



Living as a trans or non-binary older adult with dementia*

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*For more information on this topic, please see: Baril, A. & Silverman, M. (2023, forthcoming). "We're still alive, much to everyone's surprise": The experience of trans older adults living with dementia in an ageist, cisgenderist, and cognitivist society. *Journal of Aging Studies*.

Research Question

What are the experiences of trans and non-binary older adults with dementia and their support networks?

Definitions

- Cogniticism** : A system of oppression that discriminates against people with cognitive disabilities at the political, social, medical, legal, economic, and normative levels.
- Dementia** : Encompasses all types of memory-related cognitive disabilities such as mild cognitive impairment, Alzheimer's disease, vascular dementia, and Lewy Body dementia.
- Trans and non-binary identities/people** : Encompasses a large variety of gender identities and expression, including transgender, transsexual, non-binary, agender, gender non-conforming or genderqueer people, or anyone who does not identify with their sex/gender assigned at birth.

Background

- No previous empirical studies published in English or French have examined the lived experiences of trans or non-binary people with dementia, based on first-hand narratives.
- Trans and non-binary people, along with other marginalized groups, may be more susceptible to develop dementia due to a wide variety of risks factors, including minority stress and systemic violence (Fredriksen-Goldsen et al., 2018; Hardacker et al., 2019; Witten, 2016).
- Trans and non-binary people fear developing dementia and are reticent to access formal health and social services due to real and/or anticipated fears of discrimination (Ducheny et al., 2019; Willis et al., 2020).
- People living with dementia often experience social and epistemic death and are treated as though they are incapable of agency, rather than as knowledgeable subjects. This is particularly salient for people living with dementia who belong to marginalized groups.
- Trans older adults living with dementia are trapped in a tension between invisibility (in research, social policies, and public institutions) and hyper-visibility, through a vast array of mechanisms of control, gatekeeping, and surveillance (Kia, 2015; 2019).

Acknowledgements

We thank the participants of this research project, as well as Carl-Vincent Boucher, Marie-Claire Gauthier, Maude Lévesque, Elgin Pecjak, Tommy Planchat, and Ré Poulin Ladouceur.

Funding details

This research was supported by the Social Sciences and Humanities Research Council of Canada under Insight Grant 435-2019-0011.

Findings - The unique aspects of living with dementia as a trans or non-binary person

Cogniticism impacts the experience of cisgenderism and gender identity

- Based on cogniticism, participants' self-identified gender was often not taken seriously by health care providers, leading to exacerbated forms of cisgenderism, such as gatekeeping regarding gender affirming health care.
- Trans and non-binary people with dementia are often denied access to gender confirming surgeries or other treatments, such as hormone therapy, by doctors who believe that these treatments are not a priority in later life and that people with dementia cannot give informed consent.
- Not having access to medical treatments directly transforms the way gender is experienced by trans and non-binary people, and can place them at greater risk of cisgenderist violence, since their gender expression might change and their bodily features may not match their chosen gender identity.

Dementia impacts the experience of cisgenderism and gender identity

- Dementia has the potential to increase exposure to cisgenderist violence, as the need for care increases. For example, Victor had to deal with hypervisibility in a long-term care home, as his transness was the epicenter of cisgenderist curiosity and mistreatment.
- Dementia sometimes impacts the possibility for people to advocate for themselves and to defend themselves against cisgenderist micro-aggressions and violence.
- Many trans older adults who lived stealth are outed when they can no longer independently bathe, dress, or use the washroom.
- None of the trans participants, or those cared for by the carers interviewed, felt that dementia had transformed their relationship to their gender identity, and none had forgotten their chosen identity.

Cisgenderism and gender identity impact the experience of cogniticism and dementia

- The isolation, loneliness, and lack of support that many trans and non-binary people experience may increase the cogniticism they face, as there are fewer people to help denounce mistreatment.
- Structural violence can increase people's symptoms of dementia. For example, Victor had increased anxiety and hallucinations due to cisgenderist violence.
- The cisgenderism experienced by trans and non-binary people living with dementia limits their care options, both in institutional settings and at home.

Silo mentality erases intersecting identities and oppressions

- Providers often adhere to a silo mentality, in which identity components are treated as if they are separate and not connected to structural oppressions.
- Providers tend to read everything through the lens of transness or dementia, i.e., focus entirely on gender identity and neglect dementia, or focus entirely on dementia and dismiss gender identity/expression. This erasure of intersecting identities is a missed opportunity to offer better care and services.

Methodology

- One-year Canada-wide recruitment in both English and French (August 2021 - August 2022).
- N = 1625 organizations (aging/dementia organizations + 2SLGBTQIA+ organizations).
- Zoom-based narrative interviews; thematic data analysis; adapted methods for people with cognitive disabilities.
- Findings are based on interviews conducted with 2 trans participants and 4 carers who were caring for 5 trans and non-binary people with dementia.

Trans Participants*

Name/pseudonym and pronouns	Victor (he/him)	Martha (she/her)
Age	75	75
Self-identified gender	Man, masculine	Female
Self-identified sexual orientation	In a heterosexual relationship, preference for women	Lesbian
Self-identified as racialized or visible minority	No, White person	White Jewish person
Geographic location	Urban Canada	Urban Canada

*Note: the terms and expressions used reflect the participants' choice of words to self-identify.

The problem was, when I was looking into it with doctors, they said oh, you're over sixty-five, we're not gonna touch you, not gonna do surgery, you're too old, too much of a risk... [...] A famous doctor that does surgery in Thailand said anybody over sixty, I don't touch. (Martha)

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Social Sciences and Humanities Research Council of Canada

Conseil de recherches en sciences humaines du Canada





Caring for a trans or non-binary older adult with dementia*

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*For more information on this topic, please see: Silverman, M. & Baril, A. (2023). "We have to advocate so hard for ourselves and our people": Caring for a trans or non-binary older adult with dementia. *LGBTQ+ Family: An Interdisciplinary Journal*, 19, 3, 187-210: <https://www.tandfonline.com/doi/full/10.1080/27703371.2023.2169215>

Research Question

What are the experiences of trans and non-binary older adults with dementia and their support networks?

Definitions

- **Carer** : Someone who provides regular support to a friend, acquaintance, or family member (whether biological or chosen family) without being paid.
- **Dementia** : Encompasses all types of memory-related cognitive disabilities such as mild cognitive impairment, Alzheimer's disease, vascular dementia, and Lewy Body dementia.
- **Trans and non-binary identities/people** : Encompasses a large variety of gender identities and expression, including transgender, transsexual, non-binary, agender, gender non-conforming or genderqueer people, or anyone who does not identify with their sex/gender assigned at birth.

Background

- No previous empirical studies in English or French have examined the lived experiences of trans or non-binary people with dementia, nor their carers.
- Trans and non-binary older adults have a higher risk of discrimination than their 2SLGBTQIA+ counterparts, especially when it comes to long-term care (Knauer, 2016; Porter et al., 2016).
- Like 2SLGBTQIA+ older adults, trans or non-binary older adults are reticent to access formal health and social services due to real and/or anticipated fears of discrimination (Adan et al., 2021; Benbow et al., 2021; Ducheny et al., 2019; Willis et al., 2020).
- When it comes to bodily care, trans and non-binary older adults cannot go back in the closet; their gender expression, their pronouns, or their bodies speak for themselves, either with scars from surgeries, or with body parts that are seen as 'non-normative' from a cisnormative perspective.
- Trans and non-binary older adults often have few care choices, as well as fewer informal carers to whom they can turn for support (Boyd, 2019; Pang et al., 2019; Toze et al., 2021).

Methodology

- One-year Canada-wide recruitment in both English and French (August 2021 - August 2022).
- N = 1625 organizations (aging/dementia organizations + 2SLGBTQIA+ organizations).
- Sample: 2 trans participants with dementia and 4 carers of a trans or non-binary person with dementia.
- Zoom-based narrative interviews; thematic data analysis.

Findings - The unique aspects of caring for a trans or non-binary person with dementia

Becoming a carer due to marginalized status

- Three of the four carers were themselves trans or non-binary, and found themselves in caregiving roles *because of their own non-binarity or transness*.
- Carers were offering support not only because of relational ties (chosen family), nor because of certain essential qualities (such as having care experience), nor because of geographic proximity (such as living in the same location), but because of their own marginalized status.

Engaging in care tasks linked to gender identity or expression

- We identified four main areas in which carers assisted the person with dementia in the maintenance of their gender identity and the performance of their gender expression:
 - 1) Sustaining the gendered self, such as shaving, haircuts, and clothing.
 - 2) Providing gendered body care, such as help with hormones, incontinence, and bathing.
 - 3) Advocating for the trans or non-binary person with dementia, such as helping advocate for gender-affirming surgeries.
 - 4) Decision-making and future planning regarding gender identity or expression.

Confronting discrimination

- Carers faced discrimination by association, and also had to support the person with dementia in confronting multiple forms discrimination, such as excessive gatekeeping for surgeries, misgendering, professionals not taking them seriously, and cisgenderist violence in long-term care.
- These experiences of violence and discrimination confirm many trans and non-binary people's worst fears when it comes to being dependent on others for care, especially intimate care (Bishop & Westwood, 2019; Boyd, 2019; Steadman, 2019; Witten, 2017). These realities of discrimination limited the care options to which carers could turn for additional help and support.

Carer Participants

Name/pseudonym and pronouns	Jesse (they/them)	Nancy (she/her)	Lou (they/them)	Dan (he/him)
Age	34	74	42	Early 30s
Self-identified gender	Transmasculine /non-binary	Cisgender woman	Non-binary	Transmasculine
Self-identified sexual orientation	Queer	Heterosexual	Queer	Queer
Self-identified as racialized or visible minority	No	No	Yes	No
Geographic location	Rural Canada	Urban Canada	Urban Canada	Rural Canada
Caring for	Chosen family member (David), trans masculine, late 40s, early dementia due to traumatic brain injuries	Partner (Victor), trans masculine, 75 years-old, late-stage Lewy-Body dementia	Parent (Jo), non-binary, 83 years-old, early-stage dementia	Three trans people (Denise, Ben, David), various types of dementia

I suppose, you know, it was the community connections, really at that grassroots level that brought me to where I am now. Did I think I'd be, you know, spending time caring for folks, especially older trans folks with dementia? No. Absolutely not. That was never something that I even anticipated. **But here we are.**
(Dan)

Acknowledgements

We thank the participants of this research project, as well as Carl-Vincent Boucher, Marie-Claire Gauthier, Maude Lévesque, Elgin Pecjak, Tommy Planchat, and Ré Poulin Ladouceur.

Funding details

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