DISSERTATION

Advancing Health Equity among Transgender and Gender-diverse Older Adults: A Participatory Approach

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Abstract

Introduction: Facing healthcare discrimination and barriers to equitable care, many transgender and gender-diverse (TGD) adults are at risk for treatment in later life or during a serious illness that is inconsistent with their wishes. Advance care planning (ACP) is a process for documenting and sharing values, goals, and preferences for future healthcare with the potential to promote the agency of TGD adults in the healthcare system. However, as an emerging body of evidence, the literature on healthcare for TGD adults has notable gaps, and ACP resources designed to meet the unique needs of this population are limited.

Purpose: The purpose of this dissertation research was to (1) review the literature on healthcare for TGD older adults; (2) explore multilevel factors affecting health equity for TGD adults aged 50 years old and older; and (3) develop an advance care planning (ACP) resource with, and for, TGD adults.

Methods: This research was conducted as part of a qualitative descriptive study called Shaping Affirming Futures with Elders of all gender experiences (SAFEage), which consisted of a review of the evidence (Phase 0) and three phases of primary data collection (Phases 1, 2, and 3). In Phase 0, literature on healthcare for TGD older adults was reviewed and synthesized according to guidelines proposed by Whittemore and Knafl. In Phases 1 and 2, data from semi-structured interviews with TGD older adults were analyzed thematically, and themes were informed by the Intersectionality Research for Transgender Health Justice conceptual framework. In Phases 1, 2, and 3, a human-centered design approach was used to collect and analyze data from individual and group co-design sessions focused on identifying and developing ACP resources for TGD adults.

Results: In Phase 0, a review of the literature on healthcare for TGD older adults returned 35 articles that met inclusion and exclusion criteria. Seven themes were discerned, within which 20 healthcare needs and nine healthcare assets were identified for this population (Manuscript 1). Analysis of data from Phases 1 and 2 yielded six themes, with between two and five subthemes each, that describe multilevel factors affecting health equity for TGD older adults (Manuscript 2). In Phases 1 and 2, participants and researchers articulated a statement of core problems affecting healthcare for TGD adults and created an inventory of ideas for resources to support TGD adults in later life or during a serious illness. In Phases 2 and 3, participants and researchers developed three prototypes of an electronic healthcare decisions resource for TGD adults (Manuscript 3).

Significance: This research addressed gaps in the literature and responded to healthcare needs voiced by TGD adults by engaging members of this population in a participatory process to explore factors affecting health equity within their communities and to co-develop an ACP resource. This resource was designed to promote agency of TGD adults within the healthcare system and to facilitate dialogue with healthcare providers and care partners about wishes for their care in later life or during a serious illness. SAFEage is one of few studies to have practiced collaborative engagement with older adults during the research process. Findings from this study have implications for research, policy, and clinical practice. Among other implications, these findings lay the groundwork for developing interventions to advance health equity among TGD adults; draw attention to the need for policies to mitigate structural and systemic barriers to care affecting TGD older adults; and provide information and tools for clinicians to practice affirming and equitable care for TGD older adults.

Advancing Health Equity among Transgender and Gender-diverse Older Adults:

A Participatory Approach

Transgender and gender-diverse (TGD) adults often face healthcare discrimination and diminished access to care in an increasingly hostile political climate (Du Bois et al., 2018; Kinney et al., 2022). Many TGD adults experience these disparities while also grappling with chronic and serious health conditions that necessitate interaction with the healthcare system (Hughes et al., 2021; Rosa et al., 2023; Smith-Johnson, 2022). Despite the growing population of TGD adults in the United States (U.S.), research on interventions, resources, and services to promote healthcare quality and access for TGD adults in later life or during a serious illness is limited (Catlett, 2024; Rosa et al., 2023).

Decades of collective action and advocacy by TGD older adults and their allies have led to some improvements in healthcare quality and access for their communities, and some health systems have adopted gender-affirming practices as a standard of care (Du Bois et al., 2018; Restar et al., 2021). Personal strengths like resilience and resourcefulness have helped TGD older adults navigate the healthcare system and identify resources and services for gender-affirming care and for their overall well-being (Fredriksen-Goldsen et al., 2019; Sloan & Benson, 2021). Approaches to transgender health research that center the strengths of TGD older adults are warranted.

Taking into consideration health disparities and healthcare assets within communities of TGD older adults, this dissertation entitled *Advancing Health Equity among Transgender and Gender-diverse Older Adults: A Participatory Approach* details findings from a study in which researchers worked with TGD older adults to identify factors affecting health equity within their communities and to explore strategies that would promote their agency within the healthcare system. Called Shaping Affirming Futures with Elders of all gender experiences (SAFEage), this qualitative descriptive study used a human-centered design approach to co-design an advance care planning (ACP) resource with TGD U.S. residents aged 50 years old and older that would empower them to communicate wishes for their healthcare in advance of a serious illness. This dissertation document contains a Proposal for the study and three Manuscripts. The Proposal provides a detailed description and rationale for the study design and aims (see p.8). Manuscript 1 reports findings from an integrative review of the literature on healthcare for TGD older adults (p. 51), and Manuscripts 2 and 3 report findings from the SAFEage study (pp. 75 and 104).

The Proposal outlines the procedures planned for the SAFEage study. The original specific aims of this study were (1) to explore facilitators and barriers to ACP and wishes for gender-affirming care during a serious illness among TGD U.S. residents aged 50 years old and older and (2) to explore designs for communicating wishes for gender-affirming care in the context of a serious illness with TGD U.S. residents aged 50 years old and older. The study was carried out in accordance with these aims with one notable modification. The term "gender-affirming care" had been defined in this study as social, psychological, medical, and legal measures to support a person's gender identity and expression (Boyle, 2022). However, participants defined gender-affirming care more narrowly, focusing on medical and surgical measures only. So, to prevent confusion when disseminating findings, "healthcare" and "health equity" were used as substitutes, inclusive of gender-affirming care as originally defined and as defined by participants.

Manuscript 1 is entitled "Healthcare Needs and Assets of Gender-Diverse Older Adults: A Systematic Integrative Review" and has been published in the *Journal of Nursing Scholarship*. The purpose of this review was to synthesize recent studies addressing the healthcare needs and assets of gender-diverse older adults living in the United States (U.S.) and to summarize themes and subthemes relevant to improving healthcare practice, policy, and research for this population. Seven themes were identified and subdivided into twenty healthcare needs and nine healthcare assets. This study integrated findings from the evidence base on healthcare for TGD older adults in the U.S., laying the foundation for developing the SAFEage study. Specifically, this review highlighted the need for research inclusive of participants from diverse gender identities and racial and ethnic backgrounds as well as action-oriented studies to address challenges faced by TGD older adults in the healthcare system.

Manuscript 2 is entitled "Multilevel Factors Affecting Health Equity for Transgender and Gender-diverse Older Adults," and it is currently under review with the journal *Qualitative Health Research*. Covering

Proposal Aim 1, the purpose was to identify and explore limiting and facilitating factors that affect health equity for TGD adults aged 50 years old and older living in the U.S. Six primary themes describing factors that limit (L) and facilitate (F) health equity at (1) structural, (2) systemic, and (3) social levels of influence were identified: (L1) Oppression driving adverse healthcare experiences; (L2) Gaps in healthcare resources and support; (L3) Disadvantages yielding poor health outcomes; (F1) Health justice promoting affirming healthcare experiences; (F2) Catalysts for change in healthcare; and (F3) Assets fostering agency and well-being. Limiting and facilitating factors form a complex dialectic in which factors may cooccur and even overlap. This study provides further evidence to support the exploration of ACP for TGD adults documented in Manuscript 3.

Manuscript 3 is entitled “Co-developing an Advance Care Planning Resource with Transgender and Gender-diverse Adults: A Human-Centered Design Approach,” and it is currently under review with the journal *Design for Health*. Addressing Proposal Aim 2, the purpose was to co-design an ACP resource with TGD U.S. residents aged 50 years old and older that would empower them to prepare for their healthcare in later life or during a serious illness. Sixteen resource ideas and four design themes for the development of a healthcare decisions resource were identified: (1) Motivation: Promoting agency through proactive healthcare decision-making; (2) Composition: Integrating simple features, guided choices, and inclusive media; (3) Dissemination: Connecting to the community through snowball networking; and (4) Expansion: Fostering support and sustainability through grassroots efforts. Themes guided development of three prototypes of the healthcare decisions resource as a digital document. The vision that participants articulated for this resource was more expansive than study constraints could accommodate, so this manuscript sets the stage for further research and resource development.

As a whole, this document describes individual- and interpersonal-level action steps to address health disparities affecting TGD adults in later life or during a serious illness at multiple social ecological levels (NIMHD, 2024). This research was conducted to center the experiences of TGD older adults in the co-development of resources to promote agency in their care and in the co-construction of knowledge on health equity for this population.

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DISSERTATION PROPOSAL

Participatory Design of an Advance Care Planning Resource for Transgender and Gender-Diverse Adults

A. Specific Aims

Due to intersectional stigma and discrimination, transgender and gender-diverse (TGD) adults in the United States (U.S.) are at risk for poor health outcomes and treatment that is inequitable and inconsistent with their goals for gender-affirming care during a serious illness (Rosa et al., 2022). Over 1.3 million adults in the U.S. identify as transgender or gender-diverse, terms used respectively to describe gender identities that differ from sex assigned at birth or gender identities that differ from societal gender norms (Berg, 2022; Herman, Flores & O'Neill, 2022; PFLAG, 2023). In healthcare settings, as many as one third of TGD adults have reported discriminatory treatment from healthcare providers (Grant et al., 2011; James et al., 2016). Moreover, minority stress arising from intersectional stigma, which consists of negative beliefs directed toward multiple minoritized identities within a person or group (Turan et al., 2019), has been linked to poor health outcomes and higher mortality among TGD adults (Fredriksen-Goldsen et al., 2014; Hughes, King, Gamarel, Geronimus, Panagiotou & Hughto, 2022).

Discrimination and stigma can impact planning for future healthcare. An emerging body of evidence has revealed gaps in knowledge about serious illness and end-of-life (EOL) care for TGD adults, including factors affecting engagement in planning for future care (Catlett et al., 2023; Rosa et al., 2022). TGD adults are reportedly less likely than their cisgender peers to have legal documentation of their EOL care wishes or to have appointed a healthcare agent to make decisions on their behalf if they became unable to do so (Dickson, et al., 2021; Kcomt & Gorey, 2017). Factors that may influence this disparity include fear of discrimination and lack of support for EOL care wishes from healthcare providers (Reich et al., 2022).

Advance care planning (ACP) is a way for people, of all gender identities, to communicate wishes for their care prior to a serious illness. ACP is "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" that includes but is not limited to completion of advance directives (Sudore et al., 2017, p.821). Studies have shown that ACP promotes communication between patients, caregivers, and healthcare providers; decreases distress among healthcare proxies; and facilitates care consistent with patient wishes (Houben et al., 2014; McMahan, Tellez & Sudore, 2021).

Studies are lacking that explore ACP for TGD adults as a way to communicate their wishes for gender-affirming care, which refers to the social, psychological, medical, and legal measures to support a person's gender identity and expression (Boyle, 2022). ACP may help TGD adults communicate their wishes for gender-affirming care. This includes decisions about continuing gender-affirming medical treatments during a serious illness; preferences for personal care in healthcare settings; and designation of a healthcare agent from chosen (non-biological) families (Knochel & Flunker, 2021; Maingi, Bagabag & O'Mahony, 2018). Further study is needed to address ACP disparities observed in TGD communities and to expand ACP resources to address gender-affirming care during a serious illness.

In response to this need, the proposed study will use a qualitative descriptive approach in two phases (**P1** and **P2**) to address the **research question**: *how do TGD adults envision ways to communicate their wishes for gender-affirming care in the context of a serious illness?* Informed by the Intersectionality Research for Transgender Health Justice (IRTHJ) conceptual framework (Wesp, Malcoe, Elliot & Poteat, 2019), the study will incorporate principles of human-centered design (HCD), a participatory approach to problem-solving that centers the people for whom a new system, process, or product is intended (Leary et al., 2022). It will integrate *empathizing, defining the problem, ideating*, and *prototyping*, HCD processes collectively known as design thinking (Leary et al., 2022).

The **purpose** of the proposed study is to co-design an ACP resource with TGD U.S. residents aged 50 years old and older that would empower them to communicate their wishes for future gender-affirming care in advance of a serious illness. The **specific aims** are as follows:

Aim 1 (**P1**): Explore facilitators and barriers to ACP and wishes for gender-affirming care during a serious illness among TGD U.S. residents aged 50 years old and older through thematic analysis of qualitative data from semi-structured interviews. Aim 1 integrates the HCD processes of *empathizing* and *defining the problem*.

Aim 2 (**P2**): Explore designs for communicating wishes for gender-affirming care in the context of a serious illness with TGD U.S. residents aged 50 years old and older through thematic analysis of data from two participatory workshop sessions. Aim 2 integrates the HCD processes of *ideating* and *prototyping.*

In line with the health equity lens of the NINR 2022-2026 strategic plan, this study addresses a critical need for participatory engagement with TGD adults on the issue of ACP. Few studies have involved older adults in intervention co-design (Corrado, Benjamin-Thomas, McGrath, Hand & Laliberte Rudman, 2020), and even fewer have documented interventions to address healthcare inequities for TGD communities (Catlett, 2022). Without resources for communicating their wishes for future care, TGD adults may not have the means to address inequitable treatment during a serious illness, potentially leading to lower quality of palliative and EOL care, increased internalized stigma, and elevated stress for both patients and their support persons (Maingi et al., 2021; Sprik & Gentile, 2020). This study centers the knowledge and experiences of TGD adults to initiate timely action toward equitable care for their communities.

B. Research Strategy

B1. Significance

B1.1 Healthcare and Gender-affirming Care for TGD Adults

In spite of increasing visibility in healthcare settings, TGD adults often experience discrimination, lack of knowledge, and even refusal of care from healthcare providers (Grant et al., 2011; James et al., 2016). Fear of mistreatment in healthcare settings is common among TGD adults, leading some to delay seeking medical care or even contemplate suicide (Grant et al., 2011; Knochel & Flunker, 2021). This is a serious healthcare concern given that TGD adults are at risk for adverse health outcomes, such as poor physical health, depression, and disability, and transgender adults, especially black transfeminine and nonbinary adults assigned male sex at birth, have a high mortality rate relative to non-transgender adults (Fredriksen-Goldsen et al., 2014; Hughes et al., 2022a; Hughes et al., 2022b).

TGD adults have healthcare needs during a serious illness related to gender-affirming care that are distinct from the healthcare needs of cisgender adults, or persons whose gender identities align with their sex assigned at birth. Gender-affirming care refers to the social, psychological, medical, and legal measures to support a person's gender identity and expression (Boyle, 2022; Sevelius, 2013). Gender-affirming care in the context of a serious illness may include, but is not limited to gender-related personal care preferences like facial shaving and chest-binding; decision-making about ongoing gender-affirming medical treatments; appointment of a chosen family member as an advocate and healthcare agent; gender-related post-mortem care and burial preferences; and advocacy for future medical care in line with stated wishes for gender-affirming care (Knochel & Flunker, 2021; Maingi, Bagabag & O'Mahony, 2018).

B1.2 Advance Care Planning for Healthcare during a Serious Illness

Advance Care Planning (ACP) is one way for people of all gender identities to advocate for healthcare that aligns with their values and wishes in advance of a serious illness. ACP is "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" (Sudore et al., 2017, p.821). ACP was codified by the Patient Self-Determination Act of 1990 to protect patient rights for healthcare decision-making, particularly through the use of advance directives (PSDA, 1990). Advance directives are legally-recognized documents to specify a person's wishes for future medical treatment and/or to appoint a healthcare agent, a person designated to make medical decisions for another person if they become unable (Silveira, 2022). Consultation with a lawyer is usually not required to complete an advance directive. Virginia law, for example, only requires signatures of the person completing the advance directive and two witnesses on a state-specific form or approved alternative, like the Five Wishes® (Virginia Law, n.d.).

When practiced as a form of documentation alone, ACP has several limitations. Experts have debated the utility of ACP for influencing systemic change in palliative and EOL care practices, citing the low uptake of advance directives in the general population (Yadav et al., 2017) and continuing overuse of aggressive treatments at EOL (Periyakoil, Gunten, Arnold, Hickman, Morrison & Sudore, 2022). Efficacy studies of ACP interventions have had mixed outcomes for quality of care, likely due to heterogeneity in ACP delivery methods and lack of standardized outcomes measures (McMahan, Tellez & Sudore, 2021). Moreover, advance directive documentation does not necessarily guarantee goal-concordant care (McMahan, Tellez & Sudore, 2021), which some scholars believe should no longer be the focal outcome for ACP due to variability in patient preferences over time (Fried, 2022). Advance directive completion is low for minoritized racial groups, especially for the black population, due to complex factors including mistrust incurred by historical racially-motivated abuses in the U.S. healthcare system (Bazargan & Bazargan-Hejazi, 2021; Sanders, Robinson & Block, 2016). This body of evidence suggests that ACP focusing on documentation alone may not be the most culturally-appropriate approach for all populations, and it may not be sufficient to achieve systemic change in palliative and EOL care practices.

However, ACP as a multi-level, holistic, and iterative process, in which advance directive documentation is just one of several parts, has growing evidence to support its role in promoting positive outcomes for vulnerable populations (McMahan, Tellez & Sudore, 2021)**.** In recent years, planning for future medical care has shifted from the legal transactional approach characterized by completion of advance directives to the communications approach, which emphasizes contemplation of wishes for future care; discussion of wishes with loved ones and healthcare providers; accessibility of advance directive forms; and appointment of a healthcare agent (Sabatino, 2010; Sudore et al., 2008). This approach to ACP involves engagement with stakeholders at multiple levels, or "pillars," representing patients, proxies (healthcare agents), clinicians, communities, health systems, and policies (McMahan, Tellez & Sudore, 2021). Using a variety of approaches and measuring outcomes like ACP readiness, communication, documentation, quality of care, quality of life, and healthcare utilization, ACP interventions have been shown to improve communication between patients, caregivers, and healthcare providers; to decrease distress among surrogate decision-makers; and to facilitate goal-concordant care (Houben et al., 2014; McMahan, Tellez & Sudore, 2021).

B1.3 Advance Care Planning for Gender-Affirming Care during a Serious Illness

ACP documentation for TGD adults is low relative to cisgender adults. TGD adults are less likely than their cisgender peers to have legal documentation of their EOL care wishes or to have appointed a healthcare agent (Dickson, Bunting, Nanna, Taylor, Hein & Spencer, 2021; Kcomt & Gorey, 2017). A study featuring a sample of the sexual and gender (SGM) minority population, which includes TGD adults, describes factors that discourage engagement in planning for care during a serious illness, such as fear of discrimination, fear that healthcare providers will not honor their EOL care wishes, and preference for engaging in EOL care discussions outside of clinical settings (Reich et al., 2022). Actual or expected healthcare discrimination may erode trust in providers and reinforce notions of futility about planning for future care (Reich et al., 2022). Because the study by Reich et al. (2022) recruited few TGD adults within the larger sample of SGM adults, more research is needed to discern the factors affecting ACP engagement for TGD adults specifically.

Reviews of the literature confirm the need for more research on ACP for TGD older adults and adults with serious illnesses (Catlett, 2022; Rosa et al., 2022). A recent systematic review by Rosa et al. (2022) identified specific research needs related to the care of lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons with serious illnesses, including interventions to support ACP and clinician education. Recommended approaches to address the gaps include participatory intervention research to initiate systemic change (Rosa et al., 2022). Meaningful involvement of LGBTQ+ adults throughout the research process, especially as members of the research team, would strengthen these approaches by centering knowledge of the study population (Rosa et al., 2022). The proposed study responds to these recommendations by addressing the paucity of research on ACP for TGD adults using a participatory, human-centered design approach to co-design an ACP resource for gender-affirming care.

ACP for gender-affirming care will be used herein to refer to a process for TGD adults to communicate their wishes for gender-affirming care in the context of a serious illness. To my knowledge, no studies have been published to date that explore ACP for gender-affirming care, although I am aware of an advance directive that is under development for transgender adults to express their wishes for their future gender-affirming care in the context of dementia (Simmons, 2023). Consequently, ACP for gender-affirming care is an emerging area of study, and it may take shape in a variety of ways: as a workbook to aid in decision-making for future gender-affirming care; an educational reference about preparing for future gender-affirming care; a guide for appointing a healthcare agent from chosen family members; an advance directive featuring considerations for gender-affirming care during an illness that impacts patient decisional capacity; and others that this study aims to explore in collaboration with TGD adults. To illustrate the connections between ACP for medical care (established) and ACP for gender-affirming care (emerging), Table 1 details the goals for each type, paired with applications constructed from the literature and personal knowledge of gender-affirming care.

Table 1. Goals and Applications of Advance Care Planning for Medical and Gender-Affirming Care

#	ACP for Medical Care*	ACP for Gender-affirming Care**
1	**Goal**: To promote conversations about wishes for future care	**Goal**: To promote conversations about wishes for future gender-affirming care
	Application: A woman with advanced cancer discusses her options to enter hospice care or to continue chemotherapy with her close family	**Application**: A transfeminine person with advanced cancer talks to her spouse about her wishes for personal care like facial shaving and continuation of hormone treatments and gender-affirming procedures like vaginal dilation
2	**Goal**: To document wishes for future care	**Goal**: To document wishes for future gender-affirming care
	Application: A middle-aged man in good health completes an advance directive, which he includes in his medical chart and submits to his state's registry	**Application**: A transmasculine person with a family history of Alzheimer's disease completes an advance directive conveying his wishes regarding gender expression if he were to develop dementia and it were to alter his perception of his gender identity
3	**Goal**: To appoint a healthcare advocate	**Goal**: To appoint a healthcare advocate from a chosen support network
	Application: A person designates a healthcare power of attorney to make medical decisions for them if they become unable due to serious illness	**Application**: A nonbinary person designates a close friend as their healthcare agent to prevent the role from defaulting to an estranged next of kin
4	**Goal**: To facilitate goal-concordant care	**Goal**: To facilitate goal-concordant gender-affirming care, including post mortem care and burial preparations
	Application: Medical decision-making for a patient in a coma is guided by wishes documented in their advance directive	**Application**: A deceased person's body is presented at their funeral in clothing aligned with their gender identity, and the decedent's name and pronouns are used according to their wishes in announcements and memorial services

5	**Goal**: To encourage patient-provider discussions of wishes for future care	**Goal**: To encourage patient-provider discussions of wishes for future gender-affirming care
	Application: Primary care providers engage their patients in routine Medicare-reimbursed discussions about planning for future medical care	**Application**: As standard practice, palliative and hospice care providers talk to TGD patients and their support persons about measures to provide gender-affirming care
* Goals and applications for "ACP for medical care" draw from the literature (Silveira, 2022) and from personal knowledge of ACP ** Goals and applications for "ACP for gender-affirming care" are inferred from the literature (Baril & Silverman, 2022; Knochel & Flunker, 2021; Maingi, Bagabag & O'Mahoney, 2018; Simmons, 2023; Whitestone, Giles & Linz, 2020) and personal knowledge of gender-affirming care		

B1.4 Nursing Role in Advance Care Planning for Gender-Affirming Care

Further study is needed to explore the role of nurses in ACP for gender-affirming care. This study responds to the call for health equity in research from the NINR 2022-2026 strategic plan (NINR, 2022) and to the call for "intervention studies founded on community-based participatory research principles" to promote equitable palliative care from the HPNA 2023-2026 research agenda (HPNA, 2023, p.5). As patient advocates, educators, and researchers, nurses can play an important role in promoting ACP for TGD older adults, including during ACP resource development (the present study) and during implementation (in future studies and in practice). This study integrates the nursing perspective on prevention and health promotion, self-efficacy, care transitions, and EOL care. Nursing involvement in designing models of ACP for gender-affirming care may promote uptake by other healthcare providers and feasibility within current healthcare systems. Although nurses may have limited knowledge of ACP concerns specific to LGBTQ+ patients (Carabez & Scott, 2016), clinician education about gender-affirming care paired with collaborations between nurses and members of TGD communities may close the gap.

B2. Approach

B2.1. Conceptual Framework. This study draws from **Intersectionality Research for Transgender Health Justice (IRTHJ)**, a conceptual framework that articulates social justice-oriented actions for researchers working toward health equity for TGD adults (Wesp et al., 2019). Epistemologically, tenets of IRTHJ align with the transformative paradigm, a "framework of belief systems that directly engages members of culturally diverse groups with a focus on increased social justice" (Mertens, 2010, p.470) and acknowledges that "power is an issue that must be addressed at each stage of the research process" (Mertens, 2007, p.213). Specifically, IRTHJ names three actions to advance transgender health justice, "naming intersecting power relations," "disrupting the status quo," and "centering embodied knowledge," in response to intersectional causes of health inequities categorized by three layers: "structures of domination," "institutional systems," and "socio-structural processes" (Wesp et al., 2019, p.291).

In response to intersectional factors influencing health inequities named in the IRTHJ framework, this study would involve co-designing an ACP resource for gender-affirming care that recognizes transgender identity and gender diversity as "sites of self-determination" (Awkward-Rich, 2022, p.63). Self-determination is vital for TGD adults navigating predominantly white, cisnormative medical and political systems that have often misgendered, racialized, and/or pathologized them (Awkward-Rich, 2022). While this study will not dismantle entrenched health inequities, it will initiate action toward health equity by applying the IRTHJ framework, and it will use research methods that facilitate meaningful and equitable collaboration with TGD adults. The IRTHJ framework offers guidelines to equalize power relations and center participant voices such that the study is participatory and not extractive (Liboiron, 2021).

The three action steps identified in the IRTHJ framework inform the study design. I plan to "name intersecting power relations" by practicing reflexivity regarding my positionality and intentions; providing fair compensation for study participants; and giving careful attention to power dynamics (both overt and hidden) in my overall study design. To "center embodied knowledge," I will maintain a collaborative relationship with participants and key community advisers throughout the research process and center voices of TGD adults through individual interviews, collaborative workshop sessions, and member-checking. Finally, I aim to "disrupt the status quo" by collaborating on the development of an ACP resource for gender-affirming care with TGD adults and working with participants to envision ways to make gender-affirming care accessible during a serious illness within existing healthcare systems.

B2.2. Research Approach. This study uses a *qualitative descriptive* research approach. This approach stays close to the data, thereby preserving participant voices (Neergaard, Olesen, Andersen & Sondergaard, 2009; Sandelowski, 2000), which aligns with the IRTHJ action step of "centering embodied knowledge" described above. The qualitative descriptive approach may be informed by a conceptual framework, but it is less interpretive than other qualitative research approaches, like grounded theory or phenomenology. Analytic interpretations closely mirror the meanings participants convey during data collection (Sandelowski, 2000), which will be achieved in this study through thematic analysis and iterative member-checking. Additionally, Sandelowski (2000) observes that the qualitative descriptive approach may have hues, tones, or textures from theory or other qualitative approaches. The "tone" that primarily informs the qualitative descriptive approach in this study is the participatory *design approach* called *human-centered design (HCD).*

Principles of HCD inform the study design and provide tools for answering the research question. HCD is a participatory approach to problem-solving that centers the people for whom a new system, process, or product is intended (Leary et al., 2022). It is a "repeatable, creative approach to problem solving that brings together what is desirable from a human point of view with what is technologically feasible and economically viable" (Chen, Leos, Kowitt & Moracco, 2020; p.39). HCD is related to community-based participatory research (CBPR), an approach that focuses on "social, structural, and physical environmental inequities through active involvement of community members…[who] contribute their expertise to enhance understanding of a given phenomenon and integrate the knowledge gained with action to benefit the community involved" (Israel, Schulz, Parker, Becker & Community-Campus Partnerships for Health, 2001, p. 182). HCD shares several attributes with CBPR, such as co-design, bidirectional knowledge exchange, iterative engagement with community partners throughout the research process, and development of research agendas to benefit intended communities (Chen et al., 2020). However, the goal of HCD is distinct from CBPR, with a focus on generating action and scalable solutions within a relatively short time frame (Chen et al., 2020), which is in line with the scope of this study.

HCD is most often associated with a set of processes collectively known as design thinking (DT), which engage participants in designing a product or service that meets their needs. Some definitions of DT identify three stages, inspiration, ideation, and implementation (Chen et al., 2020), while other definitions delineate five *design processes*: *empathizing, defining (the problem), ideating, prototyping*, and testing (Leary et al., 2022). The latter definition was chosen for the proposed study because it provides a clear and actionable scaffold for the study design, structured by the first four processes of *empathizing*, *defining* the problem, *ideating*, and *prototyping* an ACP resource for gender-affirming care. The testing process will occur in future studies of resource acceptability, feasibility, and efficacy. Table 2 below organizes study design components by HCD processes in relation to each IRTHJ action to illustrate the connections between the design approach and the conceptual framework underpinning this study.

Table 2. Matrix of Study Components by IRTHJ Actions and HCD Processes

		IRTHJ Actions		
		Name Intersecting Power Relations	**Center Embodied Knowledge**	**Disrupt the Status Quo**
HCD Processes	**Empathizing**	• Examine study design and researcher positionality for embedded power relationships • Explore systemic barriers to ACP for TGD adults	• Base research questions on priorities of TGD adults • Develop interview guides with input from TGD adults • Center ideas and experiences of participants during interviews	• Prioritize the voices of adults with multiple marginalized identities to resist oppressive social structures like ageism and transphobia
	Defining [the	• Create diagram of barriers to ACP for TGD adults	• Member-check accuracy and acceptability of findings • Center participant knowledge to define the problem	• Engage TGD adults in defining priority areas for growth related to ACP in their communities
	Ideating	• Create diagram of possible solutions to barriers/root problem(s) affecting ACP for TGD adults	• Center ideas and experiences of participants during brainstorming	• Engage TGD adults in defining solution(s) related to ACP with the most benefit for their communities

		IRTHJ Actions		
		Name Intersecting Power Relations	**Center Embodied Knowledge**	**Disrupt the Status Quo**
	Prototyping	• Create designs for ACP resource that address barriers/root problem(s) affecting ACP for TGD adults	• Center ideas and experiences of participants while co-designing the ACP resource • Member-check accuracy and acceptability of resource	• Create an ACP resource for gender-affirming care with the potential to influence the quality and inclusivity of care during a serious illness and at EOL for TGD adults
	Testing	**N/A**	**N/A**	• Envision future studies to test the feasibility, acceptability, scalability, and efficacy of the ACP resource
	All Processes	• Check biases, assumptions, and power dynamics throughout the study process through reflexive journaling and practicing humility • Protect participant safety and privacy and provide fair compensation for study participation to recognize participant expertise and to equalize power in the study	• Collaborate with TGD older adults throughout the research process • Dismantle undue influence by the researcher on the co-design process through iterative member-checking of findings and consultation with adviser council	• Challenge hierarchies inherent in relations between academic researchers and community members • Apply participatory research methods and co-design to engage with communities with less representation in published academic literature

KEY	🟩	**Whole Study**	🟦	**Study Phase 1**	🟨	**Study Phase 2**	⬜	**Future Study**

B2.3. Preliminary Studies. This study integrates findings reported in the following preliminary studies:

1. **Catlett, L. (2022). Healthcare needs and assets of gender diverse older adults: A systematic integrative review. In *Journal of Nursing Scholarship*.**

This article reports findings from an integrative review of healthcare needs and assets of TGD older adults. Findings include seven themes. One theme, "end-of-life preparations," covers physical, psychological, and spiritual EOL care of TGD older adults; concerns for post mortem de-transitioning, or presenting a gender-diverse person after death according to their birth sex; and advance care planning, especially disparities in advance directive documentation and appointment of a healthcare agent. This review also highlights the assets of TGD older adults, such as activism, resilience, and community engagement. The proposed study aims to center the assets and expertise of TGD adults to address disparities in EOL preparations found in the review.

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

   This article is a qualitative descriptive exploration of the record of discussions from a multi-disciplinary think tank on EOL care for transgender older adults. It delineates four main themes, including "addressing end-of-life healthcare and advance care planning needs." Specifically, think tank participants expressed a need for healthcare advocacy and more accessible documents for ACP. Providing the means to appoint a healthcare agent and to document wishes for future care, ACP may address the need identified by think tank participants for advocacy in healthcare settings at EOL. This work supports further exploration of ACP for TGD adults in the proposed study. Additionally, the two-part think tank method with the use of video conferencing to engage transgender older adults in group discussion sets a precedent for the workshop structure in Phase 2 of the proposed study.

3. **Campbell, C. L., & Catlett, L. (2019). Silent illumination: A case study exploring the spiritual needs of a transgender-identified elder receiving hospice care. In *Journal of Hospice and Palliative Nursing*; Estrellita, C. (2016). *Little star* (L. Catlett, Ed.). Self-published memoir.**

   Carmelita Estrellita's book and the case study of her hospice experience illustrate a collaboration between patient and hospice volunteer that centered the voice of a transgender woman to provide insight into her EOL experience. Her narrative describes transphobic abuses she faced in healthcare and social systems throughout her life as well as her resilience through gratitude and forgiveness in times of suffering. Humility, respect, and connection to community, principles essential to my collaboration with Estrellita, will also be integral to the proposed study.

B2.4. Assumptions. Four assumptions I am making in this study are: (1) ACP is beneficial for most people who engage in it; (2) qualitative inquiry and a participatory human-centered design approach are the most suitable ways to prioritize the voices of TGD adults, equalize power imbalances, enhance health equity, and answer the research question; (3) participants will be willing and able to talk about topics related to ACP; and (4) ACP has the potential to promote gender-affirming care during a serious illness for TGD older adults.

B2.5. Reflexive Statement. In this study, I am both an insider and an outsider. As a nonbinary, agender person, I consider myself an insider with respect to the lived experience of TGD persons. I am also a white, well-educated, and middle-class young person; thus, I am an outsider with respect to age since participants will be aged 50 years old or older, and I may be an outsider with respect to race, level of education, and socioeconomic status for some participants. I acknowledge that my age, race, level of education, and socioeconomic status also carry power and privilege, and I will address power imbalances by maintaining open-mindedness and respect for participants and their ideas at every stage and by sharing decision-making during the design process. Finally, I may be an outsider due to my experience and knowledge of healthcare and ACP. Although I anticipate that some participants, as older adults, will have direct or indirect experience with ACP and/or serious illness, I plan to provide basic introductory materials about ACP and healthcare during a serious illness to ensure that those with less knowledge of these subjects feel confident to contribute their perspectives and ideas during the study.

My role as a nurse and researcher may create a power imbalance that I will address by engaging participants in collaborative design decisions and keeping a reflexive journal to monitor my influence on decision-making. Check-ins with participants after each workshop session will provide an opportunity to suggest changes to the process. My status as a student could potentially undermine confidence and trust from participants, so I will be transparent about my intentions, my areas of expertise, and gaps in my knowledge and emphasize the value of a learner’s mindset in the co-design process.

My view of ACP as a beneficial process for most, if not all, people, and especially for older adults and persons with serious illnesses, may be a source of bias. I acknowledge that ACP is enmeshed in a complex web of systems, policies, and practices that may affect the efficacy of ACP. However, ACP is an evidence-based process for communicating wishes for future healthcare that may facilitate open dialogue about aging and EOL issues in advance of a serious illness. With proper support and guidance, I believe that having these dialogues is more beneficial than not having them. During this study, I will be cognizant of interference from my bias toward ACP, and I will remain open to alternative directions suggested by participants.

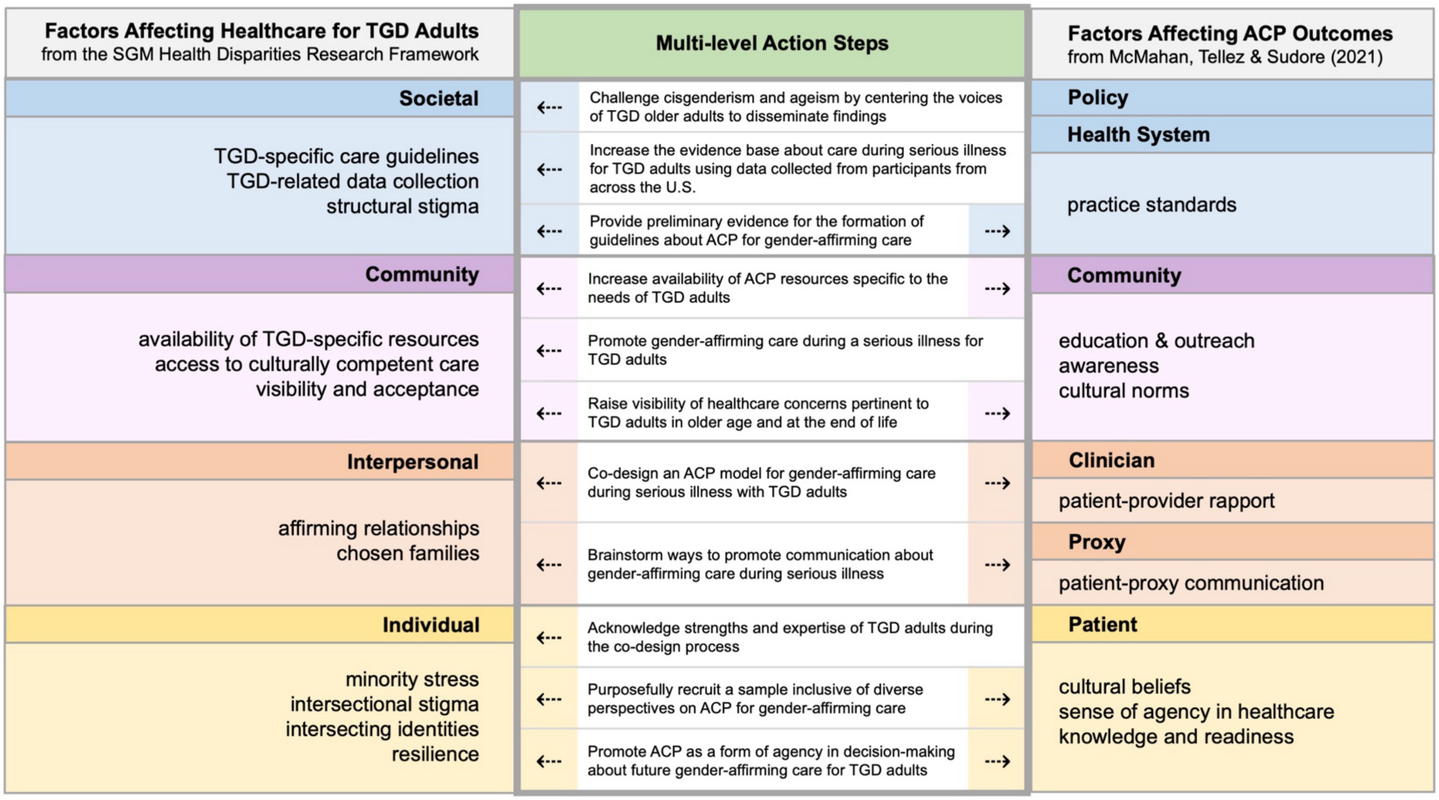
B3. Innovation

This study employs an innovative design in an emerging area of research. The study design leverages a human-centered design approach (Leary et al., 2022) and draws from best practices for co-design, a participatory approach to designing solutions in which community members are treated as equal collaborators in the design process (Leask et al., 2019). Although co-design has existed as a research method for decades (Leary et al., 2022), it has only recently been used in the design of ACP resources (Bielinska, Archer, Darzi & Urch, 2022). To my knowledge, no protocols or studies have been published on co-designing an ACP resource with TGD adults in the U.S. In fact, very few studies have involved older adults in intervention co-design (Corrado, Benjamin-Thomas, McGrath, Hand & Laliberte Rudman, 2020), and even fewer have documented interventions to address healthcare inequities for TGD communities (Catlett, 2022). Finally, by focusing on older adults in TGD communities, this study applies the IRTHJ conceptual framework and the HCD approach in novel ways to center the voices of a sector of the TGD population that has received limited attention in health research and clinical practice (Catlett, 2022).

This study also synthesizes *research frameworks* for ACP and healthcare for TGD adults in a novel way. Figure 1 illustrates the proposed action steps in this study that would address multi-level factors affecting ACP and the health and wellbeing of TGD adults. Individual, interpersonal, community, and societal factors affecting healthcare for TGD adults constitute four levels in the Sexual and Gender Minority Health Disparities Research Framework, a social-ecological model developed by the National Institute on Minority Health and Health Disparities (NIMHD) to assess research gaps and opportunities pertaining to health disparities that affect SGM populations (NIMHD, 2017). The levels of this research framework parallel the aforementioned “pillars” of

ACP described by McMahan, Tellez and Sudore (2021). These pillars convey the complex interplay of factors influencing ACP at the patient, proxy, clinician, community, health system, and policy levels, providing a framework for a holistic approach to ACP research (McMahan, Tellez & Sudore, 2021). This study unites these research frameworks through multi-level action steps to explore ACP for gender-affirming care in collaboration with TGD adults.

Figure 1. Proposed Action Steps at Multiple Levels of ACP and TGD Healthcare Research Frameworks



Factors Affecting Healthcare for TGD Adults from the SGM Health Disparities Research Framework	**Multi-level Action Steps**	**Factors Affecting ACP Outcomes** from McMahan, Tellez & Sudore (2021)
Societal	<--- Challenge cisgenderism and ageism by centering the voices of TGD older adults to disseminate findings	**Policy**
TGD-specific care guidelines TGD-related data collection structural stigma	<--- Increase the evidence base about care during serious illness for TGD adults using data collected from participants from across the U.S.	**Health System**
	<--- Provide preliminary evidence for the formation of guidelines about ACP for gender-affirming care --->	practice standards
Community	<--- Increase availability of ACP resources specific to the needs of TGD adults --->	**Community**
availability of TGD-specific resources access to culturally competent care visibility and acceptance	<--- Promote gender-affirming care during a serious illness for TGD adults	education & outreach awareness cultural norms
	<--- Raise visibility of healthcare concerns pertinent to TGD adults in older age and at the end of life --->	
Interpersonal	<--- Co-design an ACP model for gender-affirming care during serious illness with TGD adults --->	**Clinician**
affirming relationships chosen families		patient-provider rapport
	<--- Brainstorm ways to promote communication about gender-affirming care during serious illness --->	**Proxy**
		patient-proxy communication
Individual	<--- Acknowledge strengths and expertise of TGD adults during the co-design process	**Patient**
minority stress intersectional stigma intersecting identities resilience	<--- Purposefully recruit a sample inclusive of diverse perspectives on ACP for gender-affirming care --->	cultural beliefs sense of agency in healthcare knowledge and readiness
	<--- Promote ACP as a form of agency in decision-making about future gender-affirming care for TGD adults --->	

B4. Research Design & Methods

B4.1. Study Design & Rationale. The proposed study addresses the research question using a two-phase qualitative design based on principles and processes of HCD (Hesse-Biber, Rodriguez & Frost, 2016; Leary et al., 2022). The two phases of this study are a response to both the need for *knowledge* about ACP for TGD adults and the need for *action* to address ACP disparities for TGD adults. The qualitative descriptive research approach in this study, informed by the IRTHJ action steps and HCD principles, will promote participatory engagement with TGD adults to co-construct the knowledge base about ACP for gender-affirming care and to co-design an ACP resource for gender-affirming care that addresses the root problems affecting ACP in their communities.

The structure of each phase of this study will be based on four design processes often used in HCD studies (Leary et al., 2022). Phase 1/P1, corresponding to Aim 1, will cover the processes of empathizing and defining the problem during semi-structured interviews with TGD adults over six months. During the interviews, participants will be invited to discuss their wishes for future gender-affirming care and their views of the facilitators and barriers to ACP within their communities. Interviews were chosen for this phase as a way to build rapport with participants and to give each participant a chance to share their personal views and experiences before shifting to group work in the second phase. Phase 2/P2, corresponding to Aim 2, covers the processes of ideating and prototyping during a co-design workshop divided into two sessions over the course of one month. These workshop sessions will involve brainstorming and designing an ACP resource for gender-affirming care. The workshop structure was chosen for P2 to allow for collaborative design and rapid development of the resource. Both phases will take place virtually using the video conferencing platform Zoom. (In-person sessions will be considered for interviews and workshops depending on participant location.) Data from recorded discussions will be analyzed using thematic analysis in P1 and P2.

Table 3 below depicts the study design and timeline. The study phases and associated methods correspond to four design processes within the HCD approach, which is situated in the frame of qualitative descriptive research as part of the overarching qualitative methodological framework. Details about sampling, recruitment, data collection, and data analysis are provided in the following sections.

Table 3. Study Design and Timeline

Methodology	**Qualitative**			
Research Approach	**Qualitative Descriptive**			
Design Approach	**Human-Centered Design (HCD)**			
Design Processes	**Empathizing**	**Defining**	**Ideating**	**Prototyping**
Study Phase	**Phase 1 (Aim 1)**		**Phase 2 (Aim 2)**	

(Timeline)	(Nov 2023 – Jun 2024)	(Jul 2024 – Oct 2024)			
Methods (Data Collection)	Semi-structured Interviews	Two (2) Workshop Sessions			
Methods (Data Analysis)	Thematic Analysis	Thematic Analysis			

B4.2. Sample. The study sample includes TGD adults aged 50 years old or older, an age division that has been used to denote the start of older adulthood for LGBTQ+ persons (Cortes, Fletcher, Latini & Kauth, 2019; Fredriksen-Goldsen, Jen & Muraco, 2019). Although age 65, which is associated with Medicare eligibility, is commonly used as the starting point for older adulthood, TGD adults may experience premature age-related transitions and health decline due to stigma, minority stress, disparate healthcare access, and health inequities (Cortes et al., 2019; Hughes et al., 2022a). Although ACP is useful for adults of any age, TGD older adults will be chosen to participate in this study because ACP may have the most immediate relevance to their life stage.

Prospective participants will meet inclusion criteria if they (1) identify as transgender or gender-diverse; (2) are 50 years old or older; (3) are able to speak, read, and write in English; (4) have lived in the U.S for at least 10 years; (5) have capacity to give informed consent; and (6) are willing and able to participate in interviews and workshops in a private space on a *recorded* Zoom call while visible on screen. Criteria for exclusion will include (1) cisgender identity; (2) age less than 50 years old; (3) inability to speak, read, and write in English; (4) less than 10 years residency in the U.S.; (5) lack of capacity to give informed consent; and (6) inability to participate in a private space on a recorded Zoom call while visible on screen. Due to limited resources and time constraints, participants will be limited to English speakers living in the U.S.; however, it will be important to include non-English speaking and international TGD adults in my future work to avoid excluding persons who may benefit from the research.

The estimated sample size for P1 is 15-20 participants. The exact number of participants will be determined by representation of diverse perspectives, specificity of the data to the research question, and overall quality of the interviews (Malterud, Siersma & Guassora, 2016). Incorporating diverse perspectives underrepresented in the literature is important to the study aims, so a diverse sample with respect to race and gender identity will be prioritized (for details see *Sample Diversity* under *Recruitment* below). Inclusion of a diverse sample will facilitate integration of various perspectives into the ACP resource, thereby increasing its acceptability across cultures and contexts.

All participants in P1 will be invited to participate in P2. Participants will be eligible to join P2 if they meet P1 eligibility criteria and are available to attend at least one workshop session. Accounting for expected attrition and adapting guidelines from the literature (Leask et al., 2019; Wheelan, 2009), I estimate that the average group size will be 6-8 participants per workshop session. Small group sizes for the workshop sessions may facilitate discussion and collaboration among participants and create space for each participant to make meaningful contributions. Recruitment details for each phase are described in the following section.

B4.3 Recruitment. Recruitment will begin with assistance from an *adviser council* formed of 3-4 TGD adults with insight and involvement in TGD communities and diverse with respect to age, race, and gender identity. Prospective adviser council members will be identified from my personal contacts in and outside Virginia prior to application for IRB approval to assess interest and availability. The duties of the council, beginning after IRB approval and ending after one year, will be to review (1) study instruments prior to the study start date; (2) themes from P1 prior to the start of P2; and (3) findings from P2. The council may also be consulted to facilitate recruitment and to aid in decision-making if consensus cannot be reached among participants during co-design sessions. Council members will perform these duties by email and during two 30-minute Zoom meetings, conducted either individually or as a group, depending on council member availability. The council will not participate in study interviews and workshop sessions, as their primary role will be to provide guidance during the study. The anticipated time commitment for each adviser council member over the course of one year is about two hours, for which they will be compensated.

P1 participants will be recruited nationally via *purposeful (snowball) sampling* (Onwuegbuzie & Collins, 2015) through personal contacts in the TGD community, outreach to LGBTQ+ organizations (e.g., WPATH, SAGE, the Fenway Institute, the Rise Registry, Black Transmen, Equality Virginia, and the Transgender Health Alliance of Central Virginia, among others), and consultation with the adviser council. An electronic flier will be used in email communications to convey key details of the study and how to enroll. I will reach out to prospective participants upon referral, and I will recruit prospective participants who reach out to me directly. Social media will not be used as a primary method for recruitment as the risk for malicious contacts or disingenuous respondents is high; however, I expect that informational fliers for the study will be posted on social media by the aforementioned groups and individuals I plan to consult for recruitment. Thus, I will use a screening tool to prevent any irregularities in recruitment precipitated by posting study information on social media.

Screening of prospective participants for P1 will be performed using a Qualtrics survey tool prior to scheduling each interview. Phone screening will be used as an alternate plan, if needed. If the prospective participant is eligible, I will contact them to set up an interview and send them a Qualtrics link to sign the informed consent form electronically and to complete a pre-interview demographic survey; a single-page handout with an overview of ACP, links to access the Five Wishes® advance directive, and sources for more information about ACP will also be provided as an email attachment.

Participants for P1 will be recruited on an ongoing basis until a diverse sample is formed (see *Sample Diversity* below) and sufficient information power is reached (Malterud, Siersma & Guassora, 2016). Information power is a strategy for estimating sample size used as an alternative to “saturation,” a controversial method for determining sample size for non-grounded theory studies (Malterud, Siersma & Guassora, 2016). The authors state that “information power indicates that the more information the sample holds, relevant for the actual study, the lower number of participants is needed” (Malterud et al., 2016, p.1759). The model for information power has five domains for estimating sample size: study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy, which will guide the P1 recruitment process.

P1 participants will have the chance to participate in P2 following their interviews. Two months before the first workshop session in P2, participants will be contacted with a Qualtrics survey to sign up for P2. P1 participants will be eligible to join P2 if they are available to attend at least one workshop session. *Purposeful sampling* (Onwuegbuzie & Collins, 2015) will be used to fill up to ten slots in each session predetermined by estimates from the literature (Leask et al., 2019; Wheelan, 2009) and from personal experience with group work. If fewer than three P1 participants enroll for any workshop session, additional participants who meet P1 eligibility criteria will be recruited via purposeful sampling to increase the group size. Any participants recruited for P2 that did not participate in P1 will receive the ACP informational handout given to P1 participants in preparation for the workshop sessions.

An estimated 6-8 participants with a maximum of 10 will be recruited for each session in P2. This group size is large enough to aid in generating a variety of ideas, while small enough to avoid becoming unwieldy. To give each participant more time to share their ideas in the second session, two time slots will be offered if the number of participants who signed up exceeds a group size of six for a single session (Wheelan, 2009). No more than 10 participants will be recruited for each session due to the potential for reduced participation, group cohesion, and productivity at larger group sizes (Wheelan, 2009). Table 4 below details the recruitment plan.

Table 4. Recruitment Plan

P1	**Sampling Scheme**	**Purposeful (Snowball) Sampling**		
	Timeline	Ongoing until a diverse sample is recruited and sufficient information power is reached		
	Sampling Frame	TGD U.S. residents over 50 years old		
	Eligibility Criteria	(1) transgender or gender-diverse; (2) 50 years old or older; (3) able to speak, read, and write in English; (4) U.S. resident; (5) able to give informed consent; and (6) willing and able to participate in interviews and workshops in a private space on a recorded Zoom call		
	Sampling Strategy	Recruit through personal contacts	Recruit with adviser council contacts	Recruit through LGBTQ+ organizations
	Sample Size	**15-20 participants** (estimated)		
P2	**Sampling Scheme**	**Purposeful Sampling**		
	Timeline	Two months preceding the first workshop session		
	Sampling Frame	(1) P1 participants (2) Persons who meet P1 eligibility criteria		
	Eligibility Criteria	(1) meets P1 eligibility criteria; (2) available for at least the first session		

	Sampling Strategy	Recruit P1 participants	Recruit TGD adults who meet P1 eligibility criteria
	Sample Size	**6-8 participants per session** (estimated average)	

Sample diversity is important in this study as many studies of TGD older adults focus primarily on white transgender women, with transgender men and people of color represented less often in the literature (Catlett, 2022). To promote diversity in the sample, I aim to limit the percentage of white participants to less than 60% of the sample. This percentage corresponds to the non-Hispanic white population in the U.S. (United States Census Bureau, 2022). Additionally, I plan to reach out to several contacts connected with communities of queer, transgender, and indigenous people of color (QTIPOC) to invite black TGD adults to join the study. Because the population sizes of transgender men and transgender women in the U.S. are nearly equal (Herman, Flores & O'Neill, 2022), I aim to recruit approximately the same number of transmasculine and transfeminine participants. I anticipate that the number of participants who identify as gender-diverse (i.e., nonbinary, gender nonconforming) will be lower than the number of transgender participants since they make up a smaller proportion of the TGD older adult population (Wilson & Meyer, 2021). Since many of my contacts live in Virginia, I expect that up to 50% of participants will be Virginia residents. However, I will be recruiting nationally, so I aim to draw at least half the sample from places outside of Virginia to include perspectives from different medico-legal landscapes.

Since recruitment is on a rolling basis, I intend to start my outreach broadly and then focus it in response to imbalances in sample diversity. For example, if I reach the 60% threshold for white participants, I will pause recruitment for this demographic group and focus on increasing recruitment within TGD communities of color in collaboration with personal and organizational contacts. However, these percentages are only guidelines, and I will use them flexibly as parameters to ensure a diverse sample. Finally, I will be cognizant of the balance of participants with and without prior ACP engagement to ensure that different views of ACP are represented. Prior engagement in ACP is not a formal criterion for inclusion, however, because all TGD adults who are navigating the U.S. healthcare system, with or without ACP experience, will likely have insight into the factors affecting their ACP engagement, or lack thereof, and their wishes for future gender-affirming care.

B4.4. Data Sources. Qualitative data for this study will primarily come from recordings of interviews and workshop sessions, supplemented by field notes and digital artifacts from the design process. (Digital artifacts in this case are the HCD tools used for defining the problem (barriers to ACP), brainstorming ideas for the ACP resource, and prototyping the resource during the workshop. Templates will be adapted from the HCD toolset LUMA System.™) A semi-structured interview guide for P1 and workshop session guides for P2 will be used for data collection.

Informed by the IRTHJ action step of "centering embodied knowledge," the P1 interview guide (see Appendix) adapts questions selected from an existing interview guide used in the study by Reich et al. (2022) and builds on a preliminary interview guide I shared with transgender adults to assess acceptability of questions and language. The interview guide is informed by *empathizing*, the HCD process for immersion in the experience of the participant to understand their feelings, thoughts, and actions (Leary et al., 2022).

As a bridge between P1 and P2, findings from P1 will be reviewed by participants in the first workshop session in P2 as a way of *defining* the problem, the HCD process of identifying areas for growth from which participants can posit solutions (Leary et al., 2022). From barriers to ACP identified by participants in P1, a provisional problem statement will be created that will be presented to participants in P2 for validation and refinement and to guide selection of an appropriate solution.

P2 workshop session guides are structured after existing projects (Aifah et al., 2020; Yu & Perlman, 2023) and incorporate HCD methods developed by the LUMA Institute, a design thinking organization that seeks "to empower [people] to be make things better" (LUMA Institute, 2019; LUMA Institute, 2023). Specifically, workshop sessions will center on the HCD processes of *ideating* (brainstorming solutions to the problem statement) and *prototyping* (envisioning the ACP resource) using user-friendly tools like a target diagram and thumbnail sketching for prioritizing and visualizing ideas. The P2 workshop session guides initiate the IRTHJ action step of "disrupting the status quo." See Appendix for interview and workshop guides with descriptions of associated HCD tools. All instruments will be reviewed for acceptability by the adviser council prior to the start of the study.

Additionally, before their interviews, participants will complete a demographic survey along with their informed consent documentation piloted and delivered through Qualtrics. The demographic survey incorporates items from the 2015 US Transgender Survey Questionnaire (James, Herman, Rankin, Keisling, Mottet & Anafi, 2016). The purpose of the demographic survey is to provide descriptive quantitative data to contextualize qualitative findings in P1. Since some P2 participants may not have participated in P1, the demographic survey will be given to them along with their informed consent documentation through Qualtrics prior to the first workshop session. Since the small sample size for this survey precludes robust statistical analysis and integration of quantitative and qualitative analyses, the study design will not be considered “mixed methods.”

B4.5. Data Collection. Data collection will occur during interviews in P1 and workshop sessions in P2. Interviews will last no more than one hour each with up to 30 minutes extra for introduction, closing, and questions. The two workshop sessions will last approximately 1.5 hours each with an optional 30 minutes after each session for questions and feedback. Both interviews and workshop sessions will be held on Zoom (unless in-person sessions are possible and preferred by participants). The number of interviews will be determined based on diversity of the sample as well as specificity of participant experiences to the research question and iterative assessment of dialogue quality (Malterud, Siersma & Guassora, 2016). Dialogue quality is a component of “information power” (see *Screening* above). It refers to the skillfulness of the interviewer, the ability/willingness of the interviewee to express their ideas, and the rapport between interviewer and interviewee. I will assess dialogue quality through my own reflexive journaling and through initial coding (i.e., assessing whether codes are starting to create a picture of the research topic that has richness and complexity). The number of workshop sessions was predetermined by review of the evidence, estimation of time required for the design process, and assessment of participant burden (Aifah et al., 2020; Leask et al., 2017).

In P1, data from demographic surveys, which will include items related to gender identity, race/ethnicity, age, and ACP engagement, will be collected via Qualtrics before each interview. Interviews will follow a semi-structured guide reviewed by adviser council members and dissertation committee members. The guide will contain open-ended questions about gender-affirming care in the context of a serious illness and about the barriers and facilitators to ACP. Qualitative data will be collected through audio recordings and researcher memos following each interview. The purpose of P1 is to promote empathy for the viewpoints of TGD adults and to define the problem related to ACP for gender-affirming care.

In P2, workshop sessions will involve a process of idea generation and co-design, with a preliminary ACP resource for gender-affirming care as the expected outcome. Such resources may include, but are not limited to, standalone or supplemental advance directives to document wishes for gender-affirming care; guides for designating a healthcare agent; conversation aids for communicating wishes for gender-affirming care; and educational resources about planning for future gender-affirming care. Session 1 will create space for rapport-building, member-checking P1 findings, and brainstorming solutions in response to the problem statement (ACP barriers) defined in P1. Session 2 will build on participant strengths (ACP facilitators) to design an ACP resource for gender-affirming care. Qualitative data will be collected through audio recordings, and transcripts will be generated for each workshop session. See Table 5 for an outline of workshop sessions.

Table 5. Outline* of Activities for P2 Workshop Sessions

Workshop	**Session 1 (S1)**		**Session 2 (S2)**	
Purpose	Member-checking P1 findings Brainstorming solutions		Prototyping S1 solution Post-workshop planning	
Duration	90 min		90 min	
Participants (projected)	6-8		3-6	
Meeting Location	Zoom		Zoom	
Activities	15 min	Introduction	10 min	Introduction
		Group guidelines		Group guidelines
		Rapport-building		S1 review
		S1 goal-setting		S2 goal-setting
	20 min	Overview of P1 themes (presentation)	30 min	Overview of resource design (presentation)
		Review of P1 themes (group discussion)		Thumbnail sketching*** (guided independent work)

Workshop	**Session 1 (S1)**		**Session 2 (S2)**	
	5 min	BREAK	5 min	BREAK
	30 min	Problem statement** Initial solution ideas** (presentation)	30 min	Design review (group discussion)
		Brainstorming solutions Prioritizing solutions (discussion)		
	15 min	Target diagram*** Selection of solution to prototype (group exercise)	10 min	Celebration (recap)
				Next steps (planning)
	5 min	Feedback	5 min	Feedback
		Closing		Closing
Expected Outcomes	Refinement of P1 analysis		Resource conceptualization	
	Priority solution for prototyping		Foundation for future work	

* Modifiable to reflect participant input
** Developed from P1 findings and ACP literature
*** LUMA Institute (2019) human-centered design activity

Moreover, to provide a forum for shared decision-making and quality improvement, I plan to stay for an extra 30 minutes after each workshop session to receive participant questions, feedback, and concerns. In addition, I will devote at least five minutes at the end of each session to participant discussion of overall satisfaction with the design process, the strengths of the process, and areas for improvement. Participants will also be invited to share feedback over email. I opted not to give participants a formal survey for their feedback to reduce participant burden and to enhance the number and quality of responses.

B4.6. Data Analysis. Audio recordings of interviews and workshop sessions will be transcribed initially using Zoom-Otter integration, an automated transcription feature. Each transcript will be reviewed for accuracy by comparing the automated output to the original audio. A close reading of each transcript will be performed to check for errors and inconsistencies and to prepare for data analysis in each phase. Transcripts will be coded deductively and inductively using thematic analysis in both phases. Coded transcripts will be peer-reviewed by a member of the dissertation committee to assess inter-rater reliability, and any coding discrepancies will be reconciled by a second committee member. Member-checking of synthesized analyzed data will be used both as an opportunity for participant collaboration during the research process and as a method for assessing trustworthiness of the analysis (Birt, Scott, Cavers, Campbell & Walter, 2016). Supplemental materials like memos and digital artifacts will not be formally coded; however, along with demographic data, they will serve to contextualize findings from analysis of the textual data.

In P1, qualitative data from interviews will be explored using thematic analysis and assessed using the 15-point Thematic Analysis Checklist (Braun & Clarke, 2013; Braun & Clarke, 2006). After interview transcripts have been de-identified, cleaned, and verified, qualitative data will be uploaded for line-by-line coding in the qualitative data management platform Dedoose. The coding unit will be words and phrases. First, data will be coded using an a priori deductive coding schema developed from topics derived from the literature, the conceptual framework, interview guides, and the research question (Bingham & Witkowski, 2022). Second, data will be coded using an open-coding inductive approach (Bingham & Witkowski, 2022) to identify new concepts that emerge from the data. Memos and an audit trail will be kept to record rationales for decision-making, and coding schemes will be revised iteratively. Codes will be categorized and sorted by similarity to identify themes, and all codes and emerging themes will be compared within and across interviews; extreme cases, which may offer insights relevant to the research question, will also be integrated into thematic development. Emerging themes will be discussed and cross-checked with a second reviewer from the dissertation committee. De-identified findings will also be reviewed by adviser council members and presented for member-checking by participants during the first workshop session in P2. P1 findings will be used to “define the problem” and to generate a problem statement for review in the first workshop session. P1 quantitative data from the demographic survey will be analyzed using descriptive statistics in RStudio. These findings will provide a quantitative snapshot of the sample and will contextualize the findings from thematic analysis of P1 qualitative data.

In P2, workshop transcripts will provide qualitative data for deductive and inductive thematic analysis

(Braun & Clarke, 2013; Braun & Clarke, 2006). Transcripts of workshop sessions will be cleaned, de-identified, and verified; participants will not be differentiated in the transcripts since the goal of P2 is to prioritize collective ideas. The coding unit will be words and phrases, and data will be analyzed in Dedoose, first using deductive coding schemas derived from P1 findings and P2 workshop session guides and second using inductive open coding. Categories and themes will be discerned based on similarity and frequency of resultant codes, synthesizing participant ideas to facilitate development of an ACP resource for gender-affirming care. Thematic analysis will be cross-checked by a second coder from the dissertation committee, and the resource will be reviewed by the adviser council and shared with all (P1 and P2) participants for member-checking via email. In preparation for testing in future studies, the resource will likely require additional prototyping sessions after study completion to incorporate input from other community members and professionals in medicine, nursing, social work, and/or law.

B4.7. Integration of P1 and P2. To enhance the rigor of the study design, P1 and P2 will be integrated in several ways. Overall, P1 and P2 are sequential, interdependent steps in the co-design process, linked by iterative member-checking. In particular, P1 and P2 are connected through the recruitment process, as participants for P2 will be invited from a list of P1 participants for continuity of engagement throughout the study. Furthermore, findings from P1, specifically themes, ACP barriers, and initial ACP solution ideas, will be presented to participants for member-checking and further discussion in the first workshop session of P2. Finally, ACP facilitators and wishes for gender-affirming care identified in P1 will inform co-design of the ACP resource in the second workshop session of P2.

B4.8.Trustworthiness. To preserve trustworthiness, the study will follow guidelines outlined in the Journal Article Reporting Standards for Qualitative Research (JARS-Qual; Levitt et al., 2018). Specifically, credibility will be preserved through peer debriefing during coding and member-checking findings; transferability will be enhanced by recruitment of a diverse sample and collection of a rich and comprehensive dataset; reliability will be achieved by adherence to study design and ethical protocols, establishment of an audit trail of research decisions, and careful data management; and confirmability will be addressed by the audit trail and reflexive memos on my positionality, biases, and assumptions (Lincoln & Guba, 1985).

B5. Data Management. Audio data will be captured using the Zoom recording feature, the Otter transcription smartphone application, and a handheld audio recording device as back-up. Audio will be the preferred mode of record-keeping. Field notes (memos) for each discussion and digital artifacts will also be documented. All forms of data collection will be stored in UVA Box accessed from a personal computer with password protection. Computer files will be created for informed consent; for Qualtrics survey results; and for each interview and workshop session, including recordings, transcripts, field notes, slides, and related documents. Memos of decision-making throughout the study will be maintained as an audit trail. Reflexive notes will also be maintained. Documentation will contain no identifying information, unless otherwise specified in a signed release form. For back-up, data will be stored on an approved high security folder.

B6. Human Subjects Protections

B6.1. Protections. I will seek approval for this study from the University of Virginia IRB-SBS after which I will begin the informed consent process. All participation will be voluntary, and participants may choose to leave the study at any time. Furthermore, protecting participant privacy, confidentiality, and safety is of utmost importance. All data collected will be de-identified and stored securely. However, at the end of the study, collaborators will have the option to sign a release to include their name and/or initials in association with the project as a form of meaningful recognition. Participants will be expected to join Zoom calls in a private space and to use headphones, if possible, to protect the privacy and confidentiality of other participants. Additionally, IRB approval for Zoom-Otter integration will be requested to facilitate automated transcription of recordings with appropriate security measures.

Since the research topic has the potential to bring up sensitive subjects like death and dying, social support, and gender identity, I am recruiting TGD adults who are open and willing to talk about these topics. Links to national publicly available resources about ACP, LGBTQ+ aging, and grief and bereavement will be provided, if needed. Additionally, providing a safe and secure space for discussion is imperative. Each Zoom call will include a waiting room so that the identity of each participant can be verified prior to entering the meeting space, and each Zoom meeting will be locked after all verified participants have joined. At the start of the co-design process, we will set ground rules for respectful collaboration, and any conflicts that arise will be mediated in real time or discussed after the meeting with the parties in conflict to reach understanding and agreement.

B6.2. Benefits and Risks. The potential benefits of participating in this study include: involvement in developing a possible solution to health challenges faced by TGD adults; social support and networking with peers; and promotion of self-efficacy, creativity, advocacy, and agency. Throughout the study, participants will have opportunities to contribute their viewpoints and to review preliminary findings, consistent with a participatory approach that emphasizes meaningful collaboration. Participant burden will be minimized by keeping interviews and workshop sessions short (1-1.5 hours). Finally, participants will be compensated after each interview and workshop session in appreciation for their time and expertise.

The risks of participating in this study include: inadvertent breach of privacy or confidentiality; emotional distress from discussing topics related to EOL and health disparities; and frustration with the co-design process. These risks will be minimized by maintaining data security, making space for participant emotions during interviews and providing resources for further support; and checking in with participants after each co-design session to assess comfort and satisfaction with the process.

B6.3. Power Relations. Mitigating power imbalances is important in this study. First, all participation will be voluntary, with no coercion or undue inducement. Second, to equalize power relations between participants and me as a researcher, I will facilitate discussions and co-design activities such that participants can take the lead, and I will shift the locus of power toward participants during data analysis through iterative member-checking. Finally, I will transparently acknowledge my positionality and proceed through the study with respect and gratitude. Moreover, it will be important for participants to decide in the end how they would like to be acknowledged for their work in written media and subsequent studies. See Table 6 for strategies I will use to mitigate potential researcher-participant power imbalances.

Table 6. Strategies to Mitigate Researcher-Participant Power Imbalances

Potential Power Imbalance	Mitigation Strategy
Researcher position in relation to participants	• Shift important decision-making to participants • Maintain respect, humility, and gratitude • Focus on collaboration rather than control • Ensure meaningful recognition of participants
A priori decision-making by researcher	• Integrate opportunities for participant decision-making throughout the study
Difference in ACP knowledge	• Provide easy-to-follow information on ACP
Recruitment contingent on technology literacy	• Simplify reliance on technology as much as possible for participant ease of use

B7. Strengths, Limitations, and Anticipated Challenges

B7.1. Strengths. The strengths of this study include its participatory approach; its human-centered design framework; and its integration of participant involvement at various stages of the research process. The study design encourages creativity, active engagement, and teamwork using an approach that highlights participant strengths, in contrast to the deficit lens often applied to minoritized groups (Peel, Rivers, Tyler, Nodin & Perez-Acevedo, 2023). The co-design process also has the potential to yield an ACP resource that is acceptable and effective for TGD adults.

B7.2. Limitations. One limitation is the low volume of studies using a participatory co-design approach to intervention development with older adults from which to evaluate lessons learned, adapt study design elements, and anticipate challenges during data collection. However, this also offers an opportunity for contributing new knowledge about strengths-based participatory approaches with older adults and TGD persons. Another limitation is the degree of uncertainty about the use of ACP as a tool for advocacy and social change to benefit TGD adults. However, ACP has demonstrated benefits for patient outcomes and patient-provider communication, which supports exploration of ACP resources for this population and may counterbalance uncertainties regarding efficacy for advocacy and systems change.

B7.3. Anticipated Challenges. One anticipated challenge is recruitment and retention. First, eligible participants may not be interested in the subject matter or may not be available to meet. To address this concern, I will recruit older adults who may have a greater immediate need for ACP than younger adults. In recruitment materials, I will emphasize the valuable role participants can play in taking action on this important health subject, and I will streamline data collection by limiting the number and duration of interviews and workshop sessions. In P2, I will open recruitment to both P1 participants and to TGD adults who did not participate in P1, as a way to offset loss to follow-up from P1. On the other hand, the number of eligible participants who express interest may exceed the numbers needed for the study. If this occurs after recruitment ends for P1, I will add eligible participants to a waitlist for P2. If this occurs during recruitment for P2, I will offer two identical workshops of two sessions each depending on the number of eligible participants interested in joining. The project budget reflects this accommodation. The volume of data from offering two workshops will likely lengthen the time needed for data analysis, and the study timeline will be adjusted accordingly.

Another anticipated challenge is participant absence from scheduled sessions. To address this concern, I will aim to recruit in the upper limits of my expected range to accommodate attrition, and I will plan for fewer participants in the second workshop session as part of the recruitment plan. Low baseline knowledge of ACP among participants is another potential challenge. I aim to address this by including a brief overview of ACP prior to each interview and by providing a brief overview of existing ACP resources in the second workshop session. Technology may also pose a challenge for participants; therefore, I will provide an informational handout on Zoom prior to participant interviews, and I will determine the need for technology support in the form of a Zoom facilitator during workshop sessions. Finally, I expect that the subject matter of this study will be challenging. I will be sure to include the risk for emotional upset and the option to withdraw at any time in the informed consent process should the emotional burden outweigh study benefits, and I will offer online resources for further support or suggest that participants connect with their primary healthcare providers.

B8. Dissemination. I plan to use the three-manuscript model for dissemination of my dissertation work. Manuscript 1, an integrative review of the healthcare needs and assets of gender-diverse older adults, has been published open access in the *Journal of Nursing Scholarship* (Catlett, 2022). For Manuscripts 2 and 3, I plan to report findings from thematic analysis of P1 interview data (Manuscript 2) and outcomes of the co-design process spanning P1 and P2 (Manuscript 3). Possible journals for these manuscripts include *Transgender Health* and *Palliative Medicine.* I also plan to propose poster and podium presentations for the American Association of Hospice and Palliative Medicine/Hospice and Palliative Nurses Association annual assembly and the Southern Gerontological Society annual meeting in Spring 2025. For dissemination to a general audience, I plan to share study findings with members of TGD communities by preparing a study brief summarizing key takeaways and future opportunities and presenting study findings at meetings or conferences focused on LGBTQ+ aging and health, such as the Philadelphia Trans Wellness Conference. I also hope to publish at least one of the remaining two dissertation manuscripts open access, so that participants and others without access to academic journal content will be able to read and share the article. If applicable, I will work with the adviser council to prepare a policy brief proposing legislative action related to ACP for TGD adults, and I will consult with the council to determine other modes of dissemination to make information from this study accessible to their communities.

Because this study relies on collaboration and equal balance of power between researcher and participants, I will work with participants to determine the most appropriate ways to recognize them in publications and presentations, for which I will obtain IRB-approved forms of consent. I plan to send participants and adviser council members a release form after the final workshop session giving them the option to share their names in association with dissemination of study findings to a general audience. Authorship for academic publications will be possible if participants volunteer substantive contributions to writing and reviewing the manuscripts. Participants who wish to remain anonymous will be recognized collectively in acknowledgements of study contributors.

B9. Researcher and Collaborators

B9.1. Researcher. Lauren Catlett is a PhD student at the University of Virginia School of Nursing (UVA SON). Their research focuses on end-of-life care, advance care planning, and care of older adults, with a special emphasis on TGD persons. Mx. Catlett has authored or co-authored three peer-reviewed articles on healthcare for transgender older adults (Campbell & Catlett, 2019; Catlett, 2022; Catlett et al., 2023).They also co-authored an integrative review on faith-based ACP for African Americans and a cross-sectional study of ACP documentation for people with lung cancer in a rural region of the US (Catlett & Campbell, 2021; Catlett & Johnson, in production). Through these studies, Mx. Catlett has gained experience with analysis of both quantitative and qualitative data. They have also presented on ACP, EOL care, and gender-affirming care at regional and international conferences. Furthermore, Mx. Catlett has a degree in studio art and over a decade of experience facilitating creativity and collaboration for people of all ages. With this professional and research experience along with personal experience as a gender-diverse person, Mx. Catlett has valuable tools and preparation to undertake this project.

B9.2. Community Collaborators. Adviser Council: Members of the adviser council will have the option to be recognized for their contributions to the development and oversight of this study. **Participants:** Transgender or gender-diverse older adults will be acknowledged using IRB-approved forms of recognition for their valuable insights about ACP priorities for themselves and members of their communities and their contributions to the design of an ACP resource for gender-affirming care.

B9.3. Dissertation Committee.

Dr. Kimberly Acquaviva (chair) is Betty Norman Norris Endowed Professor at the UVA SON. Both interdisciplinary and collaborative, her scholarly work focuses on LGBTQ+ aging and end-of-life issues, and her clinical work has been with patients and families facing life-limiting illnesses in both hospital and hospice settings. She is the author of *LGBTQ-Inclusive Hospice & Palliative Care: A Practical Guide to Transforming Professional Practice* (Harrington Park Press, 2017) and *The Handbook for LGBTQIA-Inclusive Hospice & Palliative Care* (Columbia University Press, 2023), both important resources for my area of study. Her mentorship and expertise in collaborative approaches to engaging with the LGBTQIA+ community around palliative and EOL care will provide substantive guidance for the study's design and implementation.

Dr. Tiffany King holds the Barbara and John Glynn Research Professorship in Democracy and Equity and is Associate Professor of Women, Gender, and Sexuality at UVA. Her work is animated by abolitionist and decolonial traditions within Black Studies and Native/Indigenous Studies. She is the author of *The Black Shoals: Offshore Formations of Black and Native Studies* (Duke University Press, 2020) and co-director of the

Black & Indigenous Feminist Futures Institute (BFFI), a hub for cultivating new relationships and strengthening existing ones among scholars, artists and organizers working at the intersection of Black and Indigenous life. Her scholarship related to gender, anti-racism and anti-colonialism will offer an important perspective on the epistemology of this study and the integrity and inclusivity of the study design and research methods.

Dr. Virginia LeBaron is Associate Professor of Nursing and Kluge-Schakat Associate Professor of Compassionate Care at the UVA SON. She directs the Technology Enhanced Compassionate Care (TECC) lab, which aims to conduct innovative research that leverages technology to alleviate suffering and enhance equitable access to quality care – for patients, family caregivers, and healthcare providers – in both domestic and international settings. Her research draws upon principles and theories of community-based participatory research, implementation science, and ethnography/medical anthropology, and utilizes a Social-Ecological Model as a primary conceptual framework. Dr. LeBaron's expertise in qualitative methods, experience with design thinking, and engagement in participatory research will support the feasibility and integrity of this study.

Dr. Ishan Williams is a gerontologist and Associate Professor at the UVA SON. She studies quality of life and healthcare among older adults and their family caregivers, with a particular eye on vulnerable populations. Her current research focuses on quality-of-life issues among older adults with dementia, chronic disease management for older adults with Type 2 diabetes, and the link between cognition and vascular problems among African American adults. She also collaborates with colleagues on work focused on advance directives, end-of-life concerns, patients' transitions between home, community and hospital settings, and how individuals with chronic conditions share information about their health issues on social media. Her leadership and scholarship in the field of aging and her extensive experience with qualitative research methods will provide guidance on participant engagement and rigorous implementation of the research methods.

B9.4. Technical Support. To address questions and concerns related to technology, specifically the Zoom platform and email, informational handouts, links, and videos will be provided to all participants, regardless of comfort level with these technologies, prior to the first Zoom sessions. If needed prior to the initial interview, I will be available to troubleshoot issues with participants in need of assistance with Zoom access and usability. During workshop sessions, a Zoom facilitator, who will be a personal contact in the LGBTQ+ community, will monitor the chat and provide basic Zoom support.

C. Timeline & Budget

The expected timeline for this study is Nov 2023 – Oct 2024. The estimated costs for this study are $3600 for participant compensation only and $9870 for participant compensation plus expenses related to dissemination and researcher support.

D. Summary & Future Directions

With a human-centered design approach, this study will engage TGD adults in the collaborative development of an ACP resource for gender-affirming care. The specific form of the resource will depend on findings from data analysis and decision-making by participants. The expected outcome of this study is a preliminary ACP resource for gender-affirming care that can be further developed and tested for feasibility, acceptability, and efficacy in future studies with the goal of providing an evidence-based resource for TGD older adults to communicate their wishes for their future gender-affirming care.

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DISSERTATION

Advancing Health Equity among Transgender and Gender-diverse Older Adults: A Participatory Approach

MANUSCRIPT 1

Healthcare Needs and Assets of Gender-Diverse Older Adults: A Systematic Integrative Review

MANUSCRIPT 2

Multilevel Factors Affecting Health Equity for Transgender and Gender-diverse Older Adults

MANUSCRIPT 3

Co-developing an Advance Care Planning Resource with Transgender and Gender-diverse Adults: A Human-Centered Design Approach

MANUSCRIPT 1

Healthcare Needs and Assets of Gender-Diverse Older Adults: A Systematic Integrative Review

(published in the *Journal of Nursing Scholarship*)

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HEALTH POLICY AND SYSTEMS

Healthcare needs and assets of gender diverse older adults: A systematic integrative review

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Abstract

Introduction: Gender diverse older adults often endure health disparities, encounter discrimination in healthcare settings, and experience lack of access to healthcare. However, members of this population also have assets that help to mitigate these healthcare challenges. A systematic integrative review was performed to synthesize recent studies of the healthcare needs and assets of gender diverse older adults living in the United States.

Methods: A search of PubMed, CINAHL, Web of Science, PsycINFO, and Google Scholar was conducted. Findings from selected studies were organized by theme and subtheme.

Results: Thirty-five articles met inclusion criteria. Seven themes were identified: (1) Inclusivity and acceptance, (2) Antidiscrimination protections, (3) Community, (4) Care of mind, body, and spirit, (5) End of life preparations, (6) Financial security, and (7) Intersectionality. These themes were further divided into 20 healthcare needs and 9 healthcare assets.

Conclusion: The findings call for increased training for healthcare providers to provide safe, gender-inclusive care environments; policy to combat discrimination across all healthcare settings; supportive community resources and healthcare advocacy; empowerment of gender diverse older adults through acknowledgment of their healthcare assets; and more research to discern the role of intersectionality in the applicability of the identified themes to gender diverse older adults of various sociodemographic backgrounds.

Clinical relevance: This review benefits clinicians by suggesting practice changes to address healthcare needs of gender diverse older adults while describing healthcare assets of this population for integration into health promotion initiatives.

KEYWORDS
end-of-life care, gender diverse, gender minorities, healthcare access, older adults, palliative, transgender

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Sigma Theta Tau Beta Kappa Chapter.

INTRODUCTION

Aging members of the Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, and Asexual/Agender (LGBTQIA+) community face healthcare challenges related to their sexual and gender identities. Physical and mental health outcomes for LGBTQIA+ older adults trail health outcomes for their heterosexual, cisgender peers, and rates of discrimination within medical and legal systems have been higher for this population due to societal stigma (Stinchcombe et al., 2017). Consequently, LGBTQIA+ older adults commonly distrust healthcare providers and medical systems due to fears of mistreatment (Stinchcombe et al., 2017). At the same time, however, LGBTQIA+ older adults have healthcare-related assets, such as resilience and social support, that may mitigate the healthcare challenges they experience (Fredriksen-Goldsen, Kim, et al., 2017; Stinchcombe et al., 2017).

Gender diverse[1] older adults share many of the challenges and strengths of the larger LGBTQIA+ community while also having unique needs and assets. Gender diversity refers to identities and expressions that differ from cultural gender norms and includes gender identities such as transgender, nonbinary, and agender among others. In healthcare, studies have described physical and mental health practices that discriminate against transgender older adults (Finkenauer et al., 2012). Limited social support networks and obstacles in education, employment, government systems, and housing have also been identified in this population (Finkenauer et al., 2012). Moreover, transgender older adults demonstrated significantly poorer physical and mental health outcomes and increased stress and disability in comparison to LGB peers (Fredriksen-Goldsen et al., 2014). Transgender older adults also had significant fears and distrust of healthcare systems, affecting healthcare access (Fredriksen-Goldsen et al., 2014). In fact, the Report of the 2015 U.S. Transgender Survey found that nearly 25% of respondents avoided healthcare encounters due to fear of mistreatment by healthcare providers (James et al., 2016). Nevertheless, gender diverse older adults have demonstrated robustness and resilience in the face of significant adversity (Witten, 2014).

Understanding the healthcare needs and assets of gender diverse older adults fills an urgent need to facilitate practice and policy changes to reduce disparities and discrimination. While reviews have been conducted related to gender diverse aging and end-of-life issues (Finkenauer et al., 2012; Stinchcombe et al., 2017), a systematic review of the literature was needed to integrate findings from more recent studies. Thus, the specific aims of this systematic integrative review were (1) to synthesize recent studies addressing the healthcare needs and assets of gender diverse older adults living in the United States (US), and (2) to summarize themes and subthemes relevant to improving healthcare practice, policy, and research for this population.

METHODS

Search strategy

The integrative review format described by Whittemore and Knafl (2005) guided the search for this study. This review synthesized data from various study designs to understand the types of healthcare needs and assets of gender diverse older adults described in published research. The findings were reviewed to identify areas for practice and policy change and areas for future study.

A search of the literature was conducted on April 2, 2021 using the following databases: PubMed, CINAHL, Web of Science, PsycINFO, and Google Scholar. Inclusion criteria for this review consisted of sources that involved healthcare needs and assets of gender diverse older adults. Search terms are listed in Table 1. The search results were limited to: (1) publication year between 2015 and 2021 (2021 only for Google Scholar due to volume of results); (2) English language; (3) study population in the United States; and (4) peer reviewed articles. For the purposes of this review, the target age range was 50 years old and older, as minority groups tend to have earlier health decline and age-related life transitions (Cortes et al., 2019).

TABLE 1 Search terms

		Key terms		
Search	Database	Transgender	Aging OR end of life	Health
Search 1: Gender Diverse Aging	PubMed CINAHL Web of Science PsycINFO Google Scholar	"transgender" OR "gender non-conforming" OR "gender nonconforming" OR "gender minorities" OR "genderqueer" OR "gender queer" OR "non-binary" OR "nonbinary"	"aging" OR "older adult" OR "elderly" OR "elder"	"health"
Search 2: Gender Diverse EOL Care	PubMed CINAHL Web of Science PsycINFO Google Scholar	"transgender" OR "gender non-conforming" OR "gender nonconforming" OR "gender minorities" OR "genderqueer" OR "gender queer" OR "non-binary" OR "nonbinary"	"end of life" OR "end-of-life" OR "dying" OR "terminal" OR "hospice" OR "palliative"	__________

Data collection

The search was divided into two components, one focusing on aging and the other on end of life in order to capture results relevant to each topic of importance to older adults. Results from these two searches were combined, yielding 522 results across all databases and 479 results after merging duplicates. Articles were reviewed by title and abstract, and 399 were excluded based on the following criteria: (1) study population was located outside the US [<75% identified as US-based participants; an exception was made for one article whose results were based largely on input from US participants (Jones & Willis, 2016)]; (2) gender diverse adults were minimally included as participants or subjects [<10% of sample; an exception was made for two studies whose results focused on transgender identity-related outcomes (Dickson et al., 2021; Erosheva et al., 2016)]; (3) studies had a weak relation to aging or end-of-life care (and had few participants over 50 years old); (4) studies had weak relation to health or healthcare; and (5) results were not peer-reviewed studies. After a textual review of the remaining 80 articles, 29 were retained using the inclusion and exclusion criteria described above. The abstracts of the 450 excluded articles were reviewed twice to confirm their exclusion. A search of references yielded no additional results. To update this review, articles published between April 2021 and May 2022 using the same inclusion and exclusion criteria were reviewed as a supplement to the original search, yielding six additions. Thus, a total of 35 studies were retained (Figure 1).

Data synthesis

Data were displayed using matrices including the name, purpose, sample, design, level of evidence, results and conclusions, limitations, and implications of the studies, allowing for comparison of relevant findings. Data reduction involved dividing the findings into emergent subgroups, which were further categorized by common themes. An appraisal of level of evidence of the studies was conducted using the Johns Hopkins Nursing Evidence Based Practice Guidelines (Dang et al., 2022).

All conclusions drawn from data synthesis were verified by comparing themes with the original primary source data and in consultation with a second reviewer. An audit trail was maintained through the documentation of search and data extraction procedures and organization of data elements by subgroup in a separate matrix.

RESULTS

This search strategy yielded 35 studies, of which 9 were qualitative, 18 were quantitative, 6 were case reports, and 2 were systematic reviews or meta-syntheses (Table 2). All studies reported findings related to gender diverse aging and/or end-of-life care. The quantitative studies singularly followed cross-sectional survey designs while designs for qualitative studies varied and included qualitative descriptive (*n* = 7), ethnographic (*n* = 1), and phenomenological (*n* = 1) approaches. The systematic review article covered 66 quantitative and qualitative studies while the meta-synthesis analyzed 10 qualitative studies. The majority of studies (29) represented Level III evidence while six represented Level V evidence, according to the Johns Hopkins guidelines.

Sample size and demographics

A range of 1–1210 gender diverse older adult participants was observed across these 35 studies. Most participants in the quantitative studies were part of the National Transgender Discrimination Survey, the Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS), and the TransMetLife Survey on Later-Life Preparedness and Perceptions in Transgender-Identified Individuals. Studies employed purposeful, snowball, and convenience sampling to recruit participants either online or through community organizations. While all studies included adults over 50, some included younger participants as well.

Gender diverse identities gleaned from the demographics sections of these studies included transgender, transsexual, trans man, transmasculine, man, masculine, male, trans woman, transfeminine, woman, feminine, female, female to male, male to female, gender nonconforming, gender queer, gender fluid, nonbinary, androgynous, two-spirit, and third gender. Up to 14% of participants identified with the category of "other" (Witten, 2015). Although the majority of participants identified along the trans masculine/trans feminine binary, with more participants identifying as trans feminine overall, a range of gender identities was represented in these studies (see Table 2: Sample).

Racial and ethnic representation was homogenous with the majority of participants identifying as white (48%–93.9%); however, other identities were represented including black, Hispanic/Latinx, Native American, Hawaiian/Pacific Islander, multiracial, and "people of color." All studies recruited participants from the US with a broad geographic reach including national and regionally-specific recruitment from Alabama, California, Florida, Georgia, Illinois, Louisiana, Massachusetts, Minnesota, Mississippi, New York, North Carolina, South Carolina, the mid-Atlantic, the Midwest, the Northeast, West, and Southeast.

Themes and subthemes

From the findings of the included studies, seven themes emerged with 20 subthemes related to healthcare needs and nine subthemes related to healthcare assets for gender diverse older adults (Table 3). The seven themes were (1) inclusivity and acceptance, (2) antidiscrimination protections, (3) community, (4) care of mind, body, and spirit, (5) end of life preparations, (6) financial security, and (7) intersectionality.

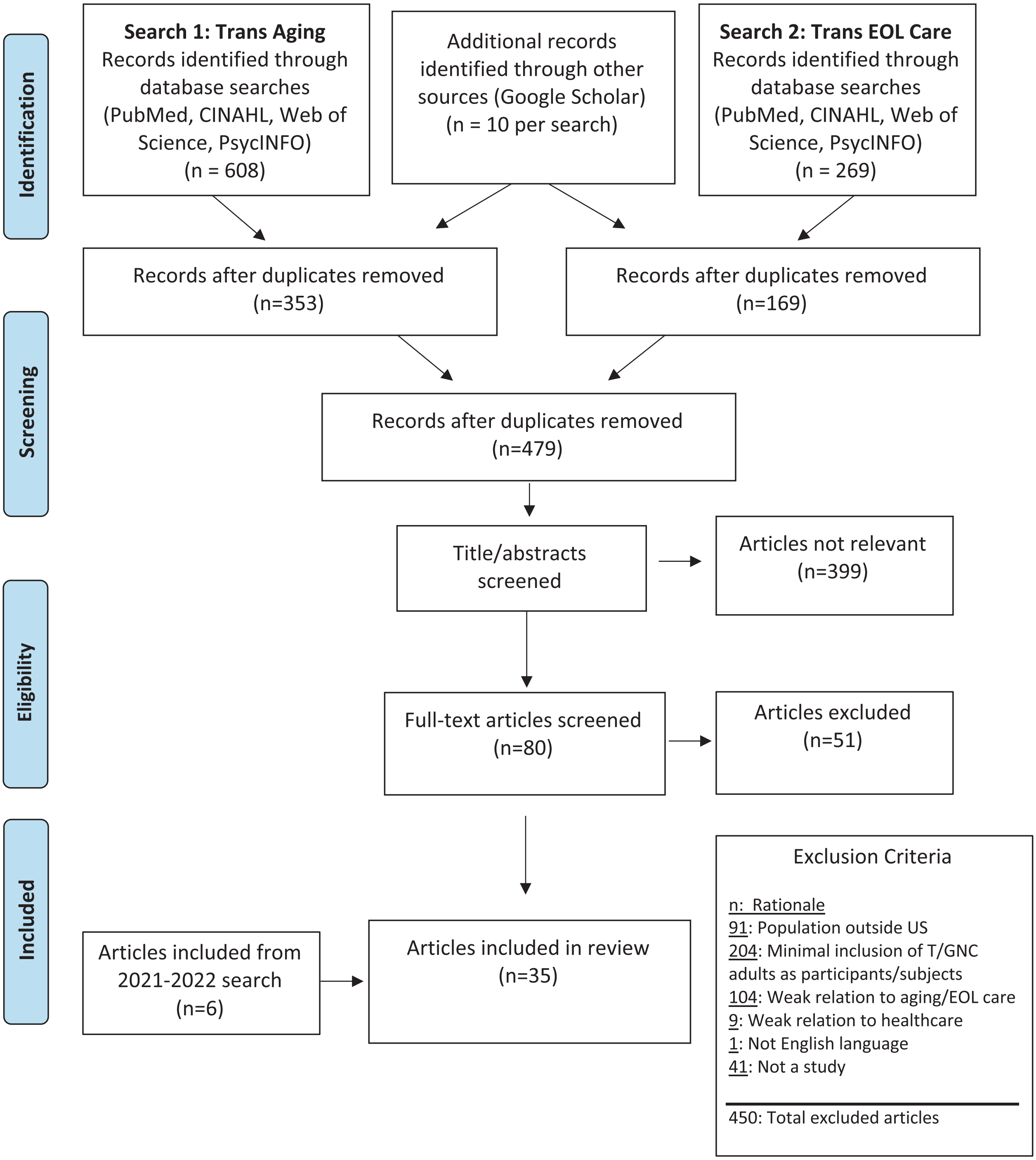

FIGURE 1 PRISMA flow diagram.

Inclusivity and acceptance

In the context of this review, inclusivity and acceptance refer to the need for healthcare personnel to provide knowledgeable, supportive, inclusive, and gender-affirming care to gender diverse older adults. Affirming and culturally-sensitive approaches to care support the gender identity of the patient or client. Just under half of the studies made reference to the need for affirming and culturally-sensitive care from healthcare providers for gender diverse older adults (Adan et al., 2021; Bell & Johnson, 2020; Carroll, 2017; Elder, 2016; Fabbre, 2015; Fredriksen-Goldsen et al., 2019; Hughto & Reisner, 2018; Jones & Willis, 2016; Kattari & Hasche, 2016; Knochel & Flunker, 2021; Scharaga et al., 2020; Sloan & Benson, 2021; Walker et al., 2017; Witten, 2015, 2016). Gender diverse older adults expressed fears of mistreatment when receiving care (Adan et al., 2021; Henry et al., 2020), and the need for training of health and human service providers was termed "critical" (Fredriksen-Goldsen et al., 2019, p. 269). Fabbre (2015) asserted that this training was necessary because "practitioners in fields such as clinical psychology, social work, counseling, education, and health care are vulnerable to perpetuating heteronormative assumptions about identity and human behavior" (p. 151). For the authors of these studies, affirming and culturally-sensitive care would incorporate cultural humility, trust-building, collaboration, diversity, intersectionality, a strengths-based approach, and a gender minority stress model of care provision, among others principles (Bell & Johnson, 2020; Elder, 2016; Hughto & Reisner, 2018; Jones & Willis, 2016; Kattari & Hasche, 2016; Scharaga et al., 2020; Sloan & Benson, 2021).

Five studies highlighted the need for inclusive healthcare environments that promote a sense of safety and acceptance of all gender identities (Henry et al., 2020; Knochel & Flunker, 2021; Lowers, 2017; Walker et al., 2017; Witten, 2016). In particular, Lowers (2017) recommended "creating an environment in which visual cues such as artwork or signage suggest inclusivity" (p. 531), and Witten (2016) advocated for creating "safe spaces for trans-identified elders to live out the rest of their lives without fear" (p. 75). Henry et al. (2020) also noted the need for spaces to convey safety to allay fears of mistreatment, while Walker et al. (2017) defined inclusive environments as those with "all-gender restrooms, patient/client registration forms that avoid gender binary language, practitioners/staff who address their patients/clients using their preferred [chosen] name and gender pronouns, as well as practitioners/staff who avoid language that implies heteronormative and cisgender-normative assumptions" (p. 431). While most studies did not specify the care environment, instead referring to healthcare settings broadly, one study called for safer, more inclusive environments in long-term care (Knochel & Flunker, 2021).

In addition to affirming care in healthcare settings, patients need mechanisms for empowerment to advocate for themselves and make healthcare decisions. This is important for gender diverse older adults because patients fear loss of agency not only due to age, but also due to provider perceptions of gender nonconformity (Adan et al., 2021). To address this fear, Walker et al. (2017) recommend the development of interventions that promote the empowerment of gender diverse older adults within healthcare settings. Such interventions may include promotion of advance care planning and appointment of advocates for older gender diverse patients to navigate general healthcare encounters.

Self-acceptance and identity disclosure may be important factors to protect gender diverse older adults from adverse outcomes when their healthcare encounters lack inclusivity, safety, and acceptance. Three studies reported on self-acceptance (Adan et al., 2021; Fabbre, 2015; Witten, 2016). Fabbre (2015) poignantly describes how "most participants shed tears of joy in … the sheer peace of accepting oneself and feeling comfortable in one's own skin" (p. 149), emphasizing the sense of release in finding self-acceptance. Further, Witten (2016) characterized the participants' report of self-acceptance as a strength in a study of transgender bisexual older adults.

While self-acceptance is an internal process, identity disclosure is an external process that involves the expression of one's gender identity in a social context. Four studies addressed this phenomenon, although the results were mixed on the application of this asset (Fredriksen-Goldsen et al., 2019; Fredriksen-Goldsen, Kim, et al., 2017; Kattari & Hasche, 2016; Sloan & Benson, 2021). Sloan and Benson (2021) point out that participants felt a sense of freedom and self-confidence with the release of constraints on gender expression. Moreover, the studies analyzed by Fredriksen-Goldsen et al. (2019) drew associations between lower disclosure rates and higher levels of depression and anxiety. While it appears that identity disclosure may be psychologically protective, the other two studies reported partial identity concealment as socially protective. One study found that presenting as one's authentic gender only part-time was associated with lower harassment than presenting full-time (Kattari & Hasche, 2016), and another found part-time concealment to be protective (Fredriksen-Goldsen, Kim, et al., 2017).

Antidiscrimination protections

Antidiscrimination protections include efforts to reduce stigma, prevent abuse, and secure rights in housing and long-term care settings. Stigma reduction and policy protections against discrimination were explicitly identified as healthcare needs in 10 studies (Carroll, 2017; Fabbre & Gaveras, 2020; Fredriksen-Goldsen, Bryan, et al., 2017; Hoy-Ellis & Fredriksen-Goldsen, 2017; Hughto & Reisner, 2018; Jones & Willis, 2016; Knochel & Flunker, 2021; Lowers, 2017; Sloan & Benson, 2021; Witten, 2016). Sloan and Benson (2021) highlighted both internalized and external stigma as salient problems for gender diverse older adults. In the study by Hoy-Ellis and Fredriksen-Goldsen (2017), internalized heterosexism (stigma) had a significant effect on depression with perceived stress as a potential mediator for the study participants. To address individual, interpersonal, and structural stigma identified in their sample, Fabbre and Gaveras (2020) suggested that life narratives may inform anti-stigma interventions, emphasizing the need for gender diverse older adult voices in shaping change.

Reporting that each additional discrimination experience conferred an 11% increase in odds of depressive distress for gender diverse older adults, Hughto and Reisner (2018) asserted that "the creation and enforcement of non-discrimination policies that protect against gender-based discrimination in everyday settings represent an essential legal protection for transgender people" (p. 10). Most of the studies reinforce this claim with evidence of discrimination among their samples. For example, Jones and Willis (2016) reported a theme of "concerns regarding discrimination and abuse in care services" among the participants, and Witten (2016) described fears of discrimination among gender diverse older adults. High rates of job-related discrimination experiences were also reported (Fredriksen-Goldsen, Bryan, et al., 2017). Studies reinforced the need for policies to address discrimination at the national level and at the level of individual healthcare settings.

TABLE 2 Review summary by study author

Study	Purpose	Sample	Design	Results/conclusions
Adan et al. (2021) Worry and wisdom: A qualitative study of transgender elders' perspectives on aging	To understand the needs of transgender elders related to healthy aging, including health care, expectations of aging, concerns for the future, and advice for young transgender people	*n* = 19 transgender older adults *Age*: 64–82 *Gender identity*: Trans woman: 10 Trans man: 9 *Race/Ethnicity*: White: 100% *Location*: US, NY (rural, suburban, and urban)	*Qualitative descriptive* thematic analysis of semi-structured interviews	Seven themes identified: (1) fear of mistreatment in elder care; (2) isolation and loneliness exacerbated by transgender identity; (3) increased vulnerability to financial stressors; (4) perceived lack of agency; (5) healthcare system and provider inclusivity; (6) giving back to one's community; (7) embracing self-truth as a path to fulfillment
Bell and Johnson (2020) Deep vein thrombosis in an aging transgender patient: Care and cultural considerations	To demonstrate the importance of addressing the physiological and psychosocial needs of aging sexual and gender diverse patients	*n* = 1 transgender older adult *Age*: 67 *Gender identity*: Trans woman *Race/Ethnicity*: African American *Location*: US, NC	*Case study* examining diagnosis and treatment of a venous thrombo-embolism related to various risk factors in a transgender patient	Main conclusions: (1) DVT likely influenced by patient's use of ethinyl estradiol which is no longer a recommended treatment; (2) importance of creating a trusting patient-provider relationship emphasized; (3) importance of cultural humility in practicing sensitivity to transgender persons' unique needs in the healthcare setting highlighted
Cai et al. (2019) Benefit of gender-affirming medical treatment for transgender elders: Later-life alignment of mind and body	To examine older age as a moderator between gender-affirming medical treatment and quality of life among transgender persons	*n* = 2420 transgender adults *Age*: 18–98 (mean = 33.8); 60+: 3.8% (92 respondents) *Gender identity*: Trans man: 1442 (59.6%) Trans woman: 978 (40.4%) *Race/Ethnicity*: (option to select 2+) White: 2001 (82.7%) Black: 154 (6.4%) Hispanic/Latinx: 165 (6.8%) Other: 170 (7.0%) *Location*: US, national	*Cross-sectional* secondary data analysis of National Transgender Discrimination Survey	Main findings: (1) Undergoing gender-affirming medical treatment associated with higher quality of life in both age groups; (2) increasing age and recent gender-affirming medical treatment associated with increased odds of higher quality of life scores; (3) higher quality of life scores reported by older participants after treatment relative to younger participants
Campbell and Catlett (2019) Silent illumination: A case study exploring the spiritual needs of a transgender-identified elder receiving hospice care	To identify the spiritual needs of a transgender woman in the last 6 months of life and to describe how a volunteer met those needs through narrative, art, and poetry	*n* = 1 transgender older adult *Age*: 59 *Gender identity*: Transgender woman *Race/Ethnicity*: White *Location*: US, mid-Atlantic	*Case study* following creative and spiritual care during transgender patient's time on hospice	Four themes identified: (1) the human element in advocacy for spiritual care; (2) the importance of safe spaces for reflection and meditation; (3) the importance of skillful means to work with transgender persons; (4) affirmation of gender identity as a spiritual need
Carroll (2017) Therapeutic issues with transgender elders	To provide practical insight into therapeutic issues for transgender older adults	*n* = 1 transgender older adult *Age*: 58 *Gender identity*: Transgender woman *Race/Ethnicity*: White *Location*: US, southeast	*Case study* following the progression of outpatient psychotherapy over 1 year for a transgender older adult	Main conclusions: (1) Complex therapeutic needs of transgender older adults discussed; (2) participant exposure to trauma related to military experience and gender identity noted; (3) continued presence of gender dysphoria and depression described

TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Cortes et al. (2019) Mental health differences between older and younger lesbian, gay, bisexual, and transgender veterans: Evidence of resilience	To examine health and identity differences between older (50+) and younger (<50) LGBT veterans	n = 254 LGBT veterans (101 transgender veterans) *Age*:19–78 (mean = 47.4); 50+: 50.3% *Gender identity*: Trans woman: 79 (31.1%) Trans man: 22 (8.7%) *Race/Ethnicity*: White: 197 (78.2%) Black: 13 (5.2%) Hispanic/Latinx: 16 (6.3%) Other: 4 (1.6%) Multiracial: 22 (8.7%) Missing: 2 (0.8%) *Location*: US	*Cross-sectional* Qualtrics online survey; measures included depression; alcohol use; anxiety; identity; outness; minority stress	Main findings: (1) Similar mental health findings among both age groups; (2) less alcohol use reported among 50+ group and transgender women; (3) older adult participants perceived less harassment and rejection than younger adults
Dickson et al. (2021) Appointment of a healthcare power of attorney among older Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) adults in the southern United States	To determine the frequency of healthcare power of attorney (HCPOA) appointment among older LGBTQ adults living in the Southern US and to describe characteristics associated with appointment of a HCPOA	n = 789 LGBTQ adults *Age*: 59 (mean) *Gender identity*: Male: 515 (65.3%) Female: 243 (30.8%) GNB/Trans/Other: 31 (3.9%) *Race/Ethnicity*: Other: 27 (3.4%) Native American: 10 (1.3%) Black: 35 (4.5%) White: 714 (90.8%) *Location*: NC, SC, GA, AL, MS, LA, FL	*Cross-sectional* online survey of LGBTQ adults over 50 years old	Main findings: (1) Gender diverse respondents were less likely to a have an appointed HCPOA relative to cisgender respondents; (2) Most respondents of any gender identity preferred to appoint a spouse or significant other as HCPOA; (3) 61.6% of respondents had appointed a HCPOA
Elder (2016) Experiences of older transgender and gender nonconforming adults in psychotherapy: A qualitative study	To provide perspectives overlooked due to marginalization of gender diverse older adults and to improve the quality of psychotherapeutic care for gender-diverse people	n = 10 gender diverse adults *Age*: 60–83 *Gender identity*: Female: 4 Male: 3 Trans woman: 1 Trans man: 1 Other: 1 *Race/Ethnicity*: White: 8 Black: 1 Asian: 1 *Location*: US, CA	*Qualitative descriptive* thematic analysis of semi-structured interviews	Three categories identified with 10 themes: (1) experiences in therapy, (a) trans-affirmative and healing experiences, (b) negative experiences, (c) positive changes; (2) life experiences, (a) transition and gender diversity issues, (b) gender diversity issues in older adulthood, (c) family of origin, (d) discrimination, harassment and abuse, (e) resiliency, community activism, education, celebration; (3) recommendations, (a) for gender diverse individuals seeking therapy, (b) for healthcare providers
Erosheva et al. (2016) Social networks of lesbian, gay, bisexual, and transgender older adults	To examine the global social networks of LGBT older adults	n = 1913 LGBT older adults (136 transgender elders) *Age*: 50+ *Gender identity*: Transgender (men and women): 136 (7%) *Race/Ethnicity*: Majority non-Hispanic White *Location*: US, national	*Cross-sectional* national survey of LGBT older adults; measures included egocentric group-specific social network data; social network size; network diversity; family relations; background characteristics	Main findings: (1) Mean total network size: 63 people; (2) transgender participants reported largest network size (mean = 86 people); (3) transgender participants had greater network diversity than lesbian and gay participants; (4) older participants had less diverse networks; (5) larger social network size and diversity associated with transgender identity (6) having a spouse or child had a positive influence on social network size; (7) service utilization and religious activity associated with larger network size and diversity

(Continues)

TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Fabbre (2015) Gender transitions in later life: A queer perspective on successful aging	To explore the experiences of transgender persons who contemplate or pursue a gender transition in later life	*n* = 22 transgender older adults *Age*: 50–60: 12 (54.5%) 60–70: 7 (31.8%) 70–80: 2 (9.1%) 80–90: 1 (4.5%) *Gender identity*: Male to Female *Race/Ethnicity*: White: 18 (81.8%) Black: 3 (13.6%) Asian: 1 (4.5%) *Location*: US, IL, Chicago	*Qualitative ethnographic* (extended case method)	Two themes identified: (1) embracing "failure," (a) navigating societal expectations and finding freedom in self-expression, (b) process of building awareness of true identity affects mental health; (2) defining success on new terms, (a) joy, strength, and liberation that comes with self-acceptance and increased self-confidence, (b) setting new expectations, (c) veteran-specific issues
Fabbre and Gaveras (2020) The manifestation of multi-level stigma in the lived experiences of transgender and gender nonconforming older adults	To apply a multi-level model of stigma to examine the manifestations of stigma in the life experiences of transgender/gender non-conforming (TGNC) older adults	*n* = 88 TGNC older adults *Age*: 50–90 *Gender identity*: Trans woman: 52.3% Trans man: 38.6% Non-Binary: 9.1% *Race/Ethnicity*: 61.4% White 22.7% Black 2.3% Asian 10.2% Latinx 3.4% Other *Location*: US, majority northeast (25%), and west (28.4%)	*Qualitative descriptive* interpretive content analysis of secondary interview data (sourced from *To Survive on This Shore: Photographs and Interviews with Transgender and Gender Non-conforming Older Adults*)	Three themes identified: (1) Presence of both individual, interpersonal, and structural stigma identified in this group; (2) nature of societal and interpersonal stigma fluctuates and is unpredictable; (3) TGNC older adults are active participants in combating stigma and enacting social change
Fredriksen-Goldsen et al. (2019) Iridescent life course: LGBTQ aging research and blueprint for the future: A systematic review	To develop an evidence-base for the field of LGBTQ aging and to assess the strengths and limitations of the existing research	*n* = 151 (median); 6–256,585 (range) LGBTQ participants *Age* (% of studies): 50+: 71.2 60+: 16.9 65+: 5.6 *Gender identity*: (% of studies): Trans-identified: 29.7 *Race/Ethnicity*: (% of studies): White (80%+): 39.4 Black included: 34.8 Hispanic included: 31.8 Asian included: 21.2 Native American included: 19.7 Other: 16.7 *Location* (% of studies): US (73.2)	*Systematic review* of 66 peer-reviewed articles published between 2009 and 2016 focusing on LGBTQ older adults aged 50+	Four themes identified: (1) interplay of lives and historical times, (a) higher rates of victimization and discrimination among transgender older adults; (2) social relationships, (a) greater social support and larger networks associated with quality of life, lower rates of disability, and less depression, (b) greater levels of social support among transgender persons; (3) timing of lives, (a) 93.7% of transgender older adults mostly or completely "out" in terms of gender identity, (b) lower disclosure rates associated with higher levels of depression and anxiety; (4) agency, (a) protective factors identified included resilience, self-esteem, self-efficacy, mastery, and hope Other findings: (1) elder abuse: 2/3 of transgender older adults reported unwanted sexual touch; (2) religious activity not significantly associated with successful aging for transgender older adults; (3) transgender older adults at increased risk for health disparities

TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Fredriksen-Goldsen, Bryan, et al. (2017) The unfolding of LGBT lives: Key events associated with health and well-being in later life	To explore the historical and environmental context that frames life experiences and adaptation of LGBT older adults	n = 411 transgender older adults (total sample = 2450 LGBT elders) *Age*: 50+ *Gender identity*: (% of sample): Transgender: 16.8 *Race/Ethnicity* (% of sample): White: 77.6 *Location*: US, national	*Cross-sectional* analysis of 2014 data from the Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS)	Main findings: (1) High rates of antidiscrimination activism reported among transgender persons (80.2% of sample); (2) high rates of job-related discrimination reported for transgender older adults; 51.4% of transgender women reported discrimination in hiring due to gender identity; (3) high rates of having children found among transgender older adults; (4) transgender participants were more likely to be "mid-life bloomers"
Fredriksen-Goldsen, Kim, et al. (2017) The cascading effects of marginalization and pathways of resilience in attaining good health among LGBT older adults	To investigate pathways by which LGBT older adults experience resilience, risk, and marginalization and their relation to positive health outcomes	n = 401 transgender older adults (total sample = 2415 LGBT older adults) *Age*: 50+ *Gender identity* (% of sample): Transgender: 16.6 *Race/Ethnicity*: (% of sample): White: 78.1 *Location*: US, national	*Cross-sectional* analysis of 2014 data from the Aging with Pride: National Health, Aging, and Sexuality/ Gender Study (NHAS)	Main findings: (1) Identity affirmation and social resources contributed positively to mental health; (2) good mental health associated with health-promoting behaviors and negatively associated with health-risk behaviors; (3) marginalization negatively linked to social resources and mental health and good physical health
Greene et al. (2016) LGBTQ aging: Mental health at midlife and older adulthood	To predict perceived LGBTQ positive mental health at midlife and in older life adulthood as a function of the potential risk factors of physical health, financial anxiety, loneliness, alienation, body shame, and protective factors of self-compassion and self-transcendence	n = 56 transgender older adults (sample = 525 LGBT adults) *Age*: Midlife (50–64): 40 (71%) Older Life (65+): 16 (29%) *Gender identity*: Transgender: 56 *Race/Ethnicity*: (sample totals) White: 419 (79.8%) Asian: 5 (1%) American Native: 5 (1%) Pacific Islander: 5 (1%) Black: 12 (2.3%) Hispanic: 26 (5%) Multiracial: 19 (3.6%) Other 34 (6.5%) *Location*: US, national	*Cross-sectional* online survey conducted between 2015 and 2016	Main findings: (1) At midlife, financial anxiety, physical health, self-compassion, alienation, self-transcendence, and body shame significantly contributed to mental health; (2) in older life, self-compassion, physical health, financial anxiety, and self-transcendence significantly contributed to mental health
Guo et al. (2022) Prevalence of Alzheimer's and related dementia diseases and risk factors among transgender adults, Florida, 2012–2020	To estimate the prevalence rates of Alzheimer's disease and related dementias (ADRD) and their risk factors in the transgender population and compare the rates to those in cisgender adults	n = 1784 transgender adults (n = 452 50+) *Age*: 39.2 years (mean); 61.5 years (mean for 50+) *Race/Ethnicity*: White: 50.6% (57.3% 50+) Black: 14.7% (12.2% 50+) Other: 2.9% (2.0% 50+) Hispanic: 16.6% (17.3% 50+) Unknown: 15.2% (11% 50+) *Location*: FL	*Cross-sectional* secondary data analysis of records from the OneFlorida Clinical Research Consortium	Main findings: (1) Generally, prevalence of ADRD was higher in transgender adults than cisgender adults, although the difference in older adults was not significant; (2) prevalence of ADRD risk factors was significantly higher in transgender adults for 11/13 risk factors; (3) older adults had significantly higher rates of ADRD risk factors for 7/13 risk factors (smoking, depression, diabetes, on antidiabetic drug, hypertension, on antihypertensives, sleep disorders)

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TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Henry et al. (2020) Transgender and gender non-conforming adult preparedness for aging: Concerns for aging, and familiarity with and engagement in planning behaviors	To record identity-specific aging concerns and assess preparation for aging among transgender/gender non-conforming (TGNC) older adults	$n = 154$ TGNC adults *Age*: 18–60 (mean 29.89) *Gender identity*: Masculine: 14.9% Transmasculine: 11.7% Feminine: 36.4% Transfeminine: 12.3% GNC: 23.4% Other: 1.3% *Race/Ethnicity*: White: 67.5% Black: 11% Asian/Latinx: 8.4% Other: 4.5% *Location*: US, national	*Cross-sectional* survey delivered online via Mturk and email; measures: aging concerns; preparedness for aging; demographics	Main findings: (1) Both general and identity specific aging concerns expressed (e.g. losing ability to care for self; going into long term care; being buried in clothing from birth gender; being denied care d/t age and medical transition); (2) low levels of EOL planning behaviors (mean sample age noted as reason); (3) lower age preparatory behaviors but higher familiarity among GNC group ($p = 0.011$ and 0.024 in comparison to trans masculine and trans feminine groups)
Hoy-Ellis et al. (2017) Prior military service, identity stigma, and mental health among transgender older adults	To examine relationships between prior military service, identity stigma, and mental health among transgender older adults	$n = 183$ transgender adults *Age*: 60.11 (mean) *Gender identity*: Trans woman: 47% Trans man: 27% Other: 26% *Race/Ethnicity*: People of color: 32% White: 68% *Location*: US, national	*Cross-sectional* secondary data analysis of 2014 data from Aging with Pride: National Health, Aging, and Sexuality/Gender Study (NHAS)	Main findings: (1) Twenty-two percent of sample had prior military experience and had significantly lower levels of depressive symptoms and higher psychological quality of life than those without prior military experience; (2) main results contrasted with negative outcomes associated with military service in other studies, suggesting post-traumatic growth
Hoy-Ellis and Fredriksen-Goldsen (2017) Depression among transgender older adults: General and minority stress	To examine the direct and indirect effects of internalized heterosexism, disclosure of gender identity, and perceived general stress in association with depression among transgender older adults	$n = 174$ transgender adults *Age*: 50–86 (mean = 60.97) *Gender identity*: Trans woman: 89 (64%) Trans man: 50 (36%) *Race/Ethnicity*: Hispanic: 6 (3.6%) Black: 8 (4.9%) American Indian: 12 (7.3%) Asian/Pacific Islander: 3 (1.8%) White: 136 (82.4%) *Location*: US, national	*Cross-sectional* secondary analysis of data from the Caring and Aging with Pride Over Time: National Health, Aging, Sexuality/Gender Study (NHAS)	Main findings: (1) Nearly half of the sample was experiencing clinically significant depressive symptoms; (2) internalized heterosexism had significant positive indirect and total effect on depression, with perceived stress as potential mediator; (3) concealment of gender identity not associated with depression; (4) perceived general stress has a significant direct effect on depression; (5) general stress may exert at least as strong an effect as minority stress on mental health
Hoy-Ellis et al. (2022) Utilization of recommended preventative health screenings between transgender and cisgender older adults in sexual and gender minority communities	To investigate the likelihood of transgender adults aged 50 and older receiving recommended preventative health-screenings, as compared to cisgender LGB adults of similar age	$n = 165$ transgender adults (total $n = 2514$) *Age*: 61 (mean) *Gender identity*: Transgender women: 104 Transgender men: 61 *Race/Ethnicity*: White: 79.8% Hispanic: 3.7% Black: 4.9% Other 11.7% *Location*: US, national	*Cross-sectional* secondary analysis of 2010 data from the Caring and Aging with Pride Study	Main findings: (1) Transgender participants less likely to have accessed 4/8 recommended screenings (Pap smear, osteoporosis test, PSA test, mammogram); (2) transgender men had lower odds than transgender women to have had two of the recommended screenings (stool test, colonoscopy)

TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Hughto and Reisner (2018) Social context of depressive distress in aging transgender adults	To investigate the relationship between discrimination and mental health in aging transgender adults	*n* = 61 gender diverse adults *Age*: 50–75 (mean = 57.7) *Gender identity*: FtM spectrum: 23% MtF spectrum: 77% *Race/Ethnicity*: White: 78.7% Black: 3.3% Hispanic/Latinx: 6.6% Multiracial: 4.9% Other: 6.6% *Location*: US, MA	*Cross-sectional* survey with purposive online sampling; measures: demographics; chronic conditions; social support; discrimination; depressive distress	Main findings: (1) Associations found between number of discrimination experiences, discrimination related to gender identity, and past-week depressive distress; (2) each additional discrimination experience conferred an 11% increase in odds of depressive distress for gender diverse older adults; (3) average of five experiences of everyday discrimination reported for this group
Jones and Willis (2016) Are you delivering trans positive care?	To canvas the concerns of transgender elders as well as their priorities and expectations for future care in later life, if needed, and to articulate a vision of trans-positive care for social care services	*n* = 9 transgender adults *Age*: 44 (mean; range: 26–57) *Gender identity*: Trans man/Trans masculine/FtM: 7 Trans woman: 1 Gender queer: 1 *Race/Ethnicity*: Not specified *Location*: US (4), International (5)	*Qualitative descriptive* thematic analysis of semi-structured interviews	Six themes identified: (1) relationship between health and social care, (a) health care needs are of high concern, (b) avoiding medical treatment common, (c) fears of exposing gendered body parts in personal care; (2) importance of networks and community; (3) need to provide culturally competent services; (4) concerns regarding discrimination and abuse; (5) expectations of an aged activist generation; (6) aspirations of future care provision, (a) merits and deficits of LGBT-specific care services, (b) need for independent advocacy
Kattari and Hasche (2016) Differences across age groups in transgender and gender non-conforming people's experience of health care discrimination, harassment, and victimization	To examine experiences of discrimination, harassment, and victimization among different age groups of transgender/gender non-conforming persons using health services	*n* = 5885 gender diverse adults (1210 older adults 50+) *Age*: Less than 50: 4675 50–64: 1096 65+: 114 *Gender identity*: Male/man: 10.2% (50–64) 9.7% (65+) Female/woman: 61.2% (50–64) 61.9% (65+) Part-time or not listed: 28.5% (50–64) 28.3% (65+) *Race/Ethnicity*: White: 88.8% (50–64); 93.9% (65+) People of color: 11.2% (50–64); 6.1% (65+) *Location*: US, Puerto Rico, Guam	*Cross-sectional* secondary data analysis of 2010 National Transgender Discrimination Survey	Main findings: (1) One fifth of participants of any age reported experiencing discrimination or harassment in health care settings related to gender identity; (2) youngest age groups reported highest discrimination in health services with discrimination decreasing with increasing age; (3) both harassment and victimization decreased with age overall except for the over 65 age group; (4) having private insurance was found to be a protective factor against discrimination; (5) older age of transition was correlated with lower reported discrimination; (6) people of color were more likely to report discrimination; (7) presenting as authentic gender only part-time associated with lower harassment than presenting full time

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TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Knochel and Flunker (2021) Long-term care expectations and plans of transgender and nonbinary older adults	To explore how gender identity affects transgender and nonbinary (TNB) older adults' fears, hopes and plans for use of institutional long-term care	*n* = 24 TNB adults *Age*: 63.5 (mean) (range: 56–73) *Gender identity*: MtF, trans woman, female: 18 (75%) FtM, trans man, male: 4 (16.7%) Nonbinary: 2 (8.3%) *Race/Ethnicity*: White: 22 (92%) *Location*: US, MN	*Qualitative descriptive* analysis of semi-structured interviews based on a framework combining critical gerontology, transfeminist theory, and queer theory	Three themes identified: (1) apprehension about mistreatment and identity loss, (a) mistreatment due to gender bias, (b) loss of gender identity through misgendering or dementia; (2) hope to avoid mistreatment and identity loss, (a) death first, (b) unbiased, respectful care, (c) dementia to avoid distress over bias, (d) conceal gender identity through physical transition; (3) plan for avoiding and navigating long-term care, (a) remain in community, (b) suicide, (c) physical transition, (d) fighting discrimination Other findings: mean age of transition was 50 years old
Lippe et al. (2021) Caring for an unconscious transgender patient at the end of life: Ethical considerations and implications	To describe an approach to the provision of affirmative, trans-inclusive care in a palliative nursing context that integrates cultural humility and self-reflection into an established patient care framework	*n* = 1 transgender adult *Age*: 30 *Gender identity*: Trans female *Race/Ethnicity*: Black *Location*: US	*Case study* of a transgender patient at end of life	Main conclusions: Outline given for trans-inclusive primary palliative nursing care (PPNC), including: (1) language and communication; (2) values, beliefs and preferences; (3) holistic care of total pain; (4) bereavement; (5) obligation to make amends Other findings: Importance of integrating concepts of cultural humility, moral archaeology, and an inclusive communication framework
Lowers (2017) End-of-life care planning for lesbian, gay, bisexual, and transgender individuals	To solicit advance care planning priorities among lesbian, gay, bisexual, and transgender (LGBT) individuals to explore whether sexual orientation and gender identity shape concerns about EOL care	*n* = 30 LGBT adults *n* = 5 (17%) transgender adults *Age*: 25–70 *Gender identity*: Male: 21 Female: 7 Other: 2 *Race/Ethnicity*: Not specified *Location*: US, NY	*Qualitative descriptive* analysis of five focus groups with semi-structured interviews	Eight themes identified: (1) loss of capacity at end of life; (2) chosen family as healthcare proxies; (3) need for an advocate; (4) identifying a healthcare proxy or advocate; (5) health care decision-making in the long-term context; (6) healthcare providers, sexual orientation, and gender identity; (7) ACP and the health care provider; (8) limitations of the health care system
Poteat et al. (2021) Cardiovascular disease in a population-based sample of transgender and cisgender adults	To describe the distribution of smoking, select cardiovascular disease (CVD) conditions, and venous thromboembolism (VTE) among transgender adults by gender identity and compared with those among cisgender adults	*n* = 114 transgender participants >40 years old *Age*: 53.5 (mean) *Gender identity*: Trans woman: 70 Trans man: 25 Gender nonbinary: 19 *Race/Ethnicity*: Black: 18% Not Black: 82% *Location*: US, national	*Cross-sectional* data analysis of a sample from the TransPop study	Main findings: (1) No meaningful differences between groups in smoking or CVD conditions; (2) increased odds of VTE among transgender women compared to cisgender women; (3) greater odds of discrimination, psychological distress, and adverse childhood experiences found among transgender participants and these were variably associated with increased odds of CVD conditions, VTE, and smoking

TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Rosenwohl-Mack et al. (2022) Building H.O.U.S.E (Healthy Outcomes Using a Supportive Environment): Exploring the role of affordable and inclusive housing for LGBTQIA+ older adults	To explore the lived experiences of older adults currently residing in a new LGBTQIA+ welcoming and affordable senior housing building, with a focus on perceived benefits for health and well-being	*n* = 21 LGBTQIA+ older adults (*n* = 3 transgender) *Age*: 61 (mean) *Gender identity*: Female: 33% Male: 57% Transgender female: 14% *Race/Ethnicity*: American Indian: 14% Black: 38% White: 48% (Hispanic: 14%) *Location*: CA	*Qualitative descriptive* analysis of three focus groups	Six themes identified: (1) housing stability improves mental health and reduces stress; (2) physical environment promotes well-being and healing; (3) community and social support are protective for health; (4) in-house support facilitates access to healthcare in LGBTQIA+ older adults; (5) mixed feelings on LGBTQIA+ welcoming housing; (6) aging in senior housing Other findings: Discrimination and housing instability were also mentioned
Scharaga et al. (2020) What happens when we forget our own narrative: Transgender dementia case study	To illustrate the assessment and treatment recommendations for a late-transitioning transgender female	*n* = 1 transgender adult *Age*: 85 *Gender identity*: Trans female *Race/Ethnicity*: White *Location*: US	*Case study* of a transgender woman with dementia	Main conclusions: (1) Table of recommendations provided; (2) diagnosis of Alzheimer's disease and cerebrovascular disease given to participant; (3) nuanced psychosocial factors present in evaluating aging transgender persons; (4) decision-making ability may be compromised with age and cognitive decline exacerbated by limited or discriminatory health services; (5) indeterminate effect of long-term hormone therapy on cognition
Sloan and Benson (2021) Toward a conceptual model for successful transgender aging	To summarize findings across the body of qualitative transgender aging research through a systematic, qualitative, theory-generating meta-synthesis	*n* = not specified (10 articles) *Age*: 50+ *Gender identity*: Transgender *Race/Ethnicity*: Not specified *Location*: US	*Systematic meta-synthesis* of 10 qualitative studies	Three themes identified: (1) gender expression, (a) transitioning, (b) sense of autonomy, (c) sexuality; (2) shedding internalized stigma, (a) release of earlier life constraints on gender expression, (b) sense of freedom and self-confidence, (c) remaining shame and regret; (3) championing a resilience mindset, (a) experiences of hardship due to discrimination, (b) development of positive sense of self, pride, perseverance, and courage, (c) active engagement with social network
Stevens and Abrahm (2019) Adding silver to the rainbow: Palliative and end-of-life care for the geriatric LGBTQ patient	To present the case of a LGBTQ older adult dying from metastatic ovarian cancer	*n* = 1 gender nonconforming older adult *Age*: 67 *Gender identity*: Legally recognized as male *Race/Ethnicity*: Not specified *Location*: US, MA Boston	*Case study* following hospitalization of gender nonconforming patient dying of cancer	Main conclusions: (1) Effect of disclosure/non-disclosure of gender identity on availability of support identified; (2) impact of limited insurance related to gender identity; (3) strengths of LGBTQ older adults included experience overcoming adversity, greater strength, and greater empathy; (4) table listing recommendations for LGBTQ elders in palliative care provided

(Continues)

TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Walker et al. (2017) Impact of anticipated bias from healthcare professionals on perceived successful aging among transgender and gender nonconforming older adults	To determine if anticipation of bias from healthcare professionals, as well as other variables, predicted successful aging among transgender and non-conforming (TGNC) older adults	*n* = 384 TGNC older adults *Age*: 51–70+ *Gender identity*: Masculine: 8.6% Feminine: 33.9% Androgynous: 3.1% Transgender:18.5% Trans man: 7.3% Trans woman: 13.3% Two-spirit: 3.6% Other: 11.7% *Race/Ethnicity*: White: 91.2% Black: 0.5% Hispanic/Latinx: 1.0% Multiracial: 2.6% Other: 4.2% *Location*: US (80.5%)	*Cross sectional* survey drawn from TransMetLife Survey on Later-Life Preparedness and Perceptions in Transgender-Identified Individuals	Main findings: (1) Larger social support networks and higher levels of confidence that a healthcare professional will respect them associated with increased odds of perceiving successful aging; (2) income and disability status were also predictors of perception of successful aging
Whitestone et al. (2020) Overcoming ungrievability: Transgender expectations for identity after death	To examine the thoughts and attitudes of older trans people (40+ years old) with regard to the phenomenon of nonconsensual de-transitioning after death and the expectations they have regarding the expression of their own identity after death	*n* = 32 transgender adults *Age* (mean): 55 (range: 41–77) *Gender identity*: Female/Woman: 6 Transwoman/Trans feminine: 6 Male/Man: 3 Trans man/Trans masculine: 3 Transgender/Trans-sexual: 7 Gender fluid: 4 Other/Gender Nonconforming: 3 *Race/Ethnicity*: White/Caucasian: 22 Asian: 6 Multiracial: 4 *Location*: US, Midwest	*Qualitative phenomenological* analysis of semi-structured interviews	Main findings: (1) Most participants had not thought much of their own post mortem de-transitioning or funeral arrangements; (2) universal negative reaction to practice of non-consensual de-conditioning among participants; (3) wide variation in preferred expression of "authenticity" at death reported [group 1: lived experience only (8); group 2: birth identity only (2); group 3: both lived and birth identities (14); group 4: do not care which identity is memorialized (8)]

TABLE 2 (Continued)

Study	Purpose	Sample	Design	Results/conclusions
Witten (2016) Aging and transgender bisexuals: Exploring the intersection of age, bisexual sexual identity, and transgender identity	To examine the experiences and needs of an international sample of current, English-speaking, bisexual, and transgender-identified adults on a number of later life and EOL perceptions, preparations, and concerns	*n* = 147 trans-bisexual adults (70 participants 51+) *Age*: 18–30: 11.6% 31–50: 40.8% 51+: 47.6% *Gender identity*: Trans feminine: 43.8% Trans masculine: 21.9% Transgender/third gender: 21.2% Other: 13% *Race/Ethnicity*: White: 89.7% Multiracial: 3.4% Hispanic: 1.4% Other: 0.7% *Location*: US (82%) International (18%)	*Cross-sectional* secondary analysis of survey data collected from the Trans MetLife Survey on Later-Life Preparedness and Perceptions in Transgender-Identified Individuals (TMLS)	Main findings: (1) Fears expressed around health care and treatment in older age, dementia, abuse, and ability to maintain identity expression; (2) overall, sample was ill-prepared for later-life legal problems; (3) general financial stress and fears of financial problems due to gender identity; (4) general identification with some form of spirituality; (5) top concerns about aging: becoming unable to care for self; being alone; dementia; gender discrimination; (6) fears of mistreatment by healthcare personnel; (7) fear of discrimination from caregivers; (8) fear of loss of privacy; (9) range of expectations for aging including journey completion, passing on wisdom, spending time with loved ones, good physical and financial health, self-euthanasia, suicide; (10) strong sense of resilience and hope; self-acceptance; taking good care; community engagement; (11) varied perceptions of successful aging; (12) most fears centered on gender identity not sexual identity
Witten (2015) Elder transgender lesbians: Exploring the intersection of age, lesbian sexual identity, and transgender identity	To examine the experiences and needs of an international sample of current, English-speaking, lesbian, transgender-identified adults around a number of later-life and EOL perceptions, preparations, and concerns	*n* = 276 trans-lesbian adults (169 participants 51+) *Age*: 18–30: 11.5% 31–50: 27.4% 51+: 61.1% *Gender identity*: Trans feminine: 73.2% Trans masculine: 2.7% Transgender/Third Gender: 9.8% Other: 14.3% *Race/Ethnicity*: White/Caucasian: 93.8% Hispanic: 1.8% Other: 4.4% *Location*: US 89% International: 11%	*Cross-sectional* secondary analysis of survey data collected from the Trans MetLife Survey on Later-Life Preparedness and Perceptions in Transgender-Identified Individuals (TMLS)	Main findings: (1) Overall feeling of aging successfully in this sample; (2) fears for the future, insecurities about access to healthcare and healthcare treatment; (3) lack of preparedness for later-life legal problems; (4) fears about dementia and inability to maintain identity expression; (5) most fears centered around gender identity not sexual identity; (6) top four concerns about aging included becoming unable to care for self; becoming dependent; dementia; becoming sick or disabled; (7) fears around potential disrespect at end of life; (8) expectations for aging included a peaceful death, journey completion, growing old with loved ones, self-euthanasia, suicide; (9) fear of (mis)treatment in institutional settings

Abbreviations: EOL, end of life; FtM, female to male; LGBTQ, Lesbian, Gay, Bisexual, Transgender, Queer; MtF, male to female; TGNC, transgender/gender nonconforming; TNB, transgender/nonbinary.

TABLE 3 Healthcare needs and assets by theme

Theme	Healthcare need	Healthcare asset
Inclusivity and Acceptance	Affirming/Culturally-Sensitive Care Inclusive Healthcare Environments Empowerment in Healthcare Settings	Self-Acceptance Identity Disclosure/Acceptance
Antidiscrimination Protections	Stigma Reduction and Antidiscrimination Policy Safety from Abuse	Activism
Community	Community Resources Social Support Advocacy	Community Engagement Social Network and Chosen Family
Care of Mind, Body and Spirit	Physical Health Care Mental Health Care Spiritual Care Trauma-Informed Care	Resilience Resourcefulness/Creativity Post-Traumatic Growth
End of Life Preparations	Palliative Care Advance Care Planning	
Financial Security	Financial/Insurance Assistance Accessible Housing	Higher Income/Insured Status
Intersectionality	Sexual Identity-Informed Care Veteran-Specific Care Race/Ethnicity-Informed Care	

In the study by Cortes et al. (2019), older adult participants perceived less harassment and rejection than younger adults. Moreover, in the study by Kattari and Hasche (2016), although 20% of participants of any age reported experiencing discrimination or harassment in healthcare settings related to gender identity, age appeared to be a protective factor against discrimination, as the prevalence decreased with increasing age. However, as the authors conjecture, older adults may have underreported discrimination due to generational differences in defining the term, so the actual prevalence of discrimination for this population remains unclear.

Safety from abuse consists of the need for elder abuse protections, which surprisingly, appeared explicitly in just one article. Fredriksen-Goldsen et al. (2019) called for elder abuse protections, finding that two thirds of study respondents reported unwanted sexual touch. Elder abuse emerges as a theme in other articles through the expressed fears of mistreatment at the hands of healthcare providers in old age (Adan et al., 2021; Elder, 2016; Jones & Willis, 2016; Knochel & Flunker, 2021; Witten, 2016). Thus, the threat of elder abuse affecting gender diverse older adults is an established, though understudied, concern for this population.

Activism served as a healthcare asset for gender diverse older adults in some studies. Fredriksen-Goldsen, Bryan, et al. (2017) found that about 80% of their study sample engaged in anti-discrimination activism. With respect to long-term care needs, one transgender man in the study by Knochel and Flunker (2021) expressed that “long-term care … can get really sticky for transgender people … if there's a long-term thing that I'm inclined to be an activist about, that might well turn out to be it” (p. 6). This “aged activist generation” (Jones & Willis, 2016, p. 55) has the potential to influence change on its own terms in order to reduce healthcare discrimination.

Community

In this context, community refers to the people and services dedicated to enhancing the social wellbeing of gender diverse older adults and the existing social networks and connections they have in their lives. Establishment of community resources is a healthcare need raised in several studies (Adan et al., 2021; Fabbre & Gaveras, 2020; Henry et al., 2020; Hughto & Reisner, 2018). One recommendation called for the creation of social programs connecting transgender elders to inclusive providers and facilities (Adan et al., 2021) contingent on the involvement of gender diverse older adults in program development (Fabbre & Gaveras, 2020). Existing LGBTQIA+ community resources, such as SAGE and FORGE, were mentioned as beneficial for gender diverse older adults (Henry et al., 2020). Additionally, suggestions for future programs and services included intergenerational programs pairing gender diverse older adults with gender diverse youth as well as programs to connect gender diverse older adults with their peers to expand social networks (Hughto & Reisner, 2018).

Participants reported that social isolation is detrimental to mental health for gender diverse older adults (Adan et al., 2021). Furthermore, Erosheva et al. (2016) found that older participants had less network diversity than younger participants. Hughto and Reisner (2018) suggest strategies to improve social support, including "helping transgender people to develop a stronger network of friends, involving transgender aging individuals in collective activism, and linking aging transgender adults with young transgender adults" (p. 10). Clinician-supported efforts to assist gender diverse older adults in building support networks were also recommended (Knochel & Flunker, 2021). Furthermore, Jones and Willis (2016) draw attention to the legal dimension of the need for recognition of extended communities and networks in the care of gender diverse older adults.

The need for advocacy involves the provision of a proxy, supporter, or ally to aid the gender diverse older adult in navigating the healthcare system and preventing abuse. In the study by Lowers (2017), the "need for advocacy and chosen family as healthcare proxies" was identified as a main theme, and an advocate was defined as someone who "would attend medical appointments with a patient to take notes and ask questions and make decisions as a health care proxy to ensure that the caregiving environment addressed not only the patient's medical needs but also the patient's identity and dignity" (p. 529). In relation to long-term care, the advocate could be a long-term care ombudsman or an ally devoted to visiting gender diverse older adults and monitoring treatment within that setting (Knochel & Flunker, 2021). In relation to spiritual care, the advocate, identified from within a care organization or faith community, would use "skillful means" to help the gender diverse older adult express spirituality and form connections with others (Campbell & Catlett, 2019). In this way, the advocate would speak on behalf of medical, social, and spiritual needs for the gender diverse older adult.

In addition to activism, community engagement is a critical asset. Giving back to the community and volunteerism were practices found among the participants in the studies for this review (Adan et al., 2021; Elder, 2016; Witten, 2016). Engaging in these activities and in the creation of their own interventions may promote a sense of agency and self-worth for gender diverse older adults (Fabbre & Gaveras, 2020). Furthermore, service utilization and involvement in religious activity were associated with larger social network size and diversity (Erosheva et al., 2016).

Social networks can be protective in a variety of ways. Fabbre and Gaveras (2020) noted that negative experiences of structural stigma were counteracted with the support of friends, families, and professionals. Fredriksen-Goldsen et al. (2019) found that greater social support and larger networks were associated with quality of life and lower rates of disability and depression and that transgender persons had higher levels of social support when compared to LGBQ peers. This finding was supported by Erosheva et al. (2016), who found that network size was positively associated with transgender identity. Moreover, Fredriksen-Goldsen, Bryan, et al. (2017) found that transgender older adults had higher rates of having children as part of their social networks. Findings also suggest that for gender diverse older adults, social networks protect against depressive distress and marginalization, help to improve perceptions of successful aging, and show promise in improving aging preparatory behaviors (Fredriksen-Goldsen et al., 2019; Fredriksen-Goldsen, Kim et al., 2017; Henry et al., 2020; Hughto & Reisner, 2018; Walker et al., 2017).

Care of mind, body, and spirit

The care of mind, body, and spirit encompasses physical, mental, and spiritual care of gender diverse older adults with attention to the trauma that many members of this population have experienced inside and outside of healthcare settings. Studies that addressed physical care attended not only to the benefits of gender-affirming treatments but also to the risks of such measures and the need for attention to non-gender-specific medical conditions in gender diverse older adults. Cai et al. (2019) reported higher quality of life among participants after receiving gender-affirming medical care compared to peers without gender-affirming treatment, highlighting the need for access to this type of care for gender diverse older adults. While gender-affirming treatments and surgeries should be accessible to gender diverse older adults, three studies expressed caution, citing the unknown long-term risks of hormone therapy; the risks involved in surgical procedures for older people; and the risks of physical transitioning used as a strategy to avoid discrimination (Bell & Johnson, 2020; Knochel & Flunker, 2021; Scharaga et al., 2020).

Physical health care of gender diverse older adults may involve attending to non-gender-specific conditions as well as personal care in long-term care settings. Transgender participants in one study were less likely to have accessed four of eight recommended health screenings, including mammogram, Pap smear, osteoporosis test, and prostate specific antigen test (Hoy-Ellis et al., 2022). Moreover, transgender older adults had significantly higher rates of risk factors for Alzheimer's disease and dementia, including smoking, depression, diabetes, and hypertension (Guo et al., 2022). Transgender older adults reported less engagement in physical activity than their cisgender peers, which was associated with poor physical health, disability, and depression and anxiety (Fredriksen-Goldsen et al., 2019). Studies found that health promotion interventions are needed to focus on physical health conditions and activity levels in this population (Fredriksen-Goldsen et al., 2019; Fredriksen-Goldsen, Kim et al., 2017).

Personal care in long-term care settings was a major concern for some gender diverse older adults. Participants expressed fears of exposure of gender nonconforming body parts during physical care like bathing and continence care in long-term care settings (Jones & Willis, 2016). Also, transfeminine participants described fears about not having timely facial shaves such that they would appear more masculine (Knochel & Flunker, 2021).

Mental health care is a need characterized by access to psychotherapy or counseling; attention to substance use and addiction; and reaction to suicide risk factors and behaviors. Carroll (2017) highlighted the importance of formal therapy and psychological care for transgender persons, and Elder (2016) went a step further to recommend psychotherapy informed by World Professional

Association for Transgender Health (WPATH) standards. Some studies communicated the need for attention to risk factors for poor mental health outcomes for gender diverse persons, including financial stress, general and minority stress, physical health, alienation, and body shame (Greene et al., 2016; Hoy-Ellis & Fredriksen-Goldsen, 2017). Attention to substance use and suicidality was also defined as a critical need (Fabbre & Gaveras, 2020; Knochel & Flunker, 2021; Witten, 2015, 2016). Of note is a phenomenon described in a few studies that addressed suicide, specifically the construct of the "planned suicide" in which gender diverse older adults cope with aging and minority stress through planning their own death (Knochel & Flunker, 2021; Witten, 2015, 2016). Although these studies did not address the prevalence of suicidality among gender diverse older adults, this emerging subtheme represents an area of critical need for attention, intervention, and research.

Spiritual care as a healthcare need refers to the provision of safe spaces for spiritual expression, clinician training in spiritual care of gender diverse older adults, cultural sensitivity training for faith-based organizations, and acceptance of diverse spiritual beliefs (Campbell & Catlett, 2019; Witten, 2015, 2016). Although religious activity was not associated with successful aging (Fredriksen-Goldsen et al., 2019), transgender participants did acknowledge identification with some form of spirituality (Witten, 2015, 2016). Spiritual expression was essential for the dying process of the transgender older adult in the case study by Campbell and Catlett (2019). Recognizing the diversity of beliefs that gender diverse older adults may hold, these studies propose the need for spiritual care in this population and the need for spiritually-tailored clinician training to provide it.

Trauma is common for gender diverse persons who have experienced discrimination, harassment, or victimization (Kattari & Hasche, 2016) and may be caused by transphobic discrimination, violence and multilevel stigma for transgender persons generally and even military service for transgender veterans specifically (Carroll, 2017; Fabbre & Gaveras, 2020). Trauma can have adverse physical and psychological effects. In one study, although no significant differences were found between rates of cardiovascular disease (CVD) in transgender and cisgender older adults, the odds of having risk factors associated with CVD, such as discrimination, psychological distress, and adverse childhood experiences, were greater for transgender participants (Poteat et al., 2021). Because trauma can affect mind, body, and spirit, trauma-informed care was included here as a separate subtheme to acknowledge the context in which care for gender diverse older adults may be situated due to histories of abuse related to gender identity.

Several studies reported on resilience as a healthcare asset. Transgender older adults may have more robust psychological resilience than younger transgender persons (Cai et al., 2019). Elder (2016) concluded that all study participants "demonstrated resilience against the discrimination and oppression they have faced by advocating for themselves and others" (p. 183). These examples corroborate the findings of other studies that also identified the presence of resilience among participants (Cortes et al., 2019; Fredriksen-Goldsen et al., 2019; Greene et al., 2016; Sloan & Benson, 2021; Stevens & Abrahm, 2019; Witten, 2015, 2016). Factors contributing to resilience included self-transcendence, self-compassion, and inner strength (Greene et al., 2016; Stevens & Abrahm, 2019), and indicators of resilience included self-esteem, self-efficacy, mastery, hope, positive sense of self, pride, perseverance, courage, and engagement with social networks (Fredriksen-Goldsen et al., 2019; Sloan & Benson, 2021). External supporters of resilience were described as psychological and social resources, which were associated with better mental and physical health (Fredriksen-Goldsen, Kim et al., 2017). Resilience in this population may stem from overcoming adversity related to gender identity and may be protective physically, psychologically, and spiritually.

Resourcefulness and creativity represent another asset particularly applicable to resilience, empowerment and self-expression. Campbell and Catlett (2019) described the creative works of a transgender older adult on hospice who, in collaboration with a volunteer, made a book of her life stories and messages of hope for her community. And Elder (2016) noted that gender diverse older adults found expression through visual art, film, music, and performance as a component of their resilience.

Post-traumatic growth was mentioned by one article in relation to military service, but it may also have implications for trauma-informed care generally. In that study, 22% of the sample had prior military experience and significantly lower levels of depressive symptoms and higher psychological quality of life than those without military experience (Hoy-Ellis et al., 2017). This suggests that a form of resilience, or post-traumatic growth, may have developed in response to military trauma. Further, Cortes et al. (2019) found that LGBT older veterans demonstrated greater resilience compared with their younger peers. Though the evidence is still emerging, traumatic experiences may represent sources of growth and resilience for this population.

End-of-life preparations

Including palliative and end-of-life care as well as advance care planning, end-of-life preparation refers to the need for gender diverse older adults to document their end-of-life wishes, name a healthcare proxy, and prevent de-transitioning after death.

Three case studies detail the need for biopsychospiritual palliative care at end of life for gender diverse persons. In Stevens and Abrahm (2019), a list of clinical recommendations for sexual and gender minorities in the hospice and palliative care setting lays out guidelines for referral, cultural competence, psychosocial assessment, spiritual assessment, advance care planning, and bereavement. In Campbell and Catlett (2019), the authors provide recommendations for meeting the transgender participant's spiritual needs, including advocacy for spiritual care, creation of safe spaces for spiritual expression, clinician development of skillful means through education, and affirmation of gender identity. And in Lippe et al. (2021), an outline for transgender-inclusive primary palliative care is provided integrating the concepts of cultural humility, moral archaeology, and a palliative communication framework. Although many of the recommendations are consistent with those described for gender diverse older adults in other studies in this review, they are based on a small sample, indicating a need for more research in the realm of palliative and end-of-life care for gender diverse older adults.

The need for advance care planning for gender diverse older adults was a thread through a number of studies (Dickson et al., 2021; Fredriksen-Goldsen et al., 2019; Henry et al., 2020; Lowers, 2017; Whitestone et al., 2020; Witten, 2015, 2016). The gender diverse participants in the study by Henry et al. (2020) showed lower likelihood of planning or having participated in age preparatory behaviors and lower levels of wills, durable power of attorney for healthcare, and informal conversations about their wishes. Similarly, although the overall rate of healthcare power of attorney (HCPOA) appointment for the sample was relatively high at almost 62%, gender diverse participants were less likely to have appointed a HCPOA relative to cisgender participants (Dickson et al., 2021).

Whitestone et al. (2020) reported that most participants had not thought much about their funeral arrangements and had varied expectations for the expression of their gender identities after death. The phenomenon of post mortem de-transitioning, or reverting a transgender person's gender expression to the one assigned at birth in the process of preparing the body for burial, represents a specific threat to dignity for gender diverse older adults that advance care planning may address (Whitestone et al., 2020). Henry et al. (2020) found that many study participants feared being buried in clothing from their birth gender, but Whitestone et al. (2020) demonstrated that representation of the birth gender in some form during the funeral may not always be undesirable by gender diverse older adults. The need for advance care planning in this population includes the establishment of legal protections, appointment of a healthcare proxy, and preparation for future medical care and funeral arrangements in order to prevent unwanted treatments, to preserve gender-affirming care, and to prevent post mortem de-transitioning.

Financial security

Financial security circumscribes both the need for financial and insurance assistance and accessible housing. As contributors to poor mental health, high financial anxiety and being underinsured are not uncommon among gender diverse older adults (Greene et al., 2016). The participant in the case study by Stevens and Abrahm (2019), for example, had limited access to insurance related to his gender identity. And three studies reported increased vulnerability of gender diverse older adults to financial stressors (Adan et al., 2021; Witten, 2015, 2016). Proposals to address this need included financial planning and more regulations supporting transgender inclusive healthcare among insurance providers (Kattari & Hasche, 2016; Witten, 2015, 2016). Absent from these studies was discussion of the role of Medicare and Medicaid in access to gender-affirming care for gender diverse older adults.

Accessible housing is a substantial healthcare need for gender diverse older adults. Only one study addressed gender diversity in housing directly, analyzing focus group discussions on LGBTQIA+-inclusive housing (Rosenwohl-Mack et al., 2022). One transgender participant commented, “My mental well-being seems to be healthier, [and] my physical [well-being]. Financially, it's affordable for me, so that relieves a lot of the stress and stuff” (Rosenwohl-Mack et al., 2022, p. 5). In presenting a novel housing option for LGBTQIA+ older adults, this study illuminates the need for reimagining senior housing to include persons of all gender identities and the potential for such housing to improve health outcomes and ease financial burdens.

Higher income and being insured are both considered assets according to findings from this review. For example, having private insurance was found to be a protective factor against discrimination in healthcare settings (Kattari & Hasche, 2016), and higher income was a predictor of perception of successful aging in another study (Walker et al., 2017). Higher income was also associated with a larger social network size, which is itself another asset (Erosheva et al., 2016). Although these factors are not exclusively protective for gender diverse older adults, they may confer access to treatments and protections against discrimination that are specific to gender identity.

Intersectionality

Several healthcare needs specific to certain subgroups such as sexual minorities, veterans, and racial and ethnic minorities were gathered from these studies. While the needs of sexual minorities and veterans were explicit, those of racial and ethnic minorities were largely implicit due to the low level of representation of these groups in the study samples.

Only two studies looked at the intersection of gender identity and sexuality for gender diverse older adults. Seeking to understand the experiences of transgender lesbian and bisexual older adults, these studies found that for both groups most of their fears around aging and end of life centered on their gender identity rather than their sexual identity (Witten, 2015, 2016). The transgender lesbian participants reported an overall feeling of aging successfully, while both groups feared mistreatment in healthcare settings as they were aging. However, these two studies provide only a glimpse of the complex interplay of gender identity and sexual identity, and more research is needed in this area.

According to Cortes et al. (2019), addressing veteran status when providing care is an important need for some gender diverse older adults. Some gender diverse veterans have been exposed to military trauma, which is often compounded by exposure to trauma related to gender identity (Carroll, 2017). In addition, gender diverse veterans may need assistance navigating these two identities, gender and military, that society often sees as incompatible (Fabbre, 2015).

Finally, policy to support the mental health of transgender veterans is paramount (Hoy-Ellis et al., 2017). As with care specific to sexual minorities, the need for care for gender diverse veterans is only just emerging in the literature.

The subtheme of care informed by race and ethnicity was discerned relative to the absence of data related to racial and ethnic identity. The main finding in this area came from the study by Kattari and Hasche (2016) which stated that gender diverse people of color were more likely to report discrimination. The fact that the overwhelming majority of participants in almost every study was white speaks to the need for research that purposefully samples people of color to gain insight into the unique needs of this population of gender diverse older adults.

DISCUSSION

Evidence from the 35 studies included in this review support seven themes encompassing the healthcare needs (20 subthemes) and assets (9 subthemes) of gender diverse older adults. These themes represent an emerging body of knowledge with ample opportunity for continued research as well as practice and policy change. Importantly, these results show that the healthcare needs of gender diverse older adults are not limited to physical and mental health care but include establishment of safe spaces, antidiscrimination policies, community supports, advance care planning, and financial resources. These needs can be met at the personal, institutional, and national level (Walker et al., 2017). Assets of gender diverse older adults come into play at all levels, from personal protections like resilience and self-acceptance to institutional and national protections like antidiscrimination activism. Gender diverse older adults may be empowered to combat multilevel stigma in order to meet their healthcare needs (Fabbre & Gaveras, 2020).

The need for gender-affirming care for gender diverse older adults emerged largely from histories and fears of mistreatment in healthcare settings. Research within the LGBTQIA+ community supports the finding that healthcare providers are largely ill-prepared to care for gender diverse older adults. Over 20% of clinician respondents in one study observed discriminatory care of transgender patients (Stein et al., 2020). Additionally, mental health providers in another study had little coursework on LGBTQIA+ issues and identified lack of training as a major barrier to quality care (Smith et al., 2019). These findings stress the importance of training in gender-inclusive care for healthcare providers.

Strategies to address general and gender-specific physical health care needs are emerging. For example, the comprehensive Trans-Specific Geriatric Health Assessment offers a gender-inclusive approach to explore cognitive function, vision and hearing, gait and stability, nutrition, sleep, functional/social status, urogenital health, psychiatric health, hormone replacement therapy, cancer screening, disease prevention, and advanced care planning (Gamble et al., 2020). Such a holistic approach is essential to identify and treat the health conditions for which gender diverse older adults are at higher risk.

Mental health care of gender diverse older adults included the need for attention to suicide risk. Nearly 60% of transgender participants in one study reported that they were close to at least one person who attempted suicide, and more than a quarter of the sample reported that they were close to at least one person who died by suicide (Cerel et al., 2021). Although the prevalence of suicidality among gender diverse older adults is unknown, these findings reinforce the need for awareness and assessment of suicidality identified in this review.

Although palliative care for gender diverse older adults would benefit from a broader and deeper empirical knowledge base, existing end-of-life care resources support the findings of this review. Acquaviva (2017) has assembled a practical guidebook for clinicians providing care to LGBTQIA+ palliative care patients, and Maingi et al. (2018) draw out a number of guidelines for LGBT-inclusive palliative care in the realms of clinical practice, research, education, and healthcare organizations and payors. More research is needed to provide recommendations for quality, gender-affirming palliative care and end-of-life planning options for gender diverse older adults.

Regarding financial security, a commentary by Bakko and Kattari (2021) asserts that transgender persons are uninsured at higher rates than their cisgender peers, and if insured, often face denials of coverage from insurance companies. The article identifies issues specific to Medicare and Medicaid for transgender persons, such as gaps in care caused by case-by-case or state-by-state rather than nationally mandated transition treatment approval criteria. Since the majority of older adults in the US are enrolled in Medicare or Medicaid, advocacy for policy changes to these insurance pathways that prevent denial of coverage for transgender-specific medical care is an important need. Furthermore, over half of US states have either policy directly excluding transition-related healthcare or no policy regarding transition-related care protections for private, Medicaid, or state employee-based insurance (Bakko & Kattari, 2021). Importantly, 14% of US Transgender Survey respondents are uninsured, with transgender people of color even more likely to lack insurance coverage (James et al., 2016). Policy changes to reinforce insurance equity for these groups are critical to ensuring access to needed medical care.

Fears of discrimination in long-term care settings was a concern expressed in several articles in this review as well as in a systematic review of studies pertaining to long-term care services for LGBTQIA+ persons (Caceres et al., 2020). In the latter, 12 of 19 total articles identified fear of discrimination as a primary concern for LGBTQIA+ persons, and seven demonstrated the need for staff training due to negative attitudes and lack of preparation to care for this population. Antidiscrimination policy and provider education may be necessary to ensure inclusive care for gender diverse older adults in long-term care.

The majority white sample of this review poses both a limitation and a critical gap in the literature with respect to racial and ethnic diversity. One article that addresses racial and ethnic minority status within the LGBTQIA+ community points to the experience of increased discrimination among people of color in relation to their white peers as well as lower income, educational attainment, identity affirmation, and social support (Kim et al., 2017). At the same time, both resilience and higher spirituality had positive effects on quality of life for aging LGBT people of color (Kim et al., 2017). These are important preliminary findings, but more research is needed to understand the healthcare needs and assets unique to gender diverse older adults of various races and ethnicities.

Several notable gaps in this sample of studies must be addressed. Future studies are needed to explore topics from the LGBTQIA+ literature, especially racial and ethnic identity, sexuality, human immunodeficiency virus, and substance use for gender diverse older adults. From this review, further study is needed on housing, palliative and end-of-life care, long-term care, dementia, insurance equity, trauma-informed care, and intersectionality for this population.

Nursing implications for this review center on creating educational opportunities to enhance care for gender diverse older adults. Specifically, continuing nursing education would integrate current recommendations for holistic care of this population as outlined in this review, with attention to cultural, political, and economic factors that influence health and wellbeing. Nurses have ample room to assume leadership roles in this growing area of research and practice. In collaboration with gender diverse older adults, nurses have the ability to influence program development, community education, and policy-making to promote inclusivity and equity in healthcare settings. This review can serve as a blueprint for these endeavors.

Limitations

This study has several limitations. No statements of causality can be made about the observed phenomena due to the level of evidence represented in the studies in this review. Consequently, any conclusions drawn in this review are associative. However, the triangulation of quantitative and qualitative studies lends validity to the findings. Although evidence supports each of the themes identified in this review, more research is needed to bolster the findings within each subtheme.

As stated previously, the lack of racial and ethnic diversity in the samples or the omission of this demographic measure altogether represents a limitation on the generalizability of the results. With the demographics provided, results may apply largely to white transgender women who made up the majority of the samples, leaving a gap in knowledge about other racial, ethnic, and gender identity groups. In some studies, age presented a limitation, as gender diverse adults in the oldest categories (over 70 years old) were not well represented. This may have been due to another limitation in the cross-sectional studies that used online survey methods, which relied on computer literacy and access.

Finally, another limitation was the definition of gender identity categories. It was unclear from some studies whether “male” or “female,” for example, included transgender participants, as some transgender adults do not identify with that term, especially after transition. This created some confusion in determining the percentage of LGBTQIA+ older adults that had transgender histories, whether or not they identified as transgender. Furthermore, gender nonconforming older adults were underrepresented in these studies. Future studies of gender diverse older adults would benefit from inclusive language in demographic surveys.

CONCLUSION

The collection of themes and subthemes from this review represents one possible interpretation of the findings of a wide range of studies relating to the healthcare needs and assets of gender diverse older adults. The synthesis provides a framework for understanding the factors affecting aging and end-of-life care for this population, which in turn may inform efforts to make healthcare safer and more inclusive. Both policy and education are needed to reduce discrimination based on gender identity in healthcare settings, and future research must focus on providing depth to the knowledge base and include a range of racial, ethnic, gender, and age groups to enhance the representativeness of subsequent findings. Both healthcare needs and assets must inform better care for gender diverse older adults in order to identify practice and policy interventions as well as to ensure that gender diverse older adults remain empowered to influence their own care. Action is required from both provider and patient. One transgender participant put it eloquently: “I've been focusing through my activist work and [...] I think the cumulative effect of all the work I do will hopefully mean that in the future there will be a space for me to exist in the world” (Jones & Willis, 2016, p. 56). Gender diverse older adults require safe, inclusive healthcare spaces in which they may be seen and respected as people and as active agents in shaping their own health and wellbeing.

CLINICAL RESOURCES

American Psychological Association (https://www.apa.org/pi/lgbt/resources/aging).

Fenway Institute National LGBTQIA+ Health Education Center (https://www.lgbtqiahealtheducation.org/resources/in/lgbtqia-older-adults/).

FORGE: Transgender Aging Network (https://forge-forward.org/resources/aging/).

National Center for Transgender Equality (https://transequality.org/issues/aging).

SAGE: Advocacy and Services for LGBTQ+ Elders (https://www.sageusa.org/).

SAGE: National Resource Center on LGBTQ+ Aging (https://www.lgbtagingcenter.org/resources/resources.cfm?s=27).

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CONFLICT OF INTEREST

I have no conflicts of interest to disclose.

DISCLAIMER

I confirm that this work is original and has not been published in whole or in part elsewhere, nor is it currently under consideration for publication elsewhere.

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ENDNOTE

[1] "Gender diverse" was selected from numerous terms as the one most inclusive and affirming of various gender identities.

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MANUSCRIPT 2

Multilevel Factors Affecting Health Equity for Transgender and Gender-diverse Older Adults

(under review with *Qualitative Health Research*)

The population of transgender and gender-diverse (TGD) older adults in the United States may face inequities in the healthcare system due to factors at multiple levels. Research is needed to identify factors that limit and facilitate equitable healthcare delivery for this population. Therefore, we conducted a qualitative descriptive study called *Shaping Affirming Futures with Elders of all gender experiences* (SAFEage) to identify and explore factors that affect health equity for TGD older adults living in the United States. Through purposeful and snowball sampling, we enrolled 20 TGD older adults of diverse gender identities and racial and ethnic backgrounds. In Phase 1 of the study, participants discussed their healthcare experiences during semi-structured interviews. In Phase 2, participants reviewed study findings in individual and group sessions. We transcribed recordings of each interview and review session and coded transcripts both deductively and inductively. Through thematic analysis, we identified six primary themes describing factors that limit (L) and facilitate (F) health equity at (1) structural, (2) systemic, and (3) social levels of influence: (L1) Oppression driving adverse healthcare experiences; (L2) Gaps in healthcare resources and support; (L3) Disadvantages yielding poor health outcomes; (F1) Health justice promoting affirming healthcare experiences; (F2) Catalysts for change in healthcare; and (F3) Assets fostering agency and well-being. Limiting and facilitating factors were considered in relation to the Intersectionality Research for Transgender Health Justice conceptual framework. Study findings may inform future research, clinical practice changes, and policies that would promote equitable and affirming healthcare for TGD older adults.

Keywords: older adult, transgender, gender-diverse, health equity, qualitative

Multilevel Factors Affecting Health Equity for Transgender and Gender-diverse Older Adults

An estimated 1.3 million adults in the United States (U.S.) identify as transgender. *Transgender* is a term used to describe a person whose gender identity differs from their sex assigned at birth (PFLAG, 2023). *Gender-diverse* is an associated term used to describe gender identities that differ from societal gender norms and are not necessarily aligned with biological sex (Thorne et al., 2019). For the purposes of this study, *transgender and gender-diverse (TGD)* is used as an inclusive term to represent multiple gender identities (Coleman et al., 2022).

More than 170,000 transgender adults in the U.S. are 65 years old and older, and this number likely underestimates the actual population of TGD older adults in the U.S. (Herman et al., 2022). Using the age threshold for Social Security and Medicare eligibility, current estimates only account for the subset of TGD older adults aged 65 years old and older. However, older adulthood may begin as early as 50 years old for some TGD older adults due to premature aging and health decline stemming from stigma, minority stress, and health disparities over the life course (Cortes et al., 2019; Fredriksen-Goldsen et al., 2019; Hughes et al., 2022a).

TGD adults of all ages may encounter limiting factors, such as discrimination, refusal of care, and lack of clinician knowledge about transgender health, that reduce their access to high quality healthcare (James et al., 2024). In the latest report of the U.S. Transgender Survey which collected data from over 92,000 TGD persons aged 16 years old and older, nearly 50% of respondents interfacing with the healthcare system reported negative experiences, and nearly 25% delayed seeking medical care due to fear of mistreatment (James et al., 2024). In addition, TGD adults may have limited access to healthcare due to underinsurance or denial of insurance coverage (Bakko & Kattari, 2021; James et al., 2024). Contributing to the elevated risk of morbidity and mortality observed among TGD adults in the U.S., these limiting factors may have deleterious consequences for TGD adults as their healthcare needs increase with age, especially for those with disabilities, chronic health conditions, and serious illnesses (Hughes et al., 2022a; Hughes et al., 2022b; Hughes et al., 2021; Rosa et al., 2023; Smith-Johnson, 2022).

By contrast, facilitating factors, such as anti-discrimination policies and inclusive medical practices, may support health and well-being and promote health equity for TGD adults (Du Bois et al., 2018; Restar et al., 2021). Health equity results from the reduction and eventual elimination of health disparities adversely affecting groups that have been excluded from or marginalized within health systems and society (Braveman et al., 2017). One facilitating factor affecting health equity for TGD adults is gender affirmation, "an interpersonal, interactive process whereby a person receives...recognition and support for their gender identity and expression" (Sevelius, 2013, p.2). The term doubly refers to medical and legal interventions as well as social acceptance and respect (Dorsen et al., 2022). Gender affirmation is associated with favorable health and wellness outcomes for TGD adults, including resilience, mental well-being, and risk reduction (Crosby et al., 2016; Hughto et al., 2020; Lelutiu-Weinberger et al., 2020; Sevelius, 2013). However, less is known about facilitating factors that may promote health equity for TGD older adults.

Because healthcare for TGD older adults is an emerging area of study, further research is needed to fill a gap in the evidence base on limiting and facilitating factors affecting health equity for this population (Fredriksen-Goldsen et al., 2014; Pharr, 2021). Although studies over the last decade have identified some limiting factors, such as discrimination and lack of access to care, the impact of both limiting and facilitating factors on health equity for TGD older adults warrants further exploration (Catlett et al., 2023; Fredriksen-Goldsen et al., 2014). Additionally, studies are needed that integrate an intersectional lens to explore factors that influence health disparities among TGD older adults of diverse gender identities and racial and ethnic backgrounds (Catlett, 2024; Catlett et al., 2023). Finally, further research on factors that limit and facilitate health equity for TGD older adults is needed to inform the development of interventions that would address these health disparities.

To address gaps in the literature on healthcare for TGD older adults, researchers conducted a thematic analysis of primary data from the study *Shaping Affirming Futures with Elders of all gender experiences* (SAFEage). Using a qualitative descriptive approach, researchers in this study sought to answer the question: *What are the factors that affect health equity for TGD older adults in the U.S.?* Thus, the purpose of this study was to identify and explore limiting and facilitating factors that affect health equity for TGD adults aged 50 years old and older living in the U.S.

Methods

In this study, researchers used a qualitative descriptive approach, staying close to the data to foreground participant voices (Neergaard et al., 2009; Sandelowski, 2000). A conceptual framework called Intersectionality Research for Transgender Health Justice (IRTHJ) informed data collection and analysis (Wesp et al., 2019). The IRTHJ framework articulates social justice-oriented actions for researchers working toward health equity for transgender adults (Wesp et al., 2019). IRTHJ actions include *centering embodied knowledge*, *disrupting the status quo*, and *naming intersecting power relations* (Wesp et al., 2019, p.291). During data collection, researchers centered embodied knowledge by maintaining the primacy and integrity of participant contributions. Additionally, reflexivity allowed researchers to name and mitigate power imbalances common in researcher-participant dynamics. Researchers aimed to disrupt the status quo by prioritizing enrollment of older adults from groups historically underrepresented in health research.

The IRTHJ framework models intersectional causes of health inequities in three layers—*structures of domination*, *institutional systems*, and *socio-structural processes* (Wesp et al., 2019, p.291). Structures of domination are forms of structural oppression like cisgenderism, ableism, and ageism, while institutional systems generate anti-transgender policies and regulations. Socio-structural processes refer to social practices or conditions that produce or reinforce health inequities for TGD adults. The three layers of this model informed the conceptualization of themes during data analysis in this study.

Study Ethics

The University of Virginia Institutional Review Board for the Social and Behavioral Sciences (UVA IRB-SBS #6104)) approved this study. Prior to joining the study, all participants provided informed consent, which was obtained in writing via electronic survey by the principal investigator. Participants also received information and resources related to topics covered during the interviews. After each interview, participants received compensation in recognition of their time and contributions to the study.

Study Design

The SAGEage study had three phases covering two specific aims. In Phase 1, the principal investigator conducted interviews to explore factors affecting health equity for TGD older adults (Aim 1). In Phases 2 and 3, researchers conducted individual and group sessions to develop a resource with participants that would empower TGD older adults to prepare for their healthcare in later life (Aim 2). This analysis primarily uses Phase 1 data to address Aim 1. However, since participants reviewed Phase 1 findings in Phase 2, some data from Phase 2 were also included. **Figure 1** details the study design and timeline.

Figure 1. Study Design and Timeline

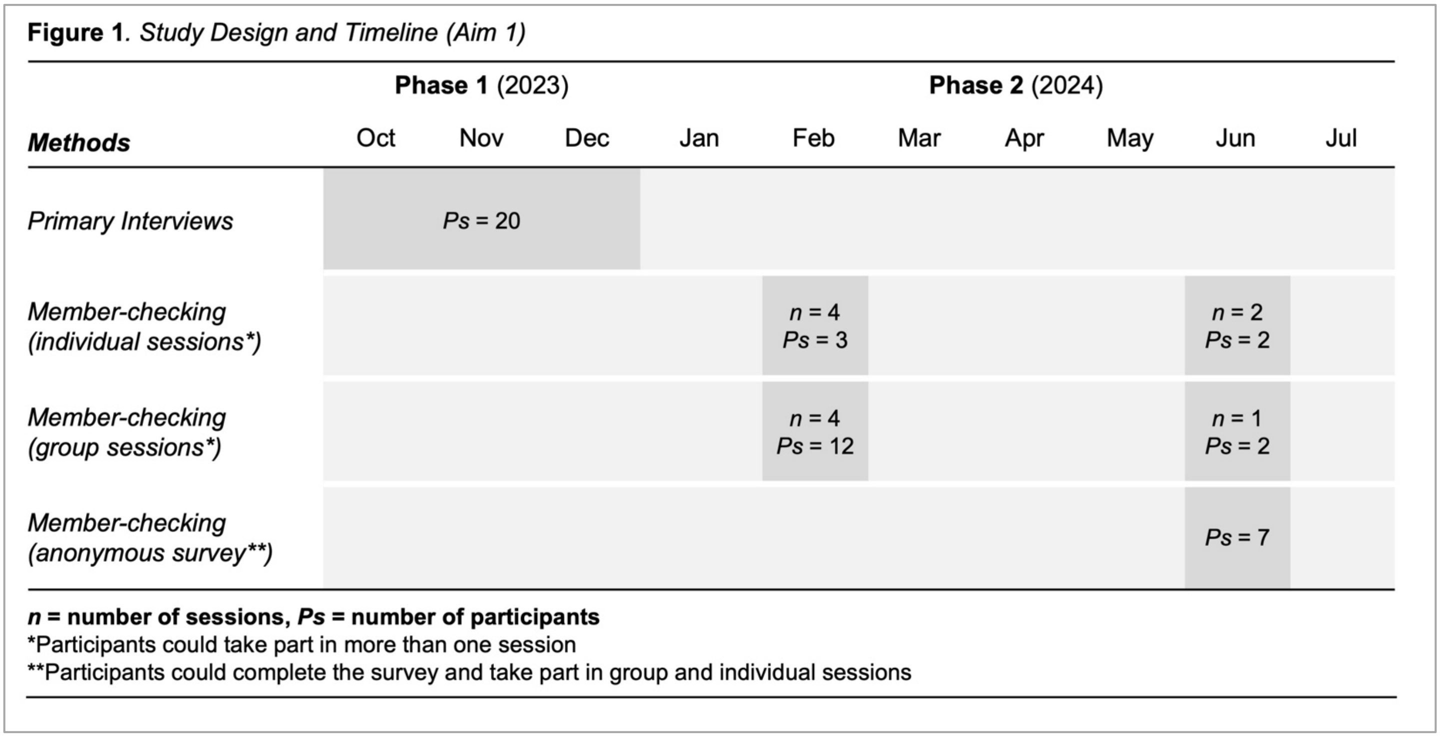

Figure 1. *Study Design and Timeline (Aim 1)*

	Phase 1 (2023)			**Phase 2** (2024)						
Methods	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul
Primary Interviews	*Ps* = 20									
Member-checking (individual sessions)*					*n* = 4 *Ps* = 3				*n* = 2 *Ps* = 2	
Member-checking (group sessions)*					*n* = 4 *Ps* = 12				*n* = 1 *Ps* = 2	
*Member-checking (anonymous survey**)*									*Ps* = 7	

***n* = number of sessions, *Ps* = number of participants**
*Participants could take part in more than one session
**Participants could complete the survey and take part in group and individual sessions

In Phase 1, participants engaged in semi-structured interviews and completed an electronic demographic survey between October and December of 2023. All interviews were audio- and video-recorded with consent from participants, and field notes were recorded after each interview. Interviews lasted between 45 and 90 minutes (65 minutes on average) and were conducted in person, by video call, and by phone to accommodate participants from across the U.S. The principal investigator used a semi-structured interview guide (see **Appendix**), which contained open-ended questions about participant experiences seeking healthcare and preparing for future care. Interview questions were informed by multiple scholarly sources as well as the knowledge and lived experiences of researchers and a group of three TGD community advisors who provided guidance during the study (Catlett, 2024; Catlett et al., 2023; Reich et al., 2022).

In Phase 2, participants reviewed study findings during individual and group sessions conducted three months and six months after Phase 1 interviews ended. At three months, participants discussed preliminary study findings during four group sessions and four individual sessions facilitated by the principal investigator. At six months, participants provided feedback on the fit between study themes and their own experiences during one group session and two individual sessions and through an anonymous online survey.

Participant Group Formation

In Phase 1, researchers engaged in purposeful and snowball sampling to form a participant group of TGD adults aged 50 years old or older (Onwuegbuzie & Collins, 2015). The principal investigator reached out to prospective participants for Phase 1 via electronic fliers sent to researcher and community advisor contacts, community gatekeepers, and LGBTQ+ organizations for distribution via email and social media. To screen for eligibility, prospective participants completed an electronic form linked in the fliers. Prospective participants were eligible to join the study if they identified as transgender or gender-diverse, were 50 years old or older, and had been living in the U.S. for at least 10 years. Fluency in English and capacity to give informed consent were required for this study. Participants who did not have access to the Internet or were not able to participate by video call were eligible for Phase 1 as long as they could meet in person or speak on the phone. All Phase 1 participants were eligible to join Phase 2 if they were able to join group and individual sessions by video call.

Researchers estimated the sample size for Phase 1 by assessing the “information power” of the evolving dataset (Malterud et al., 2016). Information power is inversely related to the sample size needed for a study and is influenced by five criteria: study aims, sample specificity, established theory, dialogue quality, and analysis strategy (Malterud et al., 2016). The SAGEage study had narrow study aims, data with high specificity to the research question, and moderately high dialogue quality, indicating high information power in the dataset and the need for a small sample size. However, the use of cross-case analysis and semi-structured integration of the theoretical framework in this study were markers of moderate information power, suggesting the need for a moderate sample size (Malterud et al., 2016). Researchers considered these factors alongside the need for more participants to enhance sample diversity, estimating that a moderate sample size (15-20 participants) would be needed for adequate information power.

Researchers were intentional about enrolling participants from diverse backgrounds to gain insight into intersectional factors affecting health equity for TGD older adults. Researchers purposefully enrolled participants of diverse gender identities and racial and ethnic backgrounds. To ensure that perspectives from different medical, legal, and political landscapes were represented, researchers aimed to enroll no more than half of participants from their home institution state (Virginia).

Study Contributors

This study integrates experiences and insights from community advisors, researchers, and participants to build understanding about the factors affecting health equity for TGD older adults. The following sections detail the role of community advisors and researchers in this study, while participant characteristics are detailed in the Results section. Initials were used as pseudonyms to represent all study contributors (initials used to name participants are substitutes for their actual initials). Consistent with efforts to mitigate power imbalances in this study, researchers opted not to assign alternate names as pseudonyms out of respect for the agency of community advisors and participants who had already chosen their names as part of their gender transition.

Community Advisors

Community advisors included three TGD adults — C.B., G.B., and A.S. — with lived experience, scholarship, and community activism relevant to the study. The principal role of the community advisors was to review study materials and early de-identified findings to help researchers conduct a study that would be affirming and accessible for TGD older adults. Community advisors gave formal written consent to participate and provided their demographic information. Their ages ranged from 53 to 84, and they described their gender identities as “trans man,” “transgender man,” and “female.” One member identified as Black, and two members identified as White. Researchers worked with each advisor during the developmental phases of the study to refine interview guides and participant handouts. Community advisors also reviewed preliminary findings and provided input on materials for participant review. C.B., G.B., and A.S. contributed to this publication as co-authors.

Research Team and Reflexivity

The research team included L.C. (they/them), principal investigator and nursing doctoral student, as well as I.W. (she/her), V.L. (she/her), and K.A. (she/her), three tenured faculty members at the University of Virginia. L.C. is a White, nonbinary person; I.W. is a straight, Black/African American, cisgender woman; V.L. is a White, cisgender woman; and K.A. is a queer, White, cisgender woman. By reflecting on their positionalities, researchers identified points of connection with participants while also illuminating their privilege and potential power imbalances. Researchers did not have established relationships with participants prior to starting the study. To build rapport, L.C. shared their gender identity and pronouns, their professional role, and their motivations for pursuing the research. To equalize power dynamics between participants and researchers, participant perspectives and priorities remained the focal point of discussions and analyses, and researchers maintained humility and gratitude throughout the study.

Data Analysis

Researchers used thematic analysis to identify themes and subthemes describing factors that affect health equity for TGD older adults (Braun & Clark, 2022). L.C. transcribed recordings from Phases 1 and 2 and reviewed transcripts twice to check for errors, inviting participants to review their own transcripts for accuracy. L.C. performed initial coding in Dedoose (Version 9.2.012), a web application used for qualitative and mixed methods data analysis.

L.C. first coded transcripts deductively, applying two codes to differentiate limiting factors from facilitating factors. Subsequently, they performed iterative inductive coding of the dataset to explore limiting and facilitating factors in more depth. Two coders (L.C. and K.A.) reviewed the inductive coding schema, and both coders modified the schema until agreement was reached. To form themes and subthemes, L.C. categorized inductive codes manually, grouping interrelated codes and exploring negative cases. The IRTHJ framework informed conceptual refinement of each theme. L.C. juxtaposed findings with excerpts and whole transcripts to assess the fit between themes and the dataset. All co-authors reviewed each theme for alignment with the study purpose.

Nine self-selected Phase 2 participants engaged in member-checking of study findings six months after the end of Phase 1. In addition to validating findings, this iteration of member-checking focused on meaning-making and social change in alignment with the social justice orientation of this study (Motulsky, 2021). Participants reviewed themes, offering feedback via video call or electronic free-response survey, and researchers modified themes based on participant observations and insights.

Trustworthiness

Researchers applied various methods to promote the trustworthiness of study findings. L.C. produced verbatim transcripts of recordings and maintained detailed observation logs during data collection. Engagement in peer debriefing and member-checking strengthened credibility of study findings. Inviting participants to review preliminary themes fostered consistency between study findings and their knowledge and experiences. Researchers enhanced transferability of the findings by recruiting a diverse participant group and building a comprehensive dataset. L.C. performed careful data management and maintained an audit trail of procedural and analytic decisions. As the principal investigator, L.C. kept a reflexive journal in which they assessed the influence of their positionality, biases, and assumptions on study processes and findings.

Findings

Of the 21 TGD older adults who enrolled in the study, 20 completed interviews in Phase 1, and a total of 15 Phase 1 participants took part in Phase 2. Participant ages ranged from 50 to 69 years old, and the average age was 58.3. Nine participants (45%) described their gender identity as transfeminine, six (30%) as transmasculine, five (25%) as nonbinary or gender nonconforming, and seven (35%) as another gender identity. Five participants (25%) used more than one term to describe their gender identity. Participants identified as biracial (5%), Black (10%), White (60%), Hispanic or Latino/a (20%), or another race or ethnicity (5%). All participants had at least a high school diploma or GED, and 13 (65%) had a college degree. **Table 1** provides additional demographic details for the participant group in Phase 1.

Table 1. Participant Group Demographic Characteristics

Group size		n=20
Characteristics	Subcategories	n(%)
Age range (years)	50-59	13(65)
	60-69	7(35)
U.S. region	Midwest	5(25)
	Northeast	1(5)
	South	13(65)
	West	1(5)
Gender identity	Agender	1(5)
	Male	2(10)
	Nonbinary or gender-nonconforming	5(25)
	Transfeminine or transwoman	9(45)
	Transmasculine or transman	6(30)
	Two Spirit	2(10)
	Another gender identity[a]	2(10)
Sexual orientation	Asexual	1(5)
	Bisexual	2(10)
	Lesbian	3(15)
	Queer	4(20)
	Straight/heterosexual	8(40)
	Another sexual orientation[b]	4(20)
Race and ethnicity	Biracial or multiracial	1(5)
	Black or African American	2(10)
	Hispanic or Latino/a/e	4(20)
	White or European American	12(60)
	Another race or ethnicity[c]	1(5)
Highest educational level	High school diploma/GED	5(25)
	Associate's degree	1(5)
	Bachelor's degree	4(20)
	Master's degree	8(40)
	Another degree/Other training[d]	3(15)

Note. Total percentages for *gender identity, sexual orientation,* and *race/ethnicity* may exceed 100% because participants could select more than one option. For *highest educational level*, participants could select *another degree/other training* in addition to one other option.

[a] "Transsexual man," "transgender"

[b] "Pansexual"

[c] One participant identified as a person of color but did not specify race or ethnicity

[d] "Some college," "military"

From participant insights and narratives, researchers discerned a set of six primary themes each with 2-5 subthemes describing factors that limit (L) and facilitate (F) health equity for TGD older adults at (1) structural, (2) systemic, and (3) social levels of influence. Primary themes were (L1) Oppression driving adverse healthcare experiences; (L2) Gaps in healthcare resources and support; (L3) Disadvantages yielding poor health outcomes; (F1) Health justice promoting affirming healthcare experiences; (F2) Catalysts for change in healthcare; and (F3) Assets fostering agency and well-being. Structural-level factors (L1 and F1) pertain to societal and health system power structures; systems-level factors (L2 and F2) pertain to healthcare procedures, policies, and institutional systems; and social-level factors (L3 and F3) pertain to personal and interpersonal circumstances affecting health and agency within the healthcare system. The following sections detail primary themes and subthemes describing limiting and facilitating factors and explore relationships among them at each level. Exemplar quotations from Phase 1 interviews and Phase 2 individual and group sessions are provided.

Limiting Factors

(L1) *"Transphobia will kill you": Oppression driving adverse healthcare experiences*

Theme L1 refers to attitudes and actions that lead to disrespect, neglect, silencing, othering, abuse, and other forms of structural oppression that participants faced within the U.S. healthcare system. Subthemes include *transphobia, racism,* and *ableism*.

Transphobia. Recent incidents of transphobia in healthcare settings were reported explicitly by seven Phase 1 participants (35%), with life-threatening consequences for some. B.H. asserted that transphobia is "running rampant" in the healthcare system, citing discriminatory experiences that he and some of his acquaintances had faced, including neglect for their care and lack of respect from healthcare professionals. "Transphobia will kill you," he said.

Transphobic treatment in healthcare settings was a common experience for participants or members of their social networks. A.T. described the sense of shock she felt hearing a transphobic remark about her genitalia when in the emergency room for a cardiac condition. O.N. remarked that reports of transphobic treatment of TGD adults at a local hospital deterred her and her peers from seeking care at the institution. "I stay out of [local hospital] because they are very anti-transgender," she said, "And we all stay away from [local hospital], at least those who I know are transgender."

Racism. Structural racism affected health equity for some TGD participants of color. In general, Phase 1 participants of color reported adverse or mixed healthcare experiences more commonly than White, non-Hispanic participants. Reflecting on the ways in which structural racism has affected his treatment as a person of color within the U.S. healthcare system, B.H. said:

> It's built into the structure of healthcare in terms of how it treated different ethnicities and bodies. It's built in that way...how the healthcare system was built and its viewpoint on Black bodies, bodies of color, anything that was outside of the mainstream.

A.T. also noted the persistence of transphobia and racism in sectors of the healthcare system, calling for healthcare personnel to "give [TGD people] the same respect [as] anyone else."

Ableism. Transphobia and racism also intersected with ableism among participants with disabilities in this study. At least two Phase 1 participants were managing a disability, and two participants shared that they were living with autism. Emphasizing the intersectional stigma affecting TGD older adults with disabilities, J.T. explained:

> If [we]'re going to talk about nonbinary and trans, we need to be having a parallel conversation about autism and about these related physical disabilities...there's all kinds of content and writing out there about how intersectional those are. And they're both things that can get you treated like absolute crap...all these things that diminish and minimize what you're feeling. Those two factors go totally into it, I think.

Highlighting the intersections between transphobia, racism, and ableism that affect health equity for TGD older adults, B.H., an older person of color with a disability, shared his experiences seeking care for the chronic health conditions he was facing. Quoting from a conversation with his medical provider, he asked, "Why haven't you recommended that I go to a doctor that knows about folk who have this...condition? Because I'm trans, and you are afraid to address the intersectionalities."

(L2) *"It's just a hairy, tangled mess": Gaps in healthcare resources and support*

Theme L2 describes dysfunctional health systems and deficiencies in resources and support that affected healthcare access and quality for participants. Subthemes include *broken systems, policy barriers, limited access to care, limited medical support,* and *limited resources*.

Broken Systems. Participants described long-standing systemic gaps in healthcare for TGD older adults exacerbated by circumstances during the COVID-19 pandemic. Accessing healthcare resources had been “just a hairy, tangled mess” for J.T., who remarked that healthcare systems have “just neglected all of us [TGD adults] for so long,” and “we’ve been relying on a bad system for a good decade or more.” Six Phase 1 participants (30%) explicitly raised concerns about systemic deficiencies affecting the care and safety of TGD older adults in long-term care settings. L.G. remarked, “You hear about people being neglected or abused in nursing homes, but those people are all cis[gender]. So, when you add being trans[gender] on top of that, I just don't see it being a good situation.”

Policy Barriers. For some participants, legislative and institutional policy barriers were threatening essential healthcare rights. Since “transgender rights are being pulled in many states” (E.R.) and some U.S. governing bodies are “trying to legislate away [the] existence [of TGD persons]” (K.P.), political actions aiming to limit medical care for TGD older adults were a “major concern” (E.R.) for these participants. Additionally, D.J. identified institutional policy barriers resulting in “legal documentation and having everything transferred over and the healthcare system not accepting those legal changes that are actually in place.” He expressed concern about the consequences of misgendering in his medical records, especially if he were to lose capacity to advocate for himself due to a serious illness.

Limited Access to Care. Systemic factors also limited participant access to healthcare. “I feel like I’m being gatekept out of healthcare,” said J.T., referring to both prohibitive healthcare costs and anti-transgender discrimination in healthcare settings. Q.P. struggled to access gender-affirming medical care for his gender transition due to insurance hurdles, repeated scheduling delays, and the burden of traveling to multiple medical appointments in different locations. For E.R., traveling long distances to access affirming care had also become burdensome with age. He explained:

> I'm seeing the doctor 45 minutes away. But it's like, if this doctor leaves, now I’ll be driving four hours away to [a major city] for healthcare. What is that going to look like five to seven years from now when I don't want to take the trip, or I can't physically take the trip?

Limited Medical Support. When they were able to access healthcare, ten Phase 1 participants (50%)

explicitly reported inadequate medical support due to lack of competency among healthcare professionals involved in their care. T.P. shared that she had to disclose and explain her gender identity to a lab technician before a routine prostate cancer screening, while M.M. "had to convince [his physician]," before undergoing a routine colonoscopy, "that [he] was born female and did not have a prostate." I.H. explained the burden that these kinds of interactions impose: "It's more uncomfortable when you have to tell a healthcare professional [about your gender identity]...More questions get asked...Sometimes I'm just like, I don't have it in me." K.P. discussed the need for competent care beyond "a healthcare practice that may deal with gerontology but does not fully comprehend and analyze aging as a transgender [person]."

Nine Phase 1 participants (45%) explicitly expressed fears that lack of medical support would result in the withdrawal of gender-affirming treatments in later life. U.T. recalled, "I've heard horror stories of people de-transitioning, and they had to go back [to their sex assigned at birth]." Contemplating the risk of developing a serious illness later in life, O.N. shared that she would be "absolutely devastated if [she] woke up after three weeks in the hospital...and found out that nobody took care of [her] as a female."

Limited Resources. Participants lamented the limited availability of affirming community services and financial resources, and they noted the lack of information and research on healthcare for TGD older adults. C.W. explained that even available health resources may not meet the nuanced needs of TGD older adults:

> Regular, heteronormative...resources for things like elder care are going to be framed for a heteronormative population, and...it feels like there's just a lack of awareness...It's not just like swapping out a gender...It's a lot more complicated and layered for us.

With limited health resources and medical support, some participants like R.L. found themselves confronting systemic barriers alone: "I feel like a lot of times we're just on our own and just navigating through the healthcare system."

(L3) *"If I get sick, I'm pretty much on my own": Disadvantages yielding poor health outcomes*

Theme L3 refers to actual and anticipated socio-structural barriers affecting health outcomes for some participants. Subthemes include *limited social support, health challenges,* and *socioeconomic inequities.*

Limited Social Support. Six Phase 1 participants (30%) explicitly reported low social support for their care in later life. “My support is slim-to-none,” said D.J. “And by support, I mean, I have support from the medical team, but in terms of family connection, I don't have that.” Without a strong support network, E.R. worried about finding someone to care for him during a serious illness, stating, “If I get sick, I'm pretty much on my own.” E.R. disclosed that he had faced the reality of his concerns during a recent hospitalization in which he found himself without a relative or friend to transport him home from the hospital. J.T. and U.T. also felt “isolated” without a robust social support system, and one participant had even contemplated suicide fearing that they would have no one to care for them if they experienced a serious illness in later life.

Health Challenges. Eleven Phase 1 participants (55%) reported prior hospitalizations for serious illness, and five participants (25%) explicitly shared that they had observed or personally faced chronic health conditions, mental illness, and substance use as negative health outcomes affecting their experience of aging.

> I'm living the life of somebody that's way older than me actually, and many of us, our bodies are breaking down earlier due to lack of care, denial of care, what-have-you, but our bodies are breaking down earlier. So, things that we expect to see at 60 and 65, we're seeing way early in us. (B.H.)

J.T. had also observed increasing morbidity and mortality among TGD people at younger ages, stating, “It’s a little bleak...talking about real life expectancies as they are right now for trans people.”

Socioeconomic Inequities. For at least six Phase 1 participants (30%), socioeconomic inequities, like financial hardship, lack of insurance, and housing insecurity, had the potential to limit their access to care and compromise their health and well-being. N.G. said that, for TGD older adults in the workforce, the risk of losing employment, and consequently insurance coverage, is “a huge issue” because “[for] a lot of jobs, if you come out [or, express your gender identity] at work, they won’t accept you.” B.H. emphasized the serious health implications of eschewing medical care due to underinsurance and fear of discrimination in healthcare settings:

> Many of us are aging without insurance. I’m talking about [those of] us, who are now afraid to go to the doctor’s and are choosing not to go to the doctor. When we’re getting to the doctor’s, our conditions are too far gone.

Facilitating Factors

(F1) *"The positive wins": Health justice promoting affirming healthcare experiences*

Theme F1 describes affirming treatment in healthcare settings and human flourishing among TGD older adults. Subthemes include *gender affirmation* and *signs of thriving.*

Gender Affirmation. Sixteen Phase 1 participants (80%) explicitly shared a desire for affirmation of their gender identity in healthcare settings, and 14 (70%) shared examples of affirming treatment they received when seeking healthcare. P.T. became tearful recalling an affirming interaction with a physician: "In my first appointment...I could tell [the physician] had gone out of her way to make sure everyone knew my name and my pronouns. And just some of the messaging there...was exactly what I needed." Participants reiterated the value of receiving respectful treatment from clinicians and medical support staff. "It [gender-affirming care] "means they [clinicians and staff] respect me as an individual exactly the same as they respect anyone else who comes in," said K.P.

Signs of Thriving. Participants recognized structural shifts that are beginning to promote longevity and quality of life for TGD older adults. Defying the adverse health outcomes he was facing, B.H. declared, "I am a disabled trans person who has survived." He shared that he had been "practicing...wellness in an understanding that says...we can thrive no matter what." S.W. described her recent healthcare experiences as positive during her gender transition, and she had been searching for opportunities to support fellow TGD older adults who face adverse treatment in healthcare settings. She issued a reminder to find encouragement in incremental progress toward health justice: "I know there's a lot of negative in the world and in our country right now. *That* we need to deal with. But you've got to focus at least once in a while on the positive wins."

(F2) *"There's been this sea change": Catalysts for change in healthcare*

Theme F2 details facilitating factors that foster systems changes to improve healthcare for TGD older adults. Subthemes include *practice changes, systems improvements, community networking,* and *emerging evidence*. In certain contexts, *practice changes* and *systems improvements* may actually *limit* health equity for TGD older adults when implementation methods and support infrastructure fail to achieve equitable and affirming outcomes.

Practice Changes. M.M. had witnessed favorable changes in the healthcare system over the preceding decades, noting a shift in awareness of transgender health: “I really do think that the...general level of knowledge and understanding about trans people has changed a lot. So, I have some hope that there’s been kind of this sea change.” Although J.T. had not personally witnessed these changes, they proposed a person-centered strategy to promote further progress: “We need a whole paradigm shift...where we need to flip this on its head, and money is the last concern, and the human aspect is the biggest.”

Without proper support infrastructure, however, practice changes may stall. I.H. described a new mechanism in his healthcare provider’s electronic record system that would “flag” TGD patient accounts, prompting clinicians to use the patient’s correct pronouns. However, he said that the feature had not led to a change in practice because “you still have to educate [clinicians] to do that, because some people are still just going to be like, ‘I don't care. I don't believe in that.’” He added that misgendering continued despite efforts to curtail it.

Systems Improvements. Participants noted how affirming health systems facilitated their access to care and helped them plan for the future. M.M. described promising changes in the electronic health record systems of the medical practices where he sought care, highlighting measures designed to reduce misgendering by healthcare professionals. D.J., E.R., and T.P. praised the quality of care in clinics that specifically address transgender health, and P.T. shared that a transgender health clinic made her gender transition possible. “I don’t know that I would have transitioned if I hadn’t had access to that care,” she said.

Intended improvements may result in disaffirming experiences in some instances. K.P. described her frustration seeing “gender dysphoria” marked repeatedly on her medical forms when the diagnosis was irrelevant to the health condition that prompted her visit. However, she recognized the need for clinicians to have access to this information. “It's an important thing to be there,” she said. “I just wished in some ways it wasn't flashing at the top of every page.”

Community Networking. Participants discussed the role of community networking in advancing change for TGD older adults within the U.S. healthcare system. C.W. had observed an increase in access to information about gender-affirming medical care from healthcare institutions, noting that in the past it had been “just the network of us talking to each other, and that's how we educated ourselves.” O.N. described online platforms that have extended these networks in recent years, providing channels to find information and support and to locate affirming clinicians. Naming peer networks across the U.S. that could fill the caregiving needs of TGD older adults in later life, F.P. expressed hope that caregiving would be “built in” within “these network communities.”

Emerging Evidence. Noticing the emergence of new studies on healthcare for TGD older adults, some participants were hopeful that ongoing research would lead to more information and resources tailored to their unique healthcare needs. F.P. shared that he was serving on the advisory boards for several research studies in progress centered on LGBTQ+ older adults. “There's people out there that are starting to research trans people, just the aging population in that community,” said R.L. “And I hope that just keeps going and helps. I'm sure it's going to help the future generations.”

(F3) *“I’m who I am now”: Assets fostering agency and well-being*

Theme F3 captures personal attributes, advantages, and actions that empowered participants to experience healthy aging, embody their true identities, and advocate for their care in later life. Subthemes include *personal strengths, personal privilege, supportive relationships, community engagement,* and *hope for change*.

Personal Strengths. Participant stories and insights revealed five key attributes, resilience, resourcefulness, self-advocacy, wisdom, and self-assurance, which allowed participants and their peers to transcend adverse healthcare experiences and find alignment of mind, body, and identity. Highlighting resilience and resourcefulness within TGD communities, R.L. said, “That’s what I like about our community is just, the people are...resilient, and that...when you’re alone, you get creative, you learn something.” D.J. identified his “ability to self-advocate” as a personal strength that had grown substantially since his “younger years.” Recognizing the embodied wisdom of TGD older adults, B.H. said, “We’ve been living in this body. We know what works as well. We have the data that's stored in us, which [healthcare professionals and researchers] haven't captured yet." After years of concealing her identity and surviving a suicide attempt that nearly ended her life, O.N. cultivated self-assurance through her gender transition. When asked about her confidence and renewed energy for life, she replied, "I'm who I am now."

Personal Privilege. Participants had privileges that benefited their health and facilitated their access to care. With the advantage of being in good health, some participants were taking preventative measures "to not be dependent" (R.L.) in later life and "to continue advocating" (D.J.) for their care. Five Phase 1 participants (25%) shared that they had financial assets and insurance coverage to support them in later life. K.P. acknowledged her "place of privilege" financially but clarified that her experience may be "different than most transgender individuals."

With expanded insurance coverage for gender-affirming medical care, many participants were "very fortunate" (K.P.) to transition in later life, experiencing a sense of inner alignment and improved health and well-being. L.G. marveled at the benefits of gender-affirming care to their health and relationships after spending "forty years just being in a state of mental anguish." Having endured pressure from family to conceal her gender identity since childhood, H.K. shared that after starting her transition, she "got out of the shower one day, and it was the first time in [her] life that [she] didn't have dysphoria when [she] looked in the mirror."

Supportive Relationships. Twelve Phase 1 participants (60%) identified social support as a benefit to their well-being or as a source of advocacy in healthcare settings. "I've been really lucky and privileged to have a...supportive family and friends and other community supports," said M.M., adding "I have a spouse who I know will advocate for me" during a serious illness. A.T. planned to name her niece as her healthcare advocate, and O.N. had appointed friends as executors of her will. S.W. acknowledged the value of her spouse's support during her gender transition: "I credit her with me coming as far as I have as my authentic self."

Community Engagement. Engagement in their communities enabled some participants to promote health equity for their peers. "I know everyone. I know the therapists, I know the doctors, the surgeons," said O.N., describing how she connected members of her local TGD community to healthcare professionals that provide gender-affirming medical and surgical care. Acknowledging her privilege to have access to high quality medical care, S.W. sought opportunities to support her community: “I want to help because my experience has been so positive. And if it’s not positive for everyone, I’d like to be that support if I can.”

Hope for Change. Through adverse healthcare experiences some participants maintained a sense of hope for change. Imagining the benefits of affirming healthcare resources and support, R.L. expressed hope in “just having that knowledge that getting older as a trans person doesn’t have to be scary.” Speaking from personal and professional experience in the field of transgender health, M.M. said, “Overall, I'm optimistic, and I think mainly that's because I've really seen a lot of change.”

“Like a lock to a key”: Modeling Limiting and Facilitating Factors at Multiple Levels

Participants acknowledged linkages between limiting and facilitating factors. While reviewing themes in Phase 2, F.P., said “These [themes] don’t strike me as extreme...these themes are more closely linked. It’s like, yes, there’s structural oppression, but...people have figured out how to navigate structures to reduce the oppression.” The complex interplay between limiting and facilitating factors was apparent in the following exchange between two Phase 2 participants, I.H., a Black transmasculine veteran living in the western region of the U.S. and S.W., a White transfeminine veteran living in the northeast:

> S.W.: [to I.H.] I feel I'm one of the lucky ones. I'm also a veteran. And I'm part of a couple of groups that I've heard some pretty horrific stories throughout the country. But where I am in [U.S. state], I have not experienced any of it.
>
> I.H.: [to S.W.] I think I fall into one of those categories where it is a little bit different. I am treated a little bit different, and that's part of life... So, it's good to hear, I mean, both sides of the story...because I know there's good and there's bad in most everything. But categorically, I experienced a lot of the bad.

S.W. and I.H. had contrasting experiences within the same government-run health system, demonstrating regional and possibly racial influences on the factors affecting health equity for them as TGD older adults. However, they each recognized the validity in the other’s perspective, showing awareness of the complex realities inhabited by a diverse population of TGD older adults seeking healthcare in the U.S. One participant who provided feedback anonymously shared that “coming out and taking control over the quality of my healthcare as a trans person has been rewarding; however, it’s also made me more aware [that] the lack of empathy, discrimination, and daily challenges are widespread concerns.”

During an individual session in Phase 2, E.R. drew parallels between the ingenuity involved in his work as a locksmith and the ingenuity required for him to navigate barriers to healthcare access that he had experienced. His narratives prompted a visualization of the limiting and facilitating factors affecting health equity for TGD older adults as locks and keys. Participants who reviewed study findings at the end of Phase 2 endorsed the visualization, rendered in **Figure 2**. E.R. said, “It fits just like a lock to a key.”

Figure 2. Lock-and-key Conceptual Model

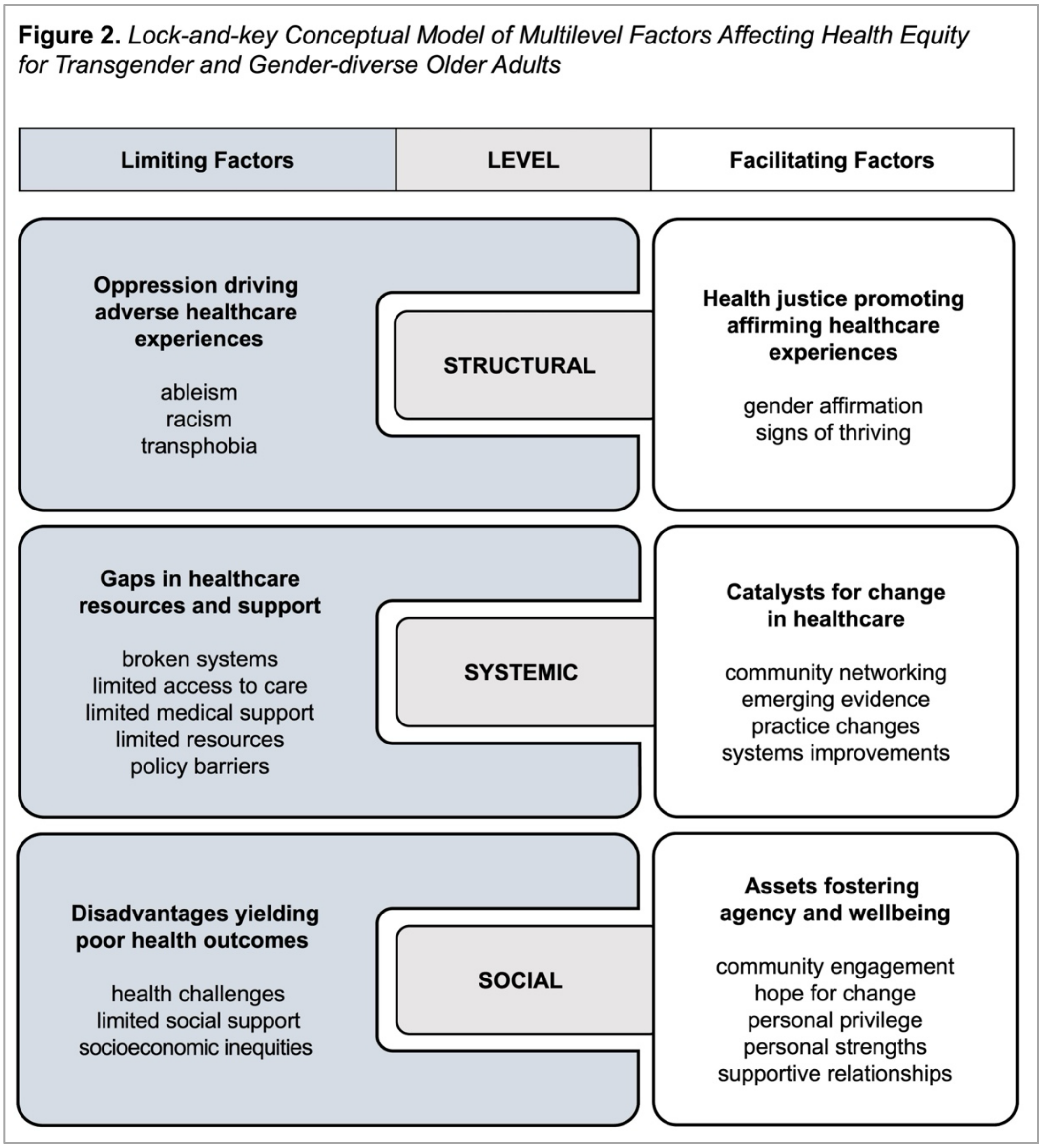

Figure 2. *Lock-and-key Conceptual Model of Multilevel Factors Affecting Health Equity for Transgender and Gender-diverse Older Adults*

Limiting Factors	LEVEL	Facilitating Factors
Oppression driving adverse healthcare experiences ableism racism transphobia	STRUCTURAL	**Health justice promoting affirming healthcare experiences** gender affirmation signs of thriving
Gaps in healthcare resources and support broken systems limited access to care limited medical support limited resources policy barriers	SYSTEMIC	**Catalysts for change in healthcare** community networking emerging evidence practice changes systems improvements
Disadvantages yielding poor health outcomes health challenges limited social support socioeconomic inequities	SOCIAL	**Assets fostering agency and wellbeing** community engagement hope for change personal privilege personal strengths supportive relationships

Discussion

Through interviews and member-checking sessions with 20 TGD older adults, researchers identified six themes describing limiting and facilitating factors that affect health equity for TGD older adults at structural, systemic, and social levels. These levels parallel the three layers of the IRTHJ conceptual framework, which "requires researchers to theorize intersecting relations of power at multiple layers of analysis" (Wesp et al., p.291). This study extended the IRTHJ framework by including not only factors that cause health inequities but also factors that promote equitable and affirming healthcare at each level.

As represented in the lock-and-key model, limiting and facilitating factors identified in this study appear to have a dialectical rather than a diametrical relationship with one another, shaping the healthcare experiences of TGD older adults concurrently. Despite criticism of binary barrier-facilitator constructs as decontextualized and overly simplistic, the dialectic between limiting and facilitating factors illustrates the complex state of health (in)equity experienced by TGD older adults in the U.S. healthcare system (Bach-Mortensen & Verboom, 2020). For instance, the degree of influence of factors like *limited medical support* may determine whether related factors like *practice change* ultimately limit or facilitate health equity. Moreover, the influence of each factor on health equity seemed to vary based on the social, regional, political, and economic contexts in which participants were situated. For example, participants receiving care within the same health system but in different regions had different experiences of care quality and gender affirmation in those settings. Lastly, paradoxical pairings of limiting and facilitating factors, such as *limited social support* and *supportive relationships; broken systems* and *systems improvements;* and *transphobia* and *gender affirmation*, represent simultaneous manifestations of repression and resistance that may occur within communities marginalized by dominant power structures (hooks, 1989).

Findings from this study complement emerging evidence reported in recent publications on barriers and facilitators affecting healthcare within TGD communities. Findings coincide with new research that identified barriers to care for TGD adults, such as disrespect and mistreatment in healthcare settings; limited access to care and medical support; socioeconomic disadvantages; and intersectional factors driving health inequities (Berrian et al., 2024; Johnson et al., 2019). Likewise, in another study, gender affirmation and peer support facilitated favorable experiences for TGD older adults within behavioral healthcare settings, which is consistent with findings from the SAFEage study (Lampe et al., 2024). However, the SAFEage study also expands on the current body of literature by presenting limiting and facilitating factors jointly, which may aid in the development of policies and interventions that address health inequities with breadth and nuance.

Research, Practice, and Policy Implications

Findings from this study may inform future research. Focused explorations of individual factors affecting health equity for TGD older adults in future research would cultivate a deeper understanding of each factor. Limiting factors with heightened urgency, such as low social support, housing insecurity, and suicidality among TGD older adults, warrant further study and timely intervention. Researchers may design multi-axis interventions to address factors affecting health equity for TGD older adults at each level of influence. Centering the knowledge of TGD older adults from diverse backgrounds in future research would be essential.

Study findings also have implications for practice and policy. In clinical practice, themes and subthemes from this study may inform educational programs designed to promote clinician competency in the care of TGD older adults. Findings also indicate the need for federal and state policies to protect the rights of TGD older adults. Such policies may secure health insurance coverage; permit preferred gender markers on official documents, such as health records and death certificates; and devote funding to further research on the healthcare needs of TGD older adults (Kinney et al., 2022).

Strengths and Limitations

This study has several limitations. Consistent with its purpose and scope, this study provides a broad view of various factors affecting health equity for TGD older adults; however, in-depth descriptions of each factor require further exploration. Limiting and facilitating factors described in this study are drawn from experiences specific to one participant group, so some factors that affect health equity for the U.S. population of TGD older adults as a whole may not be represented. Due to the complex contextual and temporal variability of barriers and facilitators, factors identified in this study may have limited transferability to contexts that differ from the situations and circumstances described by participants (Bach-Mortensen & Verboom, 2020). However, findings were consistent with existing evidence on healthcare for TGD older adults, reinforcing their applicability to different contexts.

Despite outreach to diverse communities of TGD older adults, this study does not represent the perspectives of Black transgender women, Asian TGD older adults, or Indigenous TGD older adults. This study also lacks representation of TGD older adults aged 70 and over, as well as non-English speakers and TGD older adults with cognitive impairment. In future studies, researchers should aim to diversify modes of outreach to ensure that members of these groups, as well as TGD adults with serious or terminal illnesses, are represented. Because study participation was limited to U.S. residents, findings may have limited global transferability; however, this study adds to the growing global evidence base on healthcare for TGD older adults (Banerjee & Rao, 2020; Pang et al., 2019; Reisner et al., 2016).

Conclusion

This study identified six themes describing limiting factors (oppression driving adverse healthcare experiences; gaps in healthcare resources and support; and disadvantages yielding poor health outcomes) and facilitating factors (health justice promoting affirming healthcare experiences; catalysts for change in healthcare; and assets fostering agency and well-being) affecting health equity for TGD older adults in the U.S. at structural, systemic, and social levels of influence. They form a dialectic in which limiting and facilitating factors co-occur to varying degrees. Differences in social, regional, political, and economic contexts appear to influence these factors. Filling a gap in the literature, this study augments the body of knowledge on health equity for TGD older adults with implications for future research, clinical practice, and policy change.

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MANUSCRIPT 3

Co-developing an Advance Care Planning Resource with Transgender and Gender-diverse Adults: A Human-Centered Design Approach

(under review with *Design for Health*)

Introduction: Many transgender and gender-diverse (TGD) adults face multilevel barriers to equitable care within the United States healthcare system. Concurrently, resources that would empower TGD adults to exercise their right to self-determination within the healthcare system are limited. Consequently, researchers conducted a qualitative study using a human-centered design approach to co-develop an advance care planning (ACP) resource with TGD adults. **Materials and Methods**: This qualitative descriptive study used a participatory human-centered design framework to engage TGD adults from across the United States in interviews and group sessions centered on developing an ACP resource. Data collected over three phases were analyzed thematically, and resultant themes guided iterative prototyping of the resource. **Results**: Twenty-seven participants joined the study across all three phases. In Phase 1, participants generated ideas for resources to address concerns about their healthcare in later life or during a serious illness. In Phase 2, participants discussed ideas for designing a healthcare decisions resource. Four themes were identified: (1) Motivation: Promoting agency through proactive healthcare decision-making; (2) Composition: Integrating simple features, guided choices, and inclusive media; (3) Dissemination: Connecting to the community through snowball networking; and (4) Expansion: Fostering support and sustainability through grassroots efforts. Themes guided development of three iterations of the resource in Phases 2 and 3. **Discussion**: This study addresses the gap in ACP resources for TGD adults. Moreover, the study supports future research that would promote active involvement of TGD adults of all ages in finding solutions to problems they face in the healthcare system.

Keywords: transgender, gender-diverse, advance care planning, palliative care, human-centered design, design thinking

Co-developing an Advance Care Planning Resource with Transgender and Gender-diverse Adults: A Human-Centered Design Approach

Many of the over 1.3 million transgender and gender-diverse adults in the United States (U.S.) experience health disparities due to barriers at multiple social ecological levels (Herman et al., 2022). Transgender and gender-diverse (TGD) is a term to describe people with gender identities that “differ from the gender socially attributed to the sex assigned to them at birth” (Coleman et al., 2022, p.S5). The U.S. National Institute on Minority Health and Health Disparities (NIMHD) differentiates factors at *societal, community, interpersonal*, and *individual* social ecological levels that influence health disparities for TGD adults (NIMHD, 2024). For example, anti-transgender health policies and inequities in health insurance coverage at the *societal* level have compromised access to gender-affirming care and impacted health outcomes for TGD adults (Du Bois et al., 2018; Kinney et al., 2022). Moreover, nondiscrimination policies instituted by medical centers at the *community* level are often insufficient to protect TGD adults from discriminatory healthcare practices at the *interpersonal* level (Kattari et al., 2015; Stein et al., 2020). At the *individual* level, TGD adults may have poor health outcomes with higher morbidity and mortality (Hughes et al., 2022; Hughes et al., 2021). These outcomes may stem from the cumulative effects of stigma-related stressors over the life course and the postponement of needed medical care due to fear of anti-transgender discrimination in healthcare settings (James et al., 2024; White Hughto et al., 2015).

Multilevel barriers driving health disparities for TGD adults may additionally affect their engagement in advance care planning (ACP). Codified in the U.S. Patient Self-Determination Act of 1990 to protect patient rights for healthcare decision-making (PSDA, 1990), ACP is an iterative process by which adults at any age or stage of health prepare for future medical care by identifying and sharing their values, life goals, and preferences (Sudore et al., 2017). ACP includes, but is not limited to, legal documentation of a person’s wishes for their healthcare during a serious illness in the form of an advance directive (NIA, 2022a). About one third of the U.S. population as a whole has completed an advance directive or appointed a healthcare proxy to make decisions on their behalf if they become unable to do so (Yadav et al., 2017). Notably, TGD adults may be 50-

70% less likely than their cisgender peers to have an advance directive or to have appointed a healthcare proxy (Kcomt & Gorey, 2017). Barriers to engagement such as discrimination against TGD adults in healthcare settings and disregard for their wishes by healthcare professionals may reinforce these disparities (Reich et al., 2022, Stein et al., 2020).

Despite barriers to engagement, ACP may play a role in promoting positive health outcomes in later life or during a serious illness for vulnerable populations (McMahan, Tellez & Sudore, 2021). For adults of any gender identity, ACP supports the right to self-determination in later life or during a serious illness, such as cancer, heart failure, or Alzheimer's disease, with unique implications for TGD adults (Reich et al., 2022). For example, through shared decision-making, a transgender adult and their healthcare team may proactively discuss the need for changes to their gender-affirming medical treatments and procedures during a serious illness (Maingi et al., 2018). Moreover, if a transgender or gender-expansive person is estranged from their family of origin on the basis of their gender identity and expression, they may appoint a healthcare proxy from their chosen family, a group of people with whom they share a strong bond but no biological or legal relation (Levin et al., 2020). Appointing a healthcare proxy would help ensure that their wishes are honored if they lack decision-making capacity due to a serious illness (NIA, 2022b).

An emerging body of evidence reinforces the need for more research on healthcare for TGD adults in later life, during a serious illness, and at the end of life (Catlett et al., 2023; Rosa et al., 2022). Further research is warranted to explore the role of ACP in supporting the agency of TGD adults in later life or during a serious illness (Lampe, 2023). Although several evidence-based ACP resources are available to the general public (Detering et al., 2010; Lyon et al., 2019), few resources address healthcare considerations specific to TGD adults (Catlett, 2024). Participatory research that incorporates meaningful involvement of TGD adults is needed to support the development of resources and interventions that would meaningfully address barriers affecting this population at multiple levels (Rosa et al., 2022).

A study called Shaping Affirming Futures with Elders of all gender experiences (SAFEage) was conducted to address the gap in ACP resources for TGD adults identified in the literature. This study responded to the question: how do TGD adults envision preparing for their healthcare in later life or during a serious illness? The purpose of this study was to co-design an ACP resource with TGD U.S. residents aged 50 years old and older that would empower them to prepare for their healthcare in later life or during a serious illness.

Materials and Methods

SAFEage researchers enrolled eligible participants to co-develop an ACP resource for TGD adults during interviews and group co-design sessions over three phases. The study was approved by the University of Virginia Institutional Review Board for the Social and Behavioral Sciences (UVA IRB-SBS #6104). Informed consent was obtained from all individual participants included in the study prior to data collection, and participants received compensation in the amount of $50 per interview or group session they completed. Study results have been reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007).

Methodological Approach

Researchers used a qualitative descriptive approach in the SAFEage study to preserve participant voices in representations of the findings by staying close to the data and employing minimally interpretive methods (Sandelowski, 2000). Qualitative description, which may draw from theory or other qualitative approaches (Sandelowski, 2000), was shaped by a participatory framework in this study called human-centered design (HCD). HCD centers the people for whom a new system, process, or product is intended (Leary et al., 2022) and has been used in health research and design to promote social innovation within a relatively short timeframe (Chen, Leos et al., 2020). The framework consists of five processes: *empathizing, defining (the problem), ideating, prototyping*, and *testing* (Leary et al., 2022).

Study Design

The SAFEage study implemented the first four HCD processes over three phases. In Phase 1, researchers engaged in *empathizing* by conducting interviews to understand participant concerns about their healthcare in later life or during a serious illness. *Defining the problem* involved framing participant concerns in the form of a "problem statement" from which solutions could be developed. Through *ideating* during individual and group co-design sessions, participants discussed ideas to address the problem statement. One idea was chosen for development into an ACP resource during *prototyping* in Phases 2 and 3. **Figure 1** depicts the study design with a summary of each phase.

Figure 1. Study Summary by Phase

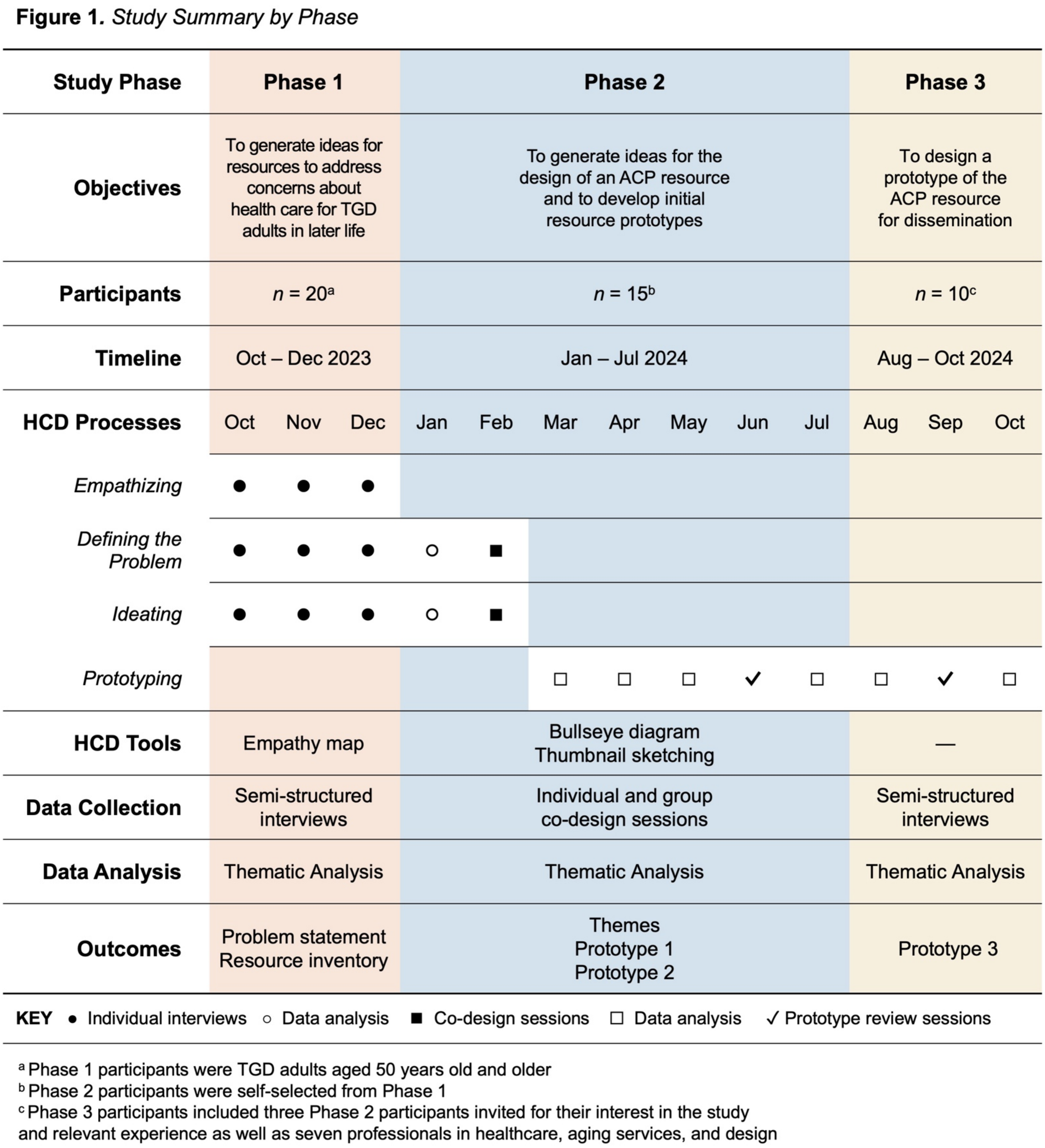


Figure 1. *Study Summary by Phase*

Study Phase	**Phase 1**			**Phase 2**							**Phase 3**		
Objectives	To generate ideas for resources to address concerns about health care for TGD adults in later life			To generate ideas for the design of an ACP resource and to develop initial resource prototypes							To design a prototype of the ACP resource for dissemination		
Participants	*n* = 20[a]			*n* = 15[b]							*n* = 10[c]		
Timeline	Oct – Dec 2023			Jan – Jul 2024							Aug – Oct 2024		
HCD Processes	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
Empathizing	●	●	●										
Defining the Problem	●	●	●	○	■								
Ideating	●	●	●	○	■								
Prototyping						☐	☐	☐	✓	☐	☐	✓	☐
HCD Tools	Empathy map			Bullseye diagram Thumbnail sketching							—		
Data Collection	Semi-structured interviews			Individual and group co-design sessions							Semi-structured interviews		
Data Analysis	Thematic Analysis			Thematic Analysis							Thematic Analysis		
Outcomes	Problem statement Resource inventory			Themes Prototype 1 Prototype 2							Prototype 3		

KEY ● Individual interviews ○ Data analysis ■ Co-design sessions ☐ Data analysis ✓ Prototype review sessions

[a] Phase 1 participants were TGD adults aged 50 years old and older
[b] Phase 2 participants were self-selected from Phase 1
[c] Phase 3 participants included three Phase 2 participants invited for their interest in the study and relevant experience as well as seven professionals in healthcare, aging services, and design

In Phase 1, the principal investigator (PI) conducted semi-structured interviews with TGD adults aged 50 years old and older between October and December 2023. Interviews were held in person, by phone, and via video conference, based on participant preference, in private or semi-private spaces chosen by participants. Phase 1 interviews and all sessions from Phases 2 and 3 were audio- and video-recorded with consent from participants, and field notes were recorded after each session. Researchers used a semi-structured interview guide informed by scholarly sources and lived experiences of community advisors involved in the study (Catlett, 2024; Catlett et al., 2023; Reich et al., 2022). See **Appendix** for excerpts from the guide.

During their interviews, participants were invited to share their experiences, concerns, and ideas related to preparing for healthcare in later life or during a serious illness. Sessions lasted between 45 and 90 minutes (65 minutes on average). Interview transcripts were returned to interested participants for review. No follow-up interviews were conducted.

In Phase 2, the PI facilitated eight individual and group co-design sessions in February 2024. All Phase 1 participants were invited to join Phase 2. As in Phase 1, sessions were held in person and via video conference in private or semi-private spaces. Group sessions lasted between 75 and 105 minutes (91 minutes on average), and individual sessions lasted between 30 and 65 minutes (46 minutes on average). These sessions focused on collaboratively designing a resource to address challenges TGD adults may face when preparing for their healthcare in later life or during a serious illness. The PI followed a semi-structured session guide for each phase (see **Appendix**). During these sessions, participants reviewed a problem statement (also included in the Appendix) that was composed by the PI to summarize key concerns participants articulated in Phase 1. They also reviewed and discussed a list of ACP resource ideas proposed by Phase 1 participants. One resource idea was selected for further development, and participants discussed design ideas for the chosen resource.

In Phase 3, individuals with personal or professional experience related to the study aims participated in interviews held in September 2024. Phase 2 participants were invited to join Phase 3 based on their relevant experience and their expressed interest in continuing on with the study. Additional Phase 3 participants were invited based on their professional experience in healthcare, aging services, and design. Interviews were held in person and by video conference and lasted between 45 and 82 minutes (60.8 minutes on average). During their interviews, participants reviewed a resource prototype that integrated design ideas from Phase 2.

Participant Group Formation

Researchers engaged in purposeful and snowball sampling to recruit Phase 1 participants (Onwuegbuzie & Collins, 2015), distributing an informational flier to community gatekeepers, TGD individuals, and LGBTQ+ organizations by email, text message, and social media. The flier contained a link to a screening form with questions to assess respondent eligibility. Researchers disqualified responses originating from IP addresses outside of the U.S. (see inclusion/exclusion criteria below), and multiple responses received within a short time frame were assessed further for signs of submission by bots or other ineligible sources.

Eligible respondents were contacted to enroll in the study by phone or email. Participants were eligible to join Phase 1 if they identified as transgender or gender-diverse, were 50 years old or older, and had been living in the U.S. for at least 10 years. These age- and gender-related inclusion criteria were chosen in order to enroll members of the TGD population most likely to find an ACP resource relevant and beneficial. Study constraints limited enrollment to participants who were fluent in English.

Participant group size was based on iterative assessment of group diversity and information power, rather than saturation, within the dataset (Malterud et al., 2016). Information power is used in qualitative research to approximate sample size based on five criteria: study aim, use of theory, analysis strategy, dialogue quality, and specificity of the data to the research question (Malterud et al., 2016). Based on these criteria, the PI determined that a moderate participant group size (15-20 participants) was needed for this study.

All participants who joined Phase 1 were eligible to screen for involvement in individual or group co-design sessions in Phase 2. Participants completed a supplementary screening form to assess their ability to join by video conference. Participants could join one or two co-design sessions. To enhance participant engagement and group cohesion, four group sessions were offered so that the group size for each session would not exceed about eight participants (Wheelan, 2009). Individual co-design sessions were offered to participants who could not attend the scheduled group sessions.

Phase 2 participants and adults of any age or gender identity with professional experience in the fields of healthcare, aging services, and design were eligible to join Phase 3. Expanded age and gender criteria in this phase allowed for representation of additional perspectives from parties with an interest in using, designing, or disseminating an ACP resource for TGD adults. The participant group size needed for Phase 3 was small (9-11 participants).

Study Contributors

Developing an ACP resource for TGD adults was a collective effort among participants, community advisors, and researchers. Each group of contributors is described below. Names have not been used to differentiate individual contributors in order to represent the value of their contributions equally while protecting their confidentiality.

Participants

Since participants served as collaborators in the development of an ACP resource for TGD adults, the authors acknowledge their contributions here as partners alongside the research team and community advisors. A detailed description of participant demographic data is covered in the study results section.

Community Advisors

Community advisors included three TGD adults over 50 years old with expertise and community connections related to the study purpose. The role of this group of advisors was to assist with outreach to TGD communities, review study materials for inclusivity and accuracy, and provide guidance throughout the study. Advisors gave informed consent to take part in the study, and they were compensated for their role. All three advisors are co-authors on this publication.

Research Team

The research team was made up of the PI, who was a master's prepared nurse and PhD student during the study period, and four tenured faculty members in the fields of nursing, gerontology, palliative care, and gender studies. The research team included two members under age 50 and three aged 50 and older; two Black/African American members and three White members; one member who identifies as a nonbinary, agender person and four members who identify as cisgender women; and one member who identifies as queer. Each researcher had experience in qualitative research, and the PI had additional training in design and group facilitation.

Researchers had no relationship to Phase 1 participants prior to starting the study, and the PI had professional relationships with some participants in Phase 3. Research team members centered participant voices throughout the study to address power differentials that their positionalities as researchers may have created. During interviews and co-design sessions, the PI built rapport with participants by disclosing their own gender identity and explaining their motivation for conducting the research (i.e., to work with TGD adults to apply their strengths toward addressing barriers to healthcare they may face in later life). To minimize bias, the PI remained open to participant suggestions and integrated collaborative decision-making into the design process.

Data Analysis

Analysis of Phase 1 data was conducted using an HCD tool called an *empathy map* that aims to build understanding of the population that may benefit from a product, service, or process (Interaction Design Foundation, 2024). Built on existing models (Mural, 2024), the empathy map created during this study consisted of participant thoughts, actions, words, feelings, observations, pains (problems and concerns), and gains (successes and wishes) related to preparing for their healthcare in later life or during a serious illness. These components of the empathy map were used as deductive codes in the first phase of data analysis, using the qualitative analysis software Dedoose (Version 9.2.22). Subsequently, excerpts coded deductively were also coded inductively, and a second coder checked a selection of these codes for consistency. All codes were entered into a codebook to form an empathy map representing the participant group as a whole.

Researchers conducted a focused analysis of the Phase 1 dataset, preparing a problem statement summarizing participant “pains,” or concerns, and forming an inventory of their “thoughts,” or resource ideas, for consideration in Phase 2. Participants suggested revisions to the problem statement in the first part of Phase 2. They also discussed a short list of resource ideas from the aforementioned inventory, which the research team and community advisors had chosen for feasibility and relevance to the research question. Each participant voted for one or two ACP resource ideas from the short list for further development. Researchers tallied the votes and consulted with community advisors to decide between options with a similar number of votes.

In the second part of Phase 2, the PI used a *bullseye diagram,* an HCD tool for prioritizing options and making decisions (LUMA Institute, 2019), to illustrate the resource selection process for participants. Subsequently, the PI facilitated an exercise called *thumbnail sketching* (LUMA Institute, 2019) in which participants wrote out and discussed ideas for designing the chosen resource. Participants reflected on and discussed nine design components selected by the PI and approved by community advisors prior to the exercise. Design components included resource accessibility, audience, content, cost, function, layout, outreach, purpose, and title (see **Appendix** for details).

Deductive codes for thematic analysis (Braun & Clarke, 2022) of the Phase 2 dataset corresponded to the aforementioned design components. For example, all excerpts pertaining to the substance of the resource were coded “Content” in parallel with the corresponding design component. During deductive coding in Dedoose, two additional design components (resource support and sustainability) were identified from excerpts that did not align with the original nine deductive codes. After deductive coding, excerpts were coded inductively and checked by a second coder. The resultant codebook served as a blueprint for developing a prototype of the resource. Deductive and inductive codes were categorized and grouped into themes representing interrelated aspects of resource design. These themes informed prototype development and described a holistic vision for present and future iterations of the resource.

Three months after Phase 2 data collection concluded, Phase 2 participants were invited to review the first resource prototype (Prototype 1) through an electronic survey, individual video calls, and one group video conference. Their feedback was incorporated into a second iteration of the resource prototype (Prototype 2), which was reviewed by Phase 3 participants. During Phase 3 interviews, the PI showed Prototype 2 to participants, who offered affirmations and suggested improvements. With input from community advisors, the PI then integrated Phase 3 data into the design of the resource, preparing a third iteration of the resource

(Prototype 3) for dissemination.

Results

SAFEage study contributors co-developed a prototype for a healthcare decisions resource to address concerns raised by participants about healthcare for TGD adults in later life or during a serious illness. Findings include a problem statement, an inventory of resource ideas, a description of four themes that informed resource design, and the outcome of the *prototyping* process. Subsequent findings are organized by HCD processes carried out in this study.

Empathizing

Researchers built understanding of the participant group, in part, by reviewing demographic characteristics and prior ACP engagement to contextualize participant lived experiences, concerns about healthcare for TGD adults, and hopes for the future. Twenty-seven unique participants were enrolled in the study across all three phases. Twenty of twenty-one eligible respondents (95%) enrolled in the study and completed Phase 1 interviews, and 15 Phase 1 participants (75%) joined Phase 2. Nine Phase 2 participants (60%) provided feedback on the initial resource prototype. Phase 3 participants included ten TGD adults and individuals with experience in healthcare, aging services, and design. Participant ages ranged from 50 to 69 years old in Phases 1 and 2, and the average ages for Phase 1 and Phase 2 were 58.3 and 57.5 respectively. In Phase 3, participant ages ranged from 25 to 70 with an average age of 49 years. Participants represented diverse gender identities and racial and ethnic backgrounds. In all three phases, most participants had college degrees. The proportion of participants with a college degree was higher in Phases 2 and 3 than in Phase 1. The occupational backgrounds of participants in Phases 1 and 2 included retail, law, real estate, social work, business, vehicle mechanics, higher education, and military service, among others. **Table 1** provides further details about participant demographic characteristics in each phase.

Table 1. Participant Group Demographic Characteristics

	Phase 1	Phase 2	Phase 3
Group size	n=20	n=15	n=10

Categories	Subcategories	n(%)	n(%)	n(%)
Age (years)	20-29	0(0)	0(0)	1(10)
	30-39	0(0)	0(0)	3(30)
	40-49	0(0)	0(0)	1(10)
	50-59	13(65)	11(73)	2(20)
	60-69	7(35)	4(27)	2(20)
	70-79	0(0)	0(0)	1(10)
U.S. region	Midwest	5(25)	5(33)	1(10)
	Northeast	1(5)	1(7)	4(40)
	South	13(65)	8(53)	4(40)
	West	1(5)	1(7)	1(10)
Gender identity	Agender	1(5)	0(0)	0(0)
	Female	0(0)	0(0)	5(50)
	Male	2(10)	2(13)	1(10)
	Nonbinary, gender nonconforming	5(25)	3(20)	2(20)
	Transfeminine, transwoman	9(45)	7(47)	4(40)
	Transmasculine, transman	6(30)	5(33)	1(10)
	Two Spirit	2(10)	2(13)	1(10)
	Another gender identity [a]	2(10)	2(13)	1(10)
Sexual orientation	Asexual	1(5)	0(0)	1(10)
	Bisexual	2(10)	2(13)	0(0)
	Lesbian	3(15)	1(7)	2(20)
	Queer	4(20)	3(20)	2(20)
	Straight, heterosexual	8(40)	8(53)	6(60)
	Another sexual orientation [b]	4(20)	3(20)	2(20)
Race and ethnicity	Asian, Asian American	0(0)	0(0)	1(10)
	Biracial, multiracial	1(5)	1(7)	1(10)
	Black, African American	2(10)	2(13)	4(40)
	Hispanic, Latino/a/e	4(20)	4(27)	0(0)
	White, European American	12(60)	7(46)	5(50)
	Another race or ethnicity [c]	1(5)	1(7)	0(0)
Highest educational level	High school diploma/GED	5(25)	2(13)	0(0)
	Associate’s degree	1(5)	1(7)	1(10)

Bachelor’s degree	4(20)	2(13)	1(10)
Master’s degree	8(40)	8(53)	4(40)
Doctoral degree	0(0)	0(0)	3(30)
Another degree/Other training [d]	3(15)	3(20)	1(10)

Note. Twenty-seven unique participants joined the study. All 15 participants in Phase 2 had participated in Phase 1, and three participants in Phase 3 had participated in Phases 1 and 2.
Note. Total percentages for *gender identity, sexual orientation, and race/ethnicity* may exceed 100% because participants could select more than one option. For *highest educational level*, participants had the option to select “another degree/other training” in addition to one other option from the list.
[a] “transsexual man,” “transgender/transitioning,” “genderfluid,” “genderqueer”
[b] “pansexual,” “demisexual”
[c] person of color, race and ethnicity unspecified
[d] “some college,” “military,” “Master of Law,” “terminal professional master’s degree”

Participants in Phases 1 and 2 answered questions about their engagement in ACP. Seven Phase 1 participants (35%) and six Phase 2 participants (40%) had documented an advance directive or appointed a healthcare proxy. Ten Phase 1 participants (50%) and nine Phase 2 participants (60%) reported engagement in other forms of ACP, like completing a will, making funeral plans, or discussing end-of-life planning with a trusted healthcare professional. Most participants were at least modestly familiar with the concept of ACP, even if they had not engaged in ACP directly.

Defining the Problem

Participants raised concerns about their healthcare in later life, during a serious illness, and at the end of life. Specific concerns included (1) mistreatment in acute care and long-term care settings; (2) involuntary discontinuation of their gender-affirming treatments; (3) insufficient social support for surrogate decision-making; and (4) forced de-transitioning after death. Considering the threat of losing access to gender-affirming treatments as a TGD older adult, one participant asked, “What about later on in life? Is someone going to try to stop me from getting the medical care that I need?”

The PI integrated participant concerns from Phase 1 into a problem statement, a description of key issues to address in the *ideating* and *prototyping* phases. The following problem statement incorporates revisions based on participant feedback in Phase 2:

Transgender and gender-diverse adults need accessible, gender-inclusive resources to help them mitigate current health challenges and prepare for future care because:

- *They may face injustices on the basis of age, race, ability, and/or gender identity, contributing to adverse health outcomes.*
- *They may have limited access to affirming healthcare services due to anti-transgender policies and dysfunctional health systems.*
- *They may lack adequate social and medical resources and support for their healthcare in later life or during a serious illness.*

Participants expressed the urgent need to "mitigate" health challenges both in the present and later in life. When reviewing a draft of the statement, one participant asked, "It may be implicit, but is there a way to build in some way, specificity for elder care?" Other participants pointed out that younger TGD adults may face premature aging and serious illness, calling for the statement to represent TGD adults under 50 years old as well. Thus, the resulting statement is inclusive of TGD adults of all ages.

In the first sub-statement, healthcare injustices that participants identified include discrimination, disrespect, implicit biases, gatekeeping, and refusal of care. Participants expressed concerns about encountering healthcare injustices in later life. One participant shared:

> I do know, and I have heard from others, that when some of the nursing homes or funeral homes find out that they are trans...they don't want to service them, or they don't call back, or there's some kind of issue.

The second sub-statement encompasses participant concerns about discriminatory policies and practices affecting the healthcare system. Participants highlighted the "broken" systems that limit access to care. "When I'm looking at this, everything seems so massively let-go for so long," said one participant. "Like, they've just neglected all of us for so long, and we rely on the worst kinds of systems."

The third sub-statement focuses on the scarcity of resources and support for some participants. In particular, having a small support network raised concerns about surrogate decision-making during a serious illness. One participant remarked, "Being a person that's solo [unpartnered, living alone], who's going to be my voice when I'm not able to speak?" Additionally, participants acknowledged the scarcity of ACP resources for TGD adults. One participant explained: "Finding resources for...people who identify as trans, gay, nonbinary, anywhere on the spectrum, a lot of services are not out there." Participants observed deficits in social and medical resources for TGD adults, fueling concerns about healthcare decision-making in later life without sufficient health information and services to guide them.

Ideating

In the ideating phase, participants generated ideas for ACP resources to support TGD adults in later life or during a serious illness (Phase 1), and they brainstormed ideas for the design of a healthcare decisions resource (Phase 2). To help TGD adults "mitigate current health challenges and prepare for future care" as articulated in the problem statement, participants envisioned measures that would promote (1) safety in healthcare spaces; (2) respectful and competent treatment by clinicians and staff; (3) advocacy in later life and during a serious illness; (4) increased access to inclusive health services; and (5) development of resources for TGD adults at any age, state of health, or stage of gender transition.

Resource Ideas

Phase 1 participants suggested ideas for resources to address concerns represented in the problem statement. Collectively, they introduced 16 unique resource ideas (**Table 2**). Resource ideas included initiatives, services, and tools that would influence change at *societal, community, interpersonal*, and *individual* social ecological levels. For example, the idea for a healthcare decisions resource would address concerns at the *interpersonal* level by equipping TGD individuals to communicate with trusted members of their support network and healthcare team about their wishes for healthcare in later life or during a serious illness.

Table 2. Inventory of Healthcare and Advance Care Planning Resources to Support Transgender and Gender-diverse (TGD) Adults in Later Life

Resource Type[a]	Description	Level[b]
Awareness initiatives	National and global outreach to increase visibility of healthcare needs specific to TGD adults in later life or during a serious illness	Societal

Resource Type[a]	**Description**	**Level**[b]
Policy protections	Governmental and institutional policies to protect the rights of TGD adults in healthcare settings in later life or during a serious illness	Societal
Research studies	Large-scale, population-based research on advance care planning and healthcare for TGD adults in later life or during a serious illness	Societal
Care coordination services	Support services with trained navigators to help TGD adults access and prepare for their healthcare in later life or during a serious illness	Community
Clinician training	Pre-licensure training and continuing education for clinicians on healthcare for TGD adults in later life or during a serious illness	Community
Inclusive housing	Programs connecting TGD adults to inclusive independent living and long-term care residences in later life or during a serious illness	Community
Inclusive medical records	Updates to health records systems to promote affirming treatment of TGD adults in later life or during a serious illness	Community
Quality improvement	Programs to assess and monitor the quality of care provided to TGD adults in later life or during a serious illness	Community
Resource directory	Websites with links to available services and resources related to healthcare for TGD adults in later life or during a serious illness	Community
Social support programs	Programs and services to help TGD adults build social networks for support in later life or during a serious illness	Community
Specialized services	Clinics and services that focus on healthcare needs specific to TGD adults in later life or during a serious illness	Community
Care conversations	Facilitated discussions for TGD adults and trusted supporters on preparing for healthcare in later life or during a serious illness	Interpersonal
Healthcare advocate guide	Digital or printed resources to help TGD adults identify and appoint a healthcare proxy to advocate for them during a serious illness	Interpersonal
Healthcare decisions resource	Digital or printed tools to help TGD adults make informed choices about their healthcare in later life or during a serious illness	Interpersonal

Resource Type[a]	Description	Level[b]
Inclusive advance directive	Legal documents for TGD adults to record wishes for their healthcare before facing a serious illness	Individual
Information package	Digital or printed resources with evidence-based information on healthcare for TGD adults in later life or during a serious illness	Individual

[a] Resources would address barriers affecting healthcare for TGD adults in later life or during a serious illness as defined in the following problem statement: *Transgender and gender-diverse adults need accessible, gender-inclusive resources to help them mitigate current health challenges and prepare for future care because (1) they may face injustices on the basis of age, race, ability, and/or gender identity, contributing to adverse health outcomes; (2) they may have limited access to affirming healthcare services due to anti-transgender policies and dysfunctional health systems, and (3) they may lack adequate social and medical resources and support for their healthcare in later life or during a serious illness.*
[b] Levels are based on the Sexual and Gender Minority Health Disparities Research Framework of the National Institute on Minority Health and Health Disparities (NIMHD).

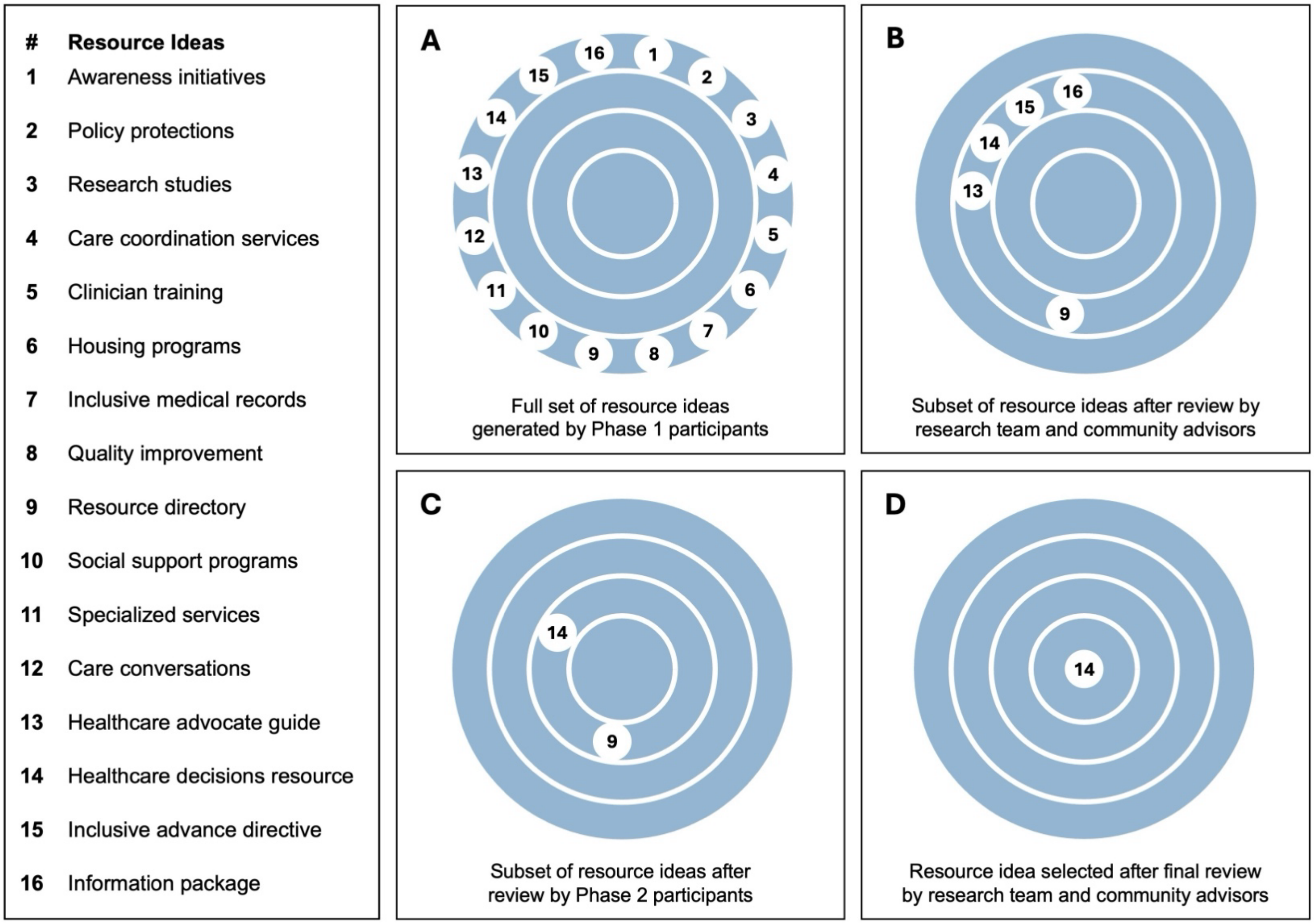
Participants discussed the following subset of five resource ideas with high priority that could be developed within the scope of the study: (1) resource directory, (2) healthcare advocate guide, (3) healthcare decisions resource, (4) inclusive advance directive, and (5) information package. After discussing the merits of ideas in this subset, Phase 2 participants each voted for one or two options for further development. The resource directory and the healthcare decisions resource received the most votes (eight votes and six votes respectively).

Participants discussed the advantages and disadvantages of each idea. Some participants were in favor of the resource directory as a website, citing the advantage of reaching a broad audience. However, participants also noted the necessity and the challenge of updating and vetting resources consistently to maintain the directory over time. Proponents of the healthcare decisions resource thought it would fill an important gap: “I'm gonna say...the decision-making aid...Primarily I say that because I think that's one of the tools that is sorely missing in healthcare, just in general.” They also saw the healthcare decisions resource as a bridge to developing other resources in the inventory: “It seems like a good starting point, and it offers options for expanding into some of the other things as well.”

Considering these advantages and disadvantages, the PI consulted with community advisors, factoring in their selections before deciding to pursue the healthcare decisions resource for further development. **Figure 2** is a bullseye diagram that summarizes the process for selecting one resource idea from the inventory generated in Phase 1. A version of this diagram was shared with participants prior to beginning the thumbnail sketching exercise in Phase 2.

Figure 2. Bullseye Diagram

Figure 2. *Shared Decision-making Process for Prioritizing Resource Ideas: A Bullseye Diagram*



#	Resource Ideas
1	Awareness initiatives
2	Policy protections
3	Research studies
4	Care coordination services
5	Clinician training
6	Housing programs
7	Inclusive medical records
8	Quality improvement
9	Resource directory
10	Social support programs
11	Specialized services
12	Care conversations
13	Healthcare advocate guide
14	Healthcare decisions resource
15	Inclusive advance directive
16	Information package

A Full set of resource ideas generated by Phase 1 participants

B Subset of resource ideas after review by research team and community advisors

C Subset of resource ideas after review by Phase 2 participants

D Resource idea selected after final review by research team and community advisors

Design Ideas

Phase 2 participants generated ideas, individually and in groups, related to the design of a healthcare decisions resource for TGD adults. From their recommendations, researchers discerned four themes: (1) Motivation: Promoting agency through proactive healthcare decision-making; (2) Composition: Integrating simple features, guided choices, and inclusive media; (3) Dissemination: Connecting to the community through snowball networking; and (4) Expansion: Fostering support and sustainability through grassroots efforts. Design themes are described in the following sections.

(1) Motivation. Promoting agency through proactive healthcare decision-making. When asked to define the purpose of the healthcare decisions resource, participants emphasized that (1) it should guide TGD adults to make informed healthcare decisions now and in later life, and (2) it should serve as a tool to communicate healthcare wishes to their support networks and healthcare professionals they trust. They viewed the resource as a tool to make “point-in-time decisions” that are “not forevermore, where they're locked in.” Thus, the resource could be used iteratively as a person’s perspectives and life circumstances change with time.

The healthcare decisions resource would “provide information and knowledge” so that “the individual is making more informed and intelligent decisions.” The resource would also be “a functional and supportive guide for elder trans folks from all walks of life, so that they have a resource to navigate the healthcare system.” The concept of “navigation” featured in definitions from other participants who saw the resource as a tool to “help maneuver through care” and “to help direct care options.”

Participants envisioned the resource as a “preventative” and “proactive” measure that could mitigate challenges during a serious illness: “It would be a great tool to know what your options are and how to go about them before there's a serious illness...so that you're not scrambling in the midst of chaos.” Moreover, some participants viewed the resource as a tool to promote the self-determination, or “agency,” of TGD adults in their healthcare:

> “I think it really is about giving people agency…giving people an understanding of what their options are, and through that, they gain some control over their lives and can make informed choices about what to [do], where to go, what care they want.”

Participants also identified the resource as a measure to facilitate communication between TGD adults, members of their healthcare team, members of their support networks, and “whoever else is going to be taking care of [them].” One participant received nods of approval from other group members when describing his vision for the resource as a tool for empowerment in interactions with healthcare professionals: “A lot of people don't know they can ask questions of [medical professionals]. They're so intimidated by doctors. And so, people need to be taught that they can ask, they can be assertive with their providers. They deserve to be.”

(2) Composition: Integrating simple features, guided choices, and inclusive media. Reflecting on the layout and content of the resource, participants emphasized simplicity, inclusivity, relevance, and user-friendliness. They also proposed ideas for the resource title that would make the purpose clear while maintaining safety and discretion for the user.

Simple features. Participants urged resource designers to “just keep it simple,” with a “simple format,” “simple imagery,” and a “simple font.” They called for a “user-friendly” format that would make it “visibly easy to navigate.” Participants explained that simplicity and user-friendliness would enhance readability and accessibility for TGD older adults and people with disabilities. Thinking ahead to the *testing* phase of resource development, another participant focused on “making sure it [the resource] is ADA [Americans with Disabilities Act] compliant and making sure that it's tested out by people who have disabilities.”

Guided choices. Participants suggested the use of icons, categories, and subheadings to guide TGD adults through information and resources for decision-making. The information contained in the resource would cover frequently asked questions and key definitions with a focus on healthcare for TGD adults in later life or during a serious illness. Connecting the composition of the resource to the concept of “navigation” embedded in the resource purpose, one participant explained, “I was thinking definitely user-friendly icons that...you don't need a translation sort of, you just see the symbol. It makes it easy to navigate.”

Participants recommended creating a “guide that would help you [know], these are the options. You can go this way or that way.” For some participants, organizing the content into categories based on goals for different life stages or stages of gender transition would facilitate resource navigation. They suggested structuring resource content as a “funnel” to guide TGD adults to the information that is most relevant to them: “If someone asks this question, they can get routed here...then have more [questions], and it funnels into the next step.” One participant emphasized the importance of preventing the resource from “overwhelming them [TGD adults] with information that’s not really relevant.”

Inclusive media. Using multiple modes of communication was important to participants to make the resource inclusive of people from diverse backgrounds and levels of ability. One participant’s suggestion to include “different pictures of all different kinds of people...pictures of people like me with a lot of diversity” resonated with others in the group. In more than one session participants discussed translating the resource into other languages for non-English speakers. One participant said, “[If] it's in more than one language, then it's accessible to me.”

Participants also underscored the need for access to the resource in digital and print formats. One participant said, “A really important thing is something that is workable on all three of those different types of platforms: laptop/desktop, tablet/phone, and an app,” while another offered the reminder that “there's always going to be a need for that printed copy, though. There are people that aren't plugged in.” For a digital resource, participants suggested accommodating different learning styles with multiple forms of engagement like text, video, audio, and images: “If it's in a digital form and it has audio and video, it would make it a lot easier because I don't have to try to read it. I can listen. Accessibility is major. If I can’t access it, then it does me no good.”

Resource title. Several participants suggested language to use in the resource title, emphasizing “choice” and “transformation.” One participant said, “Whatever the title is going to be, making sure the title is clear and it's inclusive of what this whole topic is about.” However, he also cautioned that the title should be discreet to avoid disclosing the identities of TGD adults who use the resource: “You want to let people know, but you want to keep it where they feel safe, too.” One participant proposed a full title for the resource:

> What came to me in terms of a title was ‘Transforming Elder Trans Care.’ You know, in the sense that we are actually transforming what's in place and offering the opportunity for other trans folks like us to see that healthcare is changing.

The PI incorporated these suggestions into the phrase ***TRANS****FORMING CHOICES,* a title for the resource that received approval from participants who reviewed each prototype.

(3) Dissemination: Connecting to the community through snowball networking. One participant asked, “Who are you going to get this to and how are you going to get it to them?” Subsequently, participants in each co-design session offered recommendations about the intended audience and outreach strategies for disseminating the resource. A participant described the intended audience as “gender-expansive older individuals 50 or older...explicitly noting, additionally, this could be useful for individuals who are looking at chronic or serious illness, regardless of age.” Other participants supported this description, adding that the resource would also be for “those who care about the individual,” including “family, close associates, friends,” and “providers who are working closely with [them].” To reach the intended audience, participants proposed the use of “digital fliers,” “info sessions,” and “palm cards” [hand-sized cards] with information about the resource for distribution in medical offices. One participant proposed a “snowballing” strategy, in which dissemination of the resource to key partners would lead to subsequent dissemination to their affiliates.

Participants named key partners who could aid in dissemination of the resource. They advocated for a multilevel approach to dissemination, calling for “a big advertising push when it first comes out because you want people to become aware of it.” To share the resource within the TGD community, participants suggested engaging with “LGBTQ centers,” TGD “support groups,” TGD “influencers,” and community “gatekeepers” across the U.S. “There's a lot of people…who have connections to their communities,” said one participant. “Use those gatekeepers to make those connections within communities.” They also stressed the importance of connecting to “case management, hospitals, doctors, nurses,” and healthcare professional organizations. One participant asserted that “we can help control the narrative” by disseminating the resource to healthcare professional “governing boards” with a “larger reach.” Participants also recommended the use of social media and partnership with human rights groups and governmental health agencies for broad dissemination.

(4) Expansion: Fostering support and sustainability through grassroots efforts. With various forms of support and measures to enhance sustainability, participants envisioned expansion of the resource over time to address the purpose comprehensively.

Support. Participants emphasized the need for support both for the resource itself and for the people who would use it. Articulating the need for “grassroots [efforts] to go along with whatever structures are there,” participants reinforced the value of “building [the resource] from the bottom up, using [the TGD] community” to “answer the questions around capacity-building, sustainability, and maintenance.” To promote access to all socioeconomic groups within the TGD community, one participant stated that the resource “would have to be at a cost where those who don't have any resources could access it. That is the most difficult question here: what would make it affordable?” Participants from every session addressed this question, proposing reliance on donations, grants, mutual aid, institutional sponsorship, insurance coverage, intern support, and “human capital...people that have talents that are willing to volunteer” to support the financial viability of the resource.

For TGD adults who would use the resource, participants emphasized both professional and peer support. Professional support would entail technology support specialists and clinicians in the role of “care or service navigators” to provide additional guidance for TGD adults regarding the content of the resource. Peer support was important for a number of participants who identified the need for “people who have already done it, people who are elders who have already navigated the system.” For one participant, peer support would serve as a source of advocacy for TGD older adults in healthcare settings, and they wondered “if we could somehow incorporate a network of advocates or just people that you can either chat [with] or just have a conversation about, ‘How do I do this?’” Articulating the underlying value of support for TGD adults as they prepare for their healthcare in later life or during a serious illness, one participant stated: “I don't want to go through this alone.”

Sustainability. To sustain the resource over time, several participants emphasized the need for personnel to make regular updates to content and links within the resource to promote ease of use for TGD adults. One participant cautioned that without the support of volunteers or interns “to keep the information updated,” the resource may end up with “broken [web] links” and outdated content that would deter TGD adults from using it.

In light of the potential challenges of maintaining the resource over time, another participant offered, “I think this is going to be something that would be set up as a nonprofit.”

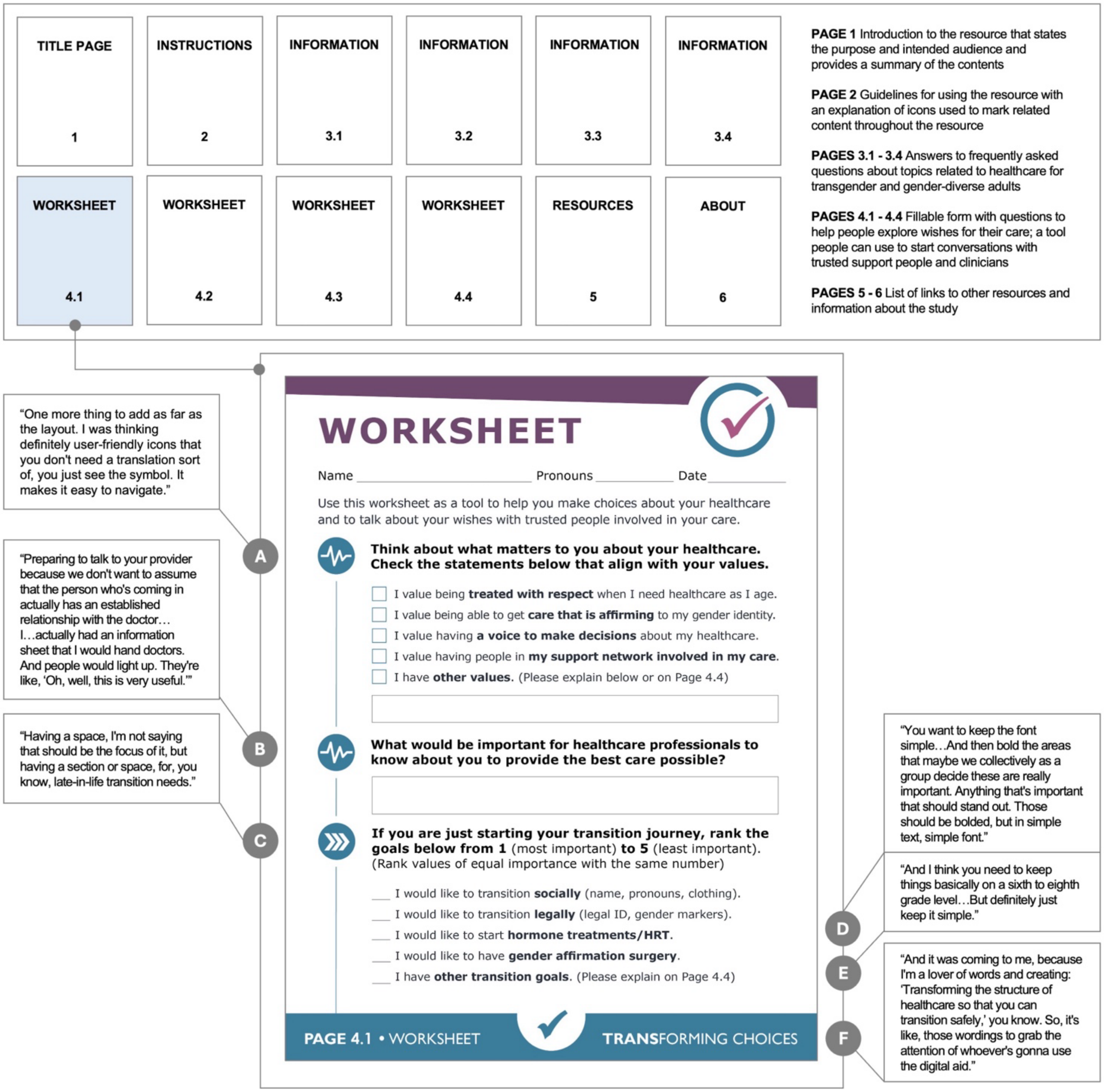
Although participants offered an expansive vision for the healthcare decisions resource, they also encouraged a stepwise process to make its development more feasible. Participants considered the healthcare decisions resource a “lower lift” in comparison to other resource ideas from the inventory generated in Phase 1, while also having the potential for both immediate action and future expansion. Thus, Prototype 1 of the healthcare decisions resource was developed in portable document format (PDF) as an immediately actionable step toward the expansive goals that participants envisioned for the resource.

Prototyping

In the *prototyping* phase, the PI used design themes to develop Prototype 1 of the resource entitled ***TRANS****FORMING CHOICES: A Healthcare Decisions Starter Guide*. This prototype underwent iterative modifications based on input from participants before it was ready for dissemination. To draft the prototype, the PI represented key features of the composition with text and images in the graphic design program Adobe InDesign. Most layout and content decisions were based on participant recommendations, and the remainder were informed by available evidence on healthcare for TGD adults in later life. The structure of the resource centered on three components: information, guided choices (worksheet), and resources. **Figure 3** illustrates the resource structure alongside a sample page annotated with participant quotations.

Figure 3. Schematic Diagram of a Healthcare Decisions Resource for Transgender and Gender-diverse Adults [see below]

Figure 3. *Schematic Diagram of a Healthcare Decisions Resource for Transgender and Gender-diverse Adults*



PAGE 1 Introduction to the resource that states the purpose and intended audience and provides a summary of the contents

PAGE 2 Guidelines for using the resource with an explanation of icons used to mark related content throughout the resource

PAGES 3.1 - 3.4 Answers to frequently asked questions about topics related to healthcare for transgender and gender-diverse adults

PAGES 4.1 - 4.4 Fillable form with questions to help people explore wishes for their care; a tool people can use to start conversations with trusted support people and clinicians

PAGES 5 - 6 List of links to other resources and information about the study

A: "One more thing to add as far as the layout. I was thinking definitely user-friendly icons that you don't need a translation sort of, you just see the symbol. It makes it easy to navigate."

B: "Preparing to talk to your provider because we don't want to assume that the person who's coming in actually has an established relationship with the doctor… I…actually had an information sheet that I would hand doctors. And people would light up. They're like, 'Oh, well, this is very useful.'"

C: "Having a space, I'm not saying that should be the focus of it, but having a section or space, for, you know, late-in-life transition needs."

D: "You want to keep the font simple…And then bold the areas that maybe we collectively as a group decide these are really important. Anything that's important that should stand out. Those should be bolded, but in simple text, simple font."

E: "And I think you need to keep things basically on a sixth to eighth grade level…But definitely just keep it simple."

F: "And it was coming to me, because I'm a lover of words and creating: 'Transforming the structure of healthcare so that you can transition safely,' you know. So, it's like, those wordings to grab the attention of whoever's gonna use the digital aid."

WORKSHEET

Name ________________ Pronouns ________ Date ________

Use this worksheet as a tool to help you make choices about your healthcare and to talk about your wishes with trusted people involved in your care.

Think about what matters to you about your healthcare. Check the statements below that align with your values.

☐ I value being **treated with respect** when I need healthcare as I age.
☐ I value being able to get **care that is affirming** to my gender identity.
☐ I value having **a voice to make decisions** about my healthcare.
☐ I value having people in **my support network involved in my care**.
☐ I have **other values.** (Please explain below or on Page 4.4)

What would be important for healthcare professionals to know about you to provide the best care possible?

If you are just starting your transition journey, rank the goals below from 1 (most important) **to 5** (least important). (Rank values of equal importance with the same number)

___ I would like to transition **socially** (name, pronouns, clothing).
___ I would like to transition **legally** (legal ID, gender markers).
___ I would like to start **hormone treatments/HRT**.
___ I would like to have **gender affirmation surgery**.
___ I have **other transition goals**. (Please explain on Page 4.4)

PAGE 4.1 • WORKSHEET **TRANS**FORMING CHOICES

Participants iteratively reviewed Prototype 1, which was modified to align more closely with participant suggestions and expectations. First, participant feedback from an anonymous survey, as well as virtual individual and group sessions, was systematically applied to update the design and content of Prototype 1. All respondents agreed with the statement that, in its current form, *the resource would be a useful tool to help trans and gender-diverse older adults make informed healthcare decisions and share their wishes with others*. One participant shared, “This resource, for me, feels good. It feels like I will go back here, like, ‘Where can I find out? I know I might start here and have it branch me somewhere.’ That's what it feels like.” Based on participant suggestions, a page of instructions was added to help TGD adults navigate the resource, and a set of links with an instructional label was added to the title page. Visual contrast and text layout were also adjusted in response to requests for greater accessibility for people with low vision and people who are neurodivergent.

Second, individuals with lived or professional experience relevant to the study reviewed a revision of the initial prototype (Prototype 2), suggesting areas for refinement. One TGD older adult affirmed the potential usefulness of the resource: “I recently had a leg injury, and it was my first time having a full-on hospital experience…So, this guide would have been very helpful for me.” And healthcare professionals believed the resource would facilitate conversations with their patients: “This will show me that they have some idea of what they would like to talk about, and it can really guide that conversation to where it's most beneficial to the patient as well.” Suggested refinements centered on ease of navigating the resource, from color adjustments to changes in word choice to the use of internal and external links. Feedback from Phase 3 participant interviews was integrated into a third iteration of the resource (Prototype 3) for dissemination (TRANSFORMING CHOICES, 2024).

Discussion

Through a sequence of participatory human-centered design processes, participants, researchers, and community advisors co-developed a healthcare decisions resource for TGD adults. Four themes influenced the design of the resource: (1) Motivation: Promoting agency through proactive healthcare decision-making; (2) Composition: Integrating simple features, guided choices, and inclusive media; (3) Dissemination: Connecting to the community through snowball networking; and (4) Expansion: Fostering support and sustainability through grassroots efforts. The goal of the healthcare decisions resource is to mitigate concerns about healthcare for TGD adults in later life or during a serious illness. The resource originates from an inventory of 16 multilevel resource ideas proposed by participants to address these concerns.

Diversity within the participant group in the SAFEage study ensured that various perspectives were represented in the design process and increased the potential to meet the needs of a broad audience. The racial and ethnic backgrounds of participants in Phases 1 and 2 paralleled population demographics (Herman et al., 2022), helping to close a gap in equitable representation of LGBTQ+ people of color in research on aging (Chen, McLaren et al., 2022). In addition, the diversity of occupational backgrounds among participants in each phase was an asset in the co-design process as participants often drew from their professional experiences when contributing ideas and insights. For example, a TGD older adult participant with experience in web design and marketing shared strategies for building a future web-based version of the healthcare decisions resource.

The proportion of participants in Phase 1 that had documented wishes for their care in later life or during a serious illness is consistent with advance directive completion rates among adults in the U.S. irrespective of gender (Yadav et al., 2017). This finding differs from previous studies that observed lower advance directive completion rates and lower likelihood of healthcare proxy appointment among TGD adults relative to cisgender adults (Dickson et al., 2021; Kcomt & Gorey, 2017). The small sample size and participant self-selection into the study on the basis of prior interest or engagement in ACP may explain this discrepancy.

Participant concerns about their healthcare and their ideas for future resources may stem from underlying fears and hopes related to their healthcare in later life or during a serious illness. For example, the need for a healthcare decisions resource may arise from participant fears about neglect, disempowerment, and lack of understanding of their needs within the U.S. healthcare system. Concurrently, participants recognized the potential for the healthcare decisions resource to help them actualize their underlying wishes for agency, knowledge, and respectful communication in healthcare decision-making. Addressing the underlying needs of TGD adults in the design of the resource may increase its utility and potential for uptake (van der Bijl-Brouwer & Dorst, 2017).

The SAFEage study engaged TGD adults aged 50 years old and older in a co-design process that has been used infrequently in participatory research involving older adults and TGD adults. In this study, participants served as collaborators alongside researchers and community advisors, which mitigated power imbalances observed between researchers and participants in prior participatory research involving older adults (Corrado et al., 2020). Additionally, the use of HCD in research to address multilevel health disparities in TGD communities is not well-documented. One exception is a recent study from the Netherlands, in which researchers and TGD adults co-developed a shared decision-making tool for gender-affirming care using a participatory approach comparable to one used in the SAFEage study (Gerritse et al., 2023). This emerging evidence demonstrates the potential for participatory research to address challenges faced by TGD adults globally.

The inventory of ideas for ACP resources proposed by study participants has implications for future research. These ideas may address health disparities at all four (societal, community, interpersonal, and individual) social ecological levels of the NIMHD Sexual and Gender Minority Health Disparities Research Framework (NIMHD, 2024). Collectively, these ideas align with a holistic approach to ACP intervention research in which patients, proxies, clinicians, communities, health systems, and policymakers serve as key agents for change (McMahan et al., 2021). These ACP resource ideas present an opportunity to operationalize the aforementioned frameworks in future research.

The four themes generated during this study may inform future studies that employ an HCD approach to design additional ACP resources for this population. Influencing resource development in an iterative and dynamic process, these themes parallel the action steps for developing healthcare interventions described by O’Cathain and colleagues (2019). In this way, these themes may serve as tenets of resource design to support timely, purposeful, and sustainable development of future resources, services, and interventions to benefit TGD adults. These may include resources to identify a healthcare advocate or proxy and care navigator programs to facilitate access to healthcare services and support.

This study had both strengths and limitations. Researcher reflexivity mitigated biases and drew attention to power imbalances among study contributors. Active participant engagement and inclusion of diverse perspectives promoted credibility and transferability of study findings. However, the resource may have limited transferability to TGD adults over 70 years old, whom researchers were unable to reach for participation in the study. Going forward, study participants emphasized the importance of using multiple media formats (electronic, paper, in-person) to reach people of all ages in their communities. Findings may also have limited global transferability as this study was conducted in the context of the U.S. healthcare system. However, research methods and HCD processes implemented in the study may have relevance in social and medical contexts outside of the U.S.

Conclusion

The SAFEage study used a participatory human-centered design approach to engage TGD adults in co-developing a resource for their healthcare in later life or during a serious illness. Through *empathizing, defining the problem, ideating*, and *prototyping*, study contributors identified problems affecting healthcare for TGD adults in later life or during a serious illness, proposed multilevel solutions, and developed a healthcare decisions resource. Four themes featuring participant design recommendations guided resource development. This study addresses the need for participatory research involving TGD adults in developing resources and interventions to address multilevel health disparities they may face. Given participant concerns about inequitable and discriminatory treatment in healthcare settings, findings from this study suggest that TGD adults in the U.S. have a need for ACP resources to support their right to self-determination in later life or during a serious illness.

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Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

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Conclusion

This dissertation research addressed gaps in the literature on healthcare for TGD older adults and augmented the body of resources available to promote the agency of TGD adults in the healthcare system in later life or during a serious illness. Manuscript 1 highlighted healthcare needs and assets of TGD older adults, noting the paucity of interventions addressing health disparities that affect this population as well as the need for attention to intersectionality in research on healthcare for TGD older adults. Manuscript 2 conceptualized multilevel limiting and facilitating factors affecting health equity for TGD older adults as locks and keys representing the complex dialectic between them and illustrating areas for further study and intervention. Manuscript 3 describes a participatory process for developing a healthcare decisions resource with, and for, TGD adults, and it includes an inventory of resource ideas and a set of themes to guide the design of similar ACP resources for this population.

The findings documented in each manuscript complement one another. Manuscript 1 provided the necessary foundation from which to conduct the SAFEage study. Manuscripts 2 and 3 build on the knowledge base related to healthcare for TGD older adults and describe action steps to address factors affecting health equity in this population. While this research does not dismantle entrenched health inequities, it initiates action toward health equity through meaningful and equitable collaboration with TGD adults in the co-construction of new knowledge and the co-development of a new resource to promote their agency within the healthcare system.

This research has implications for clinical practice and for nursing in particular. This research opens opportunities for clinicians to build understanding of the healthcare needs and assets of TGD older adults and offers a tool to foster shared decision-making between TGD older adults and their healthcare providers. The conceptualization of limiting and facilitating factors affecting health equity for TGD older adults may inform clinician education and help practitioners identify opportunities to integrate gender affirmation into their practice. For example, nurses in all settings may use findings from Manuscripts 1 and 2 to train staff members on affirming personal care practices for TGD older adults. Nurses may also apply these findings to advocate for institutional policy changes to ensure that gender affirmation is part of routine patient care. In addition, physicians and advanced practice nurses may use the healthcare decisions resource detailed in Manuscript 3 to open conversations with TGD adults about their wishes for care in later life or during a serious illness. Finally, with a holistic lens, community-engaged nursing research provides a pathway for implementing the holistic approach to care that TGD older adult participants in the SAFEage study identified as an important need.

Policy implications for this research include support for anti-discrimination protections and laws governing advance directives and healthcare powers of attorney. Especially in the current anti-transgender political climate, institutional, state, and federal policies barring discrimination of older adults on the basis of their gender identities are crucial for the protection of their rights in healthcare settings, and findings from the SAFEage study would support these measures. Since laws governing advance directives vary by state, this research would support policies ensuring equitable opportunities for TGD older adults to complete advance directives that reflect their care preferences and to name healthcare proxies from biological and chosen families.

Extensions of this research may include further exploration of individual factors affecting health equity for TGD older adults as well as the development of an intervention to promote ACP engagement in TGD communities. Because the amount of research on TGD older adults is limited, this research described the landscape of healthcare for TGD older adults in expansive terms. Thus, future studies may approach the factors affecting health equity for TGD older adults in greater depth, using the factors identified through the SAFEage study as a roadmap. The advantage of exploring each factor in more depth would be to unearth further complexities that might inform intentional, multi-axis interventions to address health inequities affecting TGD older adults. Additionally, the vision for the ACP resource that participants articulated during the SAFEage study included not only a healthcare decisions document, but also a web resource with support from clinician and peer navigators. Community-based intervention research would help bring the larger vision for the resource to fruition.

The SAFEage study is one of few studies to address health disparities affecting TGD older adults using a participatory, human-centered design approach. While limited in scope, this research opens numerous pathways for further research, policy reform, and practice change. Importantly, this research centers the voices of TGD older adults in taking action to advance health equity in their communities. Participants noted the value of this research while acknowledging that there’s “a long way to go.” After participating in the co-design process, participant D.J. remarked, “I walked away yesterday knowing that my contribution will be part of something that will support others as they too navigate the world of healthcare.” And reflecting on this research as a whole, participant E.R. said:

> It's important. I mean, just in the time that we've been talking about this, it’s begun a very serious thought process for myself. And when everything is okay, you don't really think about these things. But again, when something does occur, then it's like, ‘What now? What next? What do I do?’ And some people go into a panic, which only complicates what the illness is. When you're stressed, it makes it go at its worst. So, this alleviates some of the stress and gives you a sense of knowing that I have support. So, this is very important.

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Appendix

INTERVIEW GUIDE

Welcome [Orientation and Interviewer bio]

Introduction [Description of interview process, participant rights, risks and benefits, and permission to record]

0. Do you have any questions before we get started?

Participant Introduction

1. To start, please tell me a little about yourself. What is important for me know about you?

Follow-up Prompts
- What pronouns do you use? [if unknown]
- What made you interested in signing up to participate in this project?

Interview Part 1 In the first part of the interview, I have a few questions for you about preparing for your future <u>medical</u> care. This refers to your physical and mental health care in general.

2. What, if anything, do you know about this idea of preparing for future medical care, also called advance care planning (ACP)?

[If needed, provide more information about advance care planning: *ACP means preparing for your future medical care especially during a serious illness. This includes writing down and sharing your wishes with your loved ones, and your doctors and nurses, so that they can give you the kind of care you would prefer during a serious illness*] Do you have any questions about advance care planning before we continue?

3. Please tell me about the steps you have you taken, if any, to prepare for your future medical care?

a. [If participant <u>has</u> taken steps] What helped you take those steps?

Follow-up Prompts
- What worked well?
- What was challenging?
- What did you get out of it?

b. [If participant <u>has not</u>] What keeps you from taking steps to prepare for your future medical care?

Follow-up Prompts
- What would make it easier for you to take the first step?
- What would you hope to get out of preparing for your future medical care?

Interview Part 2 In the second part of the interview, I have a few questions for you about preparing for your future care as a [trans or nonbinary] person.

4. In your own words, what does *gender-affirming care* mean to you?

Follow-up Prompts
- What would high-quality gender-affirming care look like?
- On the flip side, what would low-quality gender-affirming care look like?

[If needed, provide a definition of gender-affirming care: *Gender-affirming care is the kind of personal, medical, and legal practices that support your gender identity and expression in healthcare settings. This may include use of your pronouns, hormone treatments, gender-affirming surgeries, personal care, name and gender marker changes on legal identification, and others*]

5. As a [trans or nonbinary] person over 50 years old, how would you describe the quality of your health care? What does access to health care look like for you?

6. If you've experienced a (serious) illness, please tell me about the quality of care you received.

7. For a moment imagine that you are unable to make healthcare decisions for yourself because of a serious illness. What would you want your caregivers [doctors, nurses, personal care assistants and others providing care] to know about the wishes you have for your care?

   Follow-up Prompts
   - Who would speak up for you?
   - How should caregivers attend to your personal care?
   - What kind of rooming arrangement would make you most comfortable?

8. Take a moment to envision ways that you could prepare for your future care. As a [trans or nonbinary] person over 50 years old:

   a. What would help you the most to prepare for your future care?

   b. What would prevent you from preparing for your future care?

Final Thoughts

9. What else would you like me to know before we finish up? Is there anything you'd like to add that I didn't ask about?

Conclusion [Closing remarks]

RESOURCE DESIGN SESSION GUIDE (Session 1)

1. Session Overview and Group Agreements

   Here is a set of agreements for us to keep in mind. Please:
   - Keep your space private for the protection of the other group members.
   - Keep your camera on so we can see each other during group discussion time.
   - Keep your microphone muted until you'd like to speak.
   - Maintain respect for group members' ideas and time to speak.
   - Avoid discussing sensitive topics like trauma, suicide, violence, etc.
   - Keep everything that is shared in the workshop confidential.

   Are there any other agreements we should add?

2. Participant Introductions and Building Rapport
   - Please share one <u>personal strength</u> that has gotten you to this point in your life. [Facilitator may prompt by sharing one of their own strengths]

3. Setting Session Goals

4. Defining Key Terms (e.g., gender-affirming care, advance directive, healthcare proxy)

5. Reviewing Problem Statement + Discussion

Example: Draft 1 of the Problem Statement (based on participant interviews)

Transgender and gender-diverse adults aged 50 and older need a simple resource to help them prepare for gender-affirming care during a serious illness because they (1) experience disrespectful treatment or refusal of care in healthcare settings related to their gender identity; (2) face barriers to gender-affirming care in health systems that lack understanding and acceptance of who they are; and (3) worry about facing a serious illness without support, information, and resources for their gender-affirming care.

Review Questions:

- What are your impressions of this statement?
- What would you change, if anything, about this statement?

Example: Final Problem Statement (after participant review)

Transgender and gender-diverse adults need accessible, gender-inclusive resources to help them mitigate current health challenges and prepare for future care because (1) they may face injustices on the basis of age, race, ability, and/or gender identity, contributing to adverse health outcomes; (2) they may have limited access to affirming healthcare services due to anti-transgender policies and dysfunctional health systems; (3) they may lack adequate social and medical resources and support for their healthcare in later life or during a serious illness.

6. Reviewing Resource Idea Inventory + Discussion

   - What questions or comments do you have about the list of resources we looked at?
   - What are the pros and cons of the short list we're focusing on now?
   - Take a moment to think about which idea stands out most to you. Please share the idea that comes to mind and why it stands out to you.
   - Do you have any other comments or questions about these ideas or the presentation overall?

A	**RESOURCE DIRECTORY**	a **website** with links to resources and services
B	**ADVOCATE FINDER**	a **guide** to find and name a healthcare proxy
C	**ADVANCE DIRECTIVE+**	a **form** to record wishes for future care
D	**DECISION-MAKING AID**	a **tool** to guide decisions about future care
E	**INFORMATION PACKAGE**	a **guide** with info on preparing for future care

Image 1. Sample presentation slide used in Session 1: Resource ideas for selection

7. Selecting a Resource Idea for Development

   - Based on what we talked about, please write down the idea that you think we should develop into a new resource. As you make your choice, remember, all of the ideas are good, and hopefully we'll develop them all into resources in the near future, even if we can't do so right now.

8. Tallying the Votes
   [Facilitator calls on each participant to share their vote with a rationale]

9. Conclusion + Open Discussion

   - What went well during this workshop session?
   - What could be changed in the next session?
   - What other comments or questions do you have?

RESOURCE DESIGN SESSION GUIDE (Session 2)

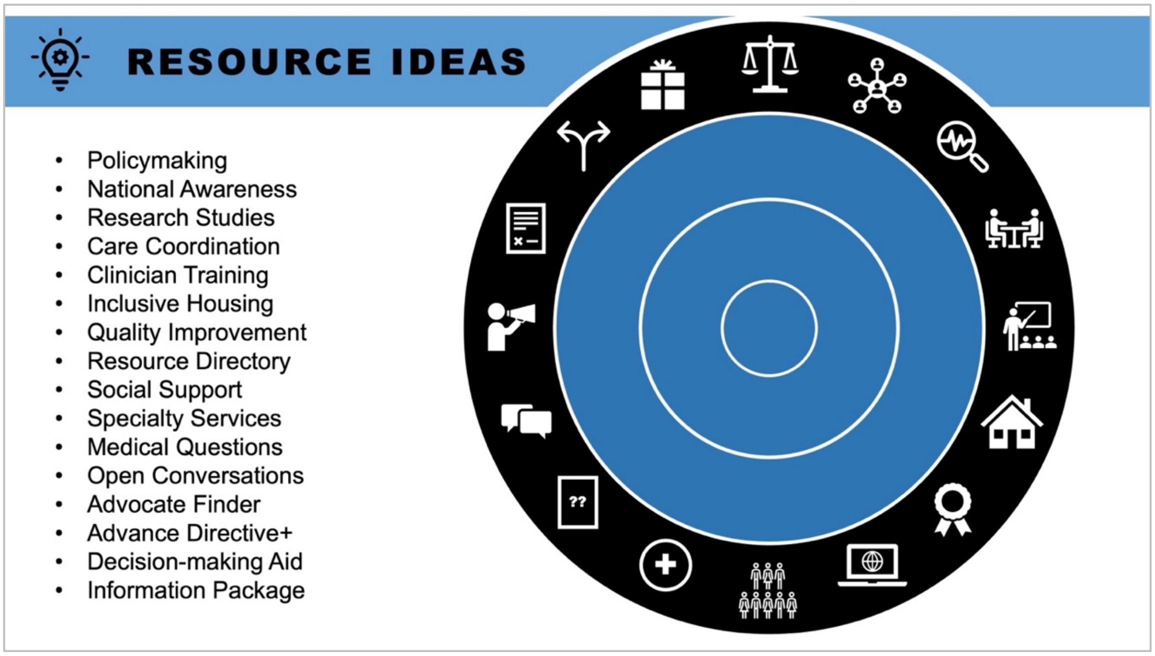
1. Session Overview and Group Agreements (see Session 1 Guide)

2. Participant Introductions and Building Rapport

   - Please share a time when you did something creative.
     [Facilitator may prompt by sharing one of their own experiences]

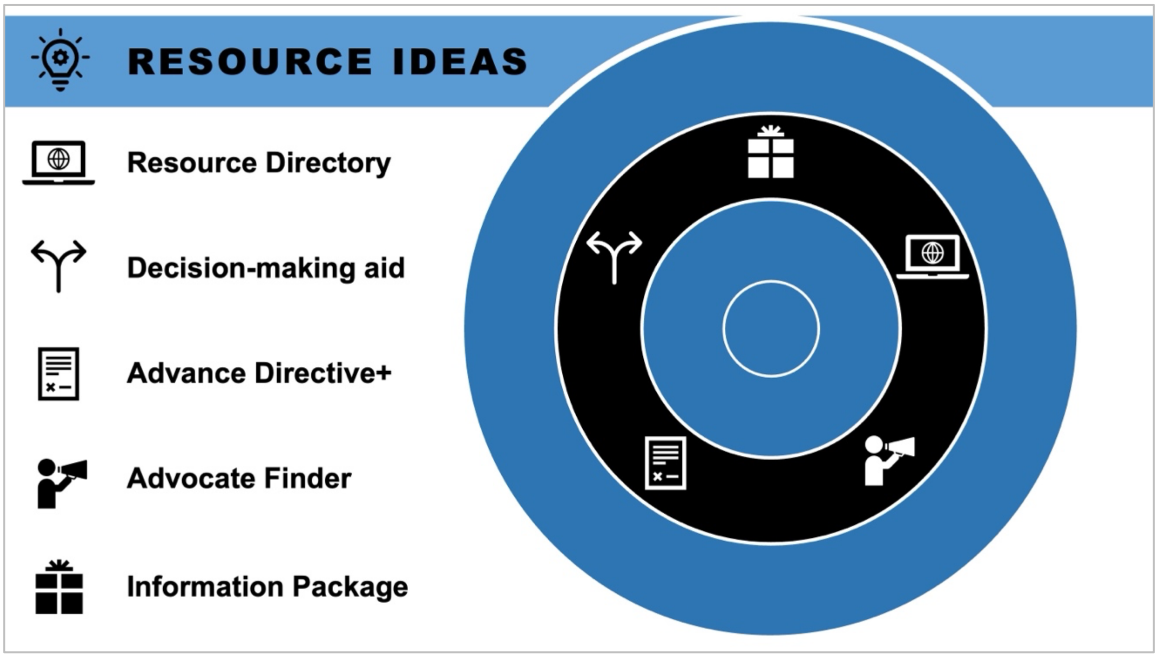
3. Setting Session Goals

4. Sharing Chosen Resource [Bullseye Diagram]



RESOURCE IDEAS

- Policymaking
- National Awareness
- Research Studies
- Care Coordination
- Clinician Training
- Inclusive Housing
- Quality Improvement
- Resource Directory
- Social Support
- Specialty Services
- Medical Questions
- Open Conversations
- Advocate Finder
- Advance Directive+
- Decision-making Aid
- Information Package



RESOURCE IDEAS

Resource Directory

Decision-making aid

Advance Directive+

Advocate Finder

Information Package

Images 2-3. Sample presentation slides from Session 2: Bullseye Diagram

Follow-up Question:

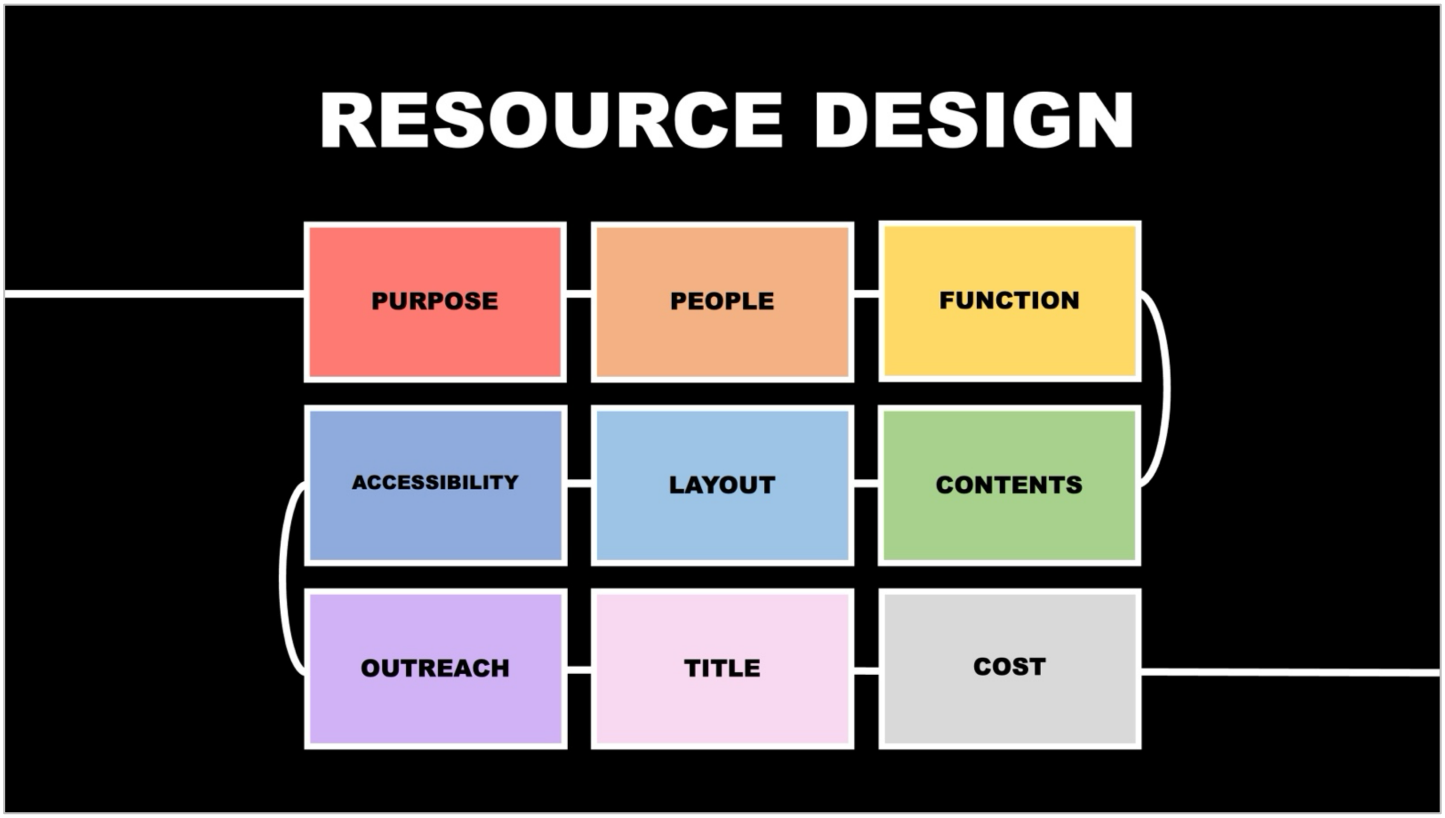
- What questions do you have about the chosen resource or the selection process?

5. Defining Key Terms (e.g., decision aid)

6. Introducing Examples related to Chosen Resource (e.g., What Matters to Me Workbook by Ariadne Labs and The Conversation Project)

   - What questions do you have about these examples?

7. Generating Resource Design Ideas [Thumbnail Sketching]
   [Facilitator leads guided independent activity in which participants write down or sketch out answers to the following prompts]



RESOURCE DESIGN

PURPOSE
PEOPLE
FUNCTION
ACCESSIBILITY
LAYOUT
CONTENTS
OUTREACH
TITLE
COST

Image 3. Sample presentation slide from Session 2: Thumbnail Sketching

- Purpose: What is the resource for? Why does it matter?
  TIP: Start with “The purpose of this resource is to...”

- People: Who will benefit from the resource? Who is it for?
  TIP: Think about who should be involved in making and using it.

- Function: What will the resource do? How will it work?
  TIP: Think about how it achieves the purpose.

- Content: What should the resource include?
  TIP: Consider topics to cover, images/audio to use, and questions to answer.

- Layout: What is the format for the resource? How would it look?
  TIP: Consider online and print media and video. Try drawing how it should look.

- Accessibility: How could we make it easy-to-use for people of diverse backgrounds?
  TIP: Consider simple designs, large font, and language translations.

- Outreach: How could the resource be shared to reach people who need it?
  TIP: Consider organizational partnerships, social media, and health clinics.

- Title: What would you name the resource?
  TIP: Consider picking a name that is clear, descriptive and eye-catching.

- Cost: What would make the resource affordable?
  TIP: Consider free access, funding, and sponsors.

- Other: What else should we consider about this resource?

8. Discussing Resource Design Ideas
   [Facilitator uses the following questions to review participant responses to thumbnail sketching activity]

   - What is this resource for? [Purpose]
   - Who is this resource for? [People]
   - What would this resource do? How would it work? [Function]
   - What would it include? [Contents]
   - How would it look? [Layout]
   - What would make it easy-to-use? [Accessibility]
   - What would you name it? [Name]
   - How could it be shared? [Outreach]
   - How could we make it affordable? [Cost]
   - What else is important to consider? [Other]

9. Celebrating the Process and Reviewing Next Steps

   - What suggestions do you have for what’s next?
   - Who else should be involved in preparing the resource to share?

10. Conclusion

    - Do you have any last comments or questions?

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TRANSFORMING CHOICES

HEALTHCARE DECISIONS
STARTER GUIDE

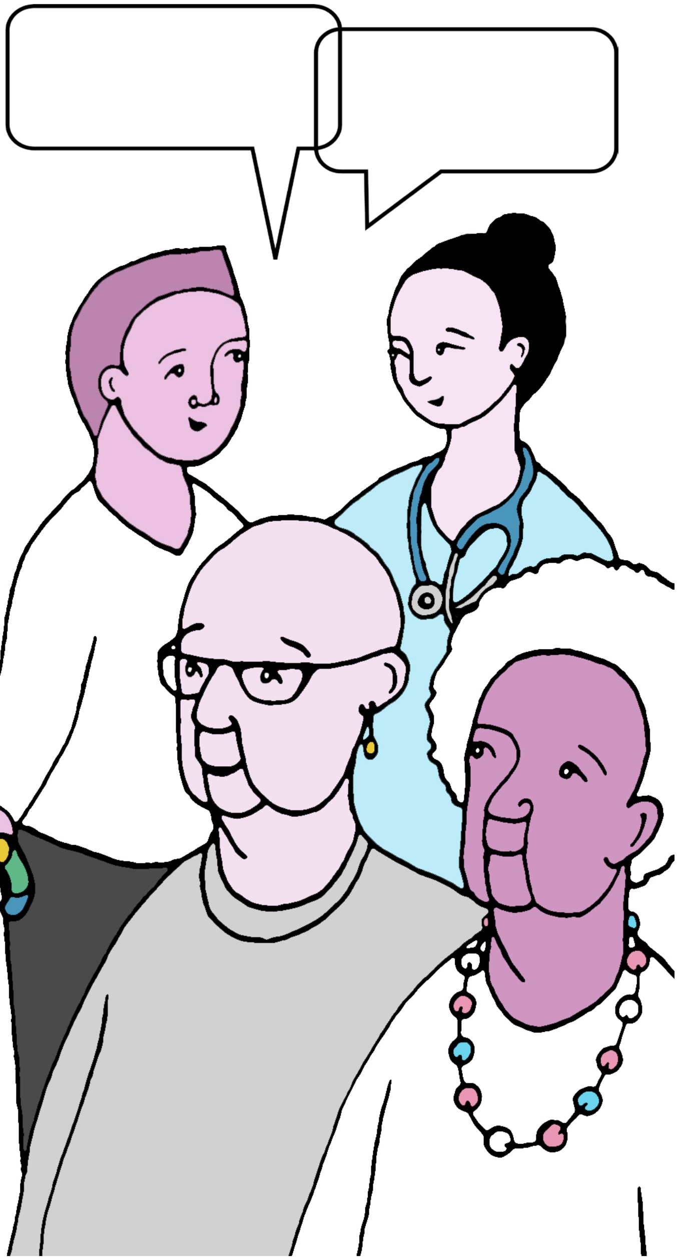
TRANSFORMING CHOICES is a guide to help you make choices about your healthcare now and later in life. It is a shared decision-making tool to help you talk about your choices with your healthcare team and people you trust.

Who may benefit from this guide?

Older transgender, gender-diverse, and gender-expansive people at any stage of transition or state of health who would like to make informed decisions about their healthcare now and in later life

Younger transgender, gender-diverse, and gender-expansive people who have a serious illness or who want to know what to expect for their care in later life

Healthcare professionals and care partners who are helping transgender, gender-diverse, and gender-expansive people make decisions about their care



What's inside this guide?

Find tools to help you navigate health care decisions now and in later life.

Click the icons below to jump ahead if you are viewing the guide electronically

INFORMATION
Pages 3.1 - 3.4

WORKSHEET
Pages 4.1 - 4.4

RESOURCES
Page 5

HOW TO USE THIS GUIDE

READ IT

Read Information about healthcare for transgender, gender-diverse, and gender-expansive people

WRITE ON IT

Write down what matters to you about your healthcare using the healthcare decisions Worksheet

TALK ABOUT IT

Discuss wishes for your care with people in your support network and healthcare professionals you trust

RECORD IT

Document your wishes using a form called an advance directive. Check out the Resources section for more

REPEAT IT

Your choices are not fixed or final! Your wishes may change over time, so use this guide as often as needed!

TALK ABOUT IT, AGAIN

When your choices change, tell people in your support network and healthcare professionals you trust

NAVIGATE IT

The icons below represent different topics in this guide. Click or follow each icon to view related content.

- **TRANSITIONING**
- **HEALTH CARE**
- **SERIOUS ILLNESS**
- **LONG-TERM CARE**
- **PREPARE & SHARE**
- **ABOUT THE GUIDE**

This guide does **not** contain medical or legal advice. Consult a healthcare professional or an attorney before making medical or legal decisions.

INFORMATION

In this section you'll find a list of keywords and answers to frequently asked questions about healthcare in later life or during a serious illness for trans, gender-diverse, and gender-expansive people. This section provides an overview of available evidence and will be updated as new research comes out.

KEYWORDS

Transgender (trans)	A word to describe gender identities that differ from sex assigned at birth
Gender-diverse, gender-expansive	Words to describe a wide range of gender identities, like *nonbinary*, *genderfluid*, and others, that differ from societal gender norms
Gender-affirming care	Social, psychological, medical, surgical, and legal measures that support your gender identity and expression
Long-term care	Services, like nursing home care, that meet your health and personal care needs when you can no longer do everyday activities on your own
Serious illness	A health condition, like cancer, heart failure, or Alzheimer's disease, that has a negative impact on daily function and quality of life
Palliative care	Specialized medical care focused on relieving symptoms during a serious illness Hospice care is a type of palliative care for people at the end of life
Advance directive	A legal document used to record your healthcare wishes if you are unable to make your own medical decisions because of a serious illness
Healthcare proxy	A trusted person, like a family member or friend, whom you authorize to make medical decisions for you if you are unable to do so

FREQUENTLY ASKED QUESTIONS

Is it possible to start transitioning later in life? What if I have an existing health condition?

It's possible! But it's important to talk to a healthcare professional who can help you weigh the pros and cons of your gender-affirming care options and what the risks would be based on your age and any health conditions you have.

EXAMPLE *A trans or gender-diverse older adult with a heart condition* may *need special precautions to prevent complications during gender affirmation surgery.*

Does my healthcare team need to know my sex assigned at birth and details about my transition?

It can be difficult to share information about your gender identity with your healthcare team. Healthcare professionals need to know this information to be able to recommend screenings, lab tests, treatments, and procedures that are right for your body. Many health systems collect information on sexual orientation and gender identity to ensure patients get care that is affirming and inclusive.

EXAMPLE *A transman* may *need to have routine screening for breast cancer, even after top surgery, depending on his family history and other factors.*

TIPS for talking to a healthcare provider about your gender identity:

- Ask around or search online for LGBTQ+ friendly medical practices
- Call ahead to ask whether a medical practice sees LGBTQ+ patients
- Bring a trusted person with you to your appointment
- When you feel comfortable, ask your provider for time during an appointment to talk about topics related to your gender identity

What should I know about getting support for my mental health and well-being?

With transphobia and anti-trans policies on the rise, coping with everyday life stressors may be all the more difficult for trans, gender-diverse, and gender-expansive people. It is important to ask for support from your community or trained professionals, especially if you are having thoughts of hurting yourself. Consider individual counseling, peer support groups, or calling a support line. For caregivers of people with serious illness, consider joining a care partner support group to prevent burnout.

EXAMPLE *A gender-expansive person who cares for their ailing spouse joins an LGBTQ-friendly care partner support group.*

What should I know if I go to the hospital for a surgery or an emergency?

In our fast-paced healthcare system, going to the hospital can be an overwhelming experience for any person, and trans, gender-diverse, and gender-expansive people may face unique challenges. Hospital providers may not have training in LGBTQ+ health or know about a person's individual gender history, so even the simple choice between a urinal or a bed pan could lead to uncomfortable or disaffirming conversations. If possible, have someone with you at the hospital who can speak up for you.

EXAMPLE *A nurse asks a trans person about their history of gender-affirming procedures to make sure a urinary catheter of the right size is used during their upcoming abdominal surgery.*

TIP To prepare ahead of time for unplanned or emergency hospital visits, think about scenarios you might face and make a plan for how you or a support person could respond to them.

What should I know about long-term care?

Older trans, gender-diverse, and gender-expansive people in long-term care settings, like nursing homes, may need assistance with personal care related to their gender identity from nurses and nurse's aides. They may also need to consider their gender preferences for rooming arrangements.

EXAMPLE *A transwoman living in a nursing home* may *need help with daily facial shaving as an essential part of her care.*

What should I know about care during a serious illness?

During a serious illness, you may receive palliative care to ease your symptoms, and you may benefit from hospice care if you are at the end of your life. You can also weigh the pros and cons of continuing certain gender-affirming treatments and procedures with your healthcare team.

EXAMPLE *A trans person with dementia* may *be able to stop certain gender-affirming procedures to promote comfort if medically indicated.*

Why should I prepare for my care in later life?

Preparing for your care can help you identify and share your wishes with people in your support network and your healthcare team. Consider completing an advance directive and choosing a healthcare proxy, especially if you would like someone outside your biological family to make healthcare decisions for you if you get sick.

EXAMPLE *A nonbinary person* may *choose a close friend as their healthcare proxy because they trust her to follow their wishes.*

WORKSHEET

Name/Pronouns ______________________________ Date ____________

Use this worksheet as a tool to help you make choices about your healthcare and to talk about your wishes with trusted people involved in your care.

Think about what matters to you about your healthcare. Check the statements below that align with your values.

- ☐ I value being **treated with respect** when I need healthcare as I age.
- ☐ I value being able to get **care that is affirming** to my gender identity.
- ☐ I value having **a voice to make decisions** about my healthcare.
- ☐ I value having people in **my support network involved in my care**.
- ☐ I have **other values**. (Please explain below or on Page 4.4)

What would be important for healthcare professionals to know about you to provide the best care possible?

If you are just starting your transition journey, rank the goals below from 1 (most important) to 5 (least important). (Rank values of equal importance with the same number)

___ I would like to transition **socially** (name, pronouns, clothing).

___ I would like to transition **legally** (legal ID, gender markers).

___ I would like to start **hormone treatments/HRT**.

___ I would like to have **gender affirmation surgery**.

___ I have **other transition goals**. (Please explain on Page 4.4)

Name/Pronouns ______________________ Date __________

How important would it be for you to get gender-affirming medical or surgical care if you had a health condition that could put you at risk for complications? (Select one)

● It would be **very important** to me. I accept the risks and I would like to find a way to receive gender-affirming treatment(s).

○ It would be **important** to me, but it's not worth the risk. I'd like to know what other options I have.

○ I am **not sure how important** it would be to me until it happens.

○ I would say **something else.** (Explain below or on Page 4.4)

If you were hospitalized or you were going to live in a long-term care residence, like a nursing home, what would be your rooming arrangement of choice? (Select one)

○ I would like a roommate with the **same gender identity** as me.

○ I would like a roommate with the **same sex assigned at birth** as me.

○ I would like a roommate of **any gender identity**.

○ I would like to have a single room with **no roommate**, if possible.

○ I would like a **different arrangement**. (Explain below or on Page 4.4)

If you were unable to keep up with grooming, dressing, and other personal care activities on your own, what would be important for the people caring for you to know?

CONSIDER preferred clothing type, accessories, shaving, makeup, etc.

Name/Pronouns ______________________ Date __________

Thinking about end-of-life circumstances, what would you like people in your support network and your health care team to know about your care? (Select all that apply)

☐ I would like to have end-of-life care that is respectful and affirming to my gender identity and sexual orientation.

☐ I would like to receive gender-affirming hormones for as long as it is possible for me.

☐ I would like some gender-affirming treatments to be discontinued:

☐ I would like people in my support network to be with me. Name(s):

☐ I would like something else. (Use the space on Page 4.4 to explain)

Which steps would you like to take to prepare for your future care? (Select all that apply)

☐ Talk to someone in my support network about what matters to me.

☐ Talk to a healthcare professional about what matters to me.

☐ Sign papers (advance directive) to document what matters to me.

☐ Sign papers to name a healthcare proxy who knows my wishes.

Who could you ask?

Have you already taken steps to prepare for your care?
You can attach a copy of your documents to this worksheet.

This worksheet is **not** an advance directive. Find the advance directive form for your state online or check out the Five Wishes, a form that meets requirements in nearly all states. In most cases, you can prepare these documents *without* an attorney.

Name/Pronouns ______________________________ Date ____________

Use the space below to answer any question in more detail or to write down anything else that is important to you about your care.

TALKING TO YOUR TEAM

You can start a conversation with your healthcare team about what you wrote down on this worksheet. Here are some tips:

- **Save a copy** of this worksheet on your phone or print a paper copy
- **Bring a digital or paper copy** of the worksheet with you to an appointment with a medical provider you trust
- **Bring a trusted person** with you to the appointment for support
- **Choose a couple topics** to focus on when talking with your provider
- **Start the conversation** with something like, “I’ve been thinking a lot about my health. I’d like to talk more about what to expect in the years ahead and how I can prepare myself for future medical decisions”
- **Discuss a couple topics** you would like to cover with your provider
- **Follow up** on this conversation at future appointments

WRAPPING IT UP

The questions in this worksheet are meant to help you start thinking about what matters to you about your care. This guide gives a broad overview of health topics relevant to trans, gender-diverse, and gender-expansive people during a serious illness or in later life. Use this as a *starting point* for making decisions about your care. For more detailed information and support, check out the resources on the next page.

RESOURCES

RESOURCE LIST

Click the links to the right or scan the QR code below to access resources that can help you learn more about your healthcare and how to prepare for it in the future. Among these resources you'll find:

A tool to find affirming long-term care
Information about palliative care
A toolkit for advance care planning

CHECK IN

Thinking about your future health and possible illnesses can be difficult. If you would like to talk to someone about how you're feeling, seek support from a trusted person, speak with a counselor, or check out SAGE x HearMe, a LGBTQ+ friendly mental wellness app.

CONTACT US

info.transformingchoices@gmail.com

Click or scan the QR code to view the guide online

TRANSITIONING

Later Life Transition Tips
TRANScestors, Vol. 1 & 2

HEALTH CARE

Standards of Care
Know Your Rights

SERIOUS ILLNESS

Serious Illness Workbook
LGBT Palliative Care

LONG-TERM CARE

Housing & LTC
LTC Equality Index

PREPARE & SHARE

Advance Care Planning
Planning for Lifelong Care

EMERGENCY CARE

Dial 911 or 988

ABOUT

TRANSFORMING CHOICES was developed as part of a research project called *Shaping Affirming Futures with Elders of all gender experiences* (SAFEage). Project contributors shared ideas for a new resource to help transgender and gender-diverse adults prepare for their healthcare in later life, and researchers put these ideas together to form this guide.

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