

Liminal Lives in Uncertain Times: Health Management During the COVID-19 Pandemic Among Transgender and Non-Binary Older Adults

Gerontology & Geriatric Medicine
Volume 8: 1–8
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DOI: 10.1177/23337214221127753
journals.sagepub.com/home/ggm



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Abstract

Older adulthood is a crucial time in the health management journeys of transgender and non-binary (TNB) people. Understanding how the COVID-19 pandemic has impacted TNB older patients (65 years and over) offers critical guidance for successful health services reform and continued delivery systems change. Using qualitative data from 47 semi-structured individual interviews, I investigate how TNB older Americans—as a medically and socially vulnerable population in the United States—manage their health during the COVID-19 pandemic. Results indicated a need for enhancing health services and resources for TNB older adults while creating a culture of age-friendly and gender-affirming healthcare. Four primary themes emerged: (1) exacerbated mental health challenges, (2) disrupted social relationships and support, (3) adopting cost-effective health management strategies, and (4) incorporating family care partners in health management. Such themes were shaped by respondents' privileged and marginalized social locations, such as access to financial security, social support, and adequate medical care. Although these research findings should not be generalized to the TNB older adult population, they suggest that broader patterns of inequity affect how TNB older Americans manage their health during the COVID-19 pandemic.

Keywords

aging, caregiving and management, gender/sexuality, health equity, qualitative research

Manuscript received: May 19, 2022; **final revision received:** July 26, 2022; **accepted:** August 24, 2022.

Introduction

An estimate of nearly one million transgender adults 50+ reside in the United States (US) (Flores et al., 2016; Hillman, 2022). The Coronavirus Disease 2019 (COVID-19) pandemic poses unique challenges in health management among transgender and non-binary (TNB) older Americans, as a medically and socially vulnerable population in US society (Nowakowski et al., 2020). As many healthcare systems continue to struggle with providing culturally-competent TNB healthcare (Lampe, Carter, & Sumerau, 2019; Shuster, 2021; Taliaferro et al., 2019), researchers have demonstrated how COVID-19 has exacerbated existing health and healthcare inequities among TNB Americans (Candrian et al., 2020; van der Miesen et al., 2020) such as delayed or denial of gender-affirming medical interventions (van der Miesen et al., 2020), mental health challenges during COVID-19 isolation (Candrian et al., 2020), and limited access to sufficient health resources (Banerjee & Rao, 2021). At the same time, older adult populations (65

years or over) show a heightened risk of COVID-19-related severe illness, hospitalization, and death compared to their younger counterparts (Centers for Disease Control and Prevention, 2022). While previous research has examined TNB health and healthcare disparities during the COVID-19 pandemic, less is known about how TNB people manage such conditions in older adulthood (Jarrett et al., 2021; van der Miesen et al., 2020). Current exceptions include an exploratory, qualitative study on older transgender adults' experiences during the COVID-19 pandemic in India ($n=10$) (Banerjee & Rao, 2021) and a clinical case study that addresses an older transgender patient's experience with COVID-19-related social isolation in the US (Candrian et al., 2020).

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Many TNB older Americans face challenging social conditions when managing their health (Nowakowski et al., 2019), such as chronicity (Dragon et al., 2017; Nowakowski et al., 2019), systemic and interpersonal violence (Hillman, 2022; Snorton, 2017), and lack of social support (Torres & Lacy, 2021). TNB older adults experience greater challenges in managing their health due to intersectional oppression in the forms of racism, classism, heterosexism, and cissexism (Crenshaw, 1989; Fredriksen-Goldsen, Jen, & Muraco, 2019). TNB people often face mental health challenges over the life course due to structural stigma, discrimination, and violence against TNB communities (Buchanan & Ikuku, 2022; Crenshaw, 1989; Hillman, 2022). TNB populations, much like other members of lesbian, gay, bisexual, transgender, queer, intersex, and/or asexual (LGBTQIA+) communities, are at risk for experiencing high rates of depression, anxiety, violence, and multiple health risk behaviors such as suicide ideation and attempt, substance and alcohol use, and eating disorders (Fredriksen-Goldsen et al., 2014; Rice et al., 2021; Su et al., 2016). Consequently, TNB adults continue to experience health inequities in older adulthood (Fredriksen-Goldsen et al., 2014). Overall, TNB older adults constitute a medically-vulnerable population with substantial health and healthcare disparities (Hash & Rogers, 2017; Nowakowski, Sumerau, & Lampe, 2020).

At the same time, these social conditions make it difficult for TNB older Americans to receive adequate social support and resources in managing their health (Torres & Lacy, 2021). Researchers have demonstrated the social and health challenges LGBTQIA+ caregivers face when caring for a loved one (Nowakowski et al., 2019; Pfeffer, 2017). Most importantly, many TNB older adults do not have access to informal and formal caregiver support systems in US society (Anderson & Flatt, 2018). Few studies directly examine the health management needs of TNB older populations (Fredriksen-Goldsen, Kim, et al., 2019; Fredriksen-Goldsen, Jen, & Muraco, 2019), especially during the COVID-19 pandemic (see Banerjee & Rao, 2021 for exception). Most medical knowledge and practices follow Western sex and gender binary systems (e.g., female/male and women/men) in healthcare delivery while erasing patients with sex and gender variations (Liang et al., 2017). TNB older Americans often experience challenges in accessing LGBTQIA+ affirming and age-friendly healthcare (Nowakowski et al., 2019), such as long-term care challenges for older transgender people living with HIV (Ing et al., 2018). Older TNB adults face multiple social and health inequities in society (Ing et al., 2018; Nowakowski et al., 2019). However, prior literature shows few clear patterns in how TNB people protect their health in older adulthood.

In this study, I investigate how TNB older adults manage their health during the ongoing COVID-19 pandemic. Utilizing qualitative data from 47 semi-structured individual interviews with TNB older Americans,

I show how TNB older adults respond to COVID-19 and make decisions about their health management. In so doing, I call for greater attention to the social conditions that aid in the reproduction of health and healthcare disparities among TNB older Americans during the COVID-19 pandemic.

Methods

Design and Procedures

Between September 2021 and January 2022, I conducted 47 semi-structured, individual interviews with TNB older Americans. Inclusion criteria for research participation were: (a) those who self-identified as transgender and/or non-binary, (b) participants were 65 years of age or over at the time of the interview, (c) lived in the US at the time of the interview, and (d) consented to be audio-recorded during the interview (see Table 1 for self-reported participant demographics). Participants were recruited through online social media and social networking services (i.e., Facebook and Twitter public posts from the author's accounts and gatekeepers then shared the posts with various groups with TNB older members), health and aged care facilities, LGBTQIA+-friendly faith communities, and LGBTQIA+ community leaders and organizations. Although snowball sampling strategies have been effective in recruiting and engaging LGBTQIA+ communities in aging research (Compton et al., 2018), most participants in my sample did not have personal relationships with other TNB adults 65+ for such strategies to be as effective in this research study. Qualitative methodology was vital for comprehensively examining TNB health management in older adulthood during the COVID-19 pandemic.

There are benefits and limitations to this participant recruitment strategy. First, my status as a young adult interviewer deterred some TNB older adults from establishing rapport during the interview process. Some interviewees did not view me as a peer (e.g., a respondent questioned whether I was "old enough" to interview them) and may have seen me as an outsider (Charmaz, 2014). Second, because TNB people of color face various forms of racial and ethnic discrimination (Buchanan & Ikuku, 2022; Kattari et al., 2015) and have been poorly mistreated by scientists and clinicians (Sumerau and Mathers, 2019) in US society, recruiting a diverse sample for the study was limited due to my positionality as a white, non-Hispanic/Latin interviewer who works at a research-intensive university in a community-focused medical school. Such recruitment challenges shaped the sample of this qualitative research study. My positionality as a TNB patient-scientist aided in obtaining narratives among TNB older adults, while developing new knowledge and insight into how respondents managed their health during the COVID-19 pandemic.

Table 1. Demographic Characteristics of Individual Interview Participants ($n = 47$).

Broad demographic category	Specific demographic identification	Number of participants	Percentage of participants
Gender identity	Transgender woman ^a	27	57.0
	Transsexual woman	1	2.0
	Transgender man	10	23.0
	Transgender	1	2.0
	Non-binary	8	16.0
	Non-binary	3	6.0
	Blended-gender	1	2.0
	Pangenderfluid	1	2.0
	Two-spirit	2	4.0
	Questioning	1	2.0
Age	65–69 ^a	32	68.0
	70–74	7	15.0
	75–79	7	15.0
	80–84	1	2.0
Sex	Intersex	13	28.0
	Endosex (not intersex) ^a	34	72.0
Sexuality	Lesbian ^a	16	34.0
	Bisexual	10	21.0
	Heterosexual	6	13.0
	Asexual	4	9.0
	Gay	4	9.0
	Pansexual	3	6.0
	Queer	3	6.0
	Flux	1	2.0
	Race, Hispanic/Latin ethnicity	Black, Non-Hispanic/Latin	6
White, Hispanic/Latin		3	6.0
Multiracial, Indigenous, Non-Hispanic/Latin		1	2.0
Multiracial, Hispanic/Latin		1	2.0
Multiracial, Non-Hispanic/Latin		2	4.0
White, Non-Hispanic/Latin ^a		34	73.0
Social class ^b	Low income	8	17.0
	Working class	7	15.0
	Middle class ^a	29	62.0
	Upper class	1	2.0
	Opted not to answer	2	4.0

^aModal category for each self-reported, demographic category.

^bSocial class is defined as social divisions in society based on socioeconomic status (Howarth, 2007).

This research study was approved by the University of South Carolina Institutional Review Board (IRB). I pretested the interview guide with two transgender older adults to ensure that interview questions are insightful, gender-affirming, and culturally appropriate. Data were collected between September 2021 and January 2022 via semi-structured, individual interviews which lasted 98 minutes on average (range: 30–346 minutes). I approached respondents with questions concerning their (i) healthcare experiences, (ii) attitudes toward advance care planning, and (iii) health needs and management throughout each interview.

Respondents received a \$40 prepaid Mastercard debit card after the completion of each interview. This amount is reasonable given the time for full participation and facilitated participant recruitment among a vulnerable aging population. The University of South Carolina IRB

required all research participants to be monetarily compensated using prepaid Mastercard debit cards due to ethical concerns. Interviews were audio-recorded and transcribed verbatim by NVivo transcription software. After completion of each interview transcription, I quality checked each interview transcript to ensure accuracy, making corrections as needed. Respondents were given pseudonyms, and all identifying information was removed during the quality checking process to ensure research participant confidentiality. Memos were also written during data collection and analysis.

Analysis

Analyses focused on how TNB older adults navigate the COVID-19 pandemic and use calculated strategies to manage their health needs. Data were coded using

NVivo software (Release 1.6) and analyzed inductively through constructivist grounded theory analysis (Charmaz, 2014). From this output, a coding scheme consisting of sets of interrelated codes was developed from the qualitative data. Developing categories and themes were reviewed throughout both data collection and analysis to discern emergent patterns and connections. I engaged in initial or open coding, meaning that I read a subset of transcripts to develop a general sense of the data and generate an initial list of codes (e.g., medical care during COVID-19).

Subsequently, I engaged in focused or thematic coding, which involves the identification of coding overlaps and divergences, resulting in the combining and collapsing of open codes to form broader thematic codes/themes that are then placed in network relationships with one another (e.g., no medical care due to COVID-19). Finally, I engaged in axial coding, linking demographic attributes in the dataset (e.g., race) to specific codes and themes, providing information about particular associations and patterns among and between various groups of respondents. Utilizing the analytic memos, the recurring themes, and prior literature, I thematically analyzed these qualitative data while exploring emerging themes concerning my research question: How do TNB older Americans manage their health during the COVID-19 pandemic?

Results

Overall, TNB older adults from my research sample revealed how the COVID-19 pandemic was an unanticipated life course disturbance that impacted their health management needs and experiences. Four, primary themes emerged: (1) exacerbated mental health challenges, (2) disrupted social relationships and support, (3) adopting cost-effective health management strategies, and (4) incorporating family care partners in health management.

Theme 1: Exacerbated Mental Health Challenges

Respondents reported exacerbated mental health challenges while coping with social isolation during the COVID-19 pandemic—an unanticipated life course disturbance. Amari, a Black, non-Hispanic/Latin, middle-class, intersex, lesbian, transgender man explained why he underwent substantial mental health challenges during the early stages of COVID-19: “I think I was lonely because, at that point, my caregiver was not around. And my kids. . . they live far away, they don’t stay in my house. So, it was lonely. Just thinking I was alone. I could barely take care of myself at that point because of it. . . Yeah, it was hard.” Most respondents described how their exacerbated mental health challenges during the COVID-19 pandemic acted as major barriers to maintaining their overall health. As Amari illustrated, some respondents were very much aware of their mental

health challenges influencing how they managed their physical health during COVID-19 (e.g., more frequent smoking use or medication management challenges).

For respondents with underlying mental health conditions (e.g., clinical depression), experiencing social isolation during COVID-19 became a substantial barrier to managing their health management goals. Antonio, a white, Latino, low-income, intersex, gay, transgender man, described how he experienced immense changes in his health after his state’s stay-at-home order was implemented:

Yeah, the changes in my emotional health are different. I really lost a lot of weight. And the loss of other ways. Like the loss of self-motivation. I’m getting too loose with each and every day. Which is really interesting. Very much riding everything one day at a time. I’m beginning to lose interest in the things I used to do before. . . Each and every day there’s a change in my mentality and physicality.

Respondents like Antonio felt they were not able to protect their overall health, especially those from racial and ethnic minority backgrounds. Antonio’s feelings of loss further illustrate how COVID-19 influenced negative mental health effects among TNB older adults as a vulnerable aging population with limited peer support services and resources dedicated to them. The COVID-19 pandemic poses noteworthy challenges among TNB older Americans in mental health management.

Theme 2: Disrupted Social Relationships and Support

Most respondents described having disrupted social relationships and support during the COVID-19 pandemic, which influenced their health management goals and experiences. One-third of respondents reported losing contact with other LGBTQIA+ friends, acquaintances, and community leaders during COVID-19. When I asked about maintaining relationships during the COVID-19 pandemic, Mary, a white, non-Hispanic/Latin, middle-class, lesbian, transgender woman explained: “I used to be friends with a lady who was [is] trans, but I haven’t seen her for a couple. . . [brief pause] years because of the pandemic and we just lost touch. That wasn’t great for me. . . health-wise.” Mary’s narrative about her disrupted friendship highlights the importance of TNB older adults maintaining their social support networks to fulfill their mental health needs.

Some respondents expressed how they used such situations as a way to improve their health. Helen, a white, non-Hispanic/Latin, lower-middle-class, bisexual, transgender woman illustrated how she reevaluated her life after her spouse’s death and decided to move forward with the medical transitioning process:

What happened was my wife was sick for a long time, she had severe dementia and, you know, I was the primary

caregiver and she passed away last July. . . [W]eeks after she passed on, then, “OK, what do I do now?” . . . I had lots of time to be myself and thinking everything through because of COVID. . . And I did a deep introspective into myself and how I felt my entire life. . . [A]nd it just came to the conclusion that, hey, this [medically transitioning] is something you know, I got to look into. . .

After her spouse’s death, Helen sought out mental health support to begin the medical transitioning process while focusing on her emotional health during these life course transitions. Much like Helen’s experience, some respondents had family members who became estranged or passed away during the pandemic, which encouraged them to seek out gender-affirming medical interventions. Overall, respondents had mixed health management experiences when navigating disrupted social relationships and support during the COVID-19 pandemic.

Some respondents emphasized the difficulty of maintaining social relationships during the COVID-19 pandemic. Summer, a multiracial, non-Hispanic/Latin, low-income, heterosexual, transgender woman, emphasized how COVID-19 made her feel:

Oh, well I would say sad. . . I had a friend that will come over and have coffee every morning, but the pandemic hit. . . And there was no more of that going on, so I wasn’t having coffee with them in the morning. That part of my everyday joy was taken away from me. It took a toll on me. . . I was just sad and bored all the time.

Summer expressed the emotional vulnerability that many TNB older Americans felt during the COVID-19 pandemic. Some respondents were worried about the possibility of never physically being able to spend time with their loved ones due to worsening, pandemic conditions globally and nationally. Such conditions reproduce health and aging inequities among TNB older Americans.

Theme 3: Adopting Cost-Effective Health Management Strategies

Over half of respondents reported adopting cost-effective strategies (e.g., outdoor exercise activities) for managing their health during the COVID-19 pandemic. Many respondents also reported how their financial concerns and insecurity worsened during COVID-19 (e.g., early retirement, sudden unemployment) was the primary reason for this shift in health management priorities. Dominique, a Black, non-Hispanic/Latin, middle-class, intersex, bisexual, transgender adult, described how she moved in with family members the following week after the World Health Organization declared the COVID-19 outbreak a global pandemic. She explained the value of her family members participating in health management activities with her: “[W]e’ve been doing the exercises in the house the whole time with them [child and grandchild]. . . we’ve done [sic] some yoga, we’ve watched some movies, so it’s

like bonding time. And then my grandson is in school. So, I would help out with his homework once in a while.” Dominique explained how her family members’ involvement in her daily routines provided fruitful opportunities in managing her health. Dominique’s narrative emphasizes the importance of familial support in TNB health management during the COVID-19 pandemic.

One-third of respondents regularly engaged in outdoor exercise and recreation activities to mitigate negative health effects during the COVID-19 pandemic. Some respondents described how visiting and participating in park activities (e.g., swimming) during COVID-19 assisted them in physical health management. When asked about her physical health status, Yvette, a white, non-Hispanic/Latin, middle-class, lesbian, transgender woman, explained: “Well, for my age, I’m good to excellent. No lung heart issues or heart issues. I walk three and a half miles a day or more. I was backpacking in April in the [US national park] wilderness for six days, five nights, 40 miles. We tracked 40-pound packs.” Yvette described how she was able to complete a long-distance hiking trip. Much like Yvette, many respondents who regularly engaged in outdoor exercise and recreation activities felt that they better managed their physical health during the COVID-19 pandemic.

Over a third of respondents in my research sample also shared that financial insecurity imposed major barriers to managing their health during the COVID-19 pandemic. Some respondents were more concerned about addressing immediate needs (e.g., housing and food security) than engaging in cost-effective, health management approaches (e.g., outdoor exercise activities) during the pandemic. Kojo, a Black, non-Hispanic/Latin, middle-class, bisexual, transgender man, explained how his COVID-19 illness management challenges depleted his finances and almost resulted in his death.

Kojo: It has been tough. I was actually sick with it [COVID-19] for a couple of months in the beginning and almost died. It was quite awful.

NML: What do you think could have helped you with any kinds of resources or forms of support during the COVID-19 pandemic? . . .

Kojo: More money and more access to doctors. I lost a lot of money [while] trying to get better.

Kojo illuminated the social inequities among many respondents who experienced financial and medical challenges that functioned as substantial barriers to bettering their health management during the COVID-19 pandemic.

TNB older adults who do not have adequate social resources and support systems during COVID-19 are in a particularly vulnerable position to comprehensively manage their health, which may worsen existing inequities among TNB aging communities. Although adopting cost-effective strategies (e.g., using mindfulness and relaxation apps) was a common method for many respondents

aiming to better manage their health and quality of life during the COVID-19 pandemic, such approaches are structurally limited due to the absence of fully addressing TNB older adults' immediate health needs in US society (e.g., food and housing assistance programs).

Theme 4: Incorporating Family Care Partners in Health Management

Almost all respondents managed acute and/or chronic health conditions. Respondents with chronic health conditions shifted their health management strategies to have family care partners (also known as family caregivers) assist them with daily living tasks (e.g., medication management, cooking nutritious meals). Many respondents also reported their family care partners advocating on their behalf during medical appointments. Miguel, a white, Latino, middle-class, intersex, heterosexual, transgender man, recalled his children's recent involvement during Miguel's telehealth appointments: "[T]hey [Miguel's children] really give me a lot. . . My children sometimes now translate for me when I'm tired of doctors who don't understand me through the computer when I tell them my meds aren't working."

Several respondents expressed their appreciation for maintaining strong family care partnerships with their spouses/partners to better manage their health during the COVID-19 pandemic. Some respondents discussed the emotional value of both receiving *and* providing care with their family care partners. Linda, a white, non-Hispanic/Latin, middle-class, lesbian, transgender woman, and a retired medical provider described how she and her spouse, Diana, provided care to each other:

I got a Poison Ivy rash the other day. So, who do you think I showed it to first? Diana. "I mean, you know, what is this?" "What do you think this is?" "This looks like vesicles, you know, [it] itches, it burns." . . . [T]hen like she [Diana] gets injections of like vitamin D-10 occasionally for neurological kinds of things. And so, I give them so, you know, [we] pretty much share that. . . I think I have great support as far as that's concerned.

Much like Linda's narrative, most respondents felt that some health needs could be easily managed with the assistance of their family care partners during the pandemic.

Despite respondents' mostly positive experiences with incorporating family care partnerships into their health management practices, there remains structural barriers (i.e., macro-level and meso-level barriers that contribute to health disparities) among TNB older respondents without familial support in independently improving their health management during COVID-19. Voluntarily maintaining family care partnerships is a social privilege in US society that many TNB older adults simply do not have due to (a) earlier effects of public policies limiting access to marriage and family

formation and (b) existing structural stigma, discrimination, and violence against TNB aging communities. Those who do not have such privileges in quality social relationships, support, and resources continue to struggle in managing their health during the COVID-19 pandemic. Such instances of social inequity aid in the reproduction of TNB health and healthcare disparities.

Discussion

This research assesses how TNB older Americans manage their health during the COVID-19 pandemic. COVID-19 dynamically shaped TNB older adults' health management decisions, practices, and challenges. Currently, a limited empirical literature addresses individual and collaborative health management that pays particular attention to TNB older adults and how they further protect their health (Nowakowski & Sumerau, 2017). These research findings reveal substantial barriers (e.g., lack of financial security, access to medical care, and social support from family and friends) to achieving TNB older adults' health management goals. Understanding TNB people's health management in older adulthood as a dynamic process—*influenced by privileged and marginalized social locations and worsened pandemic conditions*—are critical steps toward reducing and eliminating health disparities among TNB older Americans.

My findings suggest that sociomedical scholarship could benefit from greater attention to the unique conditions, vulnerabilities, and challenges that TNB older adults experience in protecting their health and quality of life during the COVID-19 pandemic. To date, little is known about how structural conditions against TNB aging communities during COVID-19 (e.g., housing insecurity) reproduce patterns of social inequality and injustice. Future research should examine health management needs, behaviors, and experiences among TNB older patient populations and implement interventions that specifically target aged care services, outreach, and support training. This research will allow practitioners to implement findings in applied contexts that directly reduces systemic inequities among TNB people in older adulthood.

Conclusion

Pervasive social inequity harms TNB people's ability to maintain basic wellness in older adulthood. Respondents in this study illustrate experiences of inequity within the specific context of health management during the COVID-19 pandemic. I further extend sociomedical scholarship by articulating how TNB older Americans protect (e.g., incorporating family care partnerships) or struggle with (e.g., exacerbated mental health challenges) their health management during COVID-19. Research findings can guide direct improvement of health and peer-support

services for TNB older adults and identify additional opportunities for TNB communities to live and age well. I call for focused funding opportunities supporting patient-centered research with TNB older adults to investigate how TNB aging communities respond to the ongoing COVID-19 pandemic and how such strategies may shape existing health inequities among TNB older adult populations.

Acknowledgments

For their valuable expertise, feedback, and encouragement on this manuscript, I thank Dr. Carla A. Pfeffer, Dr. Alexandra “Xan” C. H. Nowakowski, Dr. Jaclyn S. Wong, Dr. Andrea K. Henderson, Dr. Emily S. Mann, Dr. Tara McKay, and Atticus M. Wolfe. Finally, thank you to all of the respondents who participated in this research study.

Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research benefited from the financial support of the Office of the Vice President for Research at the University of South Carolina. I was also supported by the National Institute on Aging of the National Institutes of Health under Award Number R01AG063771 during the final stages of the journal peer review process for this manuscript. The content of this manuscript is solely my responsibility and does not necessarily represent the official views of the National Institutes of Health or the University of South Carolina.

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