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# End-of-Life Care for Transgender Older Adults

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**Abstract**

As the number of transgender older adults increases, the need for respectful and inclusive end-of-life (EOL) care for this population is becoming more apparent. Aging transgender adults often face discrimination, inadequate access to care, and poor quality of care. In response, we organized a think tank that invited participation from 19 transgender older adults, scholars in EOL care, and palliative care providers in the United States to generate recommendations for EOL care for transgender older adults. Subsequently, we conducted a qualitative descriptive exploration of the written record of think tank discussions for the purpose of identifying key EOL care considerations for transgender older adults. We identified four themes that highlight the importance of understanding the experiences of transgender older adults for the advancement of future research, policy, and education initiatives aiming to ensure inclusive and equitable provision of EOL care by nurses and other clinicians for this population.

**Keywords**

transgender, aging, older adult, end of life, palliative, United States

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## Introduction

With a growing population of transgender persons in the United States (Nolan et al., 2019) and around the world (Goodman et al., 2019), healthcare systems are likely to see an increase in members of this population needing care as they age and at the end of life (EOL). However, healthcare systems have been ill-equipped to provide gender-affirming care, which consists of various social, psychological, medical, or surgical measures to support a person's gender identity, especially given disruptions in treatments and services caused by the COVID-19 pandemic (Boyle, 2022; Jarrett et al., 2021). Transgender older adults, identified as persons aged 50 years or older whose gender identities do not match their sex assigned at birth, often face policies and practices that limit their access to gender-affirming care within current healthcare systems (Bakko & Kattari, 2021; Cortes et al., 2019; Fredriksen-Goldsen et al., 2019; PFLAG, 2021).

Healthcare needs specific to transgender older adults include access to gender-affirming hormone treatments; involvement of chosen family members in healthcare decision-making; and protections against transphobia in healthcare settings (Catlett, 2022). Some healthcare needs of transgender older adults, such as social support, advocacy, and person-centered nursing care (World Health Organization, 2022), parallel the needs of cisgender older adults, persons over age 65 years whose gender identities match their sex assigned at birth (PFLAG, 2021; United Nations et al., 2019). For transgender older adults, the need for gender-affirming care intersects with the need for gerontological nursing care. For example, in EOL care settings in which an older transgender woman requires assistance performing personal care, interventions such as prioritizing daily facial shaving may not only demonstrate person-centered gerontological nursing care but may also support the transwoman's gender expression and show respect for her gender identity (Knochel & Flunker, 2021).

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However, existing healthcare services are often inadequate to meet these needs and are even discriminatory toward transgender persons (Stein et al., 2020). Twenty percent of gender nonconforming persons of any age, including transgender persons and others who do not follow gender stereotypes, report experiencing discrimination or harassment in healthcare settings, and people of color were more likely to report discrimination than their white counterparts (Kattari & Hasche, 2016). A systematic review of studies pertaining to transgender older adults identified discrimination in healthcare policies and practice as a key threat to wellbeing for this population (Finkenauer et al., 2012). Such discrimination imposes adverse health impacts on transgender older adults, including poor physical health, disability, depression, and perceived stress (Fredriksen-Goldsen et al., 2014). Each discrimination experience reportedly results in an 11% increase in the odds of depressive distress for transgender older adults (Hughto & Reisner, 2018).

The adverse impact of transphobic discrimination on transgender older adults renders their EOL care precarious around the globe. For example, adults in lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities in the United States (USA) have raised concerns about loss of decisional capacity at EOL and the experience of discrimination in healthcare settings (Lowers, 2017). Specifically, transgender older adults have expressed fears about gender discrimination, dementia, being alone, and not being able to care for self at EOL (Witten, 2015, 2016). Additionally, discriminatory beliefs, policies, and practices restrict access to EOL care for LGBT Zimbabweans (Hunt et al., 2019). In Australia, transgender adults engaged in EOL planning face difficulty breaking their social isolation, identifying alternative caregivers, enduring lack of knowledge from caregivers, and suffering others' inability to recognize elder transgender needs (Cartwright et al., 2012).

Addressing discrimination and improving care at EOL for transgender older adults require building a culture of inclusivity among healthcare providers; changing policies to support transgender rights; strengthening social and spiritual support; and emphasizing the assets of transgender elders (Catlett, 2022). To build competency and inclusivity in EOL care for transgender older adult patients, several studies propose educational trainings for healthcare providers, especially clinicians in hospice and palliative care, a discipline that focuses on enhancing quality of life for persons with serious or terminal illnesses (Adan et al., 2021; Bell & Johnson, 2020; Campbell & Catlett, 2019; Elder, 2016; Hughto & Reisner, 2018; Jones & Willis, 2016; Walker et al., 2017). In addition to educational initiatives, policy change has emerged in the literature from the USA and Canada as a strategy for mitigating discrimination, stigma, and elder abuse (Carroll, 2017; de Vries et al., 2019; Hoy-Ellis & Fredriksen-Goldsen, 2017; Hughto & Reisner, 2018; Knochel & Flunker, 2021; Lowers, 2017). Reducing the global health burden carried by aging transgender adults also involves research that produces population-based representative samples, longitudinal studies, and improved routine life-cycle surveillance of health status (Reisner et al., 2016). Importantly, recognition of the assets of transgender older adults, such as resilience, activism, and social connectedness, supports members of this community in shaping their own EOL experiences (Elder, 2016; Erosheva et al., 2016; Fabbre & Gaveras, 2020).

### *Purpose*

Recognizing both the challenges facing transgender older adults and their strengths and assets, organizers representing nursing, chaplaincy, social work, psychology, contemplative practice, and transgender advocacy convened a think tank involving transgender older adults, community stakeholders, and academicians to investigate the needs of transgender older adults at EOL and to suggest ways to meet those needs. Over the course of 2 days, think tank participants shared their ideas and experiences, yielding a record rich with contributions for the improvement of EOL care for transgender older adults. Through a qualitative descriptive exploration of that record, we sought to address the following question: How does a diverse group of think tank participants characterize the state of EOL care for transgender older adults in the USA and envision changes for the future? The primary purpose of this exploration was to identify key considerations for research, policy, and healthcare provider education related to EOL care for transgender older adults in the USA. We share resultant themes to inform best practices for nurses and other clinicians and to influence policy change.

## Methods

This manuscript presents themes resulting from a nurse-led, 2-day think tank entitled *Silent Illumination: Compassionate End-of-Life Care for Transgender Elders*. Senior author, Cathy Campbell, proposed the idea of a think tank in response to the lack of guidelines for gender-affirming EOL care, an approach to caring for a transgender or gender nonconforming person at EOL that respects their gender identity and facilitates their gender expression. A think tank, which we defined for participants as stakeholders providing advice and ideas to solve a problem, aims to guide and capture discussions around political and social change. We sought to challenge the "democratic deficit" that often characterizes think tanks (Shaw et al., 2015, p. 74) by featuring a diverse group of stakeholders and sources of knowledge in and outside of academia. This approach is consistent with reporting in the literature regarding the use of think tanks to inform sociopolitical action (Morais et al., 2022).

### *Theoretical Context*

The Emancipatory Nursing Praxis (ENP) model provided theoretical context for conceptualizing the role of this think

tank in addressing a social justice issue affecting transgender older adults. ENP arose from constructivist grounded theory methodology connected to symbolic interactionism and pragmatism, emphasizing both the value of meaning-making and practicability in social justice-oriented action (Walter, 2017). The think tank sits squarely within the ENP concept of "engaging," and within the sub-concept of "collective strategizing" in particular (Walter, 2017), as participants, some of them nurses, engaged in active dialogue toward addressing inequities in EOL care for transgender older adults. Further, the process of generating and sharing themes from this think tank aims to "achieve equity" and enhance "human flourishing" within the ENP concept of "transforming" current practices and policies to achieve more humane ends. Although exploration of the think tank record did not evolve from one particular theoretical framework, application of the ENP model was useful in situating the nurse-led think tank process in the larger context of nursing and social justice.

## *Collective Strategizing*

A six-member planning committee met biweekly for 6 months to design and organize the think tank, a 2-day event initiated and led by Cathy Campbell. Members of the planning committee represented key stakeholder groups (transgender adults, nursing [palliative and psychiatric], chaplaincy, social work, psychology, and contemplative practice), roles (four academic employees, one transgender health nonprofit leader, and one transgender elder and advocate), and racial/ethnic identities (four black and two white members). Representing a collaboration between the community and academia, the interprofessional planning committee coordinated think tank activities to address barriers to quality EOL care for transgender older adults and to explore strategies to mitigate those challenges using a participatory approach consistent with the ENP model.

The planning committee addressed power relationships inherent in academic and leadership positions by foregrounding the voices of transgender older adults and community advocates during the think tank through panel discussions, creative and mindful exercises, and group discussions featuring their knowledge and experience. Following the think tank, Cathy Campbell communicated with participants regarding plans to share findings from think tank discussions according to the guiding principle to disseminate output co-produced and agreed to by transgender elders, community, and academic partners. Collaborative dissemination of ideas from the think tank was an essential component of initial planning in line with the objective to communicate key policy, education, and research priorities to various audiences.

*Participant Nomination.* The planning committee formed a collaborative relationship with key stakeholders in the transgender community through mutual contacts. With guidance from stakeholders, the planning committee opted to use a purposeful snowballing strategy (Kristensen & Ravn, 2015) for inviting older adults, advocates, and academics with personal or professional perspectives on gender-affirming EOL care to join the think tank. Committee members and key stakeholders invited participants from their respective networks via phone, email, or word-of-mouth. Prospective participants were eligible to join the think tank if they identified as transgender adults or older adults; if they were currently providing medical, spiritual, psychosocial, and/or post mortem care for persons at EOL; or if they were currently pursuing research related to aging and/or EOL care. Prospective participants were ineligible if they were unable to join the think tank by video conference. The planning committee concluded the nomination period after a representative group of eligible participants had formed.

*Program Design.* The 2-day think tank took place in March 2021. Each day started with a general welcome, an overview of the day, and a brief contemplative exercise to facilitate focus, self-reflection, and grounding in acknowledgement of the sensitive nature of the discussion topics. The format was iterative, with group discussions focused on topics from panel discussions held earlier in the day. The planning committee based the duration of the event on time needed to address two aims: to name barriers and facilitators to EOL care and to articulate strategies for improving EOL care for transgender older adults. Committee members opted not to use data saturation as a method to determine the length and number of sessions; instead, they assessed the "information power" of each discussion in relation to the aims of the think tank, making an interpretative judgment based on knowledge of the literature and participant consensus that the richness and depth of meaning from 2 days of discussion satisfied the event's purpose (Braun & Clarke, 2021; Malterud et al., 2016).

The first day of the think tank involved a film viewing, followed by a panelist discussion, contemplative practice, and group work breakout sessions. The film, presenting one story of aging and EOL care for a transgender older adult, and the panel discussion led by transgender older adults served to open dialogue among participants about barriers and facilitators to compassionate EOL care during the breakout sessions. The second day involved art and poetry, contemplative practice, a panel discussion led by transgender advocates and healthcare practitioners, and one group work breakout session. A presentation of the life story and creative work of a transgender older adult at EOL preceded a reflective exercise inviting participants to consider self-representation and narrative through art and poetry. A presentation of oral histories featuring healthcare experiences of transgender adults highlighted the importance of narrative and community engagement in providing gender-affirming care at EOL. The panel discussion focused on exemplars in transgender healthcare policy and practice in preparation for the breakout

discussion of pathways to improve EOL care for transgender older adults.

Discussions occurred on the video-conferencing platform Zoom which facilitated the involvement of participants from several states in the USA, including Hawaii, California, Washington, New Mexico, Texas, and Virginia. Although we originally conceptualized the think tank as an in-person event, we opted for a virtual format due to the spread of COVID-19 in March of 2021. While the virtual format may have affected interpersonal dynamics as originally envisioned, it did have the advantage of enabling participation from people across the country in a safe and convenient space for engagement. Technology support was provided to participants as needed by a member of the planning committee.

Three notetakers from the planning committee, appointed for their experience facilitating small group discussions, recorded think tank discussions and composed these notes jointly into a document that we distributed to all think tank participants for review of accuracy and completeness. Although our documentation strategy did not capture interpersonal interactions, participants characterized the dialogue as collaborative, respectful, and open. This record formed the basis for our thematic exploration of participant insights shared during the think tank.

## Thematic Exploration

Three core assumptions guided thematic exploration: (1) categorical and thematic organization of participant contributions is possible; (2) presenting participant contributions in a thematic way will facilitate dissemination of key elements to communities of transgender older adults and to researchers, policymakers, and healthcare practitioners; and (3) themes based on the discussion record can inform future research, policy, and education.

We used a qualitative descriptive approach (Sandelowski, 2000) to explore the collective written record of the event. We used qualitative description as it preserves participant voices by staying close to the data, and it is "especially amenable to obtaining straight and largely unadorned answers to questions of special relevance to practitioners and policymakers" (Sandelowski, 2000, p. 337). Drawing from strategies for thematic analysis outlined by Braun and Clarke (2006), we uploaded the think tank record with participant edits into the qualitative analytic platform Dedoose for in vivo- and process-coding and organized the resultant codes categorically according to commonalities in topic or idea (Saldana, 2015). Using an inductive approach, we sought "patterned" meanings by sorting cutouts of codes and categories and synthesizing resultant clusters into a table of preliminary themes, subthemes, codes, and their definitions (Braun & Clarke, 2006, p. 82). Four planning committee members peer-reviewed the table, from which they endorsed 4 themes and 13 sub-themes. The review process concluded with input from two participants, who approved the final iteration of thematic development.

*Trustworthiness.* We promoted trustworthiness using methods articulated by Lincoln and Guba (1985). We kept a record of all think tank documentation and steps involved in identifying themes to reinforce dependability. Member checking and peer debriefing occurred throughout the process of creating a discussion record, our set of themes, and this manuscript to enhance credibility and confirmability. We engaged in three iterations of member checking to assess accuracy of discussion records and to maintain participant involvement in collaboration and co-construction of the narrative (Birt et al., 2016; Walter, 2017). First, each participant had the chance to review and amend the think tank record. Second, all participants received an invitation to join a video-conference meeting 6 months after the think tank to discuss progress following the original event. Third, we invited participants to review the proposed themes and sub-themes and to contribute to writing and editing this manuscript. Finally, participant diversity and representativeness support transferability of ideas generated during the think tank to other contexts in the USA and internationally.

*Reflexive Statement.* The authors of this manuscript represent various academic and community roles. Lauren Catlett is a white, nonbinary gerontological nurse and emerging researcher. Kimberly Acquaviva is a cisgender, queer-identified researcher affiliated with an academic institution. Lisa Campbell is a black, cisgender researcher in psychology affiliated with an academic institution. Dallas Ducar is a white, transgender, queer-identified, non-profit CEO and psychiatric-mental health nurse practitioner. Enoch H. Page is a transgender older adult, a freelance editor, and a retired professor of anthropology. Jude Patton is a transgender older adult and editor of two anthologies featuring stories by transgender elders. Cathy Campbell is a black, cisgender nurse researcher, hospice nurse, and chaplain and is affiliated with an academic institution. All authors approached this process with attention to personal preconceptions and biases regarding gender identity, healthcare, and end of life. Those of us in academia who identify as cisgender recognized our positions of privilege as well as our heightened responsibility to represent the ideas of think tank participants with respect and accuracy. Regular virtual meetings of the planning committee and electronic correspondence between authors ensured open dialogue about positionality, bias, and fairness for participants.

## Ethical Considerations

Prior to the think tank, a summary of all planned activities underwent a review by the director of the University of Virginia Institutional Review Board (IRB) which deemed

that think tank activities did not meet the criteria for full IRB review because the data gathered were not personal or private in nature. The IRB permitted dissemination of ideas generated by the think tank participants as long as they were not connected to any individual person. Accordingly, we use no identifying information in this manuscript. In consideration of ethical imperatives to preserve the anonymity and sense of safety of individual participants, we opted to record discussions via de-identified note-taking instead of video or audio recording. We notified participants of the role of assigned notetakers and the intention to disseminate ideas from the think tank throughout the event. We invited all participants to edit notes taken during the discussion to ensure that the record accurately represented ideas they collectively expressed. Moreover, all participation was voluntary, and participants were free to withdraw at any time. Participants received monetary compensation in recognition of their time and contributions.

## Findings

### *Participant Characteristics*

The think tank involved a diverse group of 19 people including six planning committee members, who served as facilitators. Participants included older adults self-identified as transgender, hospice, and palliative care professionals, representatives from LGTBQ-friendly faith communities, funeral home services personnel, advocates for safe housing, artists, and faculty from multiple mid-Atlantic universities. Seven participants and two planning committee members self-identified as transgender or gender nonconforming (five transgender men, three transgender women, and one nonbinary person). Just over one-third of participants and committee members identified as black, and just under two-thirds identified as white. Six think tank participants who identified as transgender were over 60 years old. Participants represented various fields, with four nurses serving as participants or planning committee members. Think tank attendees served various and overlapping roles as participants, speakers, and/or planning committee members. While all attendees were participants, some had additional speaking or leadership roles each day pertaining to activity facilitation or presentation of material supplementary to discussion.

### *Key Considerations for Gender-Affirming End-of-Life Care*

Thematic exploration of the think tank discussion record yielded four major themes with several subthemes. The four themes included (1) understanding the complexities of transgender end-of-life experiences; (2) addressing end-of-life healthcare and advance care planning needs; (3) engaging with and serving communities of transgender older adults; and (4) facilitating inclusion and fighting discrimination. The following sections detail each theme and subtheme. Table 1 provides a summary of all themes and their policy, research, and education implications.

*Understanding the Complexities of Transgender End-of-Life Experiences.* This theme provides insight into particular challenges for transgender persons at EOL, including the belief that a long life is not possible; conflicts around disclosure of gender identity in healthcare settings; and a common experience of pain and suffering. Subthemes included (1) doubting prospects of a long life; (2) preserving identity; (3) facing vulnerability; and (4) holding intersectional identities. Several think tank participants expanded on their personal beliefs or beliefs of others in the transgender community that they would not have a long life due to the burdens of discrimination, transphobia, and threats to their safety. Consequently, they did not consider planning for EOL. For those that had lived longer than they expected, the fear that they would be forced to compromise their need for identity preservation at EOL represented a major challenge. For example, dependency on healthcare institutions for care can jeopardize the ability of the transgender patient to "go stealth," or conceal transgender identity, and the right not to disclose transgender identity. Moreover, participants anxiously wondered if they would be able to express their gender identity in the same ways as they age. Would they feel compelled to surrender or compromise their gender identity as they approach EOL? Would they feel compelled to abandon their gender identity, either voluntarily, for fear of discrimination, or involuntarily, due to lack of recognition of their identity by care providers servicing their needs?

Participants clearly emphasized the vulnerabilities faced by transgender older adults with intersecting racial/ethnic, socioeconomic, and occupational identities such as transgender women of color and transgender veterans. Participants also observed how the intersection of aging and gender identity compounds the invisibility of transgender older adults within healthcare systems and society. Vulnerability due to societal transphobia has led to lifelong pain and fear for some participants: "The pain and fear of living life as a transgender individual (internally and externally) is a daily part of life, starting at a young age; there is a constant need of support due to the pain induced by society." This type of pain includes threats, discrimination, and misinformation against transgender people by society. In response to these vulnerabilities, participants underscored the need for community resources to support the affected populations.

*Addressing End-of-Life Healthcare and Advance Care Planning Needs.* This theme describes the methods by which nurses and physicians can meet EOL healthcare needs and EOL planning needs. Five subthemes are: (1) planning for end of life, (2) providing healthcare advocacy, (3) supporting mental health, (4) incorporating alternative nonpharmacological treatments and therapies, and (5) adapting care during the

**Table 1.** Think Tank Themes, Key Excerpts, and Healthcare Implications.

| Theme | Subtheme | Excerpt | Implications |
|---|---|---|---|
| Understanding complexities of transgender end-of-life experiences | Facing vulnerability | "The pain and fear of living life as a transgender individual (internally and externally) is a daily part of life, starting at a young age; there is a constant need of support due to the pain induced by society." | Highlights urgent need for supportive policies and programs for transgender persons over their lifespan |
| | Preserving identity | "Many transgender people "go stealth." At the end of life, suddenly the ability to be stealth is taken away from them." | Suggests need for gender-affirming EOL care provider education |
| | Doubting prospects of a long life | "A lot of trans people don't think they're going to live full lives. . .Young trans people often never imagined they could live long enough to grow old. The idea of planning for end of life is really daunting." | Provides context for initiating advance care planning research |
| | Holding intersectional identities | "We're not all the same. Transgender people aren't a monolith and have different identity intersections as compared to cisgender people." | Calls for attention to intersectionality in research about transgender older adults |
| Addressing end-of-life healthcare and advance care planning needs | Planning for end of life | "The [healthcare] documents/paperwork are not accessible. Elders can miss important deadlines and miss out on services that can help one live longer." | Supports policy and research aimed at accessibility of healthcare and advance care planning documents |
| | Providing healthcare advocacy | "Not all transgender people are activists or advocates; self-advocacy at the EOL will be challenging for them." | Calls for healthcare advocates for transgender older adults |
| | Managing mental health | "Mental health is probably the biggest barrier for transgender people when it comes to accessing housing, employments, etc." | Highlights need for mental health care policy protections |
| | Incorporating alternative treatments | "Transgender elders need [mind-] body work, not just medical care." | Suggests direction for research on alternative EOL treatments |
| | Adapting care during a pandemic | "The pandemic gives us all an opportunity to contemplate death and dying. We never could have imagined all the people we'd lose and so many of them had decades of life still left to live." | Situates EOL care for transgender older adults in the context of the COVID-19 pandemic |
| Engaging with and serving communities of transgender older adults | Connecting with services | "We need to provide a place for people to go die. . .especially homeless trans people. There needs to be a way that people living on the street can go somewhere to die." | Supports policy and programs to give transgender older adults access to gender-inclusive spaces at EOL |
| | Connecting with services | "More in-person social support groups need to start back up when it's safe. That's how people can meet peers. If the groups are properly facilitated, they can be very beneficial." | Suggests importance of social support group facilitator education |
| | Reaching out to the community | "[We]'d like to see a local small scale pilot project tested. . .a program that is inter-generational that provides services to trans people. Starting small and then scaling it up." | Proposes pilot research of intergenerational services for transgender older adults and youth |
| Facilitating inclusion and fighting discrimination | Confronting transphobia | "Transphobia can be internalized; we can find ourselves grateful to be treated with honor and respect when we have lived our lives with honor and respect and have earned respect." | Suggests need to address internalized and societal stigma through affirming mental health care and policy protections |
| | Confronting transphobia | "One way [forward] is to proactively work to interrupt and stop the abuse and hatred that is expressed in society about trans people." | Proposes advocacy and action from LGBTQ+ allies to preempt transphobic abuse |
| | Facilitating inclusion | "Negative rights remove barriers; but there need to be more positive rights (funding and opportunities). Funding needs to be specific to target trans education and health care." | Proposes research and policy funding for advancing healthcare for transgender older adults |

COVID-19 pandemic. In general, participants agreed that "there aren't enough resources for transgender elders and resources are vulnerable to changing conditions and can quickly collapse." In response, they offered suggestions captured in the five subthemes. For EOL planning, participants proposed formal advance care planning processes, especially the appointment of healthcare surrogate decision-makers; however, they noted that transgender social support networks may look different than those of their cisgender counterparts since the transphobia of the biological family may disqualify them from having a role. Pointing out that "not all transgender people are activists or advocates and self-advocacy at the EOL will be challenging for them," participants regarded non-familial healthcare advocates at EOL for transgender older adults as essential for navigating healthcare systems and legalities.

Since the stress of trying to survive and thrive living a transgender life is so challenging and can be dangerous, participants remarked, "Mental health is probably the biggest barrier for transgender people when it comes to accessing housing, employment, etc." This statement refers to the prevalence of anxiety and depression, among other mental health challenges, in the transgender population, and highlights the importance of attending to mental health at all life stages including EOL. Participants emphasized the need for improvements in mental health services for transgender persons to increase access to housing, healthcare, community resources, and other needs. Connected to this subtheme of supporting mental health is the subtheme of incorporating alternative nonpharmacological treatments and therapies into EOL care for transgender older adults. Suggested modalities included homeopathy, chiropractic work, yoga, meditation, narrative therapy, acceptance and commitment therapy, mindfulness, and counseling. Participants asserted, "Transgender elders need [mind-] body work, not just medical care."

The COVID-19 pandemic brought mortality to the forefront. "Even after the vaccine, people are still going to be dying from COVID-19. We need to anticipate an alternate future that requires attention to it." Participants considered the reality of mortality and the ways in which a pandemic elevates the importance of planning for EOL care. Attention to this life transition is necessary not only for transgender older adults, but for all people.

*Engaging With and Serving Communities of Transgender Older Adults.* Highlighting the need for community services for transgender older adults, this theme branches into two subthemes: (1) connecting with services and (2) reaching out to the community. Participants identified key areas of need with respect to community services: housing, faith communities, financial assistance, and opportunities to make social connections.

Participants named housing and homelessness as major issues for transgender folks generally, and finding appropriate places for transgender folks to live out their remaining days was a primary concern, as gender-inclusive EOL housing accommodations are scarce. Regarding long-term care services, which provide assistance to persons unable to perform basic activities of daily living, participants remarked, "Let's not forget that long-term care facilities aren't safe for cisgender people, let alone trans people. These issues require a population-scale solution that can only be achieved in a coalitional way." Recognizing that housing options for transgender elders at EOL are often not safe or inclusive, participants called for reforms to institutional policies and attention to affordability and equity in housing.

The need for financial assistance stems from the fact that financial concerns may deepen at EOL for some transgender folks: "Transgender persons have often had a reduced ability to pay into social security, retirement, savings, etc. Thus, [they are] more financially vulnerable as older adults." Participants voiced support for transgender-inclusive services to assist with financial planning and access to resources for quality EOL care.

Finding social support, either in a faith community or within a social network, was an important need for transgender older adults. Participants described feeling isolated before seeking social support within LGBTQ+ faith communities, emphasizing not only the asset of finding a faith community, but also the importance of in person social contact with other transgender folks and their allies. Furthermore, participants considered support groups helpful in coping with gender identity and EOL concerns. As participants agreed, "the more support that can be given to trans elders, the better."

Complementary to support services, community outreach involves the ways in which healthcare and social service providers can reach transgender folks as well as the ways in which transgender elders and youth can connect with one another. Participants posited that in order to reach transgender older adults, healthcare providers, and social services that may be accessible online through telemedicine and teledentistry programs must assess their patients' reading level and comfort level with technology. Otherwise, services designed without considering the digital divide that complicates computer access for people of low socioeconomic status, diverse gender identities, or diverse racial and ethnic backgrounds likely will not reach transgender elders at EOL in a substantive way. Participants also supported the development of intergenerational programs that would link transgender youth with transgender elders to build understanding between them and to provide EOL services for elders and skills training for youth. Connecting communities of transgender older adults to services and social support was a top priority.

*Facilitating Inclusion and Fighting Discrimination.* This theme circumscribes the problem of discrimination against transgender persons and the need for solutions through policy and education efforts for healthcare providers and the general

population. Within this theme are two subthemes: (1) confronting transphobia and (2) facilitating inclusion. Participants experienced transphobia not only from heterosexual cisgender persons but also from members of the LGBTQ+ community, even including some transgender persons. Participants pointed out that "transphobia can be internalized; we can find ourselves grateful to be treated with honor and respect when we have lived our lives with honor and respect and have earned respect." Indeed, building that respect is what participants marked as essential for the development of inclusivity in healthcare environments and in society. To improve gender-affirming care at EOL, participants suggested changes in policy and education, including housing legislation and protections, transgender-inclusive long-term care policies, maintenance of certification requirements for physicians and nurses, and trainings for physicians, nurses, faith leaders, and funeral directors. In addition, they advocated for financial support for causes that benefit transgender persons at EOL: "Negative rights remove barriers; but there need to be more positive rights (funding and opportunities). Funding needs to be specific to target trans education and health care." Finally, participants added that greater acceptance of gender nonconforming persons would help build inclusivity in EOL care.

## Discussion

In alignment with our purpose, the four themes identified from the think tank record have direct implications for policy, education, and research related to EOL care for transgender adults. Policy considerations included fair housing, accessibility of medical documents, and funding for programs and services benefiting transgender older adults. Participants called for healthcare provider education addressing gender-affirming EOL care, mental health care, and advocacy for transgender persons at EOL. Participant contributions supported research focusing on, among other topics, EOL planning, intersectionality, and intergenerational connections between transgender youth and older adults. Figure 1 illustrates the correspondence of themes and subthemes to personal, interpersonal, community, and societal factors composing the Sexual & Gender Minority Health Disparities Research Framework (National Institute on Minority Health and Health Disparities, 2017). Mapping themes onto this social ecological framework reinforces the need expressed by participants for research, policy, and education "across all areas that touch trans elders at end of life."

### *Ties to International Evidence*

Themes derived from think tank discussions intersect with the growing body of literature on hospice and palliative care for LGBTQ+ persons across the globe. In terms of EOL preparedness, members of the transgender community may be 50% to 70% less likely than their lesbian, gay, and bisexual peers to have legal documentation of their wishes or to have appointed a healthcare proxy (Kcomt & Gorey, 2017). Illustrated by remarks from think tank participants, the precarity of day-to-day living, including financial and housing insecurities and transphobic violence, often precludes EOL planning for transgender people (Pang et al., 2019). Yet think tank participants requested to "have people who are part of this meeting to share information with [them] about planning for end of life." Indeed, advance care planning (ACP) is an important need in the transgender community, especially for preservation of gender identity at EOL and in the post mortem period (Henry et al., 2020; Whitestone et al., 2020). Responding to the desire of think tank participants to engage in EOL planning and to make it available to their communities would help to address this gap. Moreover, appointing a healthcare advocate to aid in decision-making and navigating the healthcare system resonated with think tank participants and aligns well with themes identified in the literature (Lowers, 2017).

Although transgender older adults have reported higher rates of social support as compared to their lesbian, gay, and bisexual counterparts (Fredriksen-Goldsen et al., 2019), creating a robust social support system presents many challenges for transgender older adults, as think tank participants explained. Among those challenges are estrangement from biological family and not having adult children for both support and caregiving. Social support networks add value because they are associated with better quality of life, lower rates of depression, and reduced marginalization among transgender older adults, and they may improve age preparatory planning behaviors in this population (Fredriksen-Goldsen et al., 2017, 2019; Henry et al., 2020). In line with recommendations in the literature citing the potential benefits of intergenerational connections between transgender elders and youth (Adan et al., 2021; Hughto & Reisner, 2018), think tank participants proposed involving transgender youth as companions or caregivers to enhance social support for transgender older adults at EOL.

The timely discussion of the impact of the COVID-19 pandemic on EOL care needs of transgender persons raised several concerns. In the context of COVID-19, the "dual burden of age and gender" articulated by transgender older adults in India may lead to marginalization and financial strain (Banerjee & Rao, 2020). Furthermore, transgender people who normally seek to avoid institutions may be forced to interface with the healthcare system and may face inappropriate gender disclosure or discriminatory treatment. One recent study makes three recommendations to address the inequities that the pandemic unveils for LGBTQ+ persons in palliative care and at EOL: (1) use of inclusive language and questions in healthcare provider assessments; (2) patient appointment of a surrogate decision-maker and sharing EOL wishes; and (3) active, empathic listening by nurses and physicians while limiting inquiries only to those relevant to the patient's present illness (Rosa et al., 2020). These

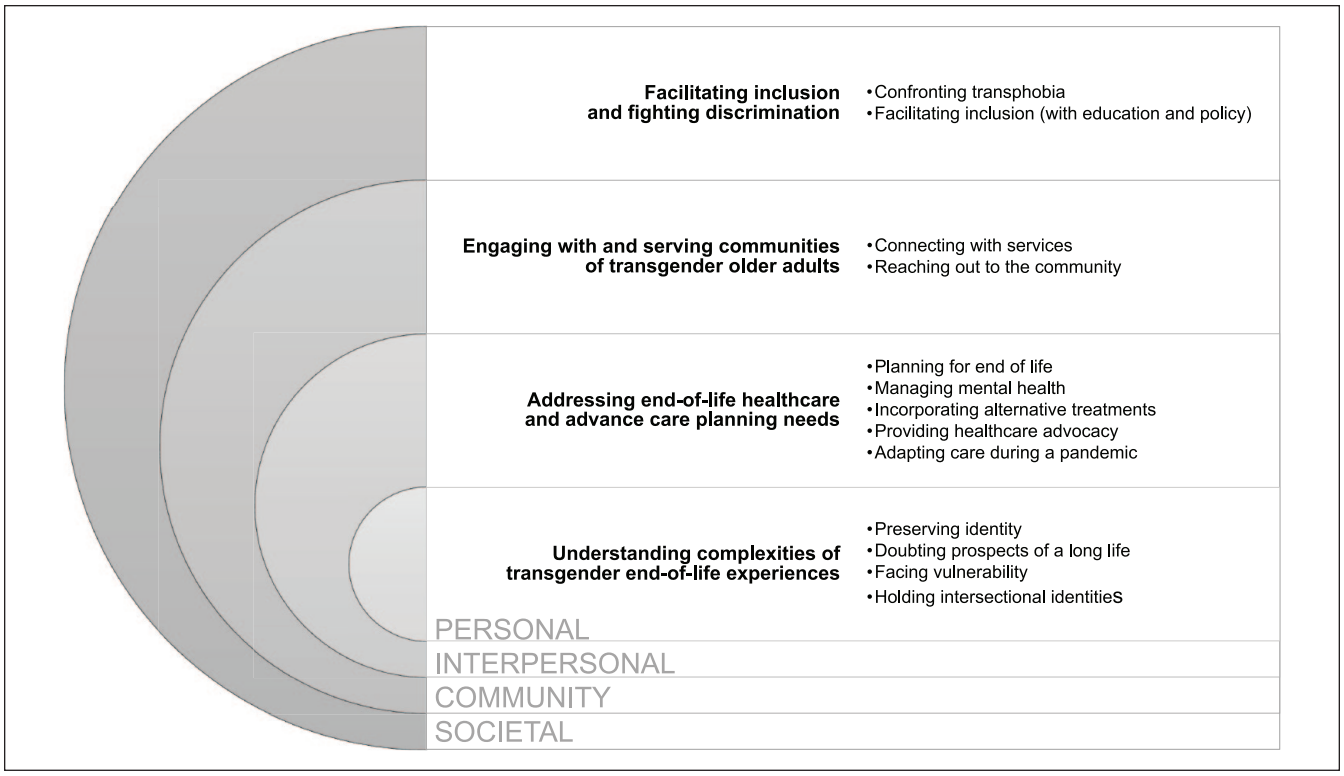


**Figure 1.** Social ecological model of think tank themes and subthemes.

recommendations may pertain to the care of transgender patients at EOL in and outside the context of COVID-19.

Understanding the complex experience of being transgender requires recognition of the intersectional sociocultural and political context. A gender-affirming model of EOL care embraces the intersectionality of gender identity, race/ethnicity, age, and the influences of multiple socioeconomic factors on the experience at EOL such as financial vulnerability, housing insecurity, and lack of advocacy. Valuing the intersections of these factors plays a vital role (Crenshaw, 1989) in addressing social determinants of health and in shaping compassionate care at EOL specifically. Think tank participants addressed intersectionality in EOL care for transgender people by emphasizing particular harms of discrimination against black transwomen, the need for sensitivity to age-appropriate communication strategies, and the effects of lower lifetime income on ability to afford housing and healthcare services. Practice and policy applications of these EOL care considerations must foreground intersectionality to address diverse and overlapping sociocultural factors in the lives of transgender older adults.

Though the work of the think tank was carried out in the USA, it has implications for transgender older adults internationally. Canadian transgender older adults have identified vulnerabilities to disaffirming care from healthcare providers, especially in hospital and long-term care settings (Pang et al., 2019). To address these vulnerabilities, think tank findings support outreach efforts to engage transgender older adults in advance care planning according to nation-specific policies in the USA and Canada. In addition, transgender persons in India may face, and internalize, societal stigma despite national pro-LGBTQ+ legislation (Banerjee & Rao, 2020). Findings from the think tank convey how internalized stigma also affects transgender persons in the USA, supporting policies and practices in both nations that integrate gender affirmation across various societal systems, including healthcare. Similarly, findings from a study of LGBTQ+ elders in South Africa underscore the need, also reflected in think tank findings, for facilitating inclusion in healthcare settings and policy, especially at the state or province level (Reygan & Henderson, 2019). Overall, think tank findings provide a set of principles for gender affirmation in EOL care that are consistent with recommendations for a global health framework promoting gender-affirming care for transgender persons in nations around the world (Reisner et al., 2016).

## *Implications for Education, Policy, and Research*

Themes from this think tank have important implications for nursing care of transgender older adults at EOL. First, they lay the foundation for development of nursing education initiatives on inclusive EOL care of transgender persons for pre-licensure students and clinicians in hospice, palliative, and long-term care. These initiatives would incorporate

action steps emphasized by think tank participants such as attending to mental health at EOL, facilitating advance care planning, and building awareness of healthcare needs and histories specific to transgender older adults. As patient advocates, nurses also have the ability to influence policy at the institutional level by serving in leadership roles to support or propose non-discrimination protections for transgender patients. Finally, hospice nurse case managers, social workers, and chaplains can act as liaisons to community resources for gender-inclusive housing, social support, and spiritual care. In these ways, nurses can actualize processes of emancipatory praxis to transform human flourishing and health equity as described in the ENP model (Walker et al., 2017).

For healthcare providers generally, understanding the complexities of the lived experience of being transgender is essential for the provision of high-quality, inclusive EOL care for transgender older adults. Transphobic interactions with healthcare providers may influence the willingness of transgender older adults to disclose their identity or even seek medical attention at all (Bristowe et al., 2018). In particular, some think tank participants bemoaned healthcare providers' lack of understanding that concealment of gender identity is an important practice for self-preservation and safety among transgender older adults. While research is mixed about the relationship between gender identity disclosure and adverse health effects, such as depression (Fredriksen-Goldsen et al., 2019; Hoy-Ellis & Fredriksen-Goldsen, 2017), gender identity concealment has the potential to mitigate harassment even though disclosure may afford feelings of freedom and self-confidence (Kattari & Hasche, 2016; Sloan & Benson, 2021). Thus, think tank participants encouraged physicians and nurses to respect transgender elders' personal decisions to reveal or conceal their gender identities such that they retain agency over their own safety and mental wellbeing. Respect for complex experiences and preferences regarding identity disclosure complements subjects like intimate care, support networks, and medication management, among others, for inclusion in healthcare provider education on EOL care for transgender older adults.

For institutional and governmental policymakers, contributions from think tank participants supported several recommendations. At the institutional level, participant contributions endorsed the adoption of nondiscrimination protections in healthcare settings such as hospitals and long-term care homes as well as education pertaining to gender-affirming EOL care for relevant staff members. At the national level, efforts to codify civil rights, such as fair housing and equitable healthcare, for transgender people align with actions recommended during the think tank. Such policies would serve to reduce discrimination in healthcare settings and improve healthcare quality and access for transgender older adults.

Think tank discussions illuminated several directions for future research. Participants raised the concern that transgender elders of color tend to be more vulnerable to abuses than are their white counterparts. Because the literature on transgender aging primarily centers the experiences of white transgender older adults, little is known about the nature or extent of the racist abuses that transgender older adults of color endure. Page (2022) highlights the way that racism propels black transgender people, and especially black transwomen, into often tragic competition with transphobic white and black cisgender persons. This and other lacunae in the LGBTQ+ literature point to an urgent need for more studies to address the intersectionality of race, ethnicity, and gender identity for the aging transgender population (Chen et al., 2020). Housing equity and access also do not appear extensively in the literature pertaining to transgender older adults, although, as think tank participants expressed, it is an area of urgent need for action and further study. Furthermore, complementary and alternative therapies and treatments at EOL for transgender older adults remain largely unexplored. According to think tank participants, these therapies have the potential to improve mental health, quality of life, and EOL experiences for transgender persons, so further research is warranted. Finally, research is needed on effective and affirming approaches to advance care planning for this population.

### *Limitations*

This endeavor had several limitations. We acknowledge that the think tank record consisted of meeting notes instead of verbatim transcripts of participant contributions, which may have sacrificed some of the content, including verbal exchanges. However, meeting notes cross-checked by three notetakers were meticulous, mitigating the potential for missing information, and since our primary purpose was to identify needs and key action items, we prioritized the record of ideas over representation of interpersonal interactions. A related limitation is the necessity to exclude some details in the process of qualitative description. We chose qualitative description in order to follow the discussion record closely and retain as much of the original content as possible in the presentation of themes. Furthermore, active involvement by participants and the planning committee at every stage of the process of identifying and presenting themes, from discussion record verification to manuscript production, made the process iterative and collaborative.

Additionally, the themes outlined herein are not necessarily exhaustive as not all possible subjects related to EOL care for transgender older adults arose from the discussion. Nevertheless, participants raised relevant points that constitute a robust representation of the subject matter of the think tank. Importantly, we acknowledge the limitation that the virtual format imposes on involvement from those with

less technology access or literacy. Participants raised this issue during discussion, reinforcing our objective to disseminate ideas from the think tank in various accessible formats. Moreover, we learned that, to maximize participant engagement, technology support facilitators are important parts of research efforts that employ this increasingly common mode of communication. Finally, global transferability is limited by localization of the think tank to the cultural context of the USA. However, in reviewing international literature on the topic of EOL care for transgender persons, we believe that key considerations reflected in the themes are transferable and adaptable for healthcare contexts outside of the USA.

## Conclusion

A comprehensive, 2-day think tank discussion generated valuable insights pertaining to EOL care for transgender older adults. Thematic exploration of the think tank record illuminated EOL care needs and assets of transgender older adults directly from the perspective of transgender older adults and their allies. Ideas from the think tank have clear implications for research, policy, and healthcare provider education that promote safe and inclusive EOL care for transgender older adults in the United States healthcare system and internationally. The process of sharing participant ideas from the think tank centered transgender older adults as guides for nursing intervention and collective action toward gender-affirming EOL care.

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Lauren Catlett: conceptualization (lead), collective strategizing (supporting), thematic exploration (lead), writing-original draft (lead), review (lead), and editing (lead); Kimberly Acquaviva: conceptualization (lead), collective strategizing (lead), thematic exploration (supporting), and review (supporting); Lisa Campbell: conceptualization (lead), thematic exploration (supporting), review (supporting), and editing (supporting); Dallas Ducar: conceptualization (lead), thematic exploration (supporting), review (supporting), and editing (supporting); Enoch H. Page: thematic exploration (supporting), review (lead), and editing (lead); Jude Patton: thematic exploration (supporting), review (supporting), and editing (supporting); Cathy Campbell: conceptualization (lead), collective strategizing (lead), thematic exploration (lead), writing-original draft (supporting), review (lead), and editing (lead)

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