



LGBTQI2S people living with dementia and their unpaid caregivers across Canada

A Package of Guiding Literature and Resources

Ashley Flanagan, PhD
National Institute on Ageing

Celeste Pang, MA, PhD (c)
Egale Canada

Acknowledgements

About Egale

Founded in 1986, Egale is Canada's national LGBTQI2S human rights organization. Egale works to improve the lives of LGBTQI2S people in Canada and to enhance the global response to LGBTQI2S issues by informing public policy, inspiring cultural change, and promoting human rights and inclusion through research, education, awareness and legal advocacy. Egale's 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.

About the National Institute on Ageing

The [National Institute on Ageing](#) (NIA) is a public policy and research centre based at Ryerson University in Toronto. 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, physical, 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.

Background

Recognizing the gap in current understandings of living and/or caring within the intersections of LGBTQI2S identities and dementia, in 2020 Egale Canada and the National Institute on Ageing at Ryerson University teamed up to conduct national research into the experiences of LGBTQI2S people living with dementia, and primary unpaid caregivers of LGBTQI2S people living with dementia.

Funded by a Public Health Agency of Canada Dementia Community Investment grant, this research is the first phase of a multi-year project seeking to increase awareness and improve supports for LGBTQI2S people living with dementia and their caregivers across Canada.

This package of guiding literature and resources was originally shared with ad-hoc advisory committee members, co-facilitators, and focus group participants in order to provide an overview of academic literature on LGBTQI2S aging and dementia and to share the researcher's ideas guiding the research.

Cite As

Flanagan, A. & Pang, C. (2020). LGBTQI2S people living with dementia and their caregivers across Canada. A Package of Guiding Literature and Resources. Toronto, ON: Egale Canada and the National Institute on Ageing.

Contents

Acknowledgements 2

 About Egale 2

 About the National Institute on Ageing 2

Background 3

 Cite As 3

**A (Brief) Review of the Literature on LGBTQI2S Aging
and Dementia 5**

 General LGBTQI2S Aging 6

 Unique Experiences of LGBTQI2S PLWD and their
 unpaid primary caregivers 7

 Why does this matter? 8

Ideas guiding our research 9

 Appreciative inquiry 9

 From “burden” to interdependence and care relationships 10

 Troubling “vulnerability” 11

 “Assuming capacity” 12

 Attention to the benefits and drawbacks of online focus groups 13

 Next Steps 14

**Additional/Useful resources
(for further reading) 14**

 Guidelines 14

 Journal Articles 14

 Reports 15

References 15

A (Brief) Review of the Literature on LGBTQI2S Aging and Dementia

Recent population projections estimate that the proportion of older adults living in Canada could increase from 17.9% in 2020 to 23.6% in 2038—gradually increasing to 27.8% of the population by 2063 (Statistics Canada [Stats Can], 2019, 2020). The most notable increases are predicted to occur between 2013 and 2030 as all members of the baby boom generation¹ reach age 65 and over (Stats Can, 2015). 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). In particular, there are over 419,000² people over the age of 65 that have been diagnosed with dementia, according to the Government of Canada's (2019) National Dementia Strategy report. While the National Dementia Strategy (2019) calls for greater focus on LGBTQ2 individuals, the prevalence of dementia among LGBTQI2S people is not known. However, it can be expected that prevalence will increase as the population ages (Le Berre & Vedel, 2020, pp.244).

Dementia, as defined by Sinha (2012), is a progressively debilitating disease that erodes cognitive and functional abilities—with Alzheimer's disease as the most common form of dementia. As the number of people living with dementia (PLWD) continues to rise, so too will the need for unpaid primary caregivers³ supporting individuals living with dementia (National Institute on Ageing [NIA], 2019).

According to baseline projections provided by the National Institute on Ageing (NIA), unpaid care will increasingly become the reality of Canadians—despite the number of available unpaid primary caregivers declining by 30%—as the number of older adults who require support increases by 120% by 2050 (MacDonald, Wolfson, & Hirdes, 2019). Typically, unpaid primary caregivers of people living with dementia provide more hours of care (e.g., preparing meals, driving to appointments, providing personal care) and experience higher levels

1 The baby boom generation or cohort is comprised of individuals born between 1946 and 1965. Individuals who were born during this period are often referred to as baby boomers or boomers.

2 This number is increasing every year as it is estimated that approximately 78,000 older adults are newly diagnosed (Government of Canada, 2019).

3 According to The Change Foundation (2016), unpaid "caregivers"—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." By pairing "caregiver" or "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, Campbell, Reddy, & Rochon, 2019). Conversely, when referring to paid care work, the National Institute on Ageing (2019) uses the term "care provider."

of distress—and potentially burnout (CIHI, 2018; Riffin, Van Ness, Wolff, & Fried, 2017; Sinha, 2012). While not all unpaid primary caregivers of people living with dementia are at risk of experiencing distress and burnout, the growing cohort of older adults may present further challenges to the long-term sustainability of unpaid care in Canada (NIA, 2018, 2019). As a result, it is imperative that we heed calls to provide equitable and comprehensive support and care for persons living with dementia and their unpaid primary caregivers—especially when taken alongside the increasing acknowledgement of the diversity within Canada’s older adult population.

General LGBTQI2S Aging

While recent shifts have sparked conversations about the heterogeneity⁴ within aging *experiences* that exists along the axes of values, age cohort, levels of independence, ability, education, race, ethnicity, indigeneity, socioeconomic status, and immigration status, there continue to be many factors that may make aging well precarious (Public Health Agency of Canada [PHAC], 2006). Specifically, the historical de-privileging of both aging and LGBTQI2S identities, experiences, and bodies has led to the invisibility of LGBTQI2S older adults in research, policy, and practice (Hafford-Letchfield, Simpson, Willis, & Almack, 2017; Kimmel, 2014; McGovern, 2014; Moreno, Laoch, & Zasler, 2017; Westwood, 2019; Wilson, Kortess-Miller, & Stinchcombe, 2018). For example, a general lack of comprehensive population-based data⁵ regarding sexual and gender identity in old age (and across the life course) prevents our ability to grasp a “complete” picture of LGBTQI2S older adults and their lived experiences of aging and old age (McGovern, 2014; Waite & Denier, 2019; Wilson, Kortess-Miller, & Stinchcombe, 2018). In particular, there have been no Canadian studies that specifically consider and center the aging experiences of Two-Spirit (or “2S”) older adults—to the best of our knowledge.

The current gaps in understanding of LGBTQI2S older adults are a reflection of the coming together—and compounding—of long histories of cis/heteronormative⁶ stigmatization, pathologization, and discrimination (e.g., homophobia, transphobia, biphobia) with pervasive ageism within Canadian society (Egale Canada, 2020; Westwood, 2019; Wilson, Kortess-Miller, &

4 Historically, the common misconception that older adults are a homogenous group (i.e., heterosexual, asexual, and/or cisgender) whose experiences are identical has led to overgeneralizations which omit the influence of social factors (i.e., age, race, gender, sexuality, socioeconomic status, family structure, friendships, and access to high-quality care) on an individual’s capacity to be supported in aging and old age (Laher, 2017; Peel, Taylor, & Harding, 2016; Kimmel, 2014; Willis, Raithby, Dobbs, Evans, & Bishop, 2020).

5 It was recently estimated that 13% of Canadians identify as lesbian, gay, bisexual, transgender, queer or intersex, or two-spirited (LGBTQI2S) (Foundation Jasmine Roy, 2017).

6 The overarching assumption that all or most people are cisgender and heterosexual—or *cishet*—reinforces *cisnormativity* and *heteronormativity* within Western society (Russo, 2014). *Cis/heteronormativity* refers to the prevalence of both *cisnormativity* and *heteronormativity* within Western society (Flanagan, 2020).

Stinchcombe, 2018). As both aging and LGBTQI2S identities continue to be devalued and marginalized within Canadian society, LGBTQI2S older adults may struggle to find support that is inclusive as they age.

Despite recent advances in the rights and freedoms of LGBTQI2S individuals living in Canada, historical context continues to be relevant within LGBTQI2S older adults' considerations of the care they will receive in aging and old age (Fredriksen- Goldsen & Muraco, 2010; Kertzner, Meyer, Frost, & Stirratt, 2009; Peel, Taylor, Harding, 2016; Wilson, Kortess-Miller, & Stinchcombe, 2018). For example, the current generation of LGBTQI2S older adults have lived through decades of historical experiences of discrimination and pathologization which may have led to precarity in housing and employment, disconnection from the LGBTQI2S community, and avoiding accessing much-needed care due to fear of discrimination and harassment (Brotman, Ryan, Jalbert, & Rowe, 2002; Corroero & Nielson, 2020; Fredriksen-Goldsen, Kim, Bryan, Shiu, & Emler, 2015; Kimmel, 2014; Le Berre & Vedel, 2020; Wilson, Kortess-Miller, & Stinchcombe, 2018). Ongoing conditions of marginalization and oppression continue to limit access to care and shape life worlds of LGBTQI2S people in Canada today, in particular for BIPOC (queer and trans Black, Indigenous, and People of Colour) and trans and non-binary people (Awwad 2015; Scheim, Zong, Giblon, & Bauer 2017; Pang, Gutman, & de Vries, 2019).

At the same time, LGBTQI2S older adults have and continue to create vibrant lives and forge meaningful social connections. In terms of care, many LGBTQI2S older adults have well-established chosen families who, in a lot of cases, are also providing care and support in aging and old age (Kimmel, 2014; Moreno, Laoch, & Zasler, 2017). Studies have found that LGBTQI2S older adults most often prefer non-biological sources of social support (e.g., close friends, chosen family, wider support networks) to provide care (e.g., personal care, financial assistance) in aging and old age (Barrett, Cramer, Lambourne, Latham, & Whyte, 2015; Hafford-Letchfield, Simpson, Willis, & Almack, 2017; Mock, Walker, et al., 2020; Peel, Taylor, & Harding, 2016; Wilson, Kortess-Miller, & Stinchcombe, 2018). Further, according to Kimmel (2014), 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 partners and friends (Moreno, Laoch, & Zasler, 2017).

Unique Experiences of LGBTQI2S PLWD and their unpaid primary caregivers

When we bring together the literature on dementia and LGBTQI2S experiences of aging and old age, there is a dearth of knowledge, policy, and practices that are relevant to the lived experiences of LGBTQI2S PLWD and their unpaid

primary caregivers—especially when it comes to the aging experiences of transgender and non-binary people, and queer and trans Black, Indigenous, and people of colour who are living with dementia (Babulal et al., 2020; Barrett, Crameri, Lambourne, Latham, & Whyte, 2015; Correro & Nielson, 2020; Moreno, Laoch, & Zasler, 2017; Peel, Taylor, & Harding, 2016; Wilson, Stinchcombe, Ismail, Kortés-Miller, 2019). Recent research has posited that lifelong social inequity (e.g., systems of homophobia, transphobia, biphobia, racism) experienced by LGBTQI2S older adults and their communities may place them at elevated risk of cognitive decline and/or developing dementia (Baril & Silverman, 2019; Correro & Nielson, 2020; Flatt, Johnson, Karpiak, Seidel, Larson, & Brennan-Ing, 2018; Fredriksen-Goldsen, Jen, Bryan, & Goldsen, 2018; Fredriksen-Goldsen et al., 2018; McGovern, 2014; Yarns, Abrams, Meeks, & Sewell, 2016), while exact prevalence and risk is currently unknown.

Given previous discussions of the intersections of dementia and unpaid care work, it is reasonable to assume that caring for a LGBTQI2S older adult living with dementia—or caring as an LGBTQI2S individual—continues to be demanding (e.g., physically, emotionally, financially), regardless of advances in rights and freedoms of LGBTQI2S individuals and communities across the world (Le Berre & Vedel, 2020; McGovern, 2014). In fact, care partnerships may be impacted by overlapping stigmas associated with identity, cognitive impairment, and growing old (McGovern, 2014). Since much of the research on the intersections of LGBTQI2S aging and dementia originates from the United Kingdom, Australia, and the United States, these findings are not necessarily directly generalizable to Canadian contexts due to differences in its medical, legal, and social support systems (McGovern, 2014; Moreno, Laoch, & Zasler, 2017; Wilson, Kortés-Miller, & Stinchcombe, 2018). Further, while “2S” is often included in study acronyms, to our knowledge there has been no specific engagement with Two-Spirit communities regarding experiences and understandings of dementia, and the care relations it engenders.

Without greater knowledge and understanding that centers the perspectives of LGBTQI2S people living with dementia and their unpaid primary caregivers, the ability of government, medical professionals, and others to provide equitable and comprehensive support and care is severely compromised, as is the ability to advocate for change.

Why does this matter?

While it is becoming more well-known that sexual and gender identity matter with respect to expectations for care and quality of life (e.g., fear of being

forced back into the closet⁷, maintaining identity) in old age, there is a need to recognize the unique experiences (e.g., historical experiences of systemic discrimination, loss of familial relationships) of LGBTQI2S persons living with dementia and their unpaid primary caregivers as we advocate to ensure sexual and gender rights are not violated in aging and old age (Baril & Silverman, 2019; Barrett, Crameri, Lambourne, Latham, & Whyte, 2015; Flatt, Johnson, Karpiak, Seidel, Larson, & Brennan-Ing, 2018). In fact, the Government of Canada's (2019) National Dementia Strategy specifically calls for specific focus on LGBTQI2S individuals—who are at higher risk dementia and/or facing barriers to equitable care.

Therefore, by centering the perspectives of LGBTQI2S PLWD and their unpaid primary caregivers, our study seeks to better understand the lived experiences of LGBTQI2S older adults living with dementia and their unpaid primary caregivers within Canada—in order to ensure they are connected to the “right care, in the right place, at the right time” (Barrett, Crameri, Lambourne, Latham, & Whyte, 2015; Egale Canada, 2020; NIA, 2019; Wilson, Stinchcombe, Ismail, Kortés-Miller, 2019). This work is particularly important in the current moment given limited access to much-needed services and programs due to COVID-19; which has disproportionately impacted the lives of older adults, unpaid primary caregivers (both paid and unpaid), and LGBTQI2S folx (Fernandez & Burch, 2020; MacCharles, 2020).

⁷ “The closet” refers to, according to Wilson, Kortés-Miller, & Stinchcombe (2018), “...being hidden for individuals who identify as LGBT. Being in the closet is an expression that is connected to a lack of disclosure of sexual orientation or gender identity, including aspects of sexual identity and sexual behaviour. Being forced back into the closet represents a fear of loss of autonomy, identity, and freedom of sexual expression. Participants expressed fear that they were at risk of being coerced back into the closet towards the end of their lives in order to feel safe during a period in which they anticipated being vulnerable and lacking in power” (p. 28).

Ideas guiding our research

In addition to knowledge of the existing literature and gaps, as researchers we also bring theoretical and ethical orientations to this research. In preparing for these focus groups, we discussed theories, concepts, and ideas that inform our thinking and that could inform the research design. We built consensus around a number of guiding ideas that orient us moving into the focus groups, and that we will, potentially, engage with as we interpret focus groups results. These guiding ideas include:

Appreciative inquiry

Stemming from organizational studies, appreciative inquiry (AI) 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’, ensuring the consent of those in the system to ‘what should be’ and collectively experimenting with ‘what can be’” (p. 41). In this way, AI 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).

Within the context of this study, AI will frame all aspects from engagement with organizations and networks accessed for recruitment to interactions with participants during the focus groups to the follow-up post-focus group. In so doing, it will be made clear throughout the research process that we (the research team) are interested in understanding experiences of care/caring through stories of what is, and what could be, *not* to reinforce narratives focused on vulnerability and suffering that have pathologized LGBTQI2S people and people living with dementia.

By engaging with LGBTQI2S PLWD and their unpaid primary caregivers with a framework of appreciate inquiry, we will be better able to understand past and current experiences of care alongside conversations that imagine forward to what care and caring could look like.

From “burden” to interdependence and care relationships

Commonly, a language of “burden” is used to describe caregiving. While caregiving can present many challenges, a focus on burden can emphasize the negative aspects (e.g., burnout, financial insecurity) of being in care

relationships, and can also create an inaccurate focus on the “caregiver” in opposition to the “cared for” person.

In this study, we are instead curious about interdependence and care relationships. Interdependence, as a theoretical concept developed in feminist care ethics and taken up across a broad range of feminist and critical disability studies analyses of care, recognizes the inherent co-constitution and inter-reliance of human lives (e.g., see Mingus, 2017; Kittay, 2020). This recognition stands in contrast to—and, especially as forwarded by critical disability activists and scholars, seeks to break down—the emphasis and value placed on narrowed visions on individualism and independence. Scholarship on queer kinship has similarly theorized kinship as mutual dependency (Freeman, 2007), and kinship as caring and being cared for (Borneman, 1997).

Analyses of interdependence and care relationships underscore the mutuality of giving and receiving care, and challenge a singular and dichotomous understanding of dependence/independence. Specifically, “interdependence” recognizes the way that lives are entangled. In this understanding, care is not a one-way street, nor framed in terms of burden. All people—in the case of this research, caregivers and LGBTQI2S people living with dementia—are understood as existing in a care relationship with each other, a relationship that is dynamic, and will come with its particular reciprocities, challenges, and creativity.

Further, recognition of interdependence shifts our focus to how communities and individuals may be best supported in care relationships, and opens space for celebrating different forms of care relations. This includes care relationships among families of choice, experiments in creating care collectives, and recognizing the expertise of lived experiences (e.g., see Piepzna-Samarasinha, 2018). In inquiring about dementia and dementia care among LGBTQI2S people and caregivers, this focus leads us to be interested in who people identify as part of their care or support network, and how they describe their experiences of engaging in care relationships, including the dynamics of reciprocity and their creative practices.

Troubling “vulnerability”

Research involving human subjects comes with multiple ethical considerations. These include agreed upon norms of research ethics that, in Canada, are outlined by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Human (or TCPS). The TCPS provides a national benchmark for the ethical conduct of research involving humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada,

& Social Sciences and Humanities Research Council, 2018, pp. 3). The core principles underlying the TCPS are respect for persons, concern for welfare, and justice. Justice, here, includes fairness and equity: in the TCPS' terms, "fairness entails treating all people with equal respect and concern", and "equity requires distributing the benefits and burdens of research participation in such a way that no segment of the population is *unduly burdened by the harms of research or denied the benefits* of the knowledge generated from it" (pp. 8, our emphases). The TCPS recognizes several groups who have historically been treated unfairly and inequitably in research, and those that may be considered "vulnerable" due to "limited decision-making capacity, or limited access to social goods, such as rights, opportunities and power" (pp. 8).

We recognize this vulnerability as researchers. However, at the same time, we agree with scholars who have critiqued the way that "vulnerability" can come to define a population of people and overshadow other aspects of their lives. Stephanie Patterson and Pamela Block, both critical disability study scholars, offer a critique that we have found useful in thinking through this study. In an edited volume book chapter called "Disability, Vulnerability, and the Capacity to Consent" they trouble the concept of vulnerability. Recognizing the histories of abuse in research that have led to enforced restrictions to protect "vulnerable" human subjects, they yet ask: "But does having a disability automatically and categorically render a person vulnerable in such circumstances?" (Patterson and Block 2019, pp. 68). They argue that in fully accessible environments risks for abuse in participating in non-medical research may be no more than for non-disabled people (pp. 68). Further, calling out the infantilization involved in "assuming that people with disability are easy prey for coercion and manipulation" (pp. 72), Patterson and Block argued that instead of dividing lines of disability or impairment categories a focus must be maintained on "ability to consent" and "power to resist manipulation" (pp. 73). In this, they shift the focus onto the social relations and power dynamics involved in research. This is a focus we embrace as critical for meaningfully including people living with dementia in research.

"Assuming capacity"

"Assuming capacity" is an orientation that resists the categorical denial of research participation on the basis of cognitive disability or difference (Kohler, 2019). Like Patterson and Block's focus on "ability to consent" and "power to resist manipulation", "assuming capacity" shifts focus onto the researcher and research environment, and how the researcher is creating conditions where participants can participate fully, and provide ongoing consent.

“Assuming capacity” is an orientation that stands against ableist⁸ ideals that disenfranchise people with disabilities from exercising full rights as citizens, including through participation in research (Kohler, 2019). This concept comes from Anne Kohler’s work among adolescents and adults with Down Syndrome, wherein she used “assisted interviewing”, where another person could be present to facilitate the participation of research participants. This is a kind of interviewing that, within a framework of “assuming capacity”, works against the notion that “the words and thoughts of participants with intellectual disabilities only become legible when partnered with those of typically developed parents, friends, or support persons”; as well as, “acknowledges the interjections of such individuals while avoiding a confirmatory lens that, we suggest, rests on the notion that those with intellectual disabilities live in a radically different (and perhaps not entirely legible) world” (Kohler, 2019, pp. 200). With this in mind, people with dementia cannot and should not be assumed to have impaired or diminished capacity (Hegde & Ellajosyula, 2016). With great sensitivity to issues of harm in research and the fundamental need for consent, we “assume capacity”, and have built ongoing processes of consent into our study.

Attention to the benefits and drawbacks of online focus groups

Online focus groups, as a “virtual method” of research, come with both benefits and limitations.

One of the greatest benefits of virtual methods is *increasing the reach* to potential participants. Online focus groups offer the potential of bringing together people who live in different locations to discuss together, where geographical distance and costs associated with travel may have otherwise limited engagement (Mann and Stewart 2000; James and Bushner 2009). Further, online focus groups may facilitate the participation of people with disabilities who may otherwise face barriers to travel and engagement in in-person research environments.

Limitations involve necessary access to the Internet and to technology, and challenges associated with mediating communication through technology (Jowett, Peel & Shaw, 2011). We recognize that access to stable Internet and to a computer or other device to connect online is a privilege, and also that our online meeting platform is likely unfamiliar to many. Further, interacting online does not offer the same interactive experience as face-to-face engagement (e.g., evoking collective excitement). Additionally, communicating through the virtual platform, once logged in, also privileges certain abilities: including ability to sit or stand in front of the screen, to be exposed to the glare of the screen for multiple hours,

⁸ Ableism is a social process of discrimination that favours certain traits of “ability”: for example, in contemporary Canada independence and autonomy are socially valued. It includes the idea that “people with disabilities as a group are inferior to non-disabled people” (Linton, 1998, pp.9).

and to speak loudly such that the computer can pick up one's sound. Virtual participation under COVID-19 restrictions in different parts of Canada may also mean that people have less ability to participate in a private space—such as a work office—and may be sharing information and stories in the focus group in a space that is not private, potentially limiting their comfort at being open.

On the part of the researcher and facilitator, virtual research requires different ethical considerations as well as interviewing or facilitation skills (Graffigna & Bosio, 2006; James & Bushner, 2009), and the researcher's ability to pick up on non-verbal cues during a focus group discussion may be more limited (Nilsson et al., 2014). Facilitators may also have less control over distractions in the environment (Jowett et al., 2011).

Our efforts to mitigate these limitations, and to take advantage of the benefit of potential greater reach include an introductory meeting (where all participants are invited to practice using the online platform); sending participants copies of the focus group questions in advance, upon request; sharing “access copies” of the co-facilitator and researcher's opening script; taking intentional breaks during the focus groups; and checking-in with all participants in advance about pronunciation of names, pronouns, and access needs (Disability Research Interest Group, 2017).

Next Steps

This research seeks to fill a critical gap in knowledge and understanding of living and caring within the intersections of LGBTQI2S identities and dementia. Informed by the literature and guiding ideas we have shared above, our next steps are to conduct online focus groups with LGBTQI2S people living with dementia and primary unpaid caregivers of LGBTQI2S people living with dementia across Canada. As our research unfolds, we look forward to fostering critical conversations about how to best support LGBTQI2S people and communities living with dementia, and to translate key findings into analyses that will advance awareness, policy, and programming initiatives in Canada.

Additional/Useful resources (for further reading)

Guidelines

[Focus group guidelines: Organizing and conducting focus groups for people living with memory loss and for family caregivers](#) by ACT on Alzheimer's.

[Guidelines for an accessible presentation](#) by Disability Research Interest Group.

[Meaningful engagement of people with dementia: A resource guide](#) by Alzheimer Society of Canada.

[Recommendations for supporting LGBT people living with dementia](#) by SAGE & Alzheimer's Association.

Journal Articles

Cottrell, L., Duggleby, W., Ploeg, J., McAiney, C., Peacock, S., Ghosh, S., Holroyd-Leduc, J. M., Nekolaichuk, C., Forbes, D., Paragg J., & Swindle, J. (2020) [Using focus groups to explore caregiver transitions and needs after placement of family members living with dementia in 24-hour care homes](#). *Aging & Mental Health*, 24(2), 227-232

Daniels, N., Gillen, P., Casson, K., & Wilson, I. (2019). [STEER: Factors to Consider When Designing Online Focus Groups Using Audiovisual Technology in Health Research](#). *International Journal of Qualitative Methods*, 18, 1609406919885786.

Kite, J., & Phongsavan, P. (2017). [Insights for conducting real-time focus groups online using a web conferencing service](#). *F1000Research*, 6, 122.

Reports

[A dementia strategy for Canada: Together we aspire](#) by Government of Canada.

[Community engagement consult for LGBTQI2S seniors](#) by Egale Canada.

[Enabling the future provision of long-term care in Canada](#) by National Institute on Ageing.

[Issues Brief: LGBT and dementia](#) by SAGE & Alzheimer's Association.

[National Action Plan for LGBTQI2S rights in Canada](#) by Egale Canada.

[The values, needs and realities of LGBT people in Canada in 2017: Research report](#) by Foundation Jasmine Roy.

[Why Canada needs to better care for its working caregivers](#) by National Institute on Ageing.

References

- ACT on Alzheimer's. (2016). Focus group guidelines: Organizing and conducting focus groups for people living with memory loss and for family caregivers. Retrieved from <https://www.actonalz.org/sites/default/files/documents/ACT%20Focus%20Group%20Guidelines.pdf>
- Awwad, J. 2015. Queer Regulation and the Homonational Rhetoric of Canadian Exceptionalism. In Omnisore H. Dryden and Suzanne Lenon (Eds.), *Disrupting Queer Inclusion: Canadian Homonationalism and the Politics of Belonging*. (pp. 19-34). Vancouver: UBC Press.
- Babulal, G. M., Quiroz, Y. T., Albeni, B. C., Arenaza-Urquijo, E., Astell, A. J., Babiloni, C., ... & Chételat, G. (2019). Perspectives on ethnic and racial disparities in Alzheimer's disease and related dementias: Update and areas of immediate need. *Alzheimer's & Dementia*, 15(2), 292-312.
- Baril, A., & Silverman, M. (2019). Forgotten lives: Trans older adults living with dementia at the intersection of cisgenderism, ableism/cogniticism and ageism. *Sexualities*, 0(0), 1-15.
- Barrett, C., Cramer, P., Lambourne, S., Latham, J. R., & Whyte, C. (2015). Understanding the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia, and their partners. *Australasian journal on ageing*, 34, 34-38.
- Borneman, J. (1997). Caring and being cared for: Displacing marriage, kinship, gender and sexuality. *International Social Science Journal*, 49(154), 573-584. <https://doi.org/10.1111/j.1468-2451.1997.tb00046.x>
- Brotman, S., Ryan, B., Jalbert, Y., & Rowe, B. (2002). Reclaiming space-regaining health: The health care experiences of two-spirit people in Canada. *Journal of Gay & Lesbian Social Services*, 14(1), 67-87.
- Busche, G.R. (1998). Appreciative inquiry in teams. *The Organization Development Journal*, 16(3), 41-50.
- Canadian Institute for Health Information (CIHI). (2018). Dementia in Canada. Ottawa, ON. Retrieved from <https://www.cihi.ca/en/dementia-in-canada>.
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council. (2018). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html
- Correro, A. N., & Nielson, K. A. (2020). A review of minority stress as a risk factor for cognitive decline in lesbian, gay, bisexual, and transgender (LGBT) elders. *Journal of Gay & Lesbian Mental Health*, 24(1), 2-19.
- Disability Research Interest Group. (2017). *Guidelines for an Accessible Presentation*. Society for Medical Anthropology. <http://www.medanthro.net/academic-resources/guidelines-for-an-accessible-presentation/>

- Egale Canada. (2020). National action plan for LGBTQI2S rights in Canada. Retrieved from <https://egale.ca/awareness/nationalactionplan/>
- Fernandez, M., & Burch, A.D.S. (2020, June 18). George Floyd, From 'I Want to Touch the World' to 'I Can't Breathe.' Retrieved from <https://www.nytimes.com/article/george-floyd-who-is.html>.
- Flanagan, A.K. (2020). *Do we really get to choose our own story? (Re)imagining community support with transgender and non-binary older adults*. UWSpace. <http://hdl.handle.net/10012/16404>
- Flatt, J. D., Johnson, J. K., Karpiak, S. E., Seidel, L., Larson, B., & Brennan-Ing, M. (2018). Correlates of subjective cognitive decline in lesbian, gay, bisexual, and transgender older adults. *Journal of Alzheimer's Disease*, 64(1), 91-102.
- Fredriksen-Goldsen, K. I., & Muraco, A. (2010). Aging and sexual orientation: A 25-year review of the literature. *Research on aging*, 32(3), 372-413.
- Fredriksen-Goldsen, K. I., Jen, S., Bryan, A. E., & Goldsen, J. (2018). Cognitive impairment, Alzheimer's disease, and other dementias in the lives of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers: Needs and competencies. *Journal of Applied Gerontology*, 37(5), 545-569.
- Fredriksen-Goldsen, K. I., Kim, H. J., Shiu, C., Goldsen, J., & Emlet, C. A. (2015). Successful Aging Among LGBT Older Adults: Physical and Mental Health-Related Quality of Life by Age Group. *The Gerontologist*, 55(1), 154-168.
- Freeman, E. (2008). Queer Belongings: Kinship Theory and Queer Theory. In *A Companion to Lesbian, Gay, Bisexual, Transgender, and Queer Studies* (pp. 293-314). John Wiley & Sons, Ltd. <https://doi.org/10.1002/9780470690864.ch15>
- Government of Canada. (2019). A dementia strategy for Canada: Together we aspire. Retrieved from <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>.
- Graffigna, G., & Bosio, A. C. (2006). The influence of setting on findings produced in qualitative health research: A comparison between face-to-face and online discussion groups about HIV/AIDS. *International Journal of qualitative methods*, 5(3), 55-76.
- Hafford-Letchfield, T., Simpson, P., Willis, P. B., & Almack, K. (2018). Developing inclusive residential care for older lesbian, gay, bisexual and trans (LGBT) people: An evaluation of the Care Home Challenge action research project. *Health & social care in the community*, 26(2), e312-e320.
- Hegde, S., & Ellajosyula, R. (2016). Capacity issues and decision-making in dementia. *Annals of Indian Academy of Neurology*, 19(Suppl 1), S34-S39. <https://doi.org/10.4103/0972-2327.192890>
- James, N., & Busher, H. (2009). *Online interviewing*. Thousand Oaks, California: Sage.

- Jowett, A., Peel, E., & Shaw, R. (2011). Online Interviewing in Psychology: Reflections on the Process. *Qualitative Research in Psychology*, 8(4), 354–369.
- Kertzner, R. M., Meyer, I. H., Frost, D. M., & Stirratt, M. J. (2009). Social and psychological well-being in lesbians, gay men, and bisexuals: The effects of race, gender, age, and sexual identity. *American Journal of Orthopsychiatry*, 79(4), 500–510.
- Kimmel, D. (2014). Lesbian, gay, bisexual, and transgender aging concerns. *Clinical Gerontologist*, 37(1), 49–63.
- Kittay, E. F. (2020). *Love's Labor: Essays on Women, Equality and Dependency*. New York: Routledge.
- Kohler, A. (2019). Assuming Capacity: Ethical Participatory Research with Adolescents and Adults with Down Syndrome. In *Research Involving Participants With Cognitive Disability and Differences: Ethics, Autonomy, Inclusion, and Innovation* (pp. 197–210). Oxford: Oxford University Press.
- Le Berre, M., & Vedel, I. (2020). Diversity considerations in Alzheimer disease and related disorders: How can our national and provincial strategies be inclusive of sexual minorities?. *Canadian Family Physician*, 66(4), 244.
- Linton, S. (1998). *Claiming Disability: Knowledge and Identity*. NYU Press.
- MacCharles, T. (2020, May 7). 82% of Canada's COVID-19 deaths have been in long-term care, new data reveals. Retrieved from <https://www.thestar.com/politics/federal/2020/05/07/82-of-canadas-covid-19-deaths-have-been-in-long-term-care.html>.
- MacDonald, B.J., Wolfson, M., and Hirdes, J. (2019). The Future Co\$t of Long-Term Care in Canada. National Institute on Ageing, Ryerson University.
- Mann, C., & Stewart, F. (2000). *Internet Communication and Qualitative Research: A Handbook for Researching Online*. Thousand Oaks, California: Sage.
- McGovern, J. (2014). The forgotten: Dementia and the aging LGBT community. *Journal of Gerontological Social Work*, 57(8), 845–857.
- Mingus, M. (2017). Access Intimacy, Interdependence and Disability Justice. *Leaving Evidence*. <https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/>
- Mock, S. E., Walker, E. P., Humble, Á. M., de Vries, B., Gutman, G., Gahagan, J., ... & Fast, J. (2020). The role of information and communication technology in end-of-life planning among a sample of Canadian LGBT older adults. *Journal of Applied Gerontology*, 39(5), 536–544.
- Moreno, A., Laoch, A., & Zasler, N. D. (2017). Changing the culture of neurodisability through language and sensitivity of providers: Creating a safe place for LGBTQIA+ people. *NeuroRehabilitation*, 41(2), 375–393.

National Institute on Ageing (NIA). (2018). Why Canada Needs to Better Care for Its Working Caregivers. Toronto, ON: National Institute on Ageing White Paper.

National Institute on Ageing (NIA). (2019). Enabling the Future Provision of Long-Term Care in Canada. Toronto, ON: National Institute on Ageing White Paper. Retrieved from <https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5d9de15a38dca21e46009548/1570627931078/Enabling+the+Future+Provision+of+Long-Term+Care+in+Canada.pdf>

Nilsson, J., Jervaeus, A., Lampic, C., Eriksson, L. E., Widmark, C., Armuand, G. M., Malmros, J., Marshall Heyman, M., & Wettergren, L. (2014). "Will I be able to have a baby?" Results from online focus group discussions with childhood cancer survivors in Sweden. *Human Reproduction (Oxford, England)*, 29(12), 2704–2711. <https://doi.org/10.1093/humrep/deu280>

Pang, C., Gutman, G., & de Vries, B. (2019). Later life care planning and concerns of transgender older adults in Canada. *The International Journal of Aging and Human Development*, 89(1), 39–56.

Patterson, S., & Block, P. (2019). Disability, Vulnerability, and the Capacity to Consent. In *Research Involving Participants With Cognitive Disability and Differences: Ethics, Autonomy, Inclusion, and Innovation* (pp. 67–76). Oxford: Oxford University Press.

Peel, E., Taylor, H., & Harding, R. (2016). Sociolegal and practice implications of caring for LGBT people with dementia. *Nursing Older People*, 28(10).

Piepzna-Samarasinha, L. L. (2018). *Care Work: Dreaming Disability Justice*. Vancouver: Arsenal Pulp Press.

Public Health Agency of Canada. (2006). Healthy aging in Canada: A new vision, a vital investment. A discussion brief prepared for the Federal, Provincial and Territorial Committee of Officials (Seniors). Retrieved from <http://www.phac-aspc.gc.ca/seniors-aines/alt-formats/pdf/publications/public/healthy-sante/vision/vision-eng.pdf>

Riffin, C., Van Ness, P. H., Wolff, J. L., & Fried, T. (2017). Family and other unpaid caregivers and older adults with and without dementia and disability. *Journal of the American Geriatrics Society*, 65(8), 1821–1828.

Scheim A., Zong, X. Giblon R., Bauer G. (2017). Disparities in access to family physicians among transgender people in Ontario, Canada. *International Journal of Transgenderism*, 18(3), 343–352.

Russo, J. (2014). *Definition of "Transmisogyny."* Retrieved from <http://queerdictionary.blogspot.com/2014/09/definition-of-transmisogyny.html>

Sinha, S. (2012). Living Longer, Living Well: Report Submitted to the Minister of Health and Long-Term Care and the Minister Responsible for Seniors on recommendations to inform a Seniors Strategy for Ontario. Retrieved from http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy_report.pdf.

- Stall, N. M., Campbell, A., Reddy, M., & Rochon, P. A. (2019). Words matter: the language of family caregiving. *Journal of the American Geriatrics Society*, 67(10), 2008–2010.
- Statistics Canada (Stats Can). (2019). *Canada's Population, July 1 2019*. Retrieved from <https://www150.statcan.gc.ca/n1/pub/11-627-m/11-627-m2019061-eng.htm>.
- Statistics Canada (Stats Canada). (2020). Canada's population estimates: Age and sex, July 1, 2020. Retrieved from <https://www150.statcan.gc.ca/n1/daily-quotidien/200929/dq200929b-eng.htm>
- Statistics Canada. (2015). *Population Projections for Canada (2013–2063), Provinces and Territories (2013–2038)*. Catalogue no. 91-520-X. Retrieved from <http://www.statcan.gc.ca/pub/91-520-x/91-520-x2014001-eng.htm>.
- Waite, S., & Denier, N. (2019). A Research note on Canada's LGBT data landscape: Where we are and what the future holds. *Canadian Review of Sociology/Revue canadienne de sociologie*, 56(1), 93–117.
- Westwood, S. (2019). Abuse and older lesbian, gay bisexual, and trans (LGBT) people: a commentary and research agenda. *Journal of elder abuse & neglect*, 31(2), 97–114.
- Whitney, D. D., & Trosten-Bloom, A. (2010). *The power of appreciative inquiry: A practical guide to positive change*. Berrett-Koehler Publishers.
- Wilson, K., Kortess-Miller, K., & Stinchcombe, A. (2018). Staying out of the closet: LGBT older adults' hopes and fears in considering end-of-life. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 37(1), 22–31.
- Wilson, K., Stinchcombe, A., Ismail, M., & Kortess-Miller, K. (2019). LGBTQ2+ aging in Canada: Building the evidence and informing action. *The Canadian Journal of Human Sexuality*, 28(3), 257–260.
- Yarns, B. C., Abrams, J. M., Meeks, T. W., & Sewell, D. D. (2016). The mental health of older LGBT adults. *Current psychiatry reports*, 18(6), 60.