

Health Equity in Aging for Transgender People

Ames Simmons

Our population is rapidly aging and increasingly identifying as transgender or non-binary (TNB). Are our health care and long-term care systems prepared to provide person-centered care to aging TNB people?

The population of the United States is rapidly aging, at the same time as more people understand themselves to be transgender or non-binary (TNB) [1]. Are our health care and long-term care systems prepared to welcome and provide person-centered care to TNB people as we age? This commentary seeks to provide information about who TNB people are and the health disparities we face, surface concerns about our systems and supports, and provide tools for filling in gaps.

Although transgender people are part of the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community, it is important to understand that transgender is not a sexual orientation and does not describe one person's attraction to another. Rather, transgender, non-binary, and cisgender are gender identities: a person's deeply held, internal sense of their gender. Cisgender people identify with the sex they were assigned at birth. Transgender people identify with a sex other than the one assigned at birth. Non-binary people reject the "gender binary," the social norm that divides reality between female and male. Because of the way the term LGBTQ has evolved to mean lesbian, gay, bisexual, transgender, and queer, it may seem confusing that a gender identity term (transgender) is included in an acronym that otherwise signifies sexual orientations (lesbian, gay, bisexual, and queer, or LGBQ). It is important to remember that people who are gender minorities, i.e., transgender or non-binary, may also be sexual minorities, i.e., lesbian, gay, bisexual, or queer (or they may be heterosexual).

The estimated portion of the population identifying as transgender is 0.6%, both nationally and in North Carolina [1]. There are about 44,750 transgender people in North Carolina [1]. If current trends continue and 20.5% of North Carolinians will be over 65 in 2035 [2], there will be about 9,174 transgender elders in North Carolina. Many of today's transgender elders either came out during times when stigma and discrimination meant hiding your transgender identity, or they have transitioned as elders and may be less certain about their aging needs. Gender transition is a complex process that can involve social changes such as new

terms of address and pronouns, medical changes such as hormone replacement therapy or surgical procedures, and legal changes such as name change and birth certificate updates. A transgender person may undergo some, all, or none of these changes, depending on how they understand their gender identity, other medical conditions they may have, and their access to the resources necessary to make the changes.

Research has shown that older transgender people may have even more health disparities than cisgender sexual minorities. Older transgender people have higher rates of depression, stress, disability, and poor health [3]. It is difficult to find an evidence base about TNB people generally, due to lack of inclusion of sexual orientation and gender identity on many surveys and instruments. It is even more difficult to locate an evidence base about dementia and transgender people. A study reported at the 2019 Alzheimer's Association International Conference found that over 14% of sexual and gender minority participants over age 55 reported subjective cognitive decline, compared to a rate of only 10% for cisgender heterosexual participants [4]. Because disaggregated data were not reported, it is difficult to estimate whether gender minority participants experienced cognitive decline at greater or lesser rates than cisgender sexual minorities in the study.

We also do not know much about transgender-specific gerontology. For example, the Minnesota Transgender Aging Project's 2017 research included a 67-year-old transgender woman's report that her health care provider seemed to be guessing as to what she might need, saying, "You probably won't be on estrogen very long because you're older and you probably won't need it after a while" [5]. For transgender men and non-binary people assigned female at birth, it would be useful to know if people who retain ovaries and uterus and take testosterone will experience menopause. In addition to questions about hormone replacement therapy, there are not readily available data about aging TNB people who have had gender-affirming surgeries. For example, a 61-year-old transgender woman reported that her surgeon's

Electronically published July 6, 2020.

Address correspondence to Ames Simmons, Equality North Carolina, 2321 Crabtree Blvd, Raleigh, NC 27604 (ames@equalitync.org).

NC Med J. 2020;81(4):257-258. ©2020 by the North Carolina Institute of Medicine and The Duke Endowment. All rights reserved. 0029-2559/2020/81410

nurse told her that *lifelong* dilation of her sex organs would be necessary in order to avoid urethral complications (personal email communication, December 20, 2019), when surgical protocols generally only call for dilation for a year post-procedure [6].

TNB people ourselves have real concerns about what may happen to us as we age. In reference to the health disparities mentioned above, fear of accessing services was a significant mediator across physical as well as mental health outcomes [3]. Twenty-nine percent of transgender North Carolina survey respondents reported having at least one negative experience when accessing health care, and almost that many (26%) reported not seeking health care due to fear of mistreatment [7].

TNB people may fear discrimination or even violence in long-term care, especially if they are experiencing cognitive decline. Indiana University and the Regenstrief Institute are investigating surrogate decision challenges for sexual and gender minority patients with Alzheimer's disease [8]. If the outcomes from this research are disaggregated by gender identity, we will have useful data about whether TNB people have more or different challenges with proxies making decisions about our medical care when we become unable to do so.

Advance directives such as health care power of attorney have not traditionally included legal language that would ensure that TNB people continue to receive hormone replacement therapy after they experience cognitive decline. There is also a health equity need for legal practitioners to draft language that will ensure that TNB people continue to be addressed using our affirmed name and pronouns if we lose capacity.

Additionally, there is a real need for TNB people to have tools to make decisions about where we want to age. Seeking to fill that gap, the Human Rights Campaign Foundation and Advocacy and Services for LGBT Elders (also known as SAGE) have created the Long-Term Care Equality Index (LEI) [9]. The LEI is a nationwide survey of residential long-term care facilities informed by experts in long-term care, aging, and the LGBTQ community. The LEI seeks to gather information about a facility's foundational practices, such as equal rights to visitation and policies of non-discrimination on the basis of sexual orientation and gender identity for both residents and employees. The LEI also looks at resident and community engagement, employee policies, and resident services and support.

For TNB people, an important component of the LEI examines gender-affirming resident services and supports, such as policies related to room assignment, terms of address, non-gendered activities, and access to clothing, hair, and grooming products and affirming medical and behavioral

health care. Facilities can now sign a Commitment to Caring Pledge to adopt these policies, and a self-assessment will be fielded soon.

With the addition of increased evidence, creative legal planning, and tools to assess the extent of affirming policies in long-term care, TNB people will be closer to resting confident that we will be able to access the health care we need as we age, and that our identities will be accepted and affirmed. **NCMJ**

Ames Simmons, JD policy director, Equality North Carolina, Raleigh, North Carolina; senior lecturing fellow, Duke University School of Law, Durham, North Carolina.

Acknowledgments

I identify as a queer, white, transgender man. I write from the perspective of marginalized identities related to being queer, socialized as a female, less binary, and transgender. However, my privileged identities of being white and male limit my perspective in ways that I consistently seek to overcome.

Potential conflicts of interest. A.S. reports no relevant conflicts of interest.

References

1. Flores AR, Herman JL, Gates GJ, Brown TNT. How Many Adults Identify as Transgender in the United States? Los Angeles, CA: The Williams Institute; 2016. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Adults-US-Aug-2016.pdf>. Accessed April 14, 2020.
2. Tippet R. NC in Focus: Population Proportion 65 and Older, 2010-2035. Carolina Demography. <https://www.ncdemography.org/2015/05/14/nc-in-focus-population-proportion-65-and-older-2010-2035/>. Published May 14, 2015. Accessed April 14, 2020.
3. Fredriksen-Goldsen KI, Cook-Daniels L, Kim H, et al. Physical and mental health of transgender older adults: an at-risk and underserved population. *Gerontologist*. 2014;54(3):488-500. doi: 10.1093/geront/gnt021
4. Toce S. LGBTQ Elders Are More Likely to be Socially Isolated, Suffer from Dementia than Straight Peers. *RVAMag.com*. <https://rvamag.com/gay-rva/lgbtq-elders-are-more-likely-to-be-socially-isolated-suffer-from-dementia-than-straight-peers.html>. Published January 2, 2020. Accessed April 14, 2020.
5. Flunker D, Knochel KA. Minnesota Transgender Aging Project Community Report: Focus on Providers. Minneapolis, MN/Duluth, MN: Rainbow Health Initiative/ University of Minnesota Duluth Department of Social Work; 2017. https://www.justushealth.org/sites/default/files/inline-files/MTAP_2017_PDF_Full_Report.pdf. Accessed April 14, 2020.
6. Meltzer T. Vaginoplasty procedures, complications and aftercare. University of California, San Francisco website. <https://transcare.ucsf.edu/guidelines/vaginoplasty>. Published June 17, 2016. Accessed May 11, 2020.
7. National Center for Transgender Equality, Equality North Carolina. 2015 U.S. Transgender Survey: North Carolina State Report. Washington, DC/Raleigh, NC: National Center for Transgender Equality/Equality North Carolina; 2017. https://www.transequality.org/sites/default/files/docs/usts/USTS_NC_state_report.pdf. Accessed April 14, 2020.
8. Study to investigate surrogate decision challenges for LGBT patients with Alzheimer's [press release]. Indianapolis, IN: EurekAlert!; December 4, 2019. https://www.eurekaalert.org/pub_releases/2019-12/ri-sti120419.php. Accessed April 14, 2020.
9. The Long-Term Care Equality Index website. <https://www.thelei.org>. Accessed April 14, 2020.