I don’t want to do that again. It was too terrifying.” That’s how it sort of has landed in my... I don’t want to say it landed in my plate, because I love the person. And I like caring for them. It’s just that there is nobody else there. And community service has been slim to none, because there’s not a lot they can provide outside of what I was providing.

Another woman, who had been with her wife for nearly 25 years and also brought her past experiences as a teacher and a nurse to her current role as a carer, stated while laughing:

“ I fell into caregiving because I said I do.”

Other pre-existing familial relationships brought participants into their caring roles. One carer participant who was South Asian described how she and her mother came into becoming carers to her queer aunt with young onset dementia through a mix of sense of responsibility, desire to help, and desire that this relative receive safe and proper care. Significantly, this participant’s mother and aunt were both single, a factor that she analyzes as part of the reason the caring roles fell to them.

“ Basically me and my mother, we look after my aunt... She wasn’t married, she doesn’t have any children. And because she’s my mom’s sister, the responsibility kind of lays upon... I wouldn’t say it was her responsibility. But my mom, she only has one sister. So she wanted to look after her. And her symptoms kind of started in the early 60s. It’s been three years now...And me and my mom both look after her. Because we feel like, you know, these care homes... and we just feel like it’s our service to help her...I want to help her out because my mom struggles with helping her out. And yeah, she does have brothers, but it’s very kind of, especially with dementia, like just doing personal tasks or like sometimes bathing her... reminding her to do [things]... like my mom would rather have a woman do it... And my mom is like a single mother anyway. So, you know, for her, she’s very kind of empathetic and she sees people’s plight and she really wants to help out. So for her it’s a duty but she also likes to do what she wants... she likes to know that she’s in a safe place.

Family members also became carers more unexpectedly. One participant who cares for her uncle described how she came into this role after becoming the executor of his will. She shared:

“ I’m a caregiver for my uncle. And I got introduced into this because he started off having heart surgery and asked for executor of the will and the whole nine yards. And I had no idea what I was up against, I had no idea. He started with complications with that, and it’s gone downhill ever since. And unfortunately, you know, it’s dementia, but it’s... it is so much more than I ever thought.

People also became part of caring relationships with people living with dementia in more circumstantial ways, especially where prior relationships were more distant. One woman described how she became a carer for a community member friend, someone who to her knowledge did not have family members around. She described their community’s coming into understanding of his condition, and her continued journey into figuring out how to best care for him and to gather other sources of support. She reflected:

“ I’m at the very beginning stages of this experience, I say probably about a few months in, with a community member friend of mine who is in his early 60s. He had been really hard to track down for a while. And actually, now that we look back on it, the last few years he had been really like, I think all of his friends thought he was mad at them, like standing them up and things like that. But now once we realized what’s going on, we sort of think like, well, maybe those were the beginning symptoms showing. So anyway, I had finally tracked him down because with the pandemic, I was getting more and more worried that no one had heard from him...And so when I went to his apartment, it was pretty apparent. I didn’t realize at the time that he needed to see a doctor but it was apparent that he wasn’t well...There was no food and it was really filthy, and it was really, you know, like all of these things that I sort of chalked up to isolation and poverty and depression at extremes during a pandemic. So, as we started spending more time together, grocery shopping and trying to get stuff going, I would notice things like, I would pick him up in my car, and he would try and get into my driver’s door. And him just asking questions repeatedly...And all of these things that I’d never experienced. I’ve never experienced dementia or Alzheimer’s, like in my mind from watching movies, I was really like, you know, you sort of think about someone not remembering who that person is, or things like that...So, yes, it sort of snowballed into this place of really trying to figure out. And I’m still trying to figure out what happens to people when they don’t have a spouse, and they don’t have blood family. And I’ve sort of, through myself and different communities that he and I belong to here—queer community and arts community—[I’ve] sort of cobbled together people that I know love him. But everyone that I called, was like, “well, I haven’t spoken to him in years,” I thought... you know. So just trying to figure out how to best care for someone, when in some respects, you sort of feel like it’s not really your place.

Others' reflections on the unexpectedness of caring relationships also reveal the potential roles of friends, communities, and non-familial others. For example, one participant described how he became a carer for a friend and roommate as they came to experience dementia symptoms. Exceptionally, one participant described her role in continuing to provide care on a volunteer basis to an older gay man who had previously been a client. She described herself as the only person on the care team who was not being paid and spoke to a life-long sense of being a caregiver and showing up for people in need. This participant would bring hot meals and run errands, filling in gaps in paid home care and continuing to show up for him.

As the reflections shared above show, coming into caring roles for people living with dementia was not always planned, with carers embracing changes and new situations in a variety of ways. The range of people who came into providing unpaid care was significant, including people who themselves identified as 2SLGBTQI and those who did not. In both Phase I focus groups and interviews and Phase II consultations, discussions of the need to bolster support for carers also emerged. Particularly in relation to calls for more support groups, carers speculated about the distinct needs or desires for spaces for 2SLGBTQI identified carers, in comparison to more general support groups open to any people in caring relationships with 2SLGBTQI-identified people living with dementia. Among non-2SLGBTQI carers, people expressed desires to be included and have the support of 2SLGBTQI communities, in the form of more informal groups where they could find support and care advice as well as more formalized services for their loved ones to access (e.g., support services). In terms of journeys into becoming carers, the relative absence or strength of networks of support were critical in how carers negotiated their roles, balanced or sought to balance multiple life responsibilities, and influenced their sense of ability to provide the best care and support.

Implications

These findings regarding pathways into becoming unpaid carers and the experiences related suggest several implications for policy, programming, future research, and efforts towards driving better health and social care and systemic change to better support 2SLGBTQI people living with dementia and those who care for them.

- **Expanding beyond a focus on spousal and child carers:** The predominant focus of much of the popular dementia care literature and guidance is aimed towards spouses, partners, or children as primary carers. Our study findings demonstrate a strong argument for expanding focus beyond the nuclear family, including friends, adult siblings and other relatives, and community members. Possible steps to better recognize and support the diverse forms of prior and developing relationships that people have with those living with dementia who they come to care for include:
 - Expanding eligibility for caregiving leave and supports, including in workplace policies and government support programs.
 - Including examples of non-familial carers and caring relationships in dementia literature, outreach, and informational materials.
 - Expanding dementia outreach and education in different community settings (e.g., through community centres, queer recreational groups) to reach broader community networks of potential carers.
- **Caring for carers:** Caring for carers involves providing support at all stages of caring journeys. Typically, primary unpaid carers of people living with dementia provide more hours of care (e.g., preparing meals, driving to appointments, providing personal care) and experience higher levels of distress—and potentially burnout (CIHI, 2018; Sinha, 2012). While not all primary unpaid carers will experience distress and burnout, the emotional, physical, and oftentimes financial demands they face are significant, and furthermore care partnerships may be impacted by overlapping stigmas associated with identity, cognitive impairment, and growing old (McGovern, 2014). Considering these potential impacts and the various pathways to becoming carers that we identified, for people caring for 2SLGBTQI people living with dementia, specific forms of support could include:
 - Increasing access to 2SLGBTQI-inclusive dementia care support groups in rural and urban areas, via virtual and in-person group spaces.
 - Increasing representation of diverse pathways into care relationships and dementia in support, outreach, and informational materials.
 - Promoting dialogue around the ambivalences of caring and caring relationships (e.g., within carer support groups, among carers and PLWD, in 2SLGBTQI community spaces).

- **Recognizing gendered dimensions of unpaid care labour:** Feminist scholarship has long recognized and critically examined gendered divisions of labour, including paid and unpaid care work. Our study findings reflect a general trend of the feminization of care labour in Canada, with unpaid care labour falling predominantly upon women (Moysers & Burlock, 2018). Among study participants, most non-spousal or partner carers identified as women. Ongoing research and advocacy work must continue to account for gendered dimensions of unpaid care labour, and work to decrease inequities faced by women and 2SLGBTQI people.
- **Recognizing diverse experiences and expertise:** While people may be “new” to their current circumstances of being carers for others in the context of dementia, they bring a range of experiences and expertise with them. Recognizing diverse experiences and expertise is a way of recognizing the work and multi-faceted identities of people who become carers. Considering caring roles and experiences through a life course perspective—especially accounting for significant changes in 2SLGBTQI people’s rights, community experiences and losses such as caring in context of HIV/AIDS, and social acceptance over time—can enhance the abilities of service providers and other community members to provide support, including in tackling barriers to accessing care. Together, recognizing experiences and expertise can enhance understanding of complex negotiations and creativity that 2SLGBTQI primary unpaid carers and care networks may bring towards caring in the context of dementia.

COMING OUT AND COMING IN TO LIVING WITH DEMENTIA

Thinking through the stories that were shared during Phase I of this study, we held the following questions at the fore: What does gender and sexual identity have to do with this story or experience? Where are the intersections? What are key commonalities? What are key differences? In so doing, the concept of change quickly emerged as a key theme in the way that participants talked about their experiences of grappling with a diagnosis of dementia and its impact on ability, relationships, and recognition.

Changes in Ability

Many participants (both people living with dementia and primary unpaid carers) shared stories about changes in their abilities linked to moving along their journey of living and caring within the context of dementia. 2SLGBTQI PLWD participants talked about changes in cognitive and/or physical abilities that often necessitated more support from their loved ones. As one participant shared:

“ I feel some difference in what I can and can't do mentally and it really, really, really bothers me and it's angry and I just don't know how to take care of that. I have an excellent gerontologist who is working with me and I'm on some medication that has given me back partially my ability to do some thinking and stay focused on some things. But for the most part I just don't have the mental capacity I did [breaths deeply].

Carer participants, on the other hand, talked about changes in their abilities in relation to their capacity to provide care and support to the degree that is needed (e.g., assisting with personal care and managing medications). For example, when reflecting on how her experience of caring evolved one participant shared:

“ Well, just last year, during the pandemic, it became impossible for me to care. I never wanted to do it... [but] my partner came to the point where we were... where the cognition went right down the hill where, you know, simple things that she used to be able to do like even use a telephone, like to be able to phone somebody, like phone me at work or phone the neighbour or phone somebody, was impossible. She couldn't use the phone. She couldn't tell you her birthday, which she was really good with, numbers, all that. So I ended up taking her to the hospital and they adjusted the meds. And we thought she could come home but I couldn't. I just said I can't... there's no support. If she comes home, I'm back in the same position I'm in and there's no... like the person basically needs... well they say 24-hour care but the problem is that they also were having strokes and seizures along the way based on medication and things like that. The physical part started to kick in as well. So she ended up in care... in long-term care with the goal to come back home but there's no supports, there just aren't.

When talking about the changes they had experienced or were currently experiencing, many participants described a process of grieving the loss of one's previous abilities or grieving the loss of "the way things were." As one participant shared:

“ I was very active and I'm finding not only with the dementia, but my physical state has deteriorated to the point where it's very difficult for me to, number one, do what I want to do, and number two, accept the fact that I cannot do those things anymore.

As this discussion evolved, participants also shared strategies they found useful in moving through grief towards learning to slow down and enjoy the little moments of day-to-day life. The following quote illustrates one strategy shared by a participant:

“ I think one of the things that I've been able to do is, I've been able to come to terms with that. And it was a number of years ago, and I made the decision and my family made the decision that you can choose. You can choose how to live with dementia, you can make the choice to embrace the day and just do your very best and this is what we have chosen to do. So our family motto is Carpe Diem. And just doing our best, getting up and whatever happens, happens. Or we could also make the choice of always being angry. And I'm not, you know, of course, we have our moments of anger and sadness and loneliness. But it's that desire to want to do my best every day that I think has helped my spirit.

Stemming from conversations about changes in abilities related to dementia, the discussion often transitioned to dialogue about aging in place and long-term care. Regardless of participants' relation to the project (i.e., PLWD, carer), all participants expressed an explicit desire to continue aging with dignity and autonomy. One of the key factors in making this a reality for participants related to *who* would be providing care and support in their later years. For some participants this meant aging in place; while others discussed the likelihood that moving into a long-term care home would be in their future. One participant stated:

“ If you talk to most people with dementia or any type of illness, they don't want to go into long-term care, they want to die in their homes, they want to age in place. So these are big things. Resources are not very accessible. Now with the pandemic, we have less PSWs going into home. So there's a lot of conundrums... I hate to tell you, we knew this tsunami was coming years and years ago. And the healthcare system, even before the pandemic, we're behind!

When discussing the possibility of living in a long-term care home, participants voiced varying opinions on the type of long-term care spaces they would feel most comfortable living within. For some participants, there was a desire for the creation and expansion of 2SLGBTQI-specific spaces in which other residents and staff would have a common point of connection and shared histories.

For example, one participant described the conversations they have had with friends about their concerns regarding long-term care:

“ But and the other thing that one of my friends talked about was buying one of these old homes and making it a hospice for the queer community. You know, we’ve, we’ve had that conversation many times, many times, because many of our community is choosing to die at home, because they don’t want the healthcare system care. Afraid that you know...and, and it’s super simple things like, I want to lie in bed beside [my partner], I want to do that, no matter where she is. And I don’t want somebody coming in, you know, and this is what happened to these two men, right? Somebody came in the room. ‘Oh, Doug, you can’t be in bed, you need to get out of there right now.’ These guys have been together 64 years. Really? 64 years. And you’re going to tell him that, like, shake your head people, you know, and I don’t care if they were spouses or not, if you need that kind of hug or touch or something. Who the hell cares if you’re married or not? I mean, you know?”

However, some participants also shared sentiments that called for the inclusion of 2SLGBTQI older adults within existing long-term care spaces. These participants felt that they (and others) had been fighting their whole lives for inclusion that the concept of a 2SLGBTQI-specific space felt like a step backward towards segregation and isolation.

Changing Relationships

In addition to changes in abilities, participants also talked about changes within their relationships—whether it was with intimate partners, family members, or friends—as they moved along their journeys of living and caring within the context of dementia. Both 2SLGBTQI PLWD and carer participants talked about how their identity roles within relationships had shifted or were shifting from that of a partner/friend/sibling/acquaintance towards strictly being one who is cared for or providing care. Participants also shared their thoughts about the subsequent negotiation of the reciprocal—or “give and take”—nature of care that often accompanied these shifts within caring relationships. For example, one person commented on language used to describe caring as follows:

“ ...If you look at the language now, even with Alzheimer’s Society and that sort of stuff, we’re really moving towards “carers” and “care partnership” more. It’s a partnership like a give and take versus “caregiving,” especially those that have dementia, cognitive impairment, or any type of illness. They find that to be very... an insulting word, to be honest with you.”

Alongside changes within their relationships, carer participants shared that their role within the relationships had evolved into coordinating care as they juggled multiple caring roles and responsibilities.

One participant shared:

“ I would say that the difference is vigilance in that I have to pay attention to... did she get enough to eat, did she have breakfast, did she take her pills? Did she take them at the right time? Is she getting dressed? Is she safe in the shower? There's a kind of vigilance that's required and, you know, you can't be absent minded and then just sort of go off and do something without lots of thought and planning. And I find that I don't mind the acts of doing the things that I do, and I don't begrudge them at all. But I do find the constant having to be on your game, to pay attention, to prevent disaster. That's how I feel my day is. I'm spending lots and lots of energy preventing accidents, or something going on fire or somebody falling. So that hypervigilance, I think, is exhausting.

Beyond the primary caring relationship, Phase I participants (both 2SLGBTQI PLWD and carers) also shared stories about relationship changes they had experienced with extended family members and/or friends following disclosure of a dementia diagnosis. In fact, some participants also drew parallels between the changes they experienced while coming into living with dementia and the relationship changes that many 2SLGBTQI people have experienced in response to coming out about their sexual and/or gender identity. Historically, coming out (i.e., disclosing one's sexual and/or gender identity) was often met with rejection and isolation from one's family of origin (e.g., parents, siblings, children), friends, or acquaintances. As one participant shared:

“ I do think that one major aspect of this conversation is the fact that many of us do not have as close of a relationship with the rest of our family, our bio families, necessarily, because they have not been comfortable with who we are. And so that has been a lifelong challenge. So we have chosen families, if you will, to some extent. I mean, I think that that lack of... Other people in my family have had dementia, but the whole family team got behind it somehow and worked on that together. Whereas in our case, I think we're doing it pretty much alone without that support from them at all. And we're not close to them anyway.

Many participants also reflected upon their experiences of loss and grief in response to these changes in relationships following a diagnosis of dementia. Participants related their feelings of grieving the loss of one's partner and/or relationship as they once were as their relationships took on new forms. One participant described this experience as ambiguous grief as she talked about the changes she was experiencing with her partner:

“ I got introduced to that concept of ambiguous grief. And, and how is that, that you are experiencing loss when the person is still sitting there right in front of your face, you know, so that has been really helpful for me to work through that. And too like you're saying...[wife] needs simplicity, consistency and routine. And that's where I am so grateful that I am a teacher and a planner. But I'm also very grateful that I've always been creative. Like there is... “no” doesn't exist in my vocabulary. If you tell me something can't be done, I'll prove to you that it can, you know. And within reasonable limits, obviously.

As participants talked about the various ways they have experienced—and will continue to experience—changes in their relationships while living and caring in the context of dementia (e.g., shifts in reciprocity, juggling more responsibilities), the need for enhanced resources to support 2SLGBTQI PLWD and their primary unpaid carers in navigating changes and grief in caring relationships became clear.

Questions of Recognition

Conversations with Phase I participants also brought up questions related to recognition. Recognition in this instance was related to shifts in recognition—or sense—of self and others, as well as concerns about experiences of erasure—or lack of recognition—within aging and dementia care spaces.

With respect to questions of recognition related to sense of self and self-hood, participants shared fears around self-recognition—about whether they would remember who they are and who they love. For example, one 2SLGBTQI PLWD participant described feeling “like an un-persona” as they struggled to reconcile their current experience and who they were becoming with who they felt they once were. Another participant who was both a primary unpaid carer and intimate partner to a 2SLGBTQI PLWD shared concerns regarding whether her partner would forget—or no longer recognize—their relationship and the life they had built together since coming out later in life (both had previous heterosexual marriages):

“ I’m in this for the long haul shall we say [laughing] in all ways, and it’s very interesting, because, as you know, when you get into dementia, and you progress down that pathway, the brain regresses into what it knows. And so I call it ‘her level of norm’... from what she operates is now definitely our pre-marriage days. It’s almost like our 25 years is starting to go. And she’ll substitute activities that happened many years ago, long before me, and put me into them, except I wasn’t there, you know. And so, you know, how do you correct... How do you do whatever...And I just I pulled all the pictures together... You know, hanging up little things in the kitchen and stuff so that those images are present for her, because when she sees a picture, her memories are very clear. But without that stimulating...

In line with concerns about recognition within intimate relationships, participants also shared experiences of lack of recognition within the realm of external care and support. Participants shared experiences of the loss—or perceived loss—of one’s queer identity as the diagnosis of dementia evolves into the primary aspect of identity, taking precedence over other aspects of identity.

Talking about her experiences of caring for her aunt, one participant shared:

“ When it comes to like her sexual orientation, we know... it doesn't really affect her caregiving. It doesn't affect our caregiving at all, because I don't think she has knowledge of it, she doesn't discuss it, or she doesn't, you know, she doesn't really touch base on that. It's... now her disease rules her life. And it's her actions based on that disease, like, you know, forgetfulness, being erratic, sometimes being aggressive, that kind of takes over. So, the LGBT part doesn't really affect anything that she does, our caregiving or her behaviour... Like, her sexual orientation is not the forefront of her identity for us. That's just her personal life. So we don't see her like, even my mom—especially because my mom still has that conservative mindset—she doesn't really like... I think also kind of my mom's in maybe a bit denial. Because my mom probably hasn't come round it 100%. But we don't really discuss it. ...And now that she's sick, we don't... it's mostly about her illness that we're more concerned about her health. We view her in terms of like her health and her situation and, you know, her mental health and physical well-being. We don't really like, discuss that.

Beyond the change in—or erasure of—queer aspects of individual identity, participants shared their concerns about whether organizations and service providers (within and beyond age-related care settings) would recognize their relationship(s). For many participants, these concerns stemmed from past encounters with age-related care providers where inaccurate (i.e., heteronormative) assumptions (e.g., parental or sibling relationship) were made about the nature of their relationship (e.g., intimate partner, friend, acquaintance).

“ I can't tell you how many times I've been asked, Is this my mom? This is the presumption... it is the presumption at the dentist, it's the presumption at the hospital, it's the presumption everywhere. And, you know, [my partner] visually has aged dramatically in the last two years or three years. And I wasn't being asked if she was my mom five years ago. But now there's this presumption and a kind of... As a spouse, I don't feel as seen as a spouse by the medical system at all. It's bizarre. Particularly now because she is needing help.

In response to these experiences of identity and/or relationship erasure, participants shared some of the strategies they have developed to prevent the possibility of future experiences of discrimination. One strategy included calling organizations and/or service providers ahead of appointments to provide context—or disclose—details about one's identity and relationships prior to meeting in-person, as made evident in the following quote from one participant:

“ I will not say that in any way, shape, or form has our same-sex couple relationship affected the care in any way that [wife] has received from any medical practitioner. You know, practical care, like optometrists, dentist, whatever, it's just not. And I always, especially if it's a new appointment with a caregiver, I ALWAYS call ahead

and say, you know, “[wife] is going to be, you know, in your care, she’s been diagnosed with vascular dementia. She’s in the early approaching middle stages. I am her wife, I am a primary caregiver”... So they’re coming in informed, you know. And I think as a teacher, you always give students ‘look fors,’ you know, “we’re going to do this, this is what I want you to look for. This is what I’m going to ask you about when we’re done.” Why don’t we do the same thing to caregivers, and, you know, service providers? And that’s why I’ve chosen to do that. So I have to say that it has not been an issue at all.

Another strategy included seeking out organizations and/or service providers who identify as part of 2SLGBTQI communities or have an established track record of providing affirming care and support. An example of this strategy in action was provided by a Phase I participant:

“ [Friend] and I had the same doctor. It’s a gay doctor with a predominantly gay practice. And although you may not be treated badly, in one situation, you are... it’s so much easier in a situation like that. It’s so much easier when the person just knows the situation. ...Everybody knows the situation and is extremely supportive of it. So it’s perhaps not that one is treated badly in other places, but in queer positive places one is treated so much better and one notices the difference.

Finally, choosing to “go with the flow”—or choosing to not correct inaccuracies—in the moment when organizations and/or service providers make assumptions about one’s identity and relationships is another strategy that was used by participants. As shared by one Phase I participant:

“ I wouldn’t [allow assumptions/go with the flow] in a situation where [for example] it’s banking. That’s stupid, because you’re telling a lie, and it’s just gonna come back and get you. ...And in the cases, when I’ve allowed people to make that assumption, you know, it’s like at emergency or something where... again, you don’t want to be caught out in a lie. But if they want to say, you know, “your father will be back from the x-ray in five minutes.” It’s just easier to let them say that as opposed to correcting it constantly. It’s more out of convenience than anything. I mean, how many times do you want to correct people and it just seems kind of boring and small-minded to keep doing so... The guy who pushes the stretcher in the hospital, you don’t need to correct them all the time. He’s just trying to do his job.

The ways in which participants talked about taking action to navigate or prevent experiences of discrimination—and best ensure they would be treated with dignity and respect—highlights significant gaps in both recognition of and support for the multiple and fluid nature of identity for 2SLGBTQI PLWD and their primary unpaid carers.

Implications

Phase I and II participants' reflections on coming out and coming into living with dementia suggest several important implications for policy, programming, future research, and efforts towards social and systemic change. These include:

- **Enhancing support for changes in caring relationships:** Building on existing literature that discusses the various ways that change is experienced in caring relationships within the context of dementia, our study findings draw parallels between some of the changes noted above and the changes that have historically been associated with coming out for 2SLGBTQI people (e.g., familial rejection, isolation). The intersection of these historical and ongoing experiences of change calls our attention to the need for additional consideration when it comes to the provision of support. Possible steps for providing enhanced support for 2SLGBTQI PLWD and their primary unpaid carers include:
 - Recognizing the histories of change that 2SLGBTQI people are carrying with them as they are navigating living and caring within the context of dementia, as well as the potential impact that histories may have on current caring relationships.
 - Recognizing and supporting various forms of loss and grief associated with changes in caring relationships (e.g., changes in recognition of self and others).
- **Recognizing the multiplicity and fluidity of individual identities:** It is now widely known that individual identities are intersectional (Crenshaw, 2014). Considering the various aspects of our social identities, our study findings highlight the need for a holistic approach to care and support that not only recognizes but embraces the intersectional identities of 2SLGBTQI PLWD and their primary unpaid carers—rather than compartmentalizing and reducing care and support to individual aspects of identity (e.g., dementia-specific, 2SLGBTQI-focused). Some examples of intersectional care and support include:
 - Creating dementia-friendly queer community groups to support multiple aspects of identities for people living with dementia, and to recognize various configurations of caring relationships (e.g., as partner, friend).
 - Recognizing intergenerational relationships and not making assumptions about people's relationships based on age or gender.
 - Recognizing various life trajectories (and changes in trajectory) that people will have had, including fluid sexual and gender identities.
- **Offer a spectrum of support to meet needs, wants, and desires of 2SLGBTQI PLWD and their primary unpaid carers:** Reflecting discussions regarding individual desires for aging and end-of-life care, our study findings highlight the need for a spectrum of support to meet the varied needs, wants, and desires of 2SLGBTQI PLWD and their primary unpaid carers. Some examples provided by Phase I and II participants included options for aging in place (e.g., in-home support, financial support and incentives), communal living in community settings (e.g., sharing a home with chosen family), and long-term care (e.g., queer-specific care spaces, inclusive generalized care spaces).

THE POWER OF SUPPORT NETWORKS: WHAT IS WORKING, MISSING, AND WISHED FOR

In our conversations with Phase I participants, we asked: “Where else are you getting support from? What is working well, what is missing, what is wished for?” In response, participants shared about seeking support from a range of sources, including family and friends, community members and groups, as well as healthcare and social services. In addition to sharing about what was working well, participants also shared stories about times where options for support fell short. In this section we focus on the power of support networks—to both affirm and harm—within the lives of 2SLGBTQI PLWD and their primary unpaid carers, and conclude by offering some pathways forward as suggested by participants.

COMING TOGETHER OF FAMILY AND FRIENDS

According to Phase I participants, the first and primary option in their network(s) of support was family and friends. While the composition of this first line of support ranged from intimate partners, extended family members, and chosen family and friends, the ways in which participants talked about their experiences and the impact of the care and support provided and received resonated across caring relationships.

For Phase I 2SLGBTQI PLWD participants, their first line of support was their primary long-term partner (e.g., spouse, life partner) and children. Each participant also spoke at length about the unfaltering support they had received—and continue to receive—from their partners throughout the highs and lows of their dementia journeys. As one participant shared:

“ She’s really the leader of our family. She’s our glue. So it’s not just about me, that’s the other thing, our daughter’s had a lot of challenges, and particularly the last six months. With those challenges, it’s a real wake up that as [my partner] says, it can’t be always all about dementia [chuckles]. It’s a good reminder, you know, there’s other things going on in our life and world that we need to pay attention to.

However, beyond their primary unpaid carers, participants who were living with dementia did not feel they had additional immediate options for support. Among other circumstances, they cited estrangement from families of origin, not wanting to place the “burden of care” on their children or friends, and/or living in a rural area with limited support resources. For example, one primary unpaid carer talked about the isolation her uncle is experiencing:

“ He’s not able to have held a close, close friendship. He’s always been alone. He’s had acquaintances, but not he’s never had a long-term relationship ever that I know of. Yeah, he’s kept his private life quiet... Very, very, very, very quiet, very quiet. And I think that has a lot to do with how he’s brought up. The world has not been very friendly.

For Phase I carer participants, feelings and reflections about the giving and receiving support underscored the often tenuous balance between responsibility and reciprocity. Some participants described a sense of duty or obligation to provide care—regardless of whether they were an intimate partner, family member (both origin and chosen), or friend. As shared by one participant:

“ But I think that’s what friends do for friends. They help them, you know, they help them no matter what the situation may be. Whether you’re prepared for it or not. But as it was just sad, it was a beautiful experience at times, but really, really difficult at times because there’s no handbook at all, and you just have to kind of do what you think is right... if you realize that a friend is at risk, and if they need that kind of support, and there’s... they don’t have the family or other friends that are willing to do it. You do it because it’s the right thing to do. ...I was it... or nobody would have been it.

Regarding feelings of reciprocity, carer participants talked about the varying levels at which the reciprocal nature care and support manifested in their relationships. For example, some participants talked about reciprocity as feeling their efforts were valued. As exemplified by one participant:

“ Like so there is the empathy that comes back. She understands the burden that I carry so quite often she’s very empathetic or, or she’ll reach out...She tries her best to do what she used to do in her own way. But just the fact that she acknowledges those things and tries. But I think it’s also based on her need as well. Her need to connect. So it’s a mutual thing, right?

However, others did not feel reciprocity in their caring relationships. For example, one participant shared:

“ And this past week, I feel very frustrated that he’s going to burn me out. That I’m not going to have that opportunity or that comfort to be able to pass it on to my own parents. And that’s... I’m feeling frustrated about that. Because it’s so much work. It’s so taxing on the family. And I feel that my parents are envious that I’m taking that opportunity... taking... giving it to somebody who doesn’t appreciate it right now.

As participants—both 2SLGBTQI PLWD and carers—shared stories about the primary support they receive in navigating care and caring within the context of dementia (e.g., unfaltering support, sense of duty or responsibility, varying levels of reciprocity), the need for enhancing the availability and accessibility of resources to support existing options for care and support quickly became evident.

EXTENDED NETWORKS OF SUPPORT FOR CARERS

When asked about who was supporting them as carers, or where they were going for support beyond their primary caring relationship, carer participants talked about a wide range of options—or lack of options—they felt they could lean on for additional support when needed. The most common option shared by participants was having friends and acquaintances who could be counted on to provide social support (e.g., going on a coffee outing or for a walk), comprehensive physical support (e.g., overnight 1:1 care), as well as be an emotional support outlet. For example, one participant shared about her experiences of their extended network of support:

“ So, a couple of weekends ago, before we got locked down again, I was able to have a very close set of friends take her for the weekend, and I had the place to myself, which I never get.

Another common option shared—or desired—by participants was having the financial resources to pay for additional formal support. As one participant shared:

“ I almost found myself in a situation where I was going to be sharing a house with [friend]... and I was warned off by a geriatrician friend who said, 'Don't try to do that. You don't realize what you're going for.' And in fact, he gave me a very long description of what I could look forward to. And I'm glad that I listened to him. Of course, not everyone has that or those options, and [friend] fortunately had some money. So we were able to hire people. So that changes things enormously.

While 2SLGBTQI PLWD and unpaid primary carer participants were grateful for the support they received from their family and friends, participants also talked about the reality of not having anywhere for support. In particular, some participants talked about how the responsibility of caring for their partner could be an isolating solo experience as there are limited resources (e.g., human, organizational) to support their health and wellbeing as a primary unpaid carer for a 2SLGBTQI PLWD.

Beyond their own options—or lack of options—for extended networks of support, Phase I and II participants also noted that such support may not be an option for everyone, and that not everyone has a robust support network or person present to notice changes and to advocate for them.

As exemplified in the following quote from one participant:

“ I mean, I think that there are lots of, we’re all acknowledging this, lots of LGBTB people who have networks, but many don’t. And I often think there must be hundreds of thousands in the city of people where there’s nobody to advocate for them...There’s nobody even to notice how much they’ve changed, because no one, you know, I mean, it’s a gradual process, and no one is around watching and saying, “okay, at this point, somebody’s got to step in [because] this person can’t. It’s not safe to live alone, etc.” So that’s really concerning. And one suspects there are more queer people. But of course, there are all kinds of people left in that situation. And it’s really dispiriting because it’s hard enough to negotiate the system. But what if you’ve got no one to advocate for you? It would be almost impossible.

The limited range of support options—beyond friends and family—that were shared by carer participants once again highlights the need for increasing the availability of resources to support the intersecting needs of 2SLGBTQI PLWD and their primary unpaid carers.

LEANING ON COMMUNITY MEMBERS AND ORGANIZATIONS/GROUPS

Beyond family and friends coming together to provide support in living with dementia, Phase I and II participants also talked about leaning on community members and organizations/groups. In particular, some Phase I participants talked about the additional support, or “peace of mind,” offered by neighbours and community members (e.g., preparing meals, “keeping an eye” on each other). For example, one participant shared:

“ So the postman saw her and phoned the paramedics and paramedics came. I got a call. The paramedics were there. She was out in the street. ...the postman recognized that she was not the same woman he saw months ago.

While community members and groups provide additional support for some PLWD and carers, in some instances these sources may be the primary source of support. We heard stories about care relationships that had evolved over time in response to changing work/volunteer roles, shifting from formal/paid support provided via a community organization to supportive friendship. As one participant shared:

“ I was a healthcare worker for 20 years. And at the end of my career, I was doing home care. But after I left work, some of my clients who live in my neighbourhood ... ex-clients still needed stuff. And so I help them out now for free [laughs]. They have home care still, but I do supplementary home care. I take them to appointments. I bring them meals, I take care of about two to three ex-clients still.

Shifting focus from interpersonal caring relationships, we also heard about the role of both dementia-specific and 2SLGBTQI-focused community groups/organizations in providing support for 2SLGBTQI PLWD and their primary unpaid carers. Reflecting on dementia-specific community groups/organizations, Phase I and II participants agreed that these services were incredibly important sources of knowledge and support—or “lifeline” according to one focus group participant—for navigating living and caring with dementia. Talking about their experience of supporting their partner in receiving a diagnosis of dementia, one participant shared:

“ About a year after the diagnosis, or less, I got connected with the Alzheimer’s Society here, which has been very supportive. And there’s lots of activities, and we have twice monthly support group. Well, first of all, I went for an 8-week training course, two hours a week... they tell you the basics, the types, the caring opportunities and options, what support to have, so it’s training. And then that segues into a support group, where we meet twice a month, for chit-chats and exchange of information. And through that, I’ve learned about so much support that is available, both in the public sector and the private sector. So much so it’s almost overwhelming.

When it comes to support from 2SLGBTQI-focused community groups/organizations, Phase I and II participants talked about these groups and organizations as key sources of social support and connection (e.g., social gatherings, events). As one participant shared:

“ What I’m seeing in the community here is that there is... there is like, there always has been an attempt to connect with the older gay community, older GLBT community. But it’s all... my impression of it has always been that it’s more of a social connection. And I mean... It’s about that. They’re not having events where somebody is talking about dementia, for example.

While Phase I and II participants both highlighted the immense importance of both dementia-specific and 2SLGBTQI-focused community groups/organizations, participants also wanted to see future programming and services to acknowledge their many identities—as both 2SLGBTQI individuals *and* people who are living and caring with dementia. As one participant shared:

“ I think that there has to be a structure so we move beyond the recreational aspect of being a ‘gay senior,’ for example. ...I mean, we have events that are recognizing seniors in general, and then maybe there needs to be more about gay seniors, and then as part of gay seniors, then we can have the spotlights coming on for these different aspects and that this will be one of those aspects. And it’s all... there needs to be better understanding and awareness of this. And that it’s not about how we’re gonna start locking people up...It’s more about education. And it’s more about expanding their role, their focus. I think right now it’s really important that we get people out of the isolation, however it’s done. And you can do through the social [part] of that, but then there needs to be more... groups need to be encouraged to think beyond either the immediate need or the obvious need.

To further highlight the importance of multi-dimensional support resources, Phase I participants talked about how much they appreciated that the focus group setting facilitated the opportunity to come together and connect with others who were living and caring within the intersection of 2SLGBTQI identities and dementia. As one participant succinctly shared:

“ I just think that I appreciate the fellowship today with common interests and common experiences and learning new experiences with people like myself. I haven't experienced this before. And I've been walking this path for a while. So that's pretty great.

This sentiment was shared by all Phase I participants as they relished the opportunity to connect with others with similar experiences and desires for resources that could support their intersecting identities.

While Phase I and II participants noted the importance of community members and groups/organizations in supporting 2SLGBTQI PLWD and their primary unpaid carers, they also commented that the COVID-19 pandemic had created a number of challenges to accessing support in both private and public domains. This included in service disruptions and program cancellations. As one participant shared about their newly formed support group for 2SLGBTQI carers:

“ I do a lot of work with the Alzheimer's Society here in trying to connect within our own queer community in [city] and starting a queer caregiver support group. And we had everything in place, we had grant money, we had meeting dates set, and then COVID hit. And all of that has gone. ...We only really were able to have the one gathering before it all got shut down. It wasn't well-formed enough to continue on its own at that point. The whole Zoom thing was too inhibiting for too many people at the beginning and whatnot.

In addition to the significant barriers and challenges, there were also a few opportunities for enhancing accessibility and connection. As programs shifted to the virtual environment, there were more opportunities for 2SLGBTQI PLWD and their primary unpaid carers to connect in ways that were previously unavailable. Thinking about the opportunities presented by the shift to online communication caused by the COVID-19 pandemic, one participant shared:

“ There needs to be queer-specific support groups and they need to be cross-country and there needs to be access to resources for people that are living in rural areas. I think the one thing that we've learned so much since this pandemic started is that, based on what we're doing here today, these things can happen virtually. So that now that we know that those things can happen, that... they need to be put into place.

Moving forward from our experience of conducting this research study during the COVID-19 pandemic, the importance of creating opportunities for individuals with similar lived and living experiences to come together and connect cannot be understated.

As exemplified in the stories shared by Phase I and II participants, the availability of community members and organizations/groups that offer knowledge, support, and connection which acknowledges the range of identities and caring relationships within the context of 2SLGBTQI identities and dementia is critical.

REACHING OUT TO HEALTHCARE AND COMMUNITY SUPPORT SERVICES

In addition to sharing about their caring relationships with family and friends, as well as community members and groups/organizations, Phase I and II participants shared stories about their experiences accessing—and attempting to access—healthcare and community support service, alongside specific insights and recommendations about what could be made better, and how. When asked specifically about experiences with general healthcare and/or community support services, many participants expressed how past experiences with healthcare and aging care services informed or shaped their current encounters both negatively and positively.

With respect to the impact of negative experiences with healthcare and community support services, Phase I and II participants talked about the various ways their caring relationships were misinterpreted or erased (as discussed earlier) by care providers. In some instances, Phase I participants talked about the need to continually “prove” their relationship/connection to the person they were caring for despite having established caring relationships.

“ I guess for me, I think it’s engaging the person that you’re being the advocate for. If I can get [brother] to say, ‘ give her permission,’ or ‘yes, she’s my advocate’ or something like that, that seems to hold more weight, because we’ve obviously talked about it, depending on where the person is that you’re caring for, [if] they’re able to do that. I think that that’s an important piece. Because... privacy, especially around doctors is, you know, usually reserved for the spouse. So yes, I think it’s important that you establish that bond first.

These encounters often lead to further questioning and assumptions made about one’s motivation for providing care (e.g., financial motives). One example shared by a participant about the skepticism they had experienced when interacting with healthcare and community support services:

“ I think they say, well, you know, why are you? They wonder what... they wonder why you’re doing it. And they wonder, you know, “shouldn’t somebody else... shouldn’t their family be doing, you know? Shouldn’t you be living your own life, and not worrying about this person? Because you have your whole life ahead of you, you know, why are you doing this for your friend? There must be a reason.” Sometimes there isn’t a reason beyond just caring.

While participants talked about the impact of heteronormative assumptions on their interactions with care providers, some participants also shared insights about how intersecting stigmas associated with both dementia and 2SLGBTQI identities and experiences impact their interactions with healthcare and community support services. As one participant expressed:

“ I think we need to educate the general population, not only about dementia, but more about the gay and lesbian communities. And that they're... We're not something to be afraid of. We're not mean. We're not cruel. And maybe, yes, there's one person or a couple people here and there that are like that. But you know, you're stigmatizing a whole segment of the population because of that. And you're stigmatizing a segment of the population because they have dementia. And then you're double hit, because you're gay, and you have dementia. That's a big whammy. And I don't know that there's enough education on what it means to be queer and to have dementia. We as a population are people, we're just people. And we should be treated as people and loved as people. You know, that's how we come down to it. That's how I come down to it. I'm just here to do my job as opposed to learning how to care... be a caring person. And the hiring, and the training, and the understanding of what dementia is. I think there's a big gap there between the general population and those of us with dementia.

Conversely, Phase I and II participants also took this opportunity to talk about the impact of positive experiences with healthcare and community support services. While participants highlighted how affirming it was when care providers acknowledged and respected their relationships, they also talked about the ongoing or lingering impacts of negative experiences and encounters on their expectations prior to and during interactions with healthcare and community support services. As one participant shared:

“ I think it's just confidence. It's one less thing you have to worry about. I think as queer people we're always imagining there might be a situation. We're always anticipating it. Because we've had to and we... this is how we've gotten through our lives. And it never... but the possibility that you might receive homophobic treatment of whatever sort is always there. It's always in your back... back of your mind. So what is markedly different about a situation like this is you go in and you just put it... put that aside, you know, that's not going to be an issue. So I think that's, that's the huge difference. I mean, that's also as a caregiver. It just becomes easier to access that service because you aren't, don't concern... you're not concerned.

Negative or positive, the experiences that 2SLGBTQI PLWD and their primary unpaid carers have had (or have heard about) with healthcare and community support services directly impacted perceptions about how future encounters may unfold. Subsequently, participants made decisions about whether to access, avoid, or refuse services provided by any individual, group, and/or organization beyond their trusted support network (i.e., a primary unpaid carer) based on these perceptions.

As one participant expressed:

“ Like, what gay men in the 60s and 70s went through was not too far short of genocide. And, you know, I... like they carry that with them. And so now when I'm meeting these 70- and 80-year-old gay men, and saying, "guys, the Alzheimer's Society is the greatest place to go." And they say... "I'm not doing that again. You know, I got shamed once when I was younger, I'm not getting shamed now, because I've now got... like, they're gonna blame my gayness for causing Alzheimer's." Because that's been so much a part of their experience. And I think that's where my push to demystify sexuality comes from, because I've seen the pain that that caused that generation. And now they're being identified with varying forms of dementia and Alzheimer's and don't want to seek that resource because of the shame involved with that.

Rooted in the ongoing impact of past experiences with healthcare and aging care services, a central focus of this conversation with Phase I and II participants was 2SLGBTQI access to services, and feelings of safety, comfort, and belonging. When it comes to seeking affirming healthcare and community support services, Phase I and II participants spoke at length about the need for greater access to healthcare and community support services for 2SLGBTQI PLWD and their primary unpaid carers, and for 2SLGBTQI older adults in general. Participants shared the perspective that many services and 2SLGBTQI-specific community groups/organizations were more readily available and accessible to residents of larger urban cities. The urban-centric location often means limited (or non-existent) access to much-needed support services for 2SLGBTQI PLWD and carers alike due to transportation and distance/time barriers. One participant shared:

“ I wanted to point out when I was caregiving, I was living in Halifax at the time. And there was always the perception at least, at least on my part, that the resources that might have been available in Toronto, for instance, were not available on the East Coast. I never knew of any sort of support group for people that were... that were either caregiving or other supports for people that were living with dementia in Atlantic Canada. And I really think that where you're geographically located plays a huge role in what kind of supports are available.

For Phase I and II participants, another one of the key contributing factors for affirming and positive experiences within healthcare and aging care services was having transparent equity, diversity, and inclusion (EDI) commitments and policies. In particular, participants talked about their awareness of signs (e.g., Pride flags, rainbow stickers on front doors, etc.) that signal that a group/organization or service provider is 2SLGBTQI-inclusive, as well as actively seeking out materials that outline a group/organization or service provider's EDI policies and procedures.

For example:

“ They’re making that promise or that statement that all services or whatever [are inclusive], and I’m feeling better right off the bat because with those statements. And if it’s not, then I feel justified that I can go and report and get something activated on it. And I have [done that in the past], and it’s been dealt with, with protocols very, very effectively and very, very nicely. And we both felt very comfortable with how it was dealt with. That’s made me feel a lot better. I felt supported in that way.

Beyond noticing organizational signifiers of equity and inclusion, Phase I and II participants talked about their intentional efforts to seek out and access 2SLGBTQI-inclusive and affirming groups/organizations and service providers, as well as their desire to see more groups/organizations make an effort to explicitly signal that their services are specifically 2SLGBTQI inclusive. For example, one participant shared their thoughts on the availability of 2SLGBTQI-specific groups/organizations and service providers:

“ Well, here’s... to me, this is a crazy concept, but you know, if I can... if I can state my preference... If I can say I want a male doctor or a female doctor, why can’t I say that I want a doctor who’s LGTB... Q... sorry, I’m so awful with the alphabet, you know, who’s queer friendly? And I mean, not to say that any of them are going to identify as not being queer friendly. But I think that it would be wonderful if there were more clinics that went out of their way to publicize that. To say, you know, we’re experienced in dealing with the queer community and with issues of dementia and the queer community, I think it would be great if that was an option.

Recognizing the varying degrees of support that are available to 2SLGBTQI PLWD and their primary unpaid carers, Phase I and II participants shared some ideas and suggestions regarding what is needed or wished for to ensure availability and accessibility of support and services. These suggestions can be summarized as (a) breaking down silos, (b) expanding services beyond large city centres, and (c) advocating with and for the rights of 2SLGBTQI PLWD.

In terms of breaking down siloed approaches to better support the multi-faceted needs of 2SLGBTQI PLWD and their primary unpaid carers, participants highlighted the need for dementia-specific and 2SLGBTQI-focused groups/organizations and service providers to come together in recognition and support of the unique experience of living and caring within the intersection of dementia and 2SLGBTQI identities.

As one participant shared:

“ And that, wherever you are, whoever you’re dealing with, has to be respectful of who you are, and what you’re doing. And I just fear that people who don’t have support, like [another participant] and I, will find themselves in a situation where they’re put into a place that takes care of people with dementia. And if they don’t understand what the LGBTQ part of their persona is, that they will be misunderstood more than just the dementia. And they need to have an understanding in order to be able to take care of them properly, and to give them the proper support and love that they need. ...if you’re that to begin with, and you have the LGBTQ stigma on top of that, I just fear that, you know, we will be so misunderstood and treatment will be that much worse, or care will be that much worse. And I think there needs to be education not only around dementia, but around the LGBTQ and their needs in their psyche and what makes them function and work and happy... in order to be treated properly.

The current generation of 2SLGBTQI older adults has a long history of advocacy and they have witnessed numerous shifts in their rights and freedoms over the past 50 years. According to participants, there is still work to be done to ensure that 2SLGBTQI PLWD and their primary unpaid carers have access to and receive the care and support they need and deserve. As shared by one participant:

“ In the years that we’ve been doing advocacy, which, for the most part until about five years ago, was unpaid. So this is very important as well, because our voices need to be heard. It shouldn’t be unpaid. Just so you know, this is another envelope that we are pushing. When it comes to our community, there’s still a lot of stigma, and [places] where our voices are not often asked as a couple to be brought forth to the table. And our perspective needs to be heard. I think that this research is extremely important. Our voices are extremely imperative. And so that’s definitely why I’m here. But this is the first time I have been as a lesbian woman with a partner with young onset dementia, I have spoken in this type of context for this type of research.

The above insights and recommendations offered by participants to improve interactions with healthcare and community support services demonstrate the need for continued efforts and advocacy to increase understanding and awareness of the experiences that 2SLGBTQI PLWD are carrying and the subsequent impact on their needs when it comes to care and support.

Implications

Rooted in the above findings regarding the power of support networks within the lives of 2SLGBTQI PLWD and their primary unpaid carers, we present the following implications for policy, programming, future research, and efforts towards social and systemic change to better support 2SLGBTQI people living with dementia and those who care for them.

- **Enhancing availability and accessibility of community care and support resources:** Reflecting long-standing gaps in support resources (e.g., support groups, specialized geriatric care), our study findings emphasize ongoing calls for the need to provide the right care in the right place at the right time by the right service provider (NIA, 2020). We heard about the value of facilitating opportunities to come together with individuals who have similar lived and living experiences alongside the affirmation of care and support provided by inclusive, understanding, and non-judgmental service providers. In order to best ensure the availability and accessibility of care and support resources for 2SLGBTQI PLWD and their primary unpaid carers, our findings suggest some key considerations:
 - Create more opportunities for 2SLGBTQI PLWD and their primary unpaid carers to come together to learn from and support one another.
 - Expanding in-person care and support services beyond large, urban city centres.
 - Directing funding and resources to community groups and direct service organizations in rural areas to enhance stability and longevity of services and programming.
- **Breaking down silos between dementia-specific and 2SLGBTQI-focused care and support resources:** Building from the need to recognize the multiplicity and fluidity of individual identities, our study findings highlight the need for cross-disciplinary support in order to provide the most comprehensive care for 2SLGBTQI PLWD and their primary unpaid carers. Breaking down silos between dementia-specific and 2SLGBTQI-focused care and support resources will create more opportunities to:
 - Better support the range of identities and caring relationships within the context of 2SLGBTQI identities and dementia (e.g., limit assumptions being made about caring relationships).
 - Enhance services and programming in ways that reflect the realities of 2SLGBTQI PLWD and their primary unpaid carers.
 - Better enable care providers to provide gender affirming care (e.g., through education and professional development opportunities).
- **Increasing understanding and awareness of the unique needs and experiences of 2SLGBTQI PLWD:** While there is indeed growing understanding and awareness of experiences of living with dementia and experiences of 2SLGBTQI people and communities, there continues to be very little outreach and advocacy around the intersection of living with dementia and 2SLGBTQI identities. Our study findings clearly articulate the need for more channels, or channels with a broader reach, to share information, resources, and tips that are directly relevant to living and caring within the context of dementia and 2SLGBTQI identities.

RECOMMENDATIONS

Dementia and dementia-related care are not isolated issues, nor, we argue, should they be siloed issues. They are social issues that are interconnected with questions of health equity, healthcare access, ageism and ableism, and support for carers, among many other social dynamics and interlocked conditions of oppression. 2SLGBTQI communities' experiences of living with dementia and the experiences and needs of primary unpaid carers are entangled with other social identities and layered experiences navigating social systems and norms.

We recognize that striving to improve care and support for people living with dementia and their primary unpaid carers must come with changes in multiple areas of life such as healthcare, housing, and financial security. In interpreting the results of the study, we have considered both nearer-term actions as well as longer-term social justice implications.

Below, we provide action-oriented recommendations for programming, policy, advocacy, and research that build on the implications outlined above in the *Key Findings* section. While these recommendations are focused on 2SLGBTQI communities and unpaid carers, they also speak to broad social and structural issues including healthcare and social service gaps, that, if addressed, could be of potential benefit to many groups.

Recommendation 1: Build 2SLGBTQI-inclusive dementia-related services and community spaces



Key enablers include:

- Create more opportunities for 2SLGBTQI PLWD to come together in support and community.
- Integrate dementia-focused discussions and education into existing 2SLGBTQI support and social groups.
- Create and increase opportunities for accessible education and professional development for potential care providers, including 2SLGBTQI community members, professional care providers, and front-line service workers.
- Build a comprehensive repository or directory of resources and organizations to support community groups, organizations, and healthcare and aging care services in better supporting 2SLGBTQI PLWD and their carers and significant others.

Recommendation 2: Increase recognition and support for primary unpaid carers of 2SLGBTQI PLWD



Key enablers include:

- Increase recognition of the diverse positions that a primary unpaid carer may have in relation to the person they care for, including in workplace and government care policies and leaves.
- Create dedicated spaces for primary unpaid carers of 2SLGBTQI PLWD to share with, learn from, and support one another (e.g., support groups, virtual information and resource sharing platforms).
- Address a lack of knowledge of where to go for support among unpaid carers, for example through the creation of local directories that identify general support and 2SLGBTQI inclusive services and groups.
- Develop greater awareness about the diverse and multiple ways that carers may be related to and involved with caring for a PLWD (e.g., community member, partner, friend) through workplace educational opportunities (e.g., for dementia care service providers), diversifying examples provided in dementia support literature, and through broader public awareness campaigns.

Recommendation 3: Enhance supports for 2SLGBTQI communities and carers through structural and systems-level change



Key enablers include:

- Integrate 2SLGBTQI histories and experiences into core course content for healthcare and social services provider training across a range of professions (e.g., nursing, PSW/personal care aide training, social work, gerontological recreation programs, etc.).
- Create more services and reduce barriers to accessing dementia-related care and support for rural and small-town communities.
- Address systems navigation challenges that PLWD and carers face, for example through creating “navigator” roles, increasing knowledge of dementia care services in information hotlines, creating local directories of services with accessible options for further support.
- Increase funding for research and direct services within the intersections of 2SLGBTQI identities and dementia care.

Recommendation 4: Broaden perspectives and deepen community engagement for future critical research



Key enablers include:

- Future research focused on 2SLGBTQI communities, dementia, and dementia care must continue to strive to meaningfully engage, learn from, and amplify the perspectives of a diverse range of people. For example, while there has been some research and published work focused on better understanding the experiences of trans people and trans issues related to living with dementia (e.g., Baril & Silverman 2019; Pang, 2022; Witten 2016) further critical engagement is needed. This includes:
 - Research that is grounded in community and that emphasizes the building of relationships of rapport, trust, and accountability with trans community members.
 - Research that continues to seek to engage and build relationships with Two-Spirit, bisexual, and intersex communities and community members to learn more about their experiences with and perspectives on living with dementia.
 - Research that interrogates the specific dynamics of settler colonialism and ongoing medicalization of different 2SLGBTQI groups, especially within qualitative research and research that takes a case-study approach.
 - Research that continues to examine the particularities of living in suburban, rural, and remote areas, including access to services, transportation, and networks of support.
 - Research that intentionally welcomes and develops relationships with Indigenous, Black, and racialized 2SLGBTQI people who are living with dementia.
- Future research could use a case-study approach in a specific location (e.g., one town or city, or province or territory) to better understand the local landscape and circumstance of 2SLGBTQI and dementia-related care and support.
- Researchers from across disciplines (e.g., sciences, social sciences, public health, humanities) can continue to collaborate in learning more about risk factors for dementia and prevention measures appropriate to different communities.
- We encourage ongoing innovations in methodological approaches to engaging in research with people living with dementia, including in qualitative and arts-based methods and approaches.

NEXT STEPS

The findings from this study will inform two subsequent phases of this project: the creation of open-access e-modules and of a guidance document to share knowledge and build capacity around better supporting 2SLGBTQI people living with dementia, unpaid carers and care providers, and an awareness campaign. In so doing, we will continue our work towards increasing knowledge and understanding, working for change at a social and systems level, and implementing some of the recommendations above. We will also continue knowledge mobilization activities through a range of formats including presentations, publications, and other modes of dissemination and engagement that can continue to spark conversations, support evidence-informed policy change and community organizing, and increase availability of equitable and inclusive supports for 2SLGBTQI PLWD and their primary unpaid carers.

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