ACTION BRIEF

MIND & LIFE INSTITUTE 35 years

End-of-life care for transgender elders: Priorities for clinical practice, research and health policy

ACKNOWLEDGEMENTS

We recognize the valuable contributions of all think tank participants to the success of the the think tank and the development of this white paper.

We acknowledge that we stand on the shoulders of giants, and wish to acknowledge the many other trans and gender-diverse elders who have contributed to this work and had to care for each other out of necessity for generations before.

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PROBLEM STATEMENT

There is a pressing need for better care for transgender older adults near and at the end of life (Campbell & Catlett, 2019). What "better care" looks like can best be described by transgender older adults.

BACKGROUND

Approximately 1.4 million Americans identify as transgender. Of the people who identify as transgender, approximately 967,000 are 25-64 years of age and 217,000 are over 65 years of age. Of those 65 years of age or older, 97% transitioned at 55 years of age or later (Flores, et al., 2016). The WHO estimates that 20 million adults across the globe need palliative and end-of-life (EOL) care, including a growing cohort of transgender older adults (World Health Organization, 2020).

Transgender older adults are vulnerable, not only because of their need for palliative care as they age, but also because they need to rely on people outside of their safe circles of support. Seeking palliative care often means needing to navigate a fragmented system of housing, medical care, social programs, financial resources, and legal advocates. In fact, some evidence points to discrimination by healthcare providers, in addition to entrenched transphobic societal stigma, as important concerns for gender diverse older adults seeking healthcare (Stevens & Abraham, 2019). At the same time, transgender older adults embody a number of protective factors, such as resilience, activism, spiritual practice and social support, that may inform future improvements in care delivery for this population (Javier, 2021; Paige, 2022). Little data exists on the intersectionality of gender identity, aging, and needs for care at end of life (Campbell & Catlett, 2019; Stein et al., 2020, Paige, 2022).

Campbell, C. Ducar, D. Acquaviva, K., Catlett, L. Page, E. Campbell, L.... & Williams, I. (2023) *End of life care for transgender elders: Priorities for clinical practice, research and health policy*. Think Tank on Compassionate End of Life Care for Transgender Elders.

THREE TAKEAWAYS

- **Transgender elders often face discrimination on the basis of age, gender, and race in various sociopolitical systems, including healthcare settings, leading to increased suffering and care inequities.**
- **Access to end-of-life care, and healthcare generally, may be limited for transgender elders due to discriminatory policies and providers, financial vulnerability, housing insecurity, and lack of resources and advocacy.**
- **Community-based intergenerational and interdisciplinary collaborations may help alleviate suffering and magnify the voices of transgender elders in shaping gender-affirming end-of-life care on their own terms.**

THE THINK TANK

The "Silent Illumination Think Tank" took place virtually on March 19 and 20, 2021. We had originally planned an in-person event but because were still in the first year of the COVID-19 pandemic we chose to have a virtual event. The think tank was a community-based discussion with key stakeholders who have an interest in compassionate end-of-life care for transgender identified older adults. Nineteen people participated in the think tank activities (9 participants, 4 people who were panelists only, and 6 planning committee members).

GUIDING PRINCIPLES FOR DISSEMINATION OF RESULTS

This report is an act of dissemination that aligns with key dissemination principles of the Transgender Elders Think Tank including:

Principle 1: Co-creation of dissemination strategy. The dissemination strategy for the knowledge stemming from the Transgender Elders Think Tank was co-created and agreed to by all transgender elders, community and academic partners involved in this effort. This strategy incorporates the additional principles below.

Principle 2: Dissemination mediums are inclusive of all forms of communication. Dissemination may take many forms and span oral, audio-visual, artistic, and written mediums. In considering all mediums of dissemination, accessibility by transgender communities will be prioritized.

Principle 3: Dissemination output is co-produced and agreed to by Think Tank partners. To ensure that dissemination output incorporates inclusive language, demonstrates respect for and represents the priorities of transgender communities, dissemination output in all mediums is discussed and agreed to by transgender elders, community, and academic partners.

Principle 4: Transgender elders' and community members' expertise and collaborative efforts are acknowledged and compensated. Efforts of academics are often valued above that of individuals and organizations producing knowledge outside of the academy. The Transgender Elder Think Tank recognizes and values the expertise of transgender elders and community partners and prioritizes compensating these partners for time and effort spent contributing to the dissemination process and outputs in all mediums (Singh, Richmond & Burnes, 2013).

Principle 5: Dissemination outlets are chosen to prioritize communication to transgender communities with attention to digital literacy and access. When choosing a dissemination outlet the Think Tank will give careful consideration to each outlet's history of prioritizing transgender audiences as well as current efforts and future plans to expand reach and access to transgender communities. Priorities around access include recognizing differences in digital literacy skills, availability of infrastructure and electronic devices that influence how elders and others access information.

Principle 6: Dissemination output in all mediums and settings centers transgender elders' voices. In written documents, conference and community presentations, media appearances, or works of performance, visual or spoken art, transgender elders' voices are centered and amplified. Think tank members will decline requests for appearances, interviews, etc., unless transgender elders or community members are present as equal partners in representing the Think Tank's work (Singh, Richmond & Burnes, 2013).

THINK TANK PLANNING PROCESS

A 6-member think tank planning committee (TTP) was assembled. Members of the planning committee represented different key stakeholder groups (transgender adults, nursing (palliative and psychiatric), chaplaincy, social work, psychology, and a contemplative practitioner. The TTP was created as an interprofessional planning group and as a collaboration between the community and academia. The TTP began to work together in the fall of 2020. Members of the planning committee were, in alphabetical order: Kimberly Acquaviva, Charley Burton, Cathy Campbell, Lisa Campbell, Dallas Ducar, and Benita Mayo. The first task was to decide on guiding principles for not only the work of the planning committee, but for principles that would guide every aspect of think tank and dissemination activities (presentations, publications, media engagement, etc.). The planning committee met twice a month from September 2020 to Feb 2021. The committee then met weekly in the last month before the event. One of the first questions addressed as a planning committee is "What is a think tank?"

The inquiry helped the TTP to be able to reach out to our diverse stakeholders. We were intentional that the exploration of this topic was an interprofessional experience as the Think Tank considered the question "How does a community provide compassionate end-of-life care to transgender elders?" At our planning sessions the following activities were completed: a list of key stakeholders was refined, an electronic invitation was created (see Appendix 1), a schedule for the video conference event with key terms (see Appendix 2) was developed, questions for our panelists and think tank discussion groups (see Appendix 3), the facilitation plan for the think tank panel discussion and discussion groups (see Appendix 4) and lastly, Think Tank Thank You Note (Appendix 5).

IDENTIFYING POTENTIAL THINK TANK PARTICIPANTS

A snowball method was used to recruit participants for the think tank. The planning committee members reached out to key stakeholders from our local five-county area (Albemarle, Green, Madison, Nelson and Orange Counties), the state of Virginia, and nationally. The TTP wanted to be sure that think tank participants reflected a diverse group of stakeholders and to affirm that end-of-life care requires an interprofessional and lay network for people, resources, and services. The TTP invited people who we knew were advocates for transgender or gender non-conforming people or older adults if they were willing to participate in the think tank and if they knew of other people in their networks who may be interested.

Having participants from the fields of endeavor of art, history, and narrative was also important to be able explore and express the lifeways of transgender elders through those ways of knowing. The invitations to the panelists were sent via email. Members of the TTP also worked through connected networks of people to reach out to everyone to confirm participation if there was not a response to email.

THINK TANK STRUCTURE & LOGISTICS

A 2-day event was held March 19th and 20th, 2021 using a video conferencing platform. As noted earlier, nineteen people participated in the think tank activities (9 participants, 4 people who were panelists only, and 6 planning committee members). Participants attended the panel discussions in the morning and the breakout discussion groups in the afternoon. Participants included transgender older adults, advocates for transgender veterans and safe housing, leaders from regional groups representing older adults, palliative care, social work, and spiritual care. The panelists presented on different topics and were available for questions from the participants. The panelists represented anthropology, the funeral industry, visual arts and narrative, the state legislature, and Veterans groups. Roshi Joan Halifax, the Abbot at Upaya Zen Center, and world-renowned expert on compassionate end-of-life care provided the keynote on Day 1.

A member of the planning committee was available at the start of each day to make sure that people were able to log-on to the meeting.

Each day started with a general welcome, an overview of the day, and was followed by a contemplative practice led by Benita Mayo. The first day involved a film viewing, followed by a panelist discussion, contemplative practices, group work/breakout sessions, and discussion. The second day involved art and poetry, more contemplative practice, an expert panel discussion, and additional group work/breakout sessions and reflections. The format was iterative, with the discussion focusing on topics from the panel discussions held earlier in the day.

The daily breakout sessions were generative in nature. Each breakout group had 8-10 participants per group. The TTP purposefully tried to ensure that the groups included individuals of multiple identities and was not divided by gender identity or whether someone identified as transgender or not. During these sessions the Planning Committee member served as a note taker/time keeper for each breakout group.

The first focus group, which met on the first day, specifically asked the following question: "What is the nature of suffering when it comes to end-of-life care for trans-identified elders?" The conversation was open-ended and thereby allowed the participants from multiple demographics to contribute their own perspectives based on their own lived experiences. Many of these discussions centered on the substantive and real-life challenges that transgender and gender-diverse elders encountered in their own communities. Many of these challenges included, but were not limited to, access to care and community services, services that are not available and the resources needed to provide compassionate care.

The second focus group, which met on the second day, began with a concrete question on what was needed: *"What will be needed to provide compassionate end-of-life care for trans-identified elders?"* Again, this conversation was also open-ended which allowed individuals who were from many walks of life to draw from their own personal and professional experiences. Moreover, the inclusion of trans and cisgender individuals in groups together led to conversations where some individuals learned about the needs of others from different identities. This dynamic was also seen across generations from trans-identified elders and those of younger generations.

The second group then followed-up with one additional question: "What would you like to see happen next after this event is over?" Again, these discussions were multidisciplinary and rooted in various perspectives and experiences. This question was intended to be centered on the end of the discussion to allow for a general movement from the nature of suffering to what is needed, practically, and then what we can do when the event ended. This general order allowed us to understand, from our breakout groups, how we could best identify the needs and act on these needs beyond the Think Tank itself.

COMPENSATION TO PARTICIPANTS

Navigating the university's policies to pay honorarium proved to be a challenge. Two major issues impacted our ability to pay honoraria to participants and to the TTP committee. Firstly, the university's policies and procedures were very complicated for lay participants to navigate.

Secondly, we were in year 1 of the COVID-19 pandemic, and many people at the University who process the payments were not working in the office. As a result, it was difficult to reach staff to get information about the process. Ultimately, we were successful in navigating the system and were able to send out gift cards and honoraria.

GUIDING QUESTIONS

- What are barriers to and facilitators of access to services and resources at end of life for transgender elders?
- What do we need to have in place to care for transgender elders?
- How do we put this plan in place in our community?

FINDINGS: DAY 1

GUIDING QUESTION

What is the nature of suffering when it comes to end-of-life care for transgender elders?

SUMMARY STATEMENT

Transgender elders face numerous challenges at end of life. Participants emphasized that transgender elders have a diverse set of lived experiences, which must be taken into account when addressing the aforementioned challenges. As noted earlier, at least one planning Committee member served as a note taker for each of the breakout groups on both days of the Think Tank.

We did not audiotape or videotape any of the sessions because we did not have permission to do so. The notes serve as a written recording (notes) of the breakout group discussions. The notes were the source for the recommendations that appear on pages 14-18.

The findings are organized as follows: Firstly, the broad themes/topics from the breakout sessions are named and defined. Secondly, the themes/topics are used as headers to organize the notes that are consistent with the themes identified. No statement or set of notes can be attributed to a specific person.

Our discussions from both days were interconnected and iterative, although for purposes of presentation in a document the themes are separated into day 1 and day 2 themes. The iteration presented itself in two ways. Firstly, the same theme/topic was discussed over multiple days. And secondly, participants chose similar words or phrases to communicate a topic/theme. For example, the theme "Facing Future Orientation" within the White Paper, at first glance it appears that the narrative is a duplication, however when the content is read again each is speaking on this theme/topic from different perspectives. To honor our commitment to amplify transgender voices we included the words of both participants.

Three opportunities were provided for the participants to reflect on the themes and provide feedback.

- Approximately one month after the Think Tank each participant received a copy of the themes to review (April 2021)

- Participants were invited to a 2.5 hour video-conference meeting facilitated by Dr. Cathy Campbell (August 8, 2021)
- Participants were sent the final draft of the white paper to review and provide feedback (July, 2022)

BROAD THEMES

- **Financial vulnerability**. Challenges with having financial resources to meet all needs.
- **Intersectional identities**. Influences of multiple factors on the experience at the end-of-life including gender, race, age, and socioeconomic status. The intersection of these multiple factors need to be explored together to understand their impact on the experience at the end of life (Crenshaw, 1989).
- **Lack of appropriate housing**. Inconsistent access to safe housing, including, but not limited to a place to receive medical and nursing care and other home-based services.
- **Access to mental and physical healthcare**. Difficulty in finding providers (primary access) and challenges with the quality of care when engaged with healthcare provider (secondary access) (Campbell & Warner, 2006)
- **Pervasive transphobia in society, LGBTQ+ and faith communities**. The transphobia could be found in interpersonal anti-transgender behaviors or within the structures and policies in an organization or particular context.
- **Difficulties associated with self-advocacy in healthcare settings.** Challenges and barriers to self-advocacy.
- **No future orientation**. Thoughts about a short life expectancy with no consideration for a life in the future.
- **Our bodies are different**. Exploration of gender identity is an embodied experience.

Financial vulnerability

Transgender persons have often had a reduced ability to pay into social security, retirement, savings, etc. Thus, they may be more financially vulnerable as older adults.

Homeless and housed transgender persons turn to sex work for survival; sex work doesn't provide healthcare or other services you need when you get older.

There aren't enough resources for transgender elders, and resources are vulnerable to changing conditions and can quickly collapse.

Intersectional identities

The poorer you are, the blacker you are, being a transwoman—all make you more vulnerable. There is a stratification of the trans community that leads to moving into and out of privilege. Intersectionality is very volatile for trans people.

Mental health and suffering: we need to have a deeper understanding of intersectionality, social determinants of health. We can't ignore the mental health impact.

We're not all the same. Transgender people aren't a monolith and have different identity intersections as compared to cisgender people. It can be hard for cisgender people to [understand] that.

My culture taught me to hold my elders in high esteem and respect their wisdom. It's disgraceful when 20-year-olds push us aside and basically say, "Old man, sit in the corner, we got this." This is why a lot of older Black transgender men REFUSE to be on panels. You're not going to listen to what I have to say anyway. It's disrespectful. Does my grey beard not mean anything? Now instead of listening to what I'm saying, young people are Googling what I'm talking about.

Lack of appropriate housing

We need to provide a place for people to go to die…especially homeless trans people. There needs to be a way that people living in the street can go somewhere to die.

Safe affordable housing for all trans people is a necessity. That is NOT available in the state of Virginia. There are only 3 shelters for transgender adults in the state. Homelessness in the in the trans community is an ongoing problem.

Access to mental and physical healthcare

Mental health is probably the biggest barrier for transgender people when it comes to accessing housing, employment, etc.

Non-binary identities are also important to this conversation; gender dysphoria is not necessarily inherent to transgender people; trans people flourish with support just like anyone else; gender dysphoria is a label that trans people have to take on to get services; anxiety and depression are the primary mental health challenges, not gender dysphoria.

For veterans it's a double-edged sword; there are increasing services for veterans in terms of supplying hormones, but they are also denying surgeries. This could be a good thing because the VA (Veterans Administration) bids out to the lowest bidder which may not have the experience. Full VA medical coverage can actually result in lower quality of care.

Pervasive transphobia in society, LGBTQ+ and faith communities

Even though there's been progress, there are still MANY LGBTQ+ people who are anti trans.

It's important to ask if an organization has a trans-inclusive non-discrimination statement. However, a church might say they are trans-inclusive but still preach scripture against transness.

The common theme among transgender persons is fear of being discovered, misused, abused, killed. That pain is common. How that is dealt with depends on the ability to run from it, not live through it but RUN from it. It is about pain that is lived.

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 the pain induced by society.

Difficulties associated with self-advocacy in healthcare settings

Not all transgender people are activists or advocates; self-advocacy at the end of life will be challenging for them.

Activism and advocacy involve risk. What's the emotional and mental health impact of carrying that burden?

Facing future orientation

A lot of trans people don't think they're going to live full lives. They don't imagine a future. I didn't think I'd live beyond 40. 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.

The transgender community is anachronistic. Transition is happening at different ages. Late transition leads to late puberty and lived experiences are out of sync with those of the same chronological age.

Our bodies are different

We have to be realistic about the fact that our bodies are different. We're always going to be different no matter how well we pass. Our understanding of ourselves may have occurred when we were very young, very old, or anywhere in between.

Non-binary identities are also important to this conversation; gender dysphoria is not necessarily inherent to transgender people; trans people flourish with support just like anyone else; gender dysphoria is a label that trans people have to take on to get services; anxiety and depression are the primary mental health challenges, not gender dysphoria.

FINDINGS: DAY 2

GUIDING QUESTION

What will be needed to provide compassionate end-of-life care for transgender elders?

SUMMARY STATEMENT

On Day 2 we turned our focus to the structures, policies and practices that would need to be in place to provide compassionate end-of-life care for transgender elders. We organized the notes from the breakout session on Day 2 into 10 major themes listed below, followed by verbatim quotes that represent each of them from Day 2 breakout groups.

BROAD THEMES

- **Legislation and policy**. Ways to protect individual liberties and ensure equity of services for transgender elders; this category also included support for increased funding for community-based organizations that benefit transgender elders and enforce legal protections.
- **Training for healthcare providers**. For example, training clergy members on inclusive language, on how to create accessible paperwork, and to pay attention to transgender civil rights.
- **Health & digital literacy**. Knowledge about how to access care and use of the internet as a resource.
- **Housing**. Need for gender-inclusive long-term care and in-home nursing care.
- **Resources pertaining to end-of-life care**. Instrumental and human resources that are needed to support end-of-life care. Resources include knowledge, skills, instrumental support, and navigators/advocates.
- **Barriers to access: Mental, emotional, and spiritual care**. Expanding access to social support, mental healthcare and spiritual care resources.
- **Alternative and complementary interventions**. Non-pharmacological methods to address pain and high levels of stress.
- **Respect for transgender persons**. Seeking actions to address pervasive transphobia.
- **Facing future orientation**. Seeing yourself as a future subject.
- **Intergenerational interaction**. Encouraging interaction between transgender elders and youths was a need that would present opportunities for both wisdom-sharing and caregiving.

Legislation and policy

We don't have any legislative protections for transgender elders. Existing legislation doesn't address eviction and other housing issues; we also need litigation and education.

Negative rights remove barriers; but there needs to be more positive rights (funding and opportunities). Funding needs to be specific to target trans education and healthcare.

It could be entered into the Virginia code that trans-inclusive training needs to be required for maintaining certification, licenses, etc. Once we add these requirements into the code, there needs to be monitoring for implementation.

Every community has an ombuds-person that could be the place to start. This could also be a place to start with trans training and education on the broader issues.

Training for healthcare providers

There are a LOT of trans clergy members in a wide variety of faiths. They are often asked to officiate. If we educate them, they could move that knowledge through their own faith communities.

A packaged training for clergy members and hospices would be helpful re: documents, wishes. There is a need to make those documents readily available in local organizations so people can get them.

There is a need to consider trainings across all areas that touch trans elders at end-of-life.

Educate your staff about respecting and using pronouns. Lots of different ways to demonstrate that respect - i.e. putting pronouns on doors.

It's a humbling experience realizing that identifying as an L, G, or B doesn't mean I understand the experience of transgender persons. Today has given me lots to think about in terms of how I can better serve transgender individuals at the end of life.

*Veterans don't always end up having access to the best surgeons for transition-related surgeons.There *are* VA centers with fantastic surgeons for surgical transition, but it's spotty.*

Health and digital literacy

We don't talk about literacy [and numeracy] enough. Older adults grew up in an era when no one talked about learning disabilities or special education. It didn't get enough attention which puts many elders at a disadvantage today.

When people say "go online," they don't understand that some transgender elders don't read or write. They don't get counted in surveys. If we want to be radically inclusive, we need to be inclusive of people who can't read. Transgender elders who don't want to be vaccinated shouldn't be forced to.

Housing

This is a good opportunity for the trans community to form a coalition: "Housing for the Dying." If someone gets a terminal diagnosis, we should be able to house them. It could be with tiny homes, any small place with utilities.

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.

Resources pertaining to end-of-life care

Trans elders need a lifeline that can help them understand and take care of paperwork, navigate and access services, etc. Lots of transgender elders don't understand documents (i.e. Medicare, welfare, etc.).

The documents/paperwork are not accessible. Elders can miss important deadlines and miss out on services that can help one live longer. Elders who are not comfortable with the internet/computers face barriers re: forms.

Barriers to access: Mental and emotional healthcare services and support

As we come out of the pandemic, 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.

All therapy is helpful to people but the problem is that it's individual. I'm talking about interventions that can be massified so that large numbers of people are experiencing the same thing at the same time.

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.

You don't have to be trans to think about death. Others find it hard to think about and wait until the last minute which can leave people hanging.

Participants concluded with a call to continue the work started during the Think Tank with recurrent meetings and action steps taken to address the needs outlined above.

Barriers to access: Spiritual care

I *used to be isolated and feel all alone. I'm an atheist but I made a conscious effort to go to an LGBTQ faith community to socialize and meet people outside of the online world.*

I would like to see meditation centers be more inclusive. I'm pretty sure I would have been ordained as Buddhist monk if I weren't trans.

This happens with faith communities, too. A church might say they are trans-inclusive but still preach scripture against transness.

When a spiritual teacher refuses to use your pronouns, it's exhausting and distressing. If you confront them, it's seen as impolite. In Buddhism, this makes no sense. If I'm not my body, why are you so concerned about it? If it's all an illusion, why is my transness your business?

Alternative and complementary interventions

Meditation changes the brain and forces you to connect with yourself. We never take the time to really get to know ourselves. Regular yoga practice is something we could engage in and benefit from.

Regular meditation and yoga practice are systemic modalities that can not only benefit the dying but those who are still with us as well.

Respect for transgender persons

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.

One way is to proactively work to interrupt and stop the abuse and hatred that is expressed in society about trans people. I don't mean censorship; I mean publicly stopping the act of hatred.

This young woman asked me if I'm gay and I say no, but I'm trans. She asked me what my boss thought of it. I went on and on about how grateful I was for how accepting they were. She said, "Why wouldn't they?" That really changed the way I think. We deserve to be accepted.

We can counteract negativity and hate with positivity and light. Shine light on positivity. A trans woman of color is on the cover of Sports Illustrated. It shows that there is love and compassion.

It's important to ask if an organization has a trans-inclusive non- discrimination statement.

Facing future orientation

The phenomenon of expecting to be dead at age 25 is one that needs to be interrogated. We can't just hope trans people come out of that.

The thought that I would be dead at 25 needs to be interrogated. We need to help people reconnect with life as something that they are entitled to. You have a right to live once you are embodied, no matter how you are embodied. It's important to have a future life, not just a present life. We have to recuperate those individuals.

"The belief we're going to die young isn't just about vulnerability to violence—it's about weariness. A lot of us would rather be dead than live the lives we were living. We have to help people recognize that life, once you're conscious, it's important for you to see yourself as a future subject not just as a present subject."

Intergenerational interaction

When a young trans person has only crafted a strong community online, it can be hard for them to envision older trans-people because they don't "see" them online. Where would they even go to get a sense of aging?

SUMMARY

This generation of transgender elders have not always been welcomed with compassionate, loving care by hospice and palliative care providers (Stein et al., 2020; Catlett & Campbell, 2019). We considered the two-day think tank as a community conversation guided by two broad questions: (1) What is the nature of suffering when it comes to end-of-life care for transgender elders? (2) What will be needed to provide compassionate end-of-life care for transgender elders? Traditionally, palliative end-of-life care has been practiced as an interprofessional model of care. This model has been a medico-centric one that conceptualizes palliative care as a constellation of symptoms to manage (i.e. symptom science). However, this model of care is not adequate to meet with EOLC needs for transgender elders (Rosa, et al., 2021). As an outcome of the two-day think tank we have recommendations in six areas: (1) intersectionality of EOLC, gender identity, race/ethnicity, (2) safe places to live and receive care, (3) training for hospice and palliative care staff, (4) gender-affirming spiritual care, and (5) gender-affirming mental health services and (6) advance care planning.

INTERSECTIONALITY OF EOLC, GENDER IDENTITY, RACE/ETHNICITY

Compassionate end-of-life care for transgender elders will require an expansion from the focus on end- of-life care as a medical issue to one in which the care is embedded in an intersectional sociocultural and political context. The experience of being transgender is complex, and therefore we intentionally gathered a group of stakeholders that could participate in this conversation.

We had transgender elders, representatives from advocacy groups for older adults, community activists, funeral home staff, housing advocates, nursing, psychology, palliative care/hospice, public policy, safe housing, spiritual care, and the state legislature. A gender-affirming model of EOLC embraces the intersectionality of end-of-life care, gender identity, race/ethnicity aging, and the influences of multiple socioeconomic factors on the experience at the end-of-life such as financial vulnerability, housing insecurity, and lack of advocacy. The intersection of these factors need to be explored together to understand their impact on care at the end of life (Crenshaw, 1989).

A quote from a participant in the think tank speaks to the challenges of transgender elders of color:

The poorer you are, the blacker you are, being a transwoman—all make you more vulnerable. There is a stratification of the trans community that leads to moving into and out of privilege. Intersectionality is very volatile for trans people.

For people considering the EOLC needs for transgender elders the most important factor that permeates every decision is gender identity. Being transgender or gender non-conforming impacts access to resources in all areas of their lives.

SAFE AND AFFORDABLE HOUSING

In end-of-life care we focus on medical and nursing care at a person's place of residence (private home, skilled nursing facility, assisted living facility). An issue for transgender older adults is the availability of a safe place to receive care, especially as their physical and cognitive abilities change.

The participants in our think tank talked about a pervasive transphobia that impacts access to resources in multiple arenas in their lives. Once a person reveals their gender identity, it is very possible that their access to safe housing may change. They could lose their place to live or they could face housing insecurity. An important concern was the lack of gender-affirming care within long-term care facilities.

We were very fortunate to have one of our state legislators participate as a panelist in the Think Tank on Day 2. Participants spoke about the need for legislative protections for transgender elders. Hospice and palliative care leaders can advocate with policy makers and for trans-inclusive policy and such as needs for safe affordable housing and places to provide care. The comments from one of our participants illuminates the important of safe affordable housing in the lives of transgender elders:

Safe affordable housing for all trans people is a necessity. That is NOT available in the state of Virginia. There are only 3 shelters for transgender adults in the state. Homelessness in the trans community is an ongoing problem.

A person who is in good health can navigate the complexities and realities of being housing insecure or homeless, but a person who may need medical, nursing or psychological care may not have the stamina that this lifestyle requires. Moreover, the intersectionality of gender identity, age, and physical vulnerabilities may make a particular housing situation unstainable or no longer feasible. For example, when a person is enrolled in a hospice program, as a person's death approaches they will need increasing levels of support. Most people will need a caregiver for direct care or care coordination.

Not all living situations are prepared to meet the practical needs of a person living with a life-limiting illness, such as consistent access to a bathroom multiple times a day, a place to rest out of the heat or cold, a safe place where can medications for symptom management can be stored and given, and access to electricity to run equipment (i.e oxygen concentrator).

TRAINING FOR HOSPICE AND PALLIATIVE CARE PROFESSIONALS

Hospice and palliative care professionals (HPC) need training to provide gender-affirming end of life and bereavement care (GA-EOLC). Training should be provided for all members of the healthcare team, including spiritual care providers. Gender-affirming care begins during the intake process. At intake HPC need to identify which questions are clinically relevant (vs. simply intrusive). We do understand there are standard questions in an intake process that are determined by the standards of care, licensure, accreditation, but questions that are not needed to develop a plan of care can be seen as intrusive and offensive to transgender elders and their circles of support. Needs of transgender or gender diverse older adults should also be integrated into spiritual assessments.

An important component of the training should include experiential experiences to explore the nature of the suffering experienced over the life course of transgender elders. A quote from a participant speaks to the suffering that is a part of the experience across the lifespan:

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 the pain induced by society.

Where possible transgender people across the lifespan should be engaged in the training as presenters and facilitators. And if transgender people are not available we should be prepared to have a conversation about what we did do to reach out to find transgender people to participate in the delivery of the content or as participants in trainings.

Misgendering is defined as "the act of referring to an individual using a word, especially a pronoun or form of address, which does not correctly reflect their gender" (PFLAG. Accessed at https://pflag.org/glossary/).
After a review of the first draft of this document a transgender participant in the think tank suggested that although in the literature best practices in gender-affirming care include asking a person about a "preferred pronoun", that we use the term "personal pronoun. Using the term "preferred pronoun" may imply that the transgender person's pronouns may be optional or considered less valid than another person's pronouns. And thus, another key component of training for HPC is the importance of asking the transgender person about a personal pronoun and gender identity during their time receiving care, while planning the funeral/memorial service, and during bereavement (for those in the circle of support and grieving transgender elders). An overview of a glossary of terms relating to gender identity, sexual orientation and transition (social, medical, surgical) should be provided to all team members providing care. The glossary should be updated on a regular basis to reflect change in language.

For the transgender elder who has made a medical or surgical transition (gender-affirming surgery) part of the plan of care should include a discussion with the hospice/palliative care medical or nursing team members with the physician or advance practice nurse managing gender-affirming hormones in the community on how they are to be integrated into the plan of care.

GENDER-AFFIRMING SPIRITUAL CARE

The planning committee intentionally included spiritual care as a topic in our panel discussions. Roshi Joan Halifax provided a keynote speech on Day 1 to help us open this path of exploration. The importance of gender-affirming spiritual care was a topic in the breakout discussion groups and Communities of spirituality and faith are often the source of great suffering for many transgender older adults. A quote from one of the participants illuminates the suffering within spiritual community:

When a spiritual teacher refuses to use your pronouns, it's exhausting and distressing. If you confront them, it's seen as impolite. In Buddhism, this makes no sense, If I'm not my body, why are you so concerned about it? If it's all an illusion, why is my transness your business?

However, the suffering that can come from within a faith community does not tell the whole story. Variances in spiritual expression and religious affiliation are part of the life course for transgender older adults. Transgender elders often have rich and diverse spiritual lives that occur through individual expressions of faith and connection with self, nature, or a self-defined faith community and the assessment of spiritual needs should be a component of the intake assessment.

GENDER-AFFIRMING MENTAL HEALTH SERVICES

The need for gender-affirming mental health services (GAC) was a topic in both discussion groups. Participants wanted to have these important services available to support well-being generally and not as a response to gender dysphoria. GAC should be scalable that is moving away from individual or small organizations providing services to better integration across the lifespan and life ways of transgender people.

Participants also thought it was important to destigmatize the need for mental healthcare for transgender adults. Mental healthcare is part of general well-being. A participant spoke of the stress carried by transgender people in an excerpt below:

The problem is the stress that we carry. The stress that trans people carry that non-trans people don't. The stress that Black people carry that white people don't, and so on. There are spiritual teachings/technologies: in Vipassana meditation, they have special activities to help people de-stress their bodies.

Psychosocial counseling is a component of hospice/palliative care programs. Counseling staff should include well-trained mental health providers. However, gender-affirming mental healthcare is not well integrated into palliative care. Only 20-25% of mental health trainees (MHT) are exposed to any course content of gender-affirming care in their course work or clinical training (Stryker et al., 2022). Mental Health providers with GAC expertise can be proactive in leading continuing education (CE) efforts within agencies, institutions or community-based settings.

Effective CE extends beyond "Safe Zone" training to include information distinct to transgender individuals. As new knowledge emerges, information is updated i.e. new terminology, changes in gender-affirming medical care. MHT in palliative care can provide critical guidance can be provide to family (chosen, biological or related by marriage) and hospice staff related to respectful communication, grieving related to a delayed transition, disenfranchised grief, and desire for post-death gender disclosures (Stryker et al., 2022).

ADVANCE CARE PLANNING

Participants spoke eloquently about the lack of a future orientation. One participant shared "I thought I would be dead at 25" Another participant expanded upon the conversation about lack of a future orientation to say:

The thought that I would be dead at 25 needs to be interrogated. We need to help people reconnect with life as something that they are entitled to...You have a right to live once you are embodied, no matter how you are embodied. It's important to have a future life, not just a present life.

Now that they are elders, advance care planning is important. In a medical model of EOL care, we spend a lot of time of getting advance care planning documentation into the medical record but what might be helpful to transgender adults is to not get so entrenched in the "perfect" advance care planning form, but focus on identifying a healthcare surrogate who can be their advocate as they negotiate the healthcare system. Ideally we would identify a primary surrogate and secondary person. Self-advocacy was identified as a challenge by participants

in the think tank. Other challenges include digital and health literacy, especially about services and resources (including hospice and palliative care).

We had a representative from a local funeral service provider talk about the importance of advance care planning for funeral or memorial services. If people do not have plans in place, including several important legal documents, blood relatives or people that the transgender elder are legally married to but no longer in relationship with can make decisions about the funeral service such as gender expression, using the pre-transition name (dead name), and choosing aspects of ceremony inconsistent with the person's wishes and gender expression (i.e. burial clothes not consistent with gender expression prior to death).

CONCLUSION

There is an urgent need for better care for transgender older adults near and at the end of life (Campbell & Catlett, 2019). We considered the two-day thinktank as a community conversation guided by two broad questions: (1) What is the nature of suffering when it comes to end-of-life care for transgender elders? (2) What will be needed to provide compassionate end-of-life care for transgender elders? As an outcome of the two-day think tank we have made recommendations in six areas: (1) intersectionality of EOLC, gender identity, race/ethnicity, (2) safe places to live and receive EOLC, (3) training for hospice and palliative care staff, (4) gender-affirming spiritual care, and (5) gender-affirming mental health services and (6) advance care planning. Our work has implications for policy, research, and clinical practice.

ACTION STEPS AND FUTURE DIRECTIONS

We would like to continue this work by building a community advisory board to guide the development of a program of research, services, education and advocacy for public policy to support the end-of-life care needs of transgender older adults. We have been informally calling this group our "Elders Council" The community advisory board will have members representing the key stakeholder groups that participated in the think tank (See Appendix 2 Program and Participant List). We want to make sure that this conversation is centered in the voices of transgender older adults. Issues and questions that are significant to the community will be our North Star. What "better care" looks like can best be imagined and created by transgender older adults (see p. 19-21 for an overview of presentations and publications).

As to implications for research, guided by the principles of participatory action research and our community advisory board, possible research projects to consider:

- What combination of programs, services, public policy are associated with quality care outcomes in a community-based interprofessional, intergenerational program to provide EOL care for transgender older adults?
- What is the effect of an educational intervention on advance care planning for transgender older adults and their circle of support?
- What are the factors associated with quality of life for transgender elders receiving gender-affirming spiritual and psychological care at end of life?

Next steps (as described by participants)

I'd like to see a local small scale pilot project tested, including all aspects: it involves youth and training and empowers caregivers of dying people; a program that is intergenerational that provides services to trans people.

Young people need purpose/significance; there is a need for pairing kids with adults for help with home care and sharing of wisdom.

I'd love it as a result of this meeting to have people who are part of this meeting to share information with me about planning for end of life. When we are planning for a pet or a grandchild, those documents don't necessarily get put in the same place. People are also putting together directories of state laws. That would be beneficial to people. It would be good if it could be stored online and be updated.

It is important to continue to network with others. Also this can be used as a springboard and invitation to others who did not participate.

It is important to make sure that we all stay in contact with each other. Is there an email list so that we can reach out to tap into your specialties? We need a safety net to avoid what usually happens--after the conference it all fizzles out.

DISSEMINATION TO DATE

MEDIA APPEARANCES- 2021

One of the key deliverables proposed in our original grant proposal was to participate in a series of podcasts to share our work. We were invited by Jeanne McCusker, host of "A Graceful Life" in Charlottesville, VA radio station, WINA. Her show features people from the local community who share their stories on aging gracefully. We participated in three separate episodes:

- Episode 1: Compassionate end-of-life care for transgender elders. Cathy Campbell, PhD, RN* https://wina.com/podcasts/transgender-older-adults-compassionate-end-of-life-planning/
- Episode 2: Aging issues facing transgender older Adults. Charley Burton*, Black Transmen Inc.; Cathy Campbell,* PhD, RN. https://wina.com/podcasts/aging-issues-facing-transgender-adults/
- Episode 3: Aging Issues facing transgender Adults. Charley Burton*, Black Transmen Inc.; Cathy Campbell*, PhD, RN. https://wina.com/podcasts/aging-issues-facing-transgender-adults-part-2/

Lunch and Learn Panel: Elder Care in the LGBTQIA+ Community hosted by Equality Virginia, June 2, 2021. Participants: Charley Burton*, Black Transmen Inc.; Cathy Campbell,* PhD, RN, University of Virginia, School of Nursing.

Equality Virginia is a transgender advocacy group that hosts a series of lunch and learn events to highlight issues pertinent to the LGBTQIA+ community. Think Tank organizers were invited to participate in an interprofessional panel to discuss access to health

care, resources available, advocacy, and updates from legislators from the Commonwealth who support LGBTQIA+ issues.

Lunch and Learn Panel: Challenges facing LGBTQIA+ older adults hosted by The Office of the Secretary of the Commonwealth, June 11, 2020. Participants: Charley Burton*, Black Transmen Inc; and Cathy Campbell, PhD, RN*, University of Virginia, School of Nursing.

Policy makers and experts providing older adult care services discussed challenges facing LGBTQIA+ older adults.

NPR interview with Sandy Houseman (WVTF 96.1 NPR Affiliate for Central/Southwest Virginia), June 16, 2021.Participants: Charley Burton*, Black Transmen Inc; and Cathy Campbell, PhD, RN*, University of Virginia, School of Nursing. https://www.wvtf.org/news/2021-06-17/advocates-call-for-better-understanding-of-medical-needs-of-transgender-people

In honor of PRIDE month, members of the planning committee were interviewed about the physical and emotional health of transgender adults.

The work of the Think Tank will be featured in Mindful Magazine in August, 2022. Dallas Ducar and Dr. Cathy Campbell were interviewed about the needs of transgender elders at end of life.

COMMUNITY PRESENTATIONS- 2021

Campell, C*., Mayo, B.*, & Page, E.** Social justice and Buddhism: Wearing the Tathagata's Teachings. End-of-life care for transgender older adults. Upaya alumni series. October, 2021. Upaya Zen Institute, Santa Fe, NM.

Two members of the planning committee (C. Campell and B. Mayo) and a think tank participant Dr. Enoch Page were invited by Roshi Joan Halifax, the Abbot at Upaya Zen Center to present on the work of the Think Tank to the Upaya Chaplain Alumni. We reviewed the knowledge gained from the think tank and Dr. Page used a powerful spoken word performance to initiate a powerful dialogue about gender dysphoria and transphobia.

MEDIA - 2022

Whitney-Coulter, A. (2022, June 14th). You are not alone. Mindful Magazine. https://www.mindful.org/you-are-not-alone/
Mindful Magazine is a monthly digital publication that focuses on practices to integrate mindfulness into one's life. Dallas Ducar and Cathy Campbell were interviewed about the work of the Think Tank.

WORKSHOPS AND PRESENTATIONS - 2022

Invited Workshop Chaplaincy Training Program

Campbell, C. & Page, E. (2022). Embodied Dharma: Awakening through sexual expression, sexual orientation, and gender identity. Upaya Zen Institute April 23, 2022.

The purpose of this workshop was to facilitate a discussion with Upaya's Chaplaincy program on spiritual care and practices for LGBTQ older adults at end of life, with a focus on exploring the needs of transgender and gender non-conforming older adults (the agenda is attached below) Twenty-four chaplaincy candidates attended the workshop (19

from the US and one each from South Korea, Belgium, Canada, and Australia).

CONFERENCE PRESENTATIONS/POSTERS - 2022

Catlett, L. (2022, February). Healthcare Needs and Protective Factors of Transgender and Gender Nonconforming Older Adults: A Systematic Integrative Review. Podium Presentation at the UVA Health Disparities Conference: Why We Can't Wait, Healthcare Justice for All, University of Virginia School of Medicine, Charlottesville, VA.

This presentation provided an exploration of not only the healthcare needs of transgender elders, but also the protective factors that are part of their lives.

Thunderword, J., Ducar, D., K. Aquaviva, Campbell, L.C., & Campbell, C.L. Transgender Elders Council: A Community Conversation about end-of-life care. Panel discussion held at the 43rd Annual Meeting and Conference of the Southern Gerontological Society, April 9, 2022, Panama City, FL.

One of the transgender elders who participated in the think tank and the members of the the planning committee held a panel discussion to discuss key observations from the Think Tank. Key observations included the intersectionality of aging, gender identity, and race; economic instability, housing insecurity, limited access to mental health services, lack of knowledge by HP care staff, and unwelcoming faith communities. Implications for HP care and services were also discussed.

MANUSCRIPTS IN PROGRESS

Integrative Review on Gender Diversity, Aging, and End of Life:

Catlett, L. (2022). Healthcare needs and assets of gender diverse older adults: A systematic integrative review. Journal of Nursing Scholarship, 10.1111/jnu.12810. Advance online publication. https://doi-org.proxy01.its.virginia.edu/10.1111/jnu.12810

Transgender Think Tank Qualitative Analysis:

Catlett, L., Acquaviva, K., Campbell, L., Ducar, D., Page, E., Patton, J. & Campbell, C. [Under review, Global Qualitative Nursing Research]. End-of-life care for transgender older adults.

DISSERTATION PROJECTS

Lauren Catlett (they/them), a Think Tank presenter and PhD student at the UVA School of Nursing, is engaged in dissertation research related to end-of-life care and advance care planning for gender diverse older adults. The proposed study name will be "Participatory Development of an Advance Care Planning Intervention for Gender Diverse Adults: A Mixed Methods Approach." They will be submitting a grant to fund this work in Spring 2023. Dr. Cathy Campbell will serve as faculty advisor for the dissertation project.

The study proposal aims to explore end-of-life wishes of gender diverse older adults and to collaborate with members of this population to develop a gender-affirming advance care planning intervention. The anticipated start date for the study is in the spring of

2023. This dissertation work falls in line with the philosophy guiding the Think Tank to create community relationships and support improvements in end-of-life care for transgender and gender nonconforming older adults.

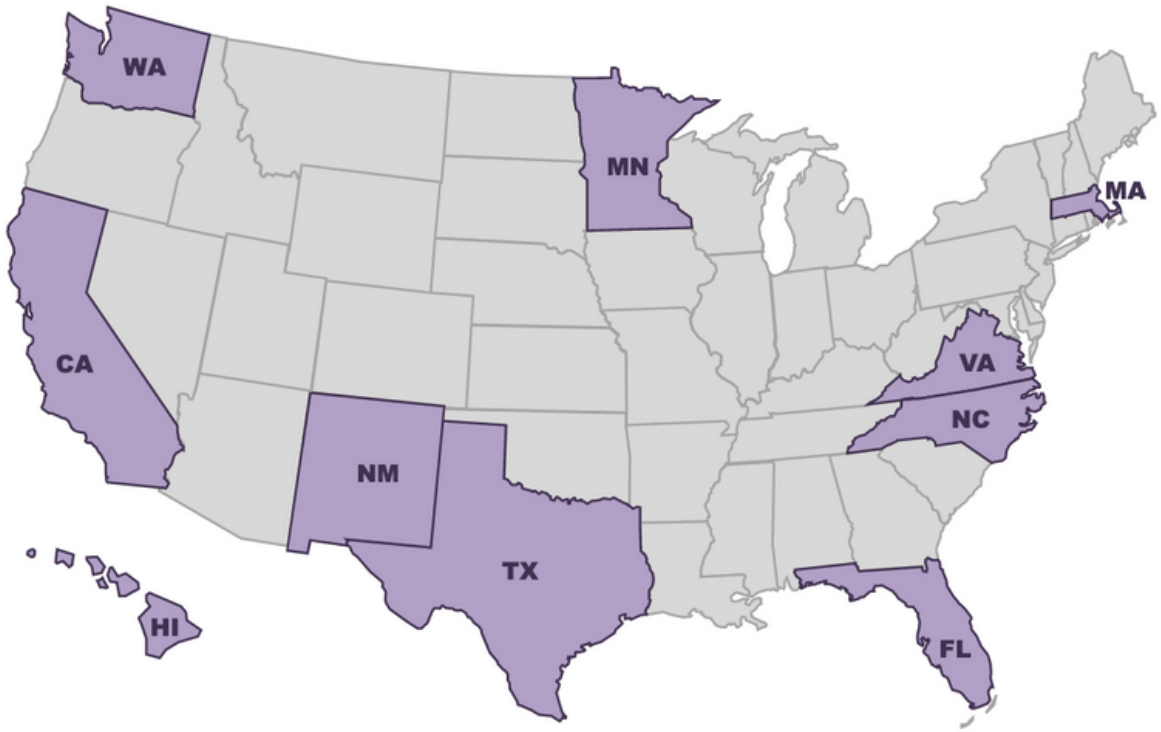
AWARDS & RECOGNITION

MLK Award presented to Dr. Cathy Campbell, member of the planning committee, by the University of Virginia's Health System in a virtual ceremony held on March 8th, 2022. Dr. Campbell is one of five 2022 MLK honorees. https://www.nursing.virginia.edu

Established in 2013, the MLK Award is bestowed annually to a student, faculty, or staff member in the health system who embodies Dr. Martin Luther King's values and teachings in their cultural competence, recognition of and work to end healthcare disparities, and as contributors to environments of inclusiveness in accordance with the institution's mission and values. https://twitter.com/uvason/status/1500895225430032388?s=10

GEOGRAPHIC REACH

States linked to Think Tank participants, media presentations, workshops, publications in progress, and dissertation projects.



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DEFINITIONS

Transgender	an umbrella term for people whose gender identity and/or expression is different from the sex they were assigned at birth
Gender Identity	a person's inner sense of being male, female, a blend of both, or neither
Dharma Talk	a public lecture by a Buddhist teacher
Embodied Practice	an activity in which you set an intention and then pay close attention to yourself in the moment
Mindfulness	a practice of contemplation and/or reflection
Think Tank	a group of experts providing advice and ideas to solve a problem

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