Summer 2022

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Recommended Citation

Lampe, N. M.(2022). *Healthy Aging Beyond Sex and Gender Binaries.* (Doctoral dissertation). Retrieved from https://scholarcommons.sc.edu/etd/6900

HEALTHY AGING BEYOND SEX AND GENDER BINARIES

by

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Submitted in Partial Fulfillment of the Requirements

For the Degree of Doctor of Philosophy in

Sociology

College of Arts and Sciences

University of South Carolina

2022

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DEDICATION

To B.B., for so many reasons.

ACKNOWLEDGMENTS

First and foremost, thank you to all the trans, non-binary, and intersex people who met with me to discuss your lives and experiences. Without you, this dissertation research would have not been possible. I hope I amplified your voices as you desired them to be authentically conveyed in research and clinical practice. Thank you also to all the LGBTQIA+ sociologists who have paved the way for me to conduct this important work. As Dr. Kimberlé Crenshaw emphasized during her plenary session at the 2016 American Sociological Association Annual Meeting: “It takes a village to raise a sociologist.”

Thank you to Dr. Carla Pfeffer, the best dissertation chair and graduate school mentor a doctoral student could ask for. Your help in making my professional goals a reality and getting me across the finish line with my academic job market and dissertation project is something for which I will be forever grateful. You have significantly contributed to making me the sociologist, educator, writer, and person I am today. Thank you to Dr. Andrea Henderson, for your continued enthusiasm and your thoughtful feedback on my work, which kept me intellectually nourished when I was feeling drained. Thank you to Dr. Emily Mann, who has undoubtedly made me a stronger writer, empathic educator, and feminist scholar. Our regular check-ins and your constant support during my time at the University of South Carolina (UofSC) have been truly memorable. Thank you to Dr. Jaclyn Wong for your openness to professional development and research suggestions along the way. This dissertation would not be as far along without the insightful knowledge, feedback, and mentorship I received from you while taking your thought-provoking, graduate sociology courses. And thank you to Dr. Xan Nowakowski, who during my time as a sociology master's student at the University of Central Florida, encouraged me to apply to Sociology Ph.D. programs and later offered me a job as their research assistant at Florida State University (FSU) College of Medicine. There were many times when I wanted to walk away from academia because I didn't believe in myself, but they encouraged me to be my own hero and persist. Without them, I would have given up on this dream long before my time at UofSC.

Thank you also to colleagues and mentors from the UofSC Department of Sociology, FSU College of Medicine, UofSC Women's and Gender Studies Program, and UofSC Office for the Study of Aging who offered valuable feedback and encouragement at various points on this project. And thank you to my undergraduate faculty mentors at the University of Tampa for your early influence on me as a sociologist. I also want to acknowledge my chosen family in Florida (Aunt Karen, Lulu, B.B., Monique, Kyle) and South Carolina (e.k., Quill, Archie, and Atticus) who have been my core social support system as I pursued this degree, even when that meant I was a stress ball. I love you all and could not have wished for a better family. Thank you to J. and Lain for our monthly book club chats, your highbrow comedy, and for teaching me that there is more to life than overworking yourself in academia. Thank you to Shay, Eve, and Mandi who have also been loving and loud voices that keep me going. A special thanks to e.k., Archie, Atticus, and Mia for our countless hours of co-working sessions and for pushing through graduate school right alongside me. I cherish our regular check-ins and all the ways we've supported each other through this wild ride. ~ Nik

ABSTRACT

An estimated 2.7 million sexual and gender minority (SGM) adults 50+ reside in the United States (US) with this number projected to increase to more than 5 million by 2060 (Flatt et al. 2022; Fredriksen-Goldsen and Kim 2017). Medical research, education, and practice in the United States (US) often erase sex and gender variation, thus ignoring the experiences of older adults living beyond Western sex and gender binary systems (e.g., female/male and women/men), particularly transgender, non-binary, and/or intersex (TNBI) populations. Such erasure stems from TNBI older adult structural incompetency or the failure to understand how macro-level systems, institutions, and structures impact TNBI older patients' social barriers to care (e.g., poor educational/instructional curriculum and practicum on TNBI health, access to social support) in providing quality, effective care to TNBI older patients.

Despite documented greater healthcare need among TNBI older adults, they have long struggled to access quality care due to key factors such as erasure and stigmatizing approaches in medical research, lack of adequate resources and social support, mistreatment by medical providers, and limited evidence-based interventions addressing TNBI older adults' health and healthcare priorities. The purpose of the present study is to analyze the current social, medical, and political state of TNBI older Americans by determining their unique needs for or barriers to (a) reproductive and sexual health services, (b) advance care planning and end-of-life preparation, and (c) health management during the COVID-19 pandemic.

Data from this study were derived from 50 semi-structured, individual interviews with TNBI older adults who reside in the US. Eligibility criteria for participation were that participants: (a) self-identified as transgender, non-binary, and/or intersex, (b) were 65 years of age or older at the time of the interview, (c) lived in the US at the time of the interview, and (d) consented to be audio-recorded during the interview. Due to participant safety concerns during the COVID-19 pandemic, I conducted 39 Zoom interviews and 11 telephone interviews during data collection. I coded data using NVivo software and conducted inductive analysis, whereby I created a coding scheme consisting of sets of networked codes that I distilled from the data. I reviewed developing categories and themes throughout both data collection and analysis in order to discern emergent patterns and connections.

For the first part of this study, I examined how TNBI older adults – as a medically and socially vulnerable sub-group within sexual and gender minority (SGM) communities – perceive, access, and utilize reproductive and sexual health services. Most respondents described medical provider ignorance in providing (i) SGM-competent and (ii) age-friendly care in reproductive and sexual healthcare settings and consequently responded to medical provider ignorance by (i) opting out or avoiding medical providers and settings and (ii) seeking out SGM-competent care. Such findings pinpoint valuable opportunities for attending to structural competency in reproductive and sexual healthcare systems and interactions for improving TNBI older adulthood and health. For the second part of this study, I assessed how TNBI older adults perceive and plan for aging and end-of-life care experiences. My analysis reveals TNBI older adults' (i) uncertainty around experiencing a 'good death,' along with their (ii) calculated strategies for reducing the possibility of a 'bad death.' Such uncertainties both reflect and reproduce health and aging inequities among TNBI older adult populations, while highlighting the consequences of structural incompetency in healthcare for TNBI older adults in US society. For the third part of this study, I examine how TNBI older adults manage and maintain their health during the COVID-19 pandemic. A life course perspective provides an insightful examination into how the COVID-19 pandemic – as an unanticipated life course disturbance – dynamically shapes TNBI older adults' health management decisions, practices, and challenges. Such findings offer potential ways to enhance structurally competent health services, peer support, and resources for TNBI older adult Americans during the COVID-19 pandemic.

My findings underscore the critical need in maintaining TNBI-competency and age-friendliness within US healthcare systems and interactions, while outlining key ingredients for structural competence when providing care to TNBI older adult patients. Future research should aim to fulfill the health, aging, and care needs and preferences of TNBI adults by tailoring intervention efforts to those from older, racial and ethnic minority, and financially disadvantaged communities. Overall, my research highlights the significance of attending to structural competency in the contexts of medical research, education, and practice, while calling for initiatives working toward improving TNBI health and aging.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
BIPOC	Black, Indigenous, and People of Color
COVID-19	Coronavirus Disease 2019
DSD	Differences or Disorders of Sex Development
HIV	Human Immunodeficiency Virus
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and/or Queer
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and/or Asexual
SGM	Sexual and/or Gender Minority
STI	Sexually Transmitted Infection
TGNC	Transgender and/or Gender Non-Conforming
TNB	Transgender and/or Non-Binary
TNBI	Transgender, Non-Binary, and/or Intersex
US	United States

CHAPTER 1: INTRODUCTION

1.1 STATEMENT OF THE PROBLEM

Sociological research in health and medicine that focuses on older adults (adults 65 years of age or over) often erases a considerable amount of sex and gender variation, thus ignoring the experiences of those living beyond Western sex and gender binary systems (e.g., female/male and women/men), particularly transgender[1] (abbreviated as *trans* hereafter), non-binary[2], and intersex[3]/differences in sex development (DSD) (abbreviated as *TNBI* hereafter) older populations (Davis, Dewey, and Murphy 2016; Sumerau and Mathers 2019). In the case of TNBI patient populations, sociologists have shifted their focus from analyses that mainly (1) combine TNBI people with lesbian, gay, bisexual, queer, and asexual populations, which conflate gender and sexual identities

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[1] *Transgender* is an umbrella term referring to people who do not conform to their gender assignment at birth (Sumerau and Mathers 2019).

[2] *Non-binary* is an umbrella term referring to people who do not conform to a social classification of the gender binary categories of women or men (Nowakowski 2019; Sumerau and Mathers 2019).

[3] *Intersex* is an umbrella term referring to people whose sex characteristics do not fit the sex binary categorization of all bodies as only either male or female (Sumerau and Mathers 2019).

(Sumerau 2020), (2) focus only on young TNBI people (Costello 2016; Hood et al. 2019), and/or (3) overlook intersex/DSD populations entirely in sexual and gender minority (SGM) medicine (Davis 2015). Much like other disciplines in the socio-medical sciences, these substantial gaps in the sociological literature leave researchers and medical practitioners knowing almost nothing about the health and healthcare needs of TNBI older adults (Liang et al. 2017; Nowakowski, Sumerau, and Lampe 2020).

Most sociological studies on lesbian, gay, bisexual, transgender, queer, intersex, and/or asexual (LGBTQIA+) populations, for example, neglect to simultaneously and routinely include TNBI people as active participants in the research process, while only symbolically including them within the LGTBQIA+ acronym/umbrella (e.g., excluding or offering outdated versions of TNBI-specific demographic questions and responses in LGBTQIA+ sociological research). Further, TNBI people continue to navigate structural erasure and marginalization within LGBTQIA+ communities and interventions targeting LGBTQIA+ communities (Costello 2019; Sumerau and Mathers 2019). In the case of intersex people, it remains contested in LGBTQIA+ communities as to whether intersex people should be included as LGBTQIA+ community members, while most LGBTQIA+-led organizations fail to meaningfully recruit and engage intersex stakeholders (Costello 2019; Davis 2015). Overall, sociologists often neglect to actively recruit, engage, and report TNBI people in their research.

At the same time, there is a critical need for researchers and medical practitioners to address TNBI people's health and healthcare needs as a medically-vulnerable and growing aging population (Nowakowski et al. 2020). Researchers from the Williams Institute have estimated that about 1.4 million transgender adults (Flores et al. 2016) and

1.2 million LGBTQ non-binary adults (Wilson and Meyer 2021) live in the US. Additionally, researchers have estimated that between 0.05% and 1.7% of people are born with intersex variations, with the larger estimate equivalent to those in the general population with red hair or green eyes (Blackless et al. 2000; Fausto-Sterling 2000; Office of the High Commissioner for Human Rights 2019). However, there remains disagreement among researchers and clinicians with what exactly "counts" as intersex or DSD (Committee on Measuring Sex, Gender Identity, and Sexual Orientation et al. 2022). Overall, these estimates highlight the critical need for a TNBI competent healthcare workforce. With the older adult population (United States Census Bureau 2020) and lesbian, gay, bisexual, transgender, queer (LGBTQ) self-identification among Americans (Gallup 2022) rapidly increasing in US society, there remains an important need for offering medical professionals more focused and comprehensive trainings in structural competency that enable them to work with TNBI older patients in an informed, ethical, and culturally-competent manner (Donald et al. 2017; Metzl and Hansen 2014).

Metzl and Hansen (2014:5) define *structural competency* as "the trained ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases [e.g., clinical depression and anxiety symptoms]… also represent the downstream implications of a number of upstream decisions about such matters" [e.g., experiences with sex, gender, and sexual discrimination]. Medical professionals must recognize the complexity of the specific healthcare needs (Davis 2015; Witten 2017), access (Davis et al. 2016; Gooren and T'Sjoen 2018), utilization (Caceres et al. 2020; Simmons 2020), experiences (Feder 2014; Porter et al. 2016), and barriers (Johnson et al. 2020) among TNBI people, and how these experiences differ by the structural constraints that TNBI people with various socially privileged and/or marginalized standpoints face in US society (Davis 2015; Sumerau and Mathers 2019).

Prior research demonstrates how intersecting systems of cumulative advantage and disadvantage, such as socioeconomic status (Johnson et al. 2020), race and ethnicity (Buchanan and Ikuku 2022; Fredriksen-Goldsen et al. 2013), disability status (Handlovsky et al. 2020; Nowakowski 2019), marital and partnership status (Bookwala 2016; Pfeffer 2017), and geographic location (Rogers 2020) substantially impact the health and well-being of TNBI populations. The Coronavirus Disease 2019 (COVID-19) pandemic also has amplified and brought greater attention the structural inequities that TNBI older adults face in US society (Flatt et al. 2022). Overall, TNBI older populations are too often absent from medical research, education, and practice altogether. Such instances of structural inequities and incompetency within US healthcare systems ultimately harms TNBI aging communities during and beyond the COVID-19 pandemic (Metzl and Hansen 2014; Nowakowski et al. 2020).

1.2 BACKGROUND AND JUSTIFICATION

TNBI aging populations have distinct healthcare access needs related to mental health (Johnson and Rogers 2020; Miller and Grollman 2015; Rosenwohl-Mack et al. 2020), physical health (Ducheny, Hardacker, and Houlberg 2019; Rosenwohl-Mack et al. 2020; Witten 2017), sexual and reproductive health (Besse, Lampe, and Mann 2020; Costello 2014), and sex and gender-affirming medical interventions (Hsieh and shuster 2021; Preves 2003). Specifically, the experiences of stigma, discrimination, and violence against TNBI people are interconnected with an increased need for mental health and peer support services among TNBI communities (Miller and Grollman 2015; Rosenwohl-

Mack et al. 2020). Researchers, for example, have demonstrated how discomfort with gender non-conformity contributes to transphobic discrimination and health-harming behaviors, such as attempted suicide and drug and alcohol misuse (Miller and Grollman 2015). In the case of sexual health, transgender people are at higher risk for human immunodeficiency virus (HIV) and other sexually transmitted infections (STIs) than their cisgender counterparts (Van Gerwen et al. 2020). At the intersections of these distinct health and healthcare needs, TNBI populations may struggle to gain sex and gender affirmation in healthcare environments and, consequently, are likely to avoid accessing and utilizing health services (Lampe and Nowakowski 2021; Preves 2003). Examining such perspectives in the context of the COVID-19 pandemic is particularly meaningful and important since COVID-19 has heightened the social and health instability of many TNBI people across the life course (Nowakowski et al. 2020).

Although there is growing interest in understanding TNBI populations within sociology and society more broadly (Sumerau 2020), less academic and mainstream attention has been dedicated to examining the needs of older TNBI adults related to chronicity management (Witten 2014), long-term care (Ing et al. 2018), and end-of-life care (Stinchcombe et al. 2017). It is imperative for medical researchers and practitioners to study and carefully evaluate existing aging, aged care, and end-of-life care disparities among older TNBI older Americans since they are a socially and medically disadvantaged population that often (a) manages acute and chronic health conditions and/or (b) has limited social support in managing their health (Latham and Barrett 2015; Nowakowski et al. 2019). Creating a more structurally-competent healthcare practice would allow TNBI older patients (e.g., TNBI residents from residential aged care facilities) to have greater likelihoods of receiving quality, effective healthcare that addresses the actual sources of their health disparities rather than receiving care that simply acts as a temporary bandage or ignores the larger-scale, social forces that drive barriers to care. (Donald et al. 2017; Grimstad et al. 2021; Metzl and Hansen 2014). Examining TNBI aged and end-of-life care disparities in the context of COVID-19 may also provide valuable information for medical practitioners with implications beyond the pandemic and with extension into other social conditions that TNBI older adults navigate in US society.

In the case of intersex older adults, Latham and Barrett (2015) use narrative data from the Intersex Ageing and Aged Care Project to document the experiences and needs of older intersex adults. They conducted a life-history interview with an older intersex person (who wished to be known as "Pat" in the study). Pat discussed their medical trauma via intersex surgeries and acknowledged how most medical providers have little knowledge and interest in helping older intersex adults or understanding their specific challenges. Pat further explained their fear of how medical providers would view and treat them if they become a resident at a residential aged care home. Pat's fears are not uncommon among TNBI aging communities. However, these fears often differ based on TNBI people's prior experiences with medical institutions and providers [e.g., an older intersex adult who did not have intersex surgeries may not have similar fears about aged care settings as Pat] (Lampe and Nowakowski 2021; Latham and Barrett 2015). Medical providers drawing upon structural competency frames in their work with older intersex adults would be better able to understand Pat's specific fears and seek out more direct solutions for intersex older residents' care needs in residential aged care settings.

Aging, aged care, and end-of-life disparities among TNBI older populations are often systemically and institutionally preventable or could be greatly reduced by medical institutions, authorities, and processes, highlighting social injustices in contemporary society (Flatt et al. 2022). For example, there is a paucity of literature on long-term care challenges for older trans people living with HIV and even fewer intervention studies actively aiming to reduce these challenges (Ing et al. 2018). Much HIV intervention research on TNB populations also neglects to meaningfully engage older TNB people or focus on aging and end-of-life needs of TNB people managing HIV (Marshall and Cahill 2021). Additionally, prior research addresses the needs of TNBI older adults from the perspectives of patients (Singh and McKleroy 2011), family care partners (i.e., family caregivers) (Nowakowski et al. 2019), and providers (Liang et al. 2017). However, most studies have neglected to address the interpersonal dialogue between patients, families, and providers surrounding important TNBI health and aging issues such as decisions surrounding advance care planning and end-of-life care (Henry et al. 2020). Further investigation on how TNBI older adults navigate US healthcare systems in relation to aging and end-of-life experiences should be examined within and beyond the context of the COVID-19 pandemic.

When examining aging and end-of-life experiences among TNBI populations, it is also critically important to offer targeted focus on the aging and end-of-life experiences of intersex populations. Intersex aging populations have distinct healthcare needs related to mental health (Davis 2015; Rosenwohl-Mack et al. 2020), physical health (Carpenter 2018; Preves 2003), chronic illness (Costello 2014; Jones 2020), and aged care (Latham and Barrett 2015). Rosenwohl-Mack (2020) and colleagues conducted the first US survey of intersex adults (n=198), which showed that fifty-three percent (53%) of intersex participants self-reported fair or poor mental health and 43% self-reported fair or poor physical health. Additionally, reporting at least one chronic health problem among survey respondents was significantly associated with older age and worse self-reported physical health (Rosenwohl-Mack et al. 2020). To date, no research fully addresses attitudes towards and experiences of long-term, aged, and end-of-life care among intersex adults beyond clinical case studies (Latham and Barrett 2015).

Intersex people often navigate US healthcare systems to obtain quality, intersex/DSD-specific care (Davis et al. 2016) and may manage health complications after receiving (often nonconsensual and medically-unnecessary) surgeries stemming from medical and mainstream discomfort with intersex/DSD embodiments (Feder 2014; Karkazis 2008). For example, some intersex people navigate significant sexual health (Costello 2014; Preves 2003) and relationship challenges with significant others and medical providers (Costello 2019) over the life course because of complications from medically unnecessary surgeries connected to their intersex traits (e.g., genitals that do not conform to normative, female/male sex binary expectations in Western medicine). Limited research addresses sexual health and well-being challenges among intersex older people and their partners, with the COVID-19 pandemic producing additional barriers to maintaining intimate relationships.

Compared to their cisgender (not transgender) and endosex (not intersex) peers, prior research illuminates a variety of risk factors associated with poor physical and mental health outcomes (Fredriksen Goldsen et al. 2019; Rosenwohl-Mack et al. 2020), substantial reproductive and sexual health needs (Callens, Kreukels, and van de Grift

2021; Lampe and Nowakowski 2021), and significant healthcare access and utilization disparities (Davis et al. 2016; Witten 2004) among TNBI patient populations. Despite documented greater healthcare needs among TNBI people (Davis et al. 2016), they have long struggled to access quality care (Davis et al. 2016) due to factors such as erasure and stigmatizing approaches in healthcare research (Bauer et al. 2009), mistreatment by healthcare providers (James et al. 2016), and limited evidence-based interventions addressing TNBI individuals' own health priorities (Nowakowski, Sumerau, and Lampe 2020). The majority of healthcare provider education and training centers on serving cisgender and endosex patient populations, while erasing sex and gender diversity from medical curricula (Liang et al. 2017; Stryker 2017). Indeed, most medical education and training in the US still operates within notions of Western sex and gender binary systems (Obedin-Maliver et al. 2011), erasing sex and gender fluidity among diverse patient populations (Stryker 2017). Such patterns reflect structural incompetency around responding to TNBI older adult's lives and needs within the American medical institution because most medical providers systematically fail to understand how macro systems, institutions and structures reproduce barriers to appropriate care and interventions at the meso level that ensure that healthcare spaces are accessible, effective, and inclusive for TNBI aging populations (e.g., facilities creating and implementing standards of care for TNBI patients and their family care partners (i.e., family caregivers) who utilize end-of-life care services).

Sociologists have also identified factors that introduce barriers to healthcare service access and utilization for TNBI patients (Davis et al. 2016; shuster 2016; shuster and Bodenheimer 2021), including clinicians' limited, incorrect, or outdated knowledge about TNBI embodiments and health issues (Costello 2016; Davis et al. 2016). Such examples include medical providers often having no or limited expertise on how hormone therapies do and/or do not affect the reproductive and sexual health of TNBI people over the life course (Costello 2014; Hines et al. 2021) and misconceptions that older age is a barrier to receiving TNBI-specific medical interventions (Flatt et al. 2022). These substantial barriers reflect structural incompetence when it comes to providing holistic and informed care to TNBI older patients within US healthcare systems by neglecting to understand the particular barriers to care that TNBI people may face (due to poor educational/instructional curriculum and practicum on TNBI health) and providing direct resources to ensure that patients have their basic needs met (e.g., access to sex, gender, and sexual affirmation in healthcare settings).

TNBI older populations also face challenges in accessing competent long-term and aged care (Ing et al. 2018; Latham and Barrett 2015), support from family and friends (Allen and Lavender-Stott 2020; Pfeffer 2017), managing chronic illness (Nowakowski et al. 2019), and making advance-care planning decisions (Henry et al. 2020). For example, there is a lack of internationally and US recognized standards of care for TNBI patients in end-of-life care settings (Stevens and Abrahm 2019). Therefore, this institutional knowledge gap creates difficulty for medical providers and staff in end-of-life care settings to be informed about TNBI older patients' health management needs and goals (e.g., a transgender older adult may desire continuing hormone therapy treatments for their mental health management while receiving hospice care).

Comprehensive medical guidelines and standards of care for providing end-of-life care to TNBI older patients are important since TNBI people experience substantial aging and end-of-life inequities (Stinchcombe et al. 2017). Overall, TNBI people continue to navigate challenging social and health conditions over the life course across a variety of institutions and situations, while translating basic survival skills into innovation in seeking competent healthcare (Bry et al. 2018; Johnson et al. 2020). Structural incompetency in medicine often acts as a significant barrier for TNBI individuals – especially TNBI older patients – because it neglects to understand how macro-level systems, institutions, and structures impact barriers to care and intervene structurally within the US healthcare systems, while failing to ensure that patients have their basic needs met (e.g., access to free or affordable medication, social support from family and friends, TNBI health resources). Ensuring that healthcare spaces are fully accessible, effective, and inclusive, for example, requires many resources (e.g., money, time, access to information) for TNBI older adults to successfully access medical providers who are knowledgeable in both TNBI and older adult health needs (Nowakowski et al. 2019).

1.3 STUDY AIMS AND OBJECTIVES

Sociological research and practice are substantially limited without a critical analysis of TNBI patient biographies, needs, and experiences within US healthcare systems. Since a critical analysis of older TNBI populations is severely limited in the sociology of health, aging, and medicine, my aim in this dissertation is to move the field towards analyzing how aged care operates through medico-moral systems of cisnormativity and endonormativity. *Cisnormativity* is an ideology wherein many cisgender people know almost nothing about TNB others while engaging in social processes that consequently “disallow trans experiences” through erasure, regulation of TNB bodies, and punishing gender non-conformity in public spaces (Sumerau, Cragun, and Mathers 2016:294). Similarly, *endonormativity* is an ideology that disallows intersex experiences, identities, and bodies that do not align neatly within a female/male endosex binary model (Costello 2019). Together, cisnormativity and endonormativity co-operate in medicine in ways that often disallow TNBI patients to access and benefit from quality healthcare (Ducheny et al. 2019; Karkazis 2008).

This dissertation examines how cisnormativity and endonormativity work together to construct structural incompetency regarding TNBI patient populations by allowing medical education, training, and practice to disregard the larger-scale, social forces, and competencies that often drive barriers to quality, effective care, while also teasing apart the multifaceted health and aging consequences older TNBI patients may face in a social world that normalizes and standardizes cisgender, endosex, and younger experiences in US healthcare systems. This dissertation examines pathways toward (and barriers in achieving) healthy aging[4] processes among TNBI older Americans to incorporate the perspectives of members of these populations more fully into sociological research, thereby expanding its reach and relevance. This dissertation is guided by the following three research questions:

(1) How do TNBI older Americans access and experience reproductive and sexual health services?

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[4] The World Health Organization defines healthy aging as the lifelong process of "developing and maintaining the functional ability that enables wellbeing in older age," which includes maintaining the ability to be or do what someone desires to achieve (Beard et al. 2016:7)

(2) How do TNBI older Americans perceive and plan for end-of-life experiences in the context of advance care planning?

(3) How do TNBI older Americans manage and maintain their health during the COVID-19 pandemic?

This dissertation produces knowledge that may inform the development of best practices for reducing and eliminating healthcare disparities for TNBI aging communities in the US. Specifically, this study provides information on pathways toward healthy aging among TNBI older adult populations through focus on: (a) examining TNBI older adults' experiences in accessing and utilizing health services, (b) pinpointing potential barriers and resources TNBI older adults encounter when navigating reproductive and sexual healthcare systems, (c) exploring TNBI older adults' perceptions and experiences with advance-care planning, and (d) analyzing what strategies TNBI older adults use to manage their health and well-being in the context of the COVID-19 pandemic.

1.4 METHODS, ANALYSIS, AND PARTICIPANTS

Study eligibility and recruitment

This study was approved by the University of South Carolina Institutional Review Board (see Appendix A). [5] Between September 2021 and January 2022, I conducted 50 semi-structured, individual interviews with TNBI older adults who reside in the US. I recruited TNBI older adults through social media, SGM and non-SGM health centers,

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[5] It is important to note that chapters 2, 3, and 4 of this dissertation should be understood as stand-alone manuscripts and that, as such, there may be specific background, sample, method, and analysis information that is repeated.

aged care facilities, SGM-friendly faith communities, and SGM community leaders and organizations. Most respondents in my research sample did not have personal relationships with other TNBI adults 65 years of age or older. This meant that strategies traditionally used to recruit SGM research participants, such as purposive social network sampling (Pfeffer 2012) and snowball sampling strategies (Compton, Meadow, and Schilt 2018), were less effective in this qualitative study.

I recruited my research sample of TNBI older respondents by (a) being open about my TNBI identities during participant recruitment and answering any questions prospective research participants had about me or the study, (b) attending SGM-led community events and meetings (e.g., attending a faith worship service virtually and SGM lay leaders introducing me to faith community members before the start of service) to share more information about the study, (c) connecting with intersex activists in the US who shared the study information in private Facebook groups for intersex community members, and (d) connecting with SGM-friendly faith community clergy and lay leaders. Many non-SGM and SGM-led organizations, especially SGM-friendly faith communities, refrained from distributing my intersex participant recruitment flyers (located in Appendix C) but eagerly shared my TNB participant recruitment flyers (located in Appendix B) with their stakeholders through their social media accounts and programming. This hesitance to share research study information about intersex populations could be due to structural erasure, stigma, and discrimination of intersex experiences throughout US society.

Importantly, there are no large-scale or long-term quantitative health studies in the US that specifically examine the health management experiences of TNBI older adults.

Thus, utilizing qualitative methodology was critical for me to employ in this research study to comprehensively examine TNBI health management in older adulthood. Eligibility included respondents who: (a) self-identified as transgender, non-binary, and/or intersex, (b) were 65 years of age or older at the time of the interview, (c) lived in the US at the time of the interview, and (d) consented to be audio-recorded during the interview (see Appendices E and F for participant demographic tables).

Instruments and interview procedure

I developed and pretested an interview guide with 3 TNBI older adults to ensure questions were insightful, affirming, and culturally appropriate (semi-structured, interview instrument located in Appendix D). Due to participant safety concerns during the COVID-19 pandemic, I conducted 39 Zoom interviews and 11 telephone interviews during data collection. To fulfill respondents' accessibility needs, particularly for those who were hard of hearing, I offered automated closed captioning and lip-reading functionality for respondents who were interviewed through Zoom.

With ethics a key concern in research with a vulnerable aging population, I developed an interview instrument with the assistance of TNBI sociologists from Sociologists for Trans Justice. I pretested the interview guide with 3 TNBI older adults to ensure that questions are insightful, sex and gender-affirming, and culturally appropriate. I approached respondents with questions concerning their (i) healthcare experiences, (ii) attitudes toward advance care planning, and (iii) health needs and management throughout each interview. This qualitative approach allowed me to build trust, comfort, and rapport with TNBI respondents. Each part of the interview contained several follow-ups or probes to ask for further information. I secured verbal consent from each participant before the start of each interview and before I asked about each interview topic (e.g., reproductive and sexual healthcare experiences, advance care planning, and health needs and management).

On average, interviews lasted 98 minutes (range: 30 to 346 minutes). Each TNBI older adult respondent received a $40 prepaid Mastercard debit card after completion of the interview to thank them for their time and contribution to the study. I audio-recorded interviews and used Nvivo transcription software to transcribe each interview. After the completion of each interview transcription, I fidelity checked each interview transcript to ensure accuracy, while making corrections as needed. I gave respondents pseudonyms and removed all identifying information during the fidelity checking process to ensure research participant confidentiality. I also wrote memos during qualitative data collection and analysis.

Researcher standpoint

My researcher standpoint as a white, non-Hispanic/Latinx, TNBI young adult living in the US Southeast certainly influenced my interview experiences with respondents. Many respondents expressed that they felt more comfortable with me interviewing them – as a TNBI interviewer – than they would be if a cisgender or endosex researcher interviewed them due to fear of negative or mediocre interview experiences (see also Sumerau and Mathers 2019). Despite me disclosing my sex and gender identities with respondents before each interview (as a TNBI person who was socially assigned female at birth), respondents perceived me as a cisgender woman, transgender man, or transgender woman in some cases (see also shuster 2021). My gender expression and respondents' assumptions about my sex and gender identities likely shaped our interactions. Additionally, my social location as a TNBI researcher residing in the US Southeast may have allowed some respondents who live in socially, politically, and/or religiously conservative areas to feel comfortable enough to be interviewed by me. My background as someone who grew up in a conservative, working-class household in the rural US Midwest also allowed me to connect with some respondents from rural and financially disadvantaged backgrounds.

Although my social standpoints produced certain benefits in terms of recruitment, there were also limitations. First, my status as a young adult interviewer, at times, discounted my credibility as a TNBI aging researcher or made me a potential outsider (e.g., a respondent asked whether I was "old enough" to interview them) with some older respondents (see Charmaz 2014 for the importance of insider versus outsider perspectives in qualitative methodology). Second, recruiting and interviewing a racially and ethnically diverse sample for the study was limited due to my positionality as a white, non-Hispanic/Latinx interviewer. Having a skewed sample does not preclude qualitative researchers, however, from obtaining meaningful data on how racial, ethnic, and economic privilege shapes the reported experiences of research participants, regardless of sex and gender identity (Riggs et al. Forthcoming). Because TNBI people of color face multiple and intersecting forms of oppression and discrimination in the US (Buchanan and Ikuku 2022; Stryker 2017; Vidal-Ortiz 2009) and have experienced medical trauma at the hands of both researchers and clinicians (Karzakis 2008; Singh and McKleroy 2011; Sumerau and Mathers 2019), relying on SGM and SGM-friendly faith community leaders of color, as trusted community gatekeepers, was necessary for me to recruit and engage with TNBI respondents of color.

Data coding and analysis

My data analyses focused on TNBI older Americans' healthcare experiences, attitudes and experiences with advance care planning, and health needs and management. I coded data using Nvivo (Release 1.6) software and analyzed inductively utilizing a constructivist grounded theory approach (Charmaz 2014). I engaged in initial or open coding, meaning I read a subset of transcripts to develop a general sense of the data and generated an initial list of codes. Subsequently, I engaged in focused or thematic coding, which involves the identification of coding overlaps and divergences, resulting in the combining and collapsing of open codes to form broader thematic codes/themes that are then placed in network relationships to one another. I also coded disconfirming evidence during the focused coding process. I then developed categories and themes from this coding scheme to discern emergent patterns and connections in the data. Finally, I engaged in axial coding, linking demographic attributes in the dataset (e.g., gender identity, socioeconomic status) to specific codes and themes, which provided information about particular patterns among and between various sub-groups of respondents.

Utilizing the analytic memos, recurring themes, and existing literature, I thematically analyzed these data while exploring emerging themes and codes concerning my research questions:

(1) How do TNBI older Americans access and experience reproductive and sexual health services?

(2) How do TNBI older Americans perceive and plan for end-of-life experiences in the context of advance care planning?

(3) How do TNBI older Americans manage and maintain their health during the COVID-19 pandemic?

Participant sample

Demographics of the participant sample are located in Appendices E and F. I conducted semi-structured, in-depth interviews with 50 TNBI older adults (65 years of age or over). Participants resided across 21 US states. Most respondents (60%) live in suburban areas, while 28% live in urban areas, and 12% live in rural areas. Regarding sex as a social category, 32% self-identified as intersex and/or as someone with intersex variations. Over half of participants (54%) self-identified as transgender women. This research sample contained mostly endosex (not intersex) and intersex TNB people. Only three respondents in the participant sample self-identified as cisgender (not transgender) intersex people. Respondents ranged from 65 to 81 years of age (average age: 69 years).

The majority of respondents were white and non-Hispanic/Latinx (74%) with 26% from racial and/or ethnic minority backgrounds. Regarding social class, most self-reported as middle-class (58%) and 18% as from low-income backgrounds. Respondents reported diverse sexual identities, with most self-identifying as lesbian (33%) or bisexual (20%). Most respondents had obtained an associate's or more advanced college degree (62%), with 22% of respondents holding a graduate degree. Most respondents were single (64%) and had no children (34%). Respondents' identities and lived experiences shaped the research findings from this dissertation study.

1.5 STUDY OVERVIEW

This dissertation contains three separate studies using the same participant research sample of 50 TNBI older Americans. In the first study, I examine how TNBI older adults perceive, access, and utilize reproductive and sexual health services through the conceptualization of resourcefulness. Most respondents described medical provider ignorance in providing (i) SGM-competent and (ii) age-friendly care in reproductive and sexual healthcare settings. Consequently, TNBI older respondents reported the use of resourceful strategies for combatting medical provider ignorance and incompetence when accessing and/or utilizing reproductive and sexual health services. Such approaches within reproductive and sexual healthcare systems are not structurally sustainable for maintaining SGM-affirming and age-inclusive care for older TNBI adults in US society.

In the second study, I analyze TNBI older adults' unique needs for (and barriers to) advance care planning and end-of-life preparation, while pinpointing what a 'good death' might mean for older TNBI people (Cain 2021). Respondents reported two primary fears that motivated their uncertainty around having a good death as an older TNBI person: (i) medical mistreatment and neglect in aged care settings and (ii) lack of social support. And second, because respondents have a great deal of uncertainty around whether they will be able to have a good death, they reported engaging in resourceful strategies that might prevent them from experiencing a bad death: (i) formalizing advance care planning documents and (ii) selecting healthcare agents. While sociologists have examined perspectives of dominant good death definitions among underserved communities in healthcare (Cain 2021; Carr 2003), my analysis reveals TNBI older adults' uncertainties around their ability to experience a good death, along with their resourceful strategies for reducing the possibility of a bad death. I further introduce the concept of satisficing around aging and death, which is a process that involves being less able to access or be assured of a good aging process and death due to existing inequalities faced by TNBI people (Cain 2021; Dickson et al. 2021).

In the third study, I investigate how TNB older Americans manage their health during COVID-19. TNBI respondents' narratives revealed that the COVID-19 pandemic was an unanticipated life course disturbance that drastically impacted their health management attitudes and experiences. Two primary themes emerged among respondents' health management experiences during the COVID-19 pandemic: (i) coping with COVID-19 related social isolation and (ii) navigating disrupted medical care. Such themes were shaped by respondents' social advantages and disadvantages, such as access to financial security, social support, and adequate medical care. Respondents from racial, ethnic, and/or social class minority communities also reported need for additional resources from medical and social service agencies to better manage their immediate health needs and quality of life during the COVID-19 pandemic. While these research findings cannot be generalized to the sexual and gender minority (SGM) older population, they suggest that broader patterns of inequity affect how TNBI older Americans access and utilize health services, perceive aging and end-of-life preparation, and manage their health during the COVID-19 pandemic.

CHAPTER 2: REPRODUCTIVE AND SEXUAL HEALTHCARE EXPERIENCES AMONG TRANSGENDER, NON-BINARY, AND INTERSEX OLDER ADULTS

2.1 INTRODUCTION

Recent research has demonstrated the need for sexual and gender minority (SGM) older adults to receive competent and inclusive aged care education, resources, and support services (Candrian and Cloyes 2021; Stevens and Abrahm 2019; Valenti et al. 2020). These studies suggest that SGM older adults often face and navigate structural inequities in the context of United States (US) healthcare interactions and systems (Candrian and Cloyes 2021; Nowakowski et al. 2019; Stinchcombe et al. 2017). For example, older transgender people living with human immunodeficiency virus (HIV) can experience substantial challenges with accessing and utilizing quality sexual healthcare in long-term care settings due to SGM- and HIV-related stigma from medical providers (Ing et al. 2018). Many SGM older adults also struggle to maintain rights to sexuality, sexual health, and sexual wellbeing/access within residential care and assisted living settings due to normative assumptions about the non-sexuality of older SGM populations, which is an example of lacking SGM older adult structural competency in care settings (Wolfenson 2017). Metzl and Hansen (2014:5) define *structural competency* as "the trained ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases (e.g., reproductive and sexual health conditions)… also represent the downstream implications of a number of upstream decisions about such matters" (e.g., experiences with sex, gender, and sexual discrimination in healthcare settings). Disparities in structural competency for SGM aged care (e.g., poor educational/instructional curriculum and practicum on SGM health, lack of understanding of SGM embodiment, lack of standards of SGM care) may further exacerbate how SGM older adults perceive, access, and utilize reproductive and sexual health services (e.g., breast/chest and prostate exams) to maintain their health in older adulthood (Metzl and Hansen 2014) rather than effectively addressing the actual sources of SGM health and healthcare disparities (e.g., sex, gender, and sexual discrimination in US society).

SGM people are exposed to *minority stress*, chronic stressors due to SGM-related stigmatization (Frost et al. 2017; Meyer 2003, 2015), while facing various structural inequities in accessing and utilizing adequate healthcare (Liang et al. 2017; Stinchcombe et al. 2017). In other words, stress does not only manifest in individual situations but is interconnected and entirely dependent on SGM people's advantaged and disadvantaged social statuses (e.g., medical trauma via unnecessary medical surgeries among intersex individuals) in US society (Pearlin et al. 1981, 1990). SGM communities experience minority stress over the life course, which makes maintaining basic wellness in older adulthood a substantial challenge for SGM older adults (Meyer 2003; Turner and Lloyd 1995). Additionally, intersecting chronic stressors – such as collective trauma among SGM communities (e.g., the HIV/AIDS epidemic) and SGM-specific stigmatization in healthcare settings - could also have negative impacts on care access, utilization, and delivery outcomes among SGM older adults (Chen et al. 2022; Hash and Rogers 2013).

At the same time, SGM health researchers have documented and conceptualized *resilience* as successful strategies from overcoming or managing challenges related to minority stress among SGM populations while exploring how social conditions (e.g., social support from family and/or friends) enhance or diminish resilience (Derickson 2016; Robinson and Schmitz 2021). Prior SGM health research uses resilience as a theoretical framework to further explain how SGM people can improve their coping skills in managing challenges, while bettering their health and healthcare outcomes (Derickson 2016). However, such work largely ignores the structural inequities of SGM health disparities and resilience among SGM people over the life course is largely influenced by existing social privileges and resources (e.g., socioeconomic privilege; easy access to SGM health centers).

Advancing the conceptualization of minority stress and resilience (Hash and Rogers 2013; Meyer 2003, 2015), I examine how transgender, non-binary, and/or intersex (TNBI) older adults – as a medically and socially vulnerable sub-group within SGM communities – perceive, access, and utilize reproductive and sexual health services as traditionally sex and gender hyper-focused specialties within US healthcare systems. Utilizing data from 50 semi-structured individual interviews with TNBI older Americans (65 years and over), I illustrate how SGM-related and older age-related chronic stressors both shape TNBI older adults' perceptions of and experiences with reproductive and sexual health services. My analysis also explains how TNBI older adults' resourcefulness, rather than resilience, influences the decision-making process when accessing and utilizing reproductive and sexual health services (Derickson 2016).

2.2 MINORITY STRESS AND RESILIENCE

Utilizing the theoretical perspectives of *minority stress* and *resilience* provides insight into the healthcare needs of older TNBI Americans (Griffin et al. 2019). Although such frameworks have been historically used to explain SGM health disparities, minority stress and resilience can be applied to further explain healthcare inequity among SGM communities (Gessner et al. 2020; Martos et al. 2018). The minority stress model posits that (a) prejudice, stigma, and discrimination against lesbian, gay, and bisexual (LGB) people produce "minority stressors" and (b) minority stressors cause adverse mental and physical health outcomes for LGB people over the life course (Meyer 2003).

According to Meyer (2003), there are three distinct types of stressors sexual minorities face: (1) general stress, (2) distal minority stress, and (3) proximal minority stress. General stressors are external stressors that are not directly associated with sexual minority status (such as living in a geographical area with a health clinic shortage designation). Distal minority stressors are external stressors caused by adverse experiences from social actors, settings, and institutions that are associated with sexual minority status, such as discrimination against sexual minority persons in healthcare settings. Finally, proximal minority stressors are interpersonal and internalized stressors that are associated with sexual minority statuses, such as the fear of discrimination due to sexual minority status or internalized stigma among sexual minority populations.

The minority stress model was later extended by examining minority stressors experienced by transgender and gender non-conforming (TGNC) populations (Meyer 2015; Testa et al. 2015). Challenging dominant discourse in the clinical and interdisciplinary health sciences that examined only individual risk factors of health behavior in the lives of SGM populations, Meyer (2003) revolutionized health research through recognition that structural stigma creates and sustains SGM health disparities in the form of minority stress while underscoring the resilience SGM people must acquire to manage minority stressors (Fredriksen Goldsen et al. 2019; Nowakowski et al. 2019).

Despite notable variations of minority stress among SGM populations (Griffin et al. 2019; Meyer 2003), research demonstrates the importance of utilizing resilience as an additional theoretical perspective for SGM health studies (Allen and Lavender-Stott 2020; Meyer 2015). Resilience is a process that occurs when individuals engage in successful coping efforts or strategies while facing proximal and distal minority stressors (Meyer 2015). Resilience among SGM populations may provide a safeguard for managing health among SGM populations while responding to minority stressors in healthier ways over the life course (Allen and Lavender-Stott 2020; Fredriksen Goldsen et al. 2019; Nowakowski 2019). For example, Allen and Lavender-Stott (2020) examined how strength and resilience operate among LGBTQ older adults despite the marginalization they experience from socio-political institutions. However, an emerging line of scholarship highlights how normative understandings of resiliency within academic and public discourse may be too narrow when examining the lives and experiences of marginalized communities (Derickson 2016; Gill and Orgad 2018).

For example, Derickson (2019) proposes utilizing conceptualizations of *resourcefulness* as an academic and political tool to inspire necessary social change for marginalized communities rather than promote or laud individual resiliency. Gill and Orgad (2018) examines the privileged gender and class dimensions of resilience as promoted within women's magazines, self-help books, and smartphone apps, calling for the social transformation of such perspectives. In a critical review of LGBTQ youth research, Robinson and Schmitz (2021) emphasize the importance of examining resistance among LGBTQ youth when navigating oppression and how collective forms of resistance may lead to positive effects on health and well-being among LGBTQ youth.

Additional research is needed to understand resourcefulness processes among older TNBI people to develop community-based interventions that safeguard health and respond to the care needs of this vulnerable aging population (Davis 2015; White Hughto and Reisner 2018). Resourcefulness, or implementing resourceful strategies, is a tactical process by which socially and medically vulnerable communities obtain and use resources (e.g., access to reliable, social support) to improve their social and health challenges. Resourcefulness is different from resiliency insofar as it acknowledges the necessity of social privilege, material and social capital, and resources to overcome difficult situations, rather than successfully using individual, psychological coping strategies alone. As such, I further examine how SGM-related and older age-related chronic stressors both shape TNBI older adults' perceptions of and experiences with reproductive and sexual health services, while pinpointing how TNBI older adults' resourceful strategies influence the decision-making process when accessing and utilizing reproductive and sexual health services (Derickson 2016).

2.3 BARRIERS TO REPRODUCTIVE AND SEXUAL CARE

There is a crisis in contemporary TNBI medicine (Davis 2015; shuster 2021) with most US medical providers lacking knowledge in TNBI health and healthcare needs (Liang et al. 2017; Obedin-Maliver et al. 2011; Stallings et al. 2021). These deficiencies in medical knowledge can lead to medical providers and staff, regardless of their intentions, placing TNBI patients in vulnerable and uncomfortable positions, such as using outdated language, disclosing patients' TNBI identities to family members without their consent, and referring to their anatomical features in gendered or medicalized ways (Lampe and Nowakowski 2021). This is especially the case for transgender and non-binary (TNB) people utilizing services in reproductive healthcare settings that are women-centric or stereotypically feminized (e.g., having all pink décor in a patient waiting area or exam room) (Besse et al. 2020). For example, Johnson and colleagues (2020) found that transgender communities face a variety of barriers to accessing quality care through medical providers, practices, and systems in the US Southeast while calling for an investigation in providing quality and gender-affirming reproductive and sexual healthcare for transgender patients. Prior research on how older TNB adults navigate reproductive and sexual healthcare settings and their interactions with medical providers and staff is severely limited.

In the case of intersex people, US healthcare interactions and systems are mainly built around endosex (i.e., not intersex) people and bodies, at the expense of intersex patients. Some examples include endonormative assumptions about intersex people's reproductive experiences (Costello 2014), the medicalization of intersex bodies and experiences (Davis et al. 2016), medically invasive intersex surgeries on infants and youth (Nowakowski et al. 2020), and the erasure of intersex populations in medical research and practice (Liang et al. 2017). Like other social institutions, normative values and beliefs are embedded in healthcare providers' assumptions that intersex patients need immediate medical attention related to their intersex variations during all patient encounters (Davis et al. 2016; Liang et al. 2017). Such intersex competency issues among medical institutions and providers may place intersex patients at greater risk for reproductive and sexual health disparities by failing to foster greater likelihoods of receiving quality, effective care that addresses the actual sources of their health disparities (e.g., lack of understanding of associated medical trauma and other side effects of enduring medically unnecessary intersex surgeries). As such, I further explore the reproductive and sexual healthcare experiences of intersex older adults while examining how medicalization impacts intersex people in older adulthood. Like those from TNB communities, intersex people often do not have the privilege of accessing and utilizing intersex-competent reproductive and sexual health services (Davis et al. 2016).

Despite ageist, cisnormative, and heteronormative assumptions about the non-sexuality/non-reproduction of older TNBI populations (e.g., TNBI older adults are sexually inactive and thus do not need reproductive and sexual health services) in the US (Nowakowski and Sumerau 2019b), sexual and reproductive care is something that greatly impacts older TNBI people. TNBI older adults, for example, have distinct reproductive and sexual healthcare needs as a medically vulnerable aging population (Ceres et al. 2018; Cottrell 2020; Patel et al. 2019; Pivo et al. 2017; Tabaac et al. 2018). Such examples include (i) breast/chest cancer risk assessment and screening among some groups of TNB people (Pivo et al. 2017), (ii) prostate-specific antigen tests among trans women and some non-binary people (Tabaac et al. 2018), (iii) cervical, endometrial, and uterine cancer screenings among some trans men, intersex, and non-binary people (Patel et al. 2019), (iv) rectal and anal cancer screenings among some TNBI people (Ceres et al. 2018), and (v) STI screenings (Cottrell 2020). Sociological research has yet to fully address how TNBI older adults access and utilize reproductive and sexual care settings.

There remains a critical need for sociologists to analyze the current state of TNBI elders in the US to determine their precise reproductive and sexual health needs and inform the development of opportunities for targeted improvement in care. For example, examining and offering competent sexual well-being counseling would be beneficial for some TNBI older adults who experience vaginal atrophy and dryness or orgasm dysfunction (Muzacz and Akinsulure-Smith 2013). Examining TNBI patient perceptions of and experiences with reproductive and sexual healthcare settings provides a valuable lens to assess whether US healthcare systems and interactions contribute to minority stress or other chronic stressors among TNBI adults over the life course (Besse et al. 2020; Meyer 2003). Prior research, for example, neglects to investigate the sexual and reproductive care needs and experiences of TNBI older survivors of sexual violence (Cook-Daniels and munson 2010) or survivors of medical trauma (e.g., nonconsensual intersex surgeries) (Davis 2015). Although researchers have increasingly examined the reproductive and sexual healthcare needs, interactions, and experiences of TNBI populations, very few studies adequately address the specific challenges TNBI people may face in older adulthood within these social contexts and settings (Porter et al. 2016).

Some older TNBI patients, for example, may experience breast/chest pain, tenderness, or loss of sensation from binding, surgeries, and hormone use/fluctuation (Lampe and Nowakowski 2021). There also may be a desire for some older TNBI adults to induce lactation in the context of later age birth, adoption, or familial/kinship arrangements and a need for medical support to achieve such care goals (MacDonald 2019). However, intervention research focused specifically on the reproductive and sexual care needs and desires of TNBI older adults (beyond HIV/STI interventions) is almost nonexistent. By understanding the particular experiences of TNBI older patients concerning healthcare access, utilization, and decision-making processes, researchers and clinicians can center and affirm TNBI older people and provide them with adequate, targeted, and SGM-competent reproductive and sexual health services in US society.

2.4 RATIONALE FOR THE PRESENT STUDY

Prior research has advanced knowledge concerning TNBI people's access to and experiences with reproductive and sexual health services, such as fertility preservation (Jones 2020; Mitu 2016), pregnancy loss (Riggs et al. 2020), and abortion access (Moseson et al. 2021). However, emerging scholarship in such areas has historically paid little attention to how TNBI patients navigate reproductive and sexual healthcare experiences in older adulthood. I call for further development within the interdisciplinary medical sciences to broaden understanding of TNBI people's reproductive and sexual healthcare needs in later life. Further, I explain how older age bias and TNBI-incompetency – TNBI older adult structural incompetency - among medical providers may simultaneously shape TNBI older adults' reported minority stress in reproductive and sexual healthcare settings by failing to understand how macro-level systems, institutions, and structures reproduce barriers to appropriate care and interventions for TNBI older patients in US society.

Metzl and Hansen (2014:5) define *structural competency* as "the trained ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases (e.g., reproductive and sexual health conditions)… also represent the downstream implications of a number of upstream decisions about such matters" (e.g., experiences with sex, gender, and sexual discrimination in healthcare settings). Medical professionals that identify, examine, and intervene against the structural factors that impact TNBI health disparities (e.g., identifying and helping TNBI patients who are survivors of intimate partner violence) maintain structural competency, while those who have limited knowledge or ignore the structural factors that impact TNBI health disparities (e.g., a medical provider neglecting to identify or provide tailored resources to a TNBI survivor of intimate partner violence) reproduces structural incompetency (Downey and Gómez 2018; Metzl and Hansen 2014). Researchers have called for further examination in how medical providers have contributed to TNBI reproductive and sexual health disparities, regardless of their intentions, by gatekeeping services, resources, education, and technologies that maintain or constrain personal autonomy via reproductive choice and the right to sexuality (Jones 2020; Riggs et al. 2020).

Perceptions of social support and resources may help TNBI older adults successfully enhance their reproductive and sexual healthcare experiences (Fredriksen Goldsen et al. 2019; Lampe and Nowakowski 2021). However, prior literature is not conclusive on how various social and medical conditions of TNBI Americans (e.g., prior instances of ageism from medical providers) shape TNBI older adults' perceptions, access, and utilization of reproductive and sexual health services. Examining the barriers to reproductive and sexual healthcare among TNBI older Americans can further advance research by addressing existing health and healthcare disparities among SGM older populations while offering opportunities to improve reproductive and sexual health services for SGM communities.

The purpose of the present study is to examine the current perceptions of and experiences with reproductive and sexual health services among TNBI older Americans. I ask the following research question: How do TNBI older Americans access and experience reproductive and sexual health services? My research pushes toward an age-friendly understanding of access and utilization of reproductive and sexual health services among SGM communities. This advancement in SGM health research is especially needed to reduce and potentially eliminate health disparities among SGM Americans. Currently, there are substantial social and medical barriers that may prevent older TNBI adults from maintaining safer sexual relationships, health, and wellbeing/access (e.g., limitations on TNBI older patients disclosing their sexual lives with medical providers and staff in residential aged care settings) (Hillman 2017).

Drawing upon data from 2,514 LGBTQ adults 50 years of age and older, Hoy-Ellis, Fredriksen-Goldsen, and Kim (2022) report that transgender older adults have significantly lower odds of obtaining four of the U.S. Preventative Services Task Force's recommended preventative health screenings compared to their cisgender LGB counterparts. Additionally, the lack of opportunities in accessing and receiving accurate sexual health information that is both SGM and age-inclusive (Hoy-Ellis, Fredriksen-Goldsen, and Kim 2022) may limit TNBI older adults' understanding of safer sex practices (e.g., HIV/STI prevention and spread) (Hillman 2017) or participation in reproductive cancer prevention and treatment efforts (Brown and Jones 2015; Fledderus et al. 2020). This research study begins to comprehensively address barriers to TNBI older adult structural competency within reproductive and sexual healthcare settings by understanding how macro-level systems, institutions, and structures reproduce barriers to appropriate care and interventions at the meso level in order to provide direct resources and meet the basic needs of TNBI older patients.

2.5 METHODS, ANALYSIS, AND PARTICIPANTS

Study eligibility and recruitment

This study was approved by the University of South Carolina Institutional Review Board (see Appendix A). Between September 2021 and January 2022, I conducted 50 semi-structured, individual interviews with TNBI older adults who reside in the US. I recruited TNBI older adults through social media, SGM and non-SGM health centers, aged care facilities, SGM-friendly faith communities, and SGM community leaders and organizations. To minimize bias in participant recruitment, I avoided recruiting TNBI older adults from venues that overrepresented patients who may manage reproductive or sexual health conditions (e.g., HIV/AIDS care providers, urological care providers). Most respondents in my research sample did not have personal relationships with other TNBI adults 65 years of age or older. This meant that strategies traditionally used to recruit SGM research participants, such as purposive social network sampling (Pfeffer 2012) and snowball sampling strategies (Compton et al. 2018), were less effective in this qualitative research study.

I recruited my research sample of TNBI older respondents by (a) being open about my TNBI identities during participant recruitment and answering any questions prospective research participants had about me or the study, (b) attending SGM-led community events and meetings (e.g., attending a faith worship service virtually and SGM lay leaders introducing me to the congregation during announcements) to share more information about the study, (c) connecting with intersex activists in the US who shared the study information in private Facebook groups for intersex community members, and (d) connecting with SGM-friendly faith community clergy and lay leaders.

Many non-SGM and SGM-led organizations, especially SGM-friendly faith communities, refrained from distributing my intersex participant recruitment flyers (located in Appendix C) but eagerly shared my TNB participant recruitment flyers (located in Appendix B) with their stakeholders through their social media accounts and programming. This hesitance to share research study information about intersex populations could be due to structural erasure, stigma, and discrimination of intersex experiences throughout US society.

Importantly, there are no large-scale or long-term quantitative health studies in the US that specifically examine the health management experiences of TNBI older adults. Thus, utilizing qualitative methodology was critical for me to employ in this research study to comprehensively examine TNBI reproductive and sexual healthcare in older adulthood. Eligibility included respondents who: (a) self-identified as transgender, non-binary, and/or intersex, (b) were 65 years of age or older at the time of the interview, (c) lived in the US at the time of the interview, and (d) consented to be audio-recorded during the interview (see Appendices E and F for participant demographics). I did not limit inclusion to TNBI older adults who had experiences with reproductive and sexual health services because I wanted to include those who have not accessed these services due to potential barriers of care (e.g., no or limited health insurance coverage).

Instruments and interview procedure

I developed and pretested an interview guide with 3 TNBI older adults to ensure questions were insightful, affirming, and culturally appropriate (semi-structured, interview instrument located in Appendix D). Due to participant safety concerns during the COVID-19 pandemic, I conducted 39 Zoom interviews and 11 telephone interviews during data collection. To fulfill respondents' accessibility needs, particularly for those who were hard of hearing, I offered automated closed captioning and lip-reading functionality for respondents who were interviewed through Zoom.

With ethics a key concern in research with a vulnerable aging population, I developed an interview instrument with the assistance of TNBI sociologists from Sociologists for Trans Justice. I pretested the interview guide with 3 TNBI older adults to ensure that questions are insightful, sex and gender-affirming, and culturally appropriate. I approached respondents with questions concerning their (i) healthcare experiences, (ii) attitudes toward advance care planning, and (iii) health needs and management throughout each interview. This qualitative approach allowed me to build trust, comfort, and rapport with TNBI respondents. Each part of the interview contained several follow-ups or probes to ask for further information. I secured verbal consent before the start of each interview and before I asked about respondents' reproductive or sexual healthcare experiences, which included various follow-up questions about what factors respondents think might have shaped their care experiences and interactions. I did not instruct respondents to focus explicitly or elaborate on minority stressors until after they disclosed that information during the interview. Only then did I instruct respondents to further explain minority stressors (e.g., respondent feeling SGM erasure after their medical provider assumed they were heterosexual, cisgender, and/or endosex) in greater detail and how such stressors might impact their health and healthcare experiences.

On average, interviews lasted 98 minutes (range: 30 to 346 minutes). Each TNBI older adult respondent received a $40 prepaid Mastercard debit card after completion of the interview to thank them for their time and contribution to the study. I audio-recorded interviews and used Nvivo transcription software to transcribe each interview. After the completion of each interview transcription, I fidelity checked each interview transcript to ensure accuracy, while making corrections as needed. I gave respondents pseudonyms and removed all identifying information during the fidelity checking process to ensure research participant confidentiality. I also wrote memos during qualitative data collection and analysis.

Researcher standpoint

My researcher standpoint as a white, non-Hispanic/Latinx, TNBI young adult living in the US Southeast certainly influenced my interview experiences with respondents. Many respondents expressed that they felt more comfortable with me interviewing them – as a TNBI interviewer – than they would be if a cisgender or endosex researcher interviewed them due to fear of negative or mediocre interview experiences (see also Sumerau and Mathers 2019). Despite me disclosing my sex and gender identities with respondents before each interview (as a TNBI person who was socially assigned female at birth), respondents perceived me as a cisgender woman, transgender man, or transgender woman in some cases (see also shuster 2021). My gender expression and respondents' assumptions about my sex and gender identities likely shaped our interactions. Additionally, my social location as a TNBI researcher residing in the US Southeast may have allowed some respondents who live in socially, politically, and/or religiously conservative areas to feel comfortable enough to be interviewed by me. My background as someone who grew up in a conservative, working-class household in the rural US Midwest also allowed me to connect with some respondents from rural and financially disadvantaged backgrounds.

Although my social standpoints produced certain benefits in terms of recruitment, there were also limitations. First, my status as a young adult interviewer, at times, discounted my credibility as a TNBI aging researcher or made me a potential outsider (e.g., a respondent asked whether I was "old enough" to interview them) with some older respondents (see Charmaz 2014 for the importance of insider versus outsider perspectives in qualitative methodology). Second, recruiting and interviewing a racially and ethnically diverse sample for the study was limited due to my positionality as a white, non-Hispanic/Latinx interviewer. Having a skewed sample does not preclude qualitative researchers, however, from obtaining meaningful data on how racial, ethnic, and economic privilege shapes the reported experiences of research participants, regardless of sex and gender identity (Riggs et al. Forthcoming). Because TNBI people of color face multiple and intersecting forms of oppression and discrimination in the US (Buchanan and Ikuku 2022; Stryker 2017; Vidal-Ortiz 2009) and have experienced medical trauma at the hands of both researchers and clinicians (Karzakis 2008; Singh and McKleroy 2011; Sumerau and Mathers 2019), relying on SGM and SGM-friendly faith community leaders of color, as trusted community gatekeepers, was necessary for me to recruit and engage with TNBI respondents of color.

Data coding and analysis

My data analyses focused on how TNBI older Americans access and experience reproductive and sexual health services while pinpointing the unique factors of minority stress that may delay or negatively impact such services. I coded data using Nvivo (Release 1.6) software and analyzed inductively utilizing a constructivist grounded theory approach (Charmaz 2014). I engaged in initial or open coding, meaning I read a subset of transcripts to develop a general sense of the data and generated an initial list of codes with potential minority stress codes (e.g., mistreatment in healthcare settings). From this output, I developed a coding scheme consisting of sets of minority stress codes and then developed corresponding descriptions for each. Subsequently, I engaged in focused or thematic coding, which involves the identification of coding overlaps and divergences, resulting in the combining and collapsing of open codes to form broader thematic codes/themes that are then placed in network relationships to one another. I also coded disconfirming evidence during the focused coding process. I then developed categories and themes from this coding scheme to discern emergent patterns and connections in the data. Finally, I engaged in axial coding, linking demographic attributes in the dataset (e.g., gender identity, sexual identity, socioeconomic status) to specific codes and themes, which provided information about particular patterns among and between various sub-groups of respondents.

Utilizing the analytic memos, recurring themes, and existing literature, I thematically analyzed these data while exploring emerging themes and codes concerning my research question: How do TNBI older Americans access and experience reproductive and sexual health services? My data analysis revealed TNBI older adults' social contexts in experiencing minority stressors within reproductive and sexual healthcare settings and how they address (or not address) minority stress within such settings. Ultimately, I found that structural inequities within reproductive and sexual healthcare settings contribute to the reproduction of health and healthcare disparities for TNBI older adults.

Participant sample

Demographics of the participant sample are located in Appendices E and F. I conducted semi-structured, in-depth interviews with 50 TNBI older adults (65 years of age or over). Participants resided across 21 US states. Most respondents (60%) live in suburban areas, while 28% live in urban areas and 12% live in rural areas. Regarding sex as a social category, 32% self-identified as intersex and/or as someone with intersex variations. Regarding gender identity, over half of participants (54%) self-identified as transgender women. This research sample contained mostly endosex (not intersex) and intersex TNB people. Only three respondents in the participant sample self-identified as cisgender (not transgender) intersex people. Respondents ranged from 65 to 81 years of age (average age: 69 years).

The majority of respondents were white and non-Hispanic/Latinx (74%) with 26% from racial and/or ethnic minority backgrounds. Regarding social class, most self-reported as middle-class (58%) and 18% as from low-income backgrounds. Respondents reported diverse sexual identities, with most identifying as lesbian (33%) or bisexual (20%). Most respondents reported obtaining an associate's or more advanced college degree (62%), with 22% of respondents holding a graduate degree. Most respondents were single (64%) and had no children (34%). Respondents' identities and lived experiences shaped the research findings from this dissertation study. In what follows, I discuss how TNBI older respondents access and utilize reproductive and sexual health services in the US.

2.6 FINDINGS

Almost all respondents reported experiencing minority stressors while navigating reproductive and sexual healthcare settings and interactions (e.g., SGM-related discrimination from a medical provider). First, most respondents described medical provider ignorance as a source of minority stress in providing (i) SGM-competent *and* (ii) age-friendly care in reproductive and sexual healthcare settings. Such domains of reproductive and sexual healthcare (i.e., SGM-competency and age-friendliness) are most often separated in sociomedical research and practice (Nowakowski and Sumerau 2019b). Second, participants responded to medical provider ignorance through resourcefulness within reproductive and sexual healthcare settings by (i) transgender men and some non-binary respondents opting out or avoiding medical providers and settings and (ii) transgender women and some non-binary respondents seeking out SGM-competent care. However, these resourceful strategies involve precarity and require respondents to assume personal responsibility for access and receipt of quality reproductive and sexual healthcare, a structurally unaccountable and unsustainable model for ensuring SGM-affirming and age-friendly care for older TNBI older adults as a health disparity population in the US.

2.7 MEDICAL PROVIDER IGNORANCE AS A CENTRAL SOURCE OF MINORITY STRESS

Respondents often described medical provider ignorance when discussing experiences with receiving care services in reproductive and sexual healthcare settings. For most respondents, their primary concern was whether medical providers could address their health needs in reproductive and sexual healthcare settings, as patients who are SGM *and* older (e.g., receiving age-friendly and SGM-inclusive sexual health education and counseling, obtaining competent information and resources for safely resuming sexual practices post-bottom surgery). Respondents reported two primary domains of medical provider ignorance that shape their attitudes toward and experiences within such care settings: (i) SGM-competency and (ii) age-friendliness.

Lack of SGM-competency

Respondents primarily expressed their fears of or experiences with receiving SGM-incompetent care from reproductive and sexual healthcare providers. Specifically, respondents described their discomfort with medical providers who fail to fully affirm their SGM identities (e.g., misgendering TNB respondents, assuming intersex, cisgender patients are transgender, assuming TNBI respondents are in heterosexual partnerships) and explained how medical providers often have no or limited knowledge of providing care for SGM patient populations. Respondents expressed their frustration as TNBI patients when medical providers would use normative assumptions to drive their medical decision-making when providing reproductive and sexual health services, especially if respondents had experienced childbirth.

For example, Dominique, a Black, middle-class, intersex, bisexual, transgender adult, described her negative experience with accessing sexual health resources to better manage her chronic health condition:

> I had to go to the doctor for contraceptives… [W]hen I went to the doctor… He was like, "Have you decided what you want to be [referring to SGM identities]? How will you tell your kids about yourself? And what about contraceptives? You're no longer going to see men. So why do you need them?" So, they were peppering me with questions and the fact that I had decided to go for birth control methods, which means I should just decide to be with a man or a woman. But these talks were like, "Why do need them? You decided you're going to be with a woman, so why do you need them? So?" I don't know. I think that experience overall was bad.

Dominique shared her experience of facing difficulty with accessing sexual health resources after disclosing her SGM identity to her medical provider during her previous visit. Much like the reluctance of Dominique's medical provider to provide sexual health resources to Dominique due to her SGM status, most respondents expressed how medical providers may draw upon normative assumptions of sex, gender, and sexuality to inform their medical decision-making process.

As Dominique's experience reveals, some medical providers may assume TNBI people do not need reproductive and sexual health services because they are in "same-sex" partnerships. Instead of simply offering sexual health resources, Dominique's doctor asked medically inappropriate questions about her spouse and children to further discourage Dominique from receiving such sexual health resources. Such a lack of SGM-competency highlights the limited medical knowledge and decision-making around providing quality health services and resources for SGM patients in reproductive and sexual healthcare settings. Structural competency training would pinpoint and address how structural forces (e.g., heteronormativity, cisnormativity, and endonormativity in medicine) shaped Dominique's interaction with her medical provider that influenced gaps in her healthcare (Donald et al. 2017). This instance of structural incompetency via medical provide ignorance operates as a source of minority stress.

Jessie, a white, upper-middle-class, intersex, asexual, blended-gender adult described her experience with disclosing her intersex status to medical assistants at her gynecological care office. Jessie explained how the clinical encounter unfolded and her reaction to the medical provider's ignorance of intersex variations.

> [I]t was interesting when I went to see my gynecologist and her two assistants came in beforehand to, you know, do the… "What are you here for?" And I said, "I'm here for, you know, an overdue checkup, etc." And I said, "And I wanted her to know that I'm intersex." And the girl [medical assistant] was writing, she kind of stopped. She looked at me [and] said, "What is that?" And I thought, "Whoa! Whoa! Whoa! Somebody working in a gynecologist office doesn't know what intersex is." And most people don't, you know that.

Jessie's experience highlights the structural erasure that intersex patients face in US healthcare systems and interactions. As Jessie acknowledged, many people – including medical providers – do not have even basic knowledge about intersex populations. It was especially concerning for Jessie that a medical assistant who helps provide reproductive and sexual health services did not have the medical knowledge and training to understand Jessie's health needs as an intersex patient. Jessie's healthcare interaction further demonstrates how medical provider ignorance impacts the reproductive and sexual healthcare experiences of TNBI people.

In similar situations, all intersex respondents in my research sample reported instances of medical provider ignorance of intersex people and bodies (e.g., not knowing what intersex variations are) within reproductive and sexual healthcare settings. Some intersex respondents described how medical providers pressured them to undergo unnecessary, medical interventions (e.g., hormone therapy treatments, intersex surgeries) in order to "normalize" their bodies within an endosex female/male binary. Other intersex respondents explained how medical providers ridiculed them when disclosing fears and anxieties surrounding clinical interactions and procedures due to intersex-specific medical trauma (e.g., intersex surgeries during childhood). These narratives are especially problematic because many of respondents' intersex-specific healthcare needs are interrelated with their reproductive and sexual health. Medical providers who lack intersex competency in their care practices reproduces structural gaps in intersex health and healthcare needs. Thus, medical providers' ignorance in providing SGM-competent care reproduces minority stress via structural erasure and discrimination against many SGM Americans who access and utilize reproductive and sexual health services but who are often called upon to shift from patient to medical educator in the clinical interaction.

Contemporary healthcare systems maintain medical provider ignorance of SGM patient populations and their care needs in the context of reproductive and sexual health services, a subfield in medicine that needs to be SGM-competent due to the high demand for reproductive and sexual health care among SGM communities. Normalization of heterosexual, cisgender, and endosex bodies and experiences in US society reproduces a fundamental social problem in which American medical professionals often know very little about SGM patients and consequently fail to maintain SGM structural competency by reproducing healthcare spaces that are inaccessible, ineffective, and exclusive towards SGM patients in making sure their basic care needs are fully met (Davis 2015; Metzl and Hansen 2014; shuster 2021). This social problem of reproducing structural incompetency of SGM patient populations in American medicine is especially problematic because SGM patients' care is automatically directed toward sexual and reproductive healthcare providers—making these providers frontline practitioners for working with SGM populations (Downey and Gómez 2018; Spurlin 2019). Thus, understanding the particular barriers to care that SGM older adults may face (e.g., poor educational/instructional curriculum and practicum on SGM health, lack of understanding of SGM embodiment, lack of standards of care) would reflect more structurally-competent approaches in reproductive and sexual healthcare settings. Further intervention on actively incorporating medical provider education and training on SGM and TNBI health and healthcare needs via structural competency training, while addressing medical providers' preexisting biases of SGM patient populations, may reduce the gaps in SGM and TNBI affirming reproductive and sexual healthcare (Downey and Gómez 2018; Lampe and Nowakowski 2021).

Lack of age-friendliness

Researchers have called for greater recognition in providing reproductive and sexual healthcare screenings, treatment, and resources for older patient populations (Granville and Pregler 2018; Nowakowski and Sumerau 2019b). In my research sample, about half of the respondents explained how medical facilities and providers operate with ageist assumptions of respondents not needing reproductive and sexual health services, such as STI screenings or Pap tests. This pattern primarily stems from normative misconceptions in US society that older people are not sexually active and/or completely abstinent from sexual activities.

When I asked him if there is anything medical providers should do to provide better sexual healthcare for transgender people, Amari, a Black, middle-class, intersex, lesbian, transgender man explained:

> I think there is an emphasis with trans young people getting all the [sexual health] services. I'm not complaining but it seems that doctors don't understand that we age. We grow older. We also have lots of sex. Like a lot of it. [laughs] We sag

> and get wrinkles… I just want a doctor who will at least ask about it [sexual health needs, services, and resources].

Amari emphasized the lack of age-friendliness and inclusion in reproductive and sexual healthcare settings, with sexual health screenings, treatment, and resources targeted at younger transgender people. Amari's feelings of being excluded from accessing and utilizing sexual health services due to medical providers' assumptions of Amari as an older adult stem from minority stressors of intersecting forms of SGM-related and age-related stigma and invisibility within US healthcare systems. To maintain structural competency (Donald et al. 2017; Metzl and Hansen 2014), SGM older adults should have full access to sexual health education, services, and resources via clinical encounters, regardless of older age and SGM identities.

While many respondents utilized reproductive and sexual health services in older adulthood, some expressed that they experienced structural or interactional ageism in reproductive and sexual healthcare environments (e.g., medical providers speaking too loudly to respondents, staff assuming that respondents are waiting for their younger family members in the lobby areas). Mary, a white, middle-class, endosex, lesbian, transgender woman recollected her experience of seeking out sexual health resources:

> A year after my divorce was finalized, I was finally ready to start dating again and potentially be intimate with someone, someone who loves me for me. When I shared this information with a sexual health counselor at [SGM health clinic], they… they didn't take me seriously—that someone my age wanted to be sexually active again and seeking out resources to have sex safely... I also think they thought I was gross not only because of my age but because of my weight. This

> "medical professional" was more concerned about me losing weight and me being old and horny than giving me the resources I needed. My self-confidence was shit for a while after that.

Mary's experience highlights intersecting forms of ageism and fatphobia that were apparent in the sexual health communication with their sexual health counselor at an SGM health clinic. Mary sought out sexual health resources at this SGM health clinic because she thought their services would fulfill her sexual health and care needs. Despite this SGM health clinic being SGM-competent, the sexual health counselor did not initially offer the resources Mary needed because of her age and weight. Mary acknowledging that this sexual healthcare experience diminished her self-confidence is an example of how medical provider ignorance in the context of age-friendliness can occur in SGM-specific healthcare settings.

Similarly, Ms. Ali, a Black, low income, endosex, gay, Two-Spirit adult, explained her experience with a case manager at an SGM-friendly sexual health clinic:

> [W]hen she [case manager] had to do a sexual history on me… I said, "Yes, I am the receiver. Always." And it seemed to me that she was surprised, and I asked her, "Why did you get this assumption that I… was asexual?" I love sex just like anybody else. But it could have been… it could have been my age. It could have been my demeanor. But I told her at that point, "You should never make an assumption."… It was kind of a teaching moment for her.

Indeed, a major barrier to seeking and utilizing services at SGM-specific health centers that older TNBI respondents reported in my research sample was frequent exclusion and stigma of older SGM people within these settings. This social pattern emphasizes the importance of maintaining age-inclusive reproductive and sexual healthcare settings, regardless of whether they are tailored to serve SGM communities.

Even when visiting age-friendly reproductive and sexual healthcare providers, some respondents struggled to obtain medical information concerning information about potential reproductive and sexual health impacts in older adulthood of receiving TNBI-specific health services (e.g., intersex surgeries, gender-affirmation surgeries, hormone therapies). Petra, a white, low income, intersex, heterosexual, cisgender woman explained her experience with seeking access to intersex-specific health information:

> I had breast cancer and they [breasts] were removed... And the plastic surgeon asked me if I wanted an operation to fix me down there [so I] could look more female. And it still didn't bother me that, you know, it's something that I just like. "Okay, why not?" … But no one would tell me or actually had a clue how many female [sexual health] problems I would have later in my life, like right now…

Petra underwent intersex surgery as a mid-life adult and consequently manages many sexual health challenges throughout older adulthood. Similarly related to Petra's experience, all intersex respondents self-reported experiencing reproductive and/or sexual health issues in older adulthood, while be offered no or only limited information about these issues and their relationship to earlier medical interventions. Lack of information possessed by healthcare providers and then conveyed to their patients concerning the reproductive and sexual health of TNBI older adults highlights the structural ageism that many TNBI older adults must navigate in US healthcare systems. In what follows, I explore what approaches TNBI older respondents use to combat medical provider ignorance when accessing and/or utilizing reproductive and sexual health services. I find that TNBI respondents practiced resourcefulness or using resourceful strategies – rather than resilience – when successfully coping with medical provider ignorance within reproductive and sexual healthcare settings.

2.8 LIMITATIONS OF RESILIENCY

Respondents responded to minority stress via medical provider ignorance within reproductive and sexual healthcare settings by (i) opting out or avoiding medical providers and settings and (ii) seeking out SGM-competent care. Specifically, I found a bifurcation in respondents' narratives with most trans men respondents opting out of receiving sexual and reproductive health services when navigating medical provider ignorance, while trans women and non-binary respondents sought out SGM-competent care. As such, there were differences among these chosen strategies concerning gender identity/expression. Echoing findings from Derickson (2019), which focused on the structural limitations of using resiliency as a theoretical perspective, I find that TNBI older respondents engaged in resourceful strategies – rather than resiliency - when navigating challenges in accessing and utilizing reproductive and sexual health services.

Resourcefulness, or implementing resourceful strategies, is a tactical process in which socially and medically vulnerable communities obtain and use resources (e.g., access to reliable, social support) to improve their social and health challenges. Resourcefulness is different from resiliency because it requires SGM people to have social privilege, capital, and resources to overcome difficult situations, rather than successfully coping strategies alone. Resourcefulness is more accurate to the reproductive and sexual healthcare experiences of TNBI older respondents, in comparison to resiliency. Specifically, resourcefulness is a more accurate descriptor of the processes occurring among respondents than resiliency due to respondents' access and use of resources when navigating reproductive and sexual healthcare settings. However, these approaches all require respondents to expend emotional labor and resourcefully assume both individual and primary responsibility for receipt of quality healthcare. Unfortunately, their resourcefulness cannot structurally reduce or eliminate reproductive and sexual health and healthcare disparities for TNBI communities.

Opting out of receiving health services

Almost all transgender men respondents reported opting out of receiving healthcare from reproductive and sexual healthcare settings when being asked about their reproductive and sexual healthcare experiences and interactions with medical providers. Some trans men respondents described their significant discomfort and vulnerability being in reproductive and sexual health centers that are women-centric or normatively feminine (e.g., pink décor in patient exam rooms and waiting areas, only women's restrooms in patient lobby areas, advertisements that show only models with feminine gender expressions). For example, Kojo, a Black, middle-class, endosex, bisexual, transgender man explained, "I just don't feel comfortable being in that sort of space. Being women-focused… It's unnecessary."

Similarly, Antonio, a Latino, low income, intersex, gay, transgender man elaborated on his feelings with accessing mammography:

> When I go to a reproductive center, God, it's all pink and there are women everywhere. They are on the brochures. They are in the offices or waiting in the lobby. And they would stare at me or mock me. The treatment [screening mammogram services], I should just say, should be slightly different with the treatment and the more potentially gender-neutral… Or even a wing for men… I

> want to avoid any psychological, emotional, or mental issues that would come along with those spaces.

Antonio’s narrative highlights the implications of hyper-feminized healthcare settings that some transgender men respondents actively avoid to further protect their mental health and well-being. Antonio explained how “there are women everywhere” in reproductive healthcare settings, which made him feel excluded and vulnerable as a transgender man seeking screening mammogram services because of his familial history with chest cancer (i.e., breast cancer). Such strategy of avoidance demonstrates resourcefulness of assuming individual responsibility opting out of reproductive health services, while having the option of using these services if warranted. Although such resourceful strategies may endanger their physical health, trans men respondents opting out or avoiding reproductive and sexual care settings are instances of resourcefulness that serves to preserve their mental health, wellbeing, and masculine selfhood.

Healthcare systems that disallow gender diversity and inclusion reproduce healthcare inequities for those whose experiences and bodies do not meet normative assumptions of sex and gender in US society. In such environments, many transgender men respondents avoid or opt out of receiving reproductive and sexual healthcare services, which places their reproductive and sexual health at risk through not obtaining necessary preventative screenings, treatments, and resources. At the same time, it allows transgender men respondents to resourcefully assume primary responsibility of their own receipt of reproductive and sexual healthcare.

Some transgender men respondents also felt that they did not need to access reproductive and sexual health services in older adulthood. When I asked James, a white, middle-class, endosex, queer, transgender man, about whether he has ever used reproductive or sexual health services since medically transitioning as a transgender man, he explained:

> Part of the process [medical transitioning], one of the hoops that I had to jump through was getting a mammogram, getting a Pap smear, going through… that whole set of things. But once that's done, you know, I'm old enough that I don't really have to go through that anymore. And I sort of check-in about my sex life once in a while with my primary health doc, but... It's really not relevant...

Others even asked to skip the reproductive/sexual healthcare experience question completely in their interviews due to their uneasiness with the topic. After asking if it was okay to ask about his reproductive and sexual healthcare experiences, Rémy a Black, lower-middle-class, intersex, bisexual, transgender man replied: "Yeah, I feel I'm uncomfortable talking about it."

Much like Rémy's decision to avoid discussing his reproductive and sexual healthcare experiences, other transgender men respondents actively avoided discussing this interview topic, which may be connected with the hyper-feminization of many reproductive and sexual healthcare environments. Other decisions to avoid utilizing reproductive and sexual health services stemmed from prior negative experiences with medical providers and staff. When asked about prior care experiences within reproductive and sexual healthcare settings, Ralph, a white, working-class, endosex, gay, transgender man, responded: "I did one time, she [medical provider] was so judgmental so I had to shun that, [I] am not planning to see any[one] in [the] future otherwise." Ralph plans on not seeking reproductive or sexual health services for himself in the future due to a negative experience interacting with a reproductive/sexual healthcare provider.

Although the majority of TNBI respondents in my research sample – regardless of their gender identity/expression – regularly receive reproductive and sexual health services, almost all transgender men respondents reported refraining from accessing and utilizing such services. Especially since trans men may need (i) breast/chest cancer risk assessment and screenings (Pivo et al. 2017), (ii) cervical, endometrial, and uterine cancer screenings (Patel et al. 2019), (iv) rectal and anal cancer screenings (Ceres et al. 2018), and (v) STI screenings (Cottrell 2020) due to heightened risk within transgender communities, such resourceful strategy widens the reproduction of health and healthcare inequalities among transgender men. Although opting out or avoiding reproductive and sexual healthcare does not acquire tangible resources per say, such strategies demonstrate resourcefulness by taking over both individual and primary responsibility for eliminating clinical encounters that make transgender men uncomfortable or vulnerable, an example of masculine behavior and socialization. Intervention research and clinical practice is needed to enhance TNBI older adult structural competency within reproductive and sexual healthcare systems.

Seeking out SGM-competent care

There is a bifurcation in respondents' narratives with most trans men respondents opting out of receiving sexual and reproductive health services when navigating medical provider ignorance, while trans women and non-binary respondents sought out SGM-competent care. Most transgender women and non-binary respondents in my research sample reported seeking out SGM-competent care services and resources after receiving poor quality, discriminatory, and/or mediocre concerning reproductive and sexual healthcare. In such cases, these instances were especially related to medical providers not being equipped to offer quality STI screening and prevention services. Ms. Ali explained how her medical provider initially disclosed her HIV+ status in an unethical manner:

> [H]e [doctor] went through everything as far as my labs and everything. And then he says, “Oh yeah, by the way, you tested positive for the [HIV] virus... But it's not a lot of people that's going to do what I did. I told him, I said, “You know what? You didn’t have anybody on your staff to counsel me or whatever. You didn’t know how I would be digesting this information that could have led… [to] an overdose of pills. I could of jumped into the [river]. You, as a doctor, I think you need to get yourself educated and if you don’t feel comfortable in letting people know, you know, this information, you need to get somebody on staff [who is].”

After following up with Ms. Ali about how she felt after that news and how poorly that clinical interaction went, she responded:

> I had already been tied to HIV organizations and I had already shared with a prevention individual that I had… an HIV test. You know, and he had mentioned to me, “Well, how are you gonna handle that if it [HIV test] comes back positive?” Well, you know, I didn’t know how… You know, there was really no answer to that question… I don’t know. But that day when he [doctor] told me then [HIV positive status]…. I remember crying in the office. I mean I left his office and I cried. And then immediately I got on the phone and called the [HIV] prevention individual. And he [HIV counselor] told me at that point, he said “You

> know, it's not the end of the world. You will survive, you know, you will survive. And here I am. [chuckles] You know, I'm surviving.

Ms. Ali's narrative emphasizes the importance of obtaining SGM-competent care services (e.g., HIV prevention and care hotline) as a resourceful way to mitigate negative reproductive and sexual healthcare experiences. In this case, a medical provider failed to appropriately empathize and provide counsel to Ms. Ali after disclosing her HIV+ test result and did not provide her with any HIV/AIDS care resources. Ms. Ali utilized HIV care resources she knew of through SGM friends and community members involved in HIV care advocacy organizations, while shifting the primary responsibility of accessing quality healthcare to herself. Such as Ms. Ali's experience, seeking and obtaining SGM-competent care resources when navigating negative, mediocre, or traumatic healthcare experiences allowed trans women respondents to improve their social conditions within reproductive and sexual healthcare settings.

Unlike the transgender men respondents in my research sample, many trans women respondents did seek out patient exams and screenings within reproductive and sexual healthcare settings. Some transgender women respondents reported feeling affirmed in their womanhood and femininity in such care environments. Darlene, a white, upper-middle-class, endosex, lesbian, transgender woman explained how she sought out a trans-friendly medical provider for screening mammogram services:

> …I went to them [obstetrician-gynecologist] and asked, I said, "You know, I want to go someplace that is trans-friendly because I don't just want to go into any old radiologist's office with this prescription and, and have to potentially run into any problems." So, they, they recommended the cancer center at the hospital, where

> the LGBTQ center is also located. And they were wonderful. Actually, the same technician took care of me both times and she was great. She was very affirming. You know, one of her comments was, you know, "Welcome to our world, the world of women." In terms of, you know, because the first time I had a mammogram, I didn't know what to expect.

Darlene successfully found a trans-competent medical provider for screening mammogram services through a referral from their obstetrician-gynecologist. Darlene demonstrated resourcefulness by assuming individual and primary responsibility for selecting and receiving care from a trans-friendly medical provider, while having the financial and referral resources to have access to quality mammogram services.

Many trans women respondents, like Darlene, described how important it was for them to seek out SGM-competent reproductive and sexual health services, which required a lot of their time, emotional labor, and tapping into existing social networks. Such process constitutes resourcefulness through socioeconomic privilege and engagement of gendered expectations of self-caregiving and care work. Thus, non-binary and transgender women respondents actively sought out SGM-competent reproductive and sexual healthcare to prevent or reduce their chances of experiencing felt stigma in the context of healthcare interactions. This approach, however, did not stem from resiliency but, instead, required non-binary and transgender women respondents to resourcefully draw upon their existing medical resources and support to ensure that their reproductive and sexual health needs are fully met. Resourcefulness does not, however, structurally eliminate or reduce SGM health and aging disparities.

2.9 DISCUSSION

Advancing the conceptualization of minority stress and resilience (Hash and Rogers 2013; Meyer 2003, 2015), I examine how TNBI older adults – as a medically and socially vulnerable sub-group within SGM communities – perceive, access, and utilize reproductive and sexual health services through resourcefulness. Specifically, most respondents described medical provider ignorance in providing (i) SGM-competent and (ii) age-friendly care in reproductive and sexual healthcare settings. Additionally, TNBI respondents responded to medical provider ignorance within reproductive and sexual healthcare settings through resourcefulness. Specifically, I found a bifurcation in respondents' narratives in using resourceful strategies to combat medical provider ignorance with (i) trans men respondents opting out of receiving sexual and reproductive health services and (ii) trans women and non-binary respondents seeking out SGM-competent care providers, services, and resources.

Although such resourceful strategies may endanger their physical health, trans men respondents opting out or avoiding reproductive and sexual healthcare settings are often working to preserve their mental health, wellbeing, and masculine selfhood. Differing from trans men respondents' experiences, trans women and non-binary respondents actively sought out SGM-competent care on their own or through medical referrals, while using resourcefulness via financial resources, emotional labor, and care work. Such resourceful strategies differed by respondents' gender identities, expressions, and socialization within reproductive and sexual healthcare settings. However, these strategies require TNBI respondents to assume individual and primary responsibility for receipt of quality reproductive and sexual healthcare or to assume the potential personal health costs of opting out of sexual and reproductive healthcare entirely in service of their mental health. Such approaches are neither individually nor structurally sustainable for maintaining SGM-affirming and age-friendly care for older TNBI Americans as a health disparity population.

My findings underscore the importance of maintaining SGM-competency and age-friendliness within reproductive and sexual healthcare systems and interactions, while addressing how TNBI older adults engage in resourceful strategies to further protect their health and well-being when navigating reproductive and sexual healthcare settings. Although some TNBI older respondents reported satisfying reproductive and sexual healthcare experiences, many respondents described minority stressors in the forms of SGM and older age stigma. Whereas older trans women and non-binary respondents sought out SGM-competent care to fulfill their reproductive and sexual healthcare needs, older trans men respondents resourcefully avoided reproductive and sexual healthcare settings to protect their mental health, wellbeing, and masculine selfhood. Although aging research on TNBI older populations has increased in recent years (see e.g., (Ducheny et al. 2019; Latham and Barrett 2015; Porter et al. 2016)), there remains limited focus on how older age bias and ageism can influence minority stress among SGM older adults in reproductive and sexual healthcare settings.

Future research should aim to address the reproductive and sexual healthcare needs and care gaps of TNBI adults by tailoring medical education and health intervention efforts to focus on those from older, racial and ethnic minority, and financially disadvantaged communities. Existing sociological research shows that researchers increasingly recognize that healthcare inequalities are shaped by interlocking systems of oppression and privilege, especially in relation to race, class, and gender (Bowleg 2012; Brown, Mitchell, and Ailshire 2020; Crenshaw 1989). However, there is very limited research that comprehensively addresses how SGM older adults of color, low-income and working-class SGM older adults, and SGM older adults living with chronic health conditions access and experience health services, particularly those targeting sexual and reproductive health (Nowakowski et al. 2019). To date, current SGM health research on TNBI older adults with these identities, backgrounds, and experiences is even more scant.

At the same time, TNBI older respondents' narratives illustrate social patterns of structural stigma and erasure in reproductive and sexual healthcare settings. I further extend existing scholarship on TNBI reproductive and sexual healthcare experience by articulating how older TNBI adults navigate minority stress in care settings and engage in resourceful strategies to mitigate the impact of experiencing inadequate, poor, or no treatment from reproductive and sexual healthcare systems. This research investigation begins to fill both empirical research gaps on TNBI aged care in the context of sexual and reproductive healthcare. Such findings may also be utilized to inform future directions for medical education development and focus to improve TNBI older adult structural competency within medical settings so that TNBI older patients can have greater likelihoods of receiving quality, effective care that addresses the actual sources of their health disparities.

CHAPTER 3: SATISFICING IN AGING AND DEATH: THE ADVANCE CARE PLANNING EXPERIENCES OF TRANSGENDER, NON-BINARY, AND INTERSEX OLDER ADULTS

3.1 INTRODUCTION

Emerging research examines the impact of social inequalities in death and dying perceptions and experiences (Abramson 2015; Cain and McCleskey 2019; Livne 2019; Thomeer et al. 2017). These studies find that broader social and health inequities influence existing death and dying perceptions and experiences among underserved populations in healthcare (Abramson 2015; Cain and McCleskey 2019; Pirtle 2020). For example, Pirtle (2020) demonstrates how the overrepresentation in mortality among Black Americans, or the *death gap*, is a result of structural violence (Ansell 2017) and created through a racial capitalist system (Robinson 1983). Such inequities fundamentally shape how socially and medically disadvantaged populations perceive, prepare for, and experience death. Further investigation is needed on how existing social and medical conditions (e.g., uninsured or underinsured status) function as powerful systems of medicalized knowledge and control, while reproducing uncertainty in perceiving, preparing for, and experiencing death for underserved aging communities, such as sexual and gender minority (SGM) older populations. Such process reinforces the need for SGM older adult structural competency in medical education, training, and practice so TNBI older patients can have greater likelihoods of receiving quality, effective care that addresses the structural sources of their health and healthcare disparities.

In the United States (US), social constructions of what it means to die well are collectively referred to in interdisciplinary medical scholarship as *a good death*. A good death involves a set of conditions during the dying process that allows an individual to gain awareness, acceptance, and preparation for death, such as dying at home, pain control, or being surrounded by loved ones (McNamara, Waddell, and Colvin 1995), whereas *a bad death* is having no or limited awareness, control, or preparation for death, such as a painful dying experience all alone (Lang, Frankus, and Heimerl 2022). Using a good death perspective, I examine how transgender, non-binary, and/or intersex (TNBI) older adults – as a medically and socially vulnerable sub-group within SGM communities – perceive and plan for end-of-life experiences in the context of advance care planning. Utilizing data from 50 semi-structured individual interviews with TNBI older Americans (65 years and over), I demonstrate how social and medical conditions endured by SGM communities (e.g., SGM-incompetent long-term care services) reinforce uncertainty for a good death among TNBI older adults. My conceptualization of satisficing, through the social contexts of aging and death, explains how TNBI older adults' perspectives exemplify the systematic limitations of aging and end-of-life preparation among SGM communities and the need to develop structurally competent care practices. Specifically, I offer the conceptualization of satisficing around death to describe the process of being relatively unable to assure a good death, so actively working to prevent a bad death using the process of resourcefulness, a tactical process in which socially and medically vulnerable communities obtain and use resources (e.g., access to reliable, social support) to improve their social and health challenges.

3.2 A GOOD DEATH

Sociologists have demonstrated how death and dying are intertwined biological and social processes shaped by and through social authorities and institutions (Broom 2016; Conrad and Barker 2010; Seale 1998). For example, structural competency gaps in end-of-life care settings may negatively shape medical providers' assumptions of how patients from socially and medically underserved communities (e.g., Black and Hispanic/Latinx populations, SGM populations) perceive their death and dying experiences (Cain and McCleskey 2019; Metzl and Hansen 2014). Death and dying have also become increasingly medicalized processes over time (Conrad 2007). Before the twentieth century, death and dying experiences were managed in a less medicalized context until the establishment of medical authority through the Enlightenment period in the 18th century (Conrad 2007; Karsoho et al. 2016). Broom (2015:6) contends that "dying from medical illness was gradually transformed over the twentieth century into a medical challenge, not just an existential moment," while medical authorities establish medical expertise and control over the dying process.

Glaser and Strauss (1965:29) found that American physicians were reluctant to disclose impending death to their patients and nurses were not allowed to disclose information without the consent of physicians, a state termed as "closed awareness of dying." Glaser and Strauss' (1965) case study is an example of the broader social process that Becker (1973) explains as the experience of death being socially invisible. Zimmermann and Rodin (2004:121) have noted that contemporary Western societies are death-denying, reflecting what sociologists have termed the “denial of death thesis” – believing that death is something to be resisted, postponed, or avoided. End-of-life care movements have encouraged medical providers to utilize a more open, transparent, and liberatory approach to providing ethical care to patients living with terminal illness or dying (Glaser and Strauss 1965; Livne 2019; Zimmermann and Rodin 2004).

Cultural perspectives of what it means to live and die well vary by existing social and medical conditions among aging communities (Cain and McCleskey 2019). What makes a death better or worse is conceptualized in interdisciplinary medical scholarship using a binary frame of “good’ versus “bad” (Seale and van der Geest 2004). The Institute of Medicine (1997:1) defines a good death as dying “free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards.” Accordingly, traditional care customs (such as access to traditional knowledge and healing practices in medical facilities) can better support a good death among Indigenous communities (Institute of Medicine (US) Committee on Care at the End of Life, Field, and Cassel 1997; Moeke-Maxwell et al. 2020).

But a good death varies across aging communities and is influenced by broader patterns of inequity. As Cain (2021:2) notes, “what is considered a good death is patterned by institutional and generational experiences of inequality,” meaning how underserved communities in healthcare conceptualize what a good death means is influenced by how their end-of-life experiences are exacerbated by cumulative disadvantage in social and health inequities. Many people from socially and medically underserved communities do not have the privilege of gaining agency over their dying preferences and process (Cain 2021; Cain and McCleskey 2019). Having no or limited awareness of, control over, and preparation for death constitutes a bad death (Lang et al. 2022). Future research must move beyond binary good/bad death perspectives to better understand the social processes of death and dying among socially and medically disadvantaged communities (see Cain and McCleskey 2019; Lang et al. 2022 as case examples). TNBI older adults, for example, may not be able to realistically achieve a good death in a society that systematically erases, marginalizes, and neglects TNBI lives. In such cases, I offer the conceptualization of *satisficing around death* to describe the process of being relatively unable to assure a good death, so actively working to prevent a bad death using the process of resourcefulness, a tactical process in which socially and medically vulnerable communities obtain and use resources (e.g., access to reliable, social support) to improve their social and health challenges.

3.3 SGM AGED CARE

An estimated 2.7 million SGM adults 50+ reside in the US (Fredriksen-Goldsen and Kim 2017). Despite the increased social acceptance of SGM communities, older SGM Americans continue to experience aging and end-of-life disparities (Allen and Lavender□Stott 2020; Arthur 2015; Fredriksen-Goldsen et al. 2013) with limited access to SGM-competent health and peer support services (Nowakowski et al. 2019). Due to SGM-related stigma and limited medical training on SGM aged care (Obedin-Maliver et al. 2011), SGM older adults are at risk for their healthcare wishes to be disregarded by their families or medical providers (Candrian and Cloyes 2021). SGM older adults face substantial challenges with preparation for end-of-life experiences, such as SGM-incompetent medical care (de Vries et al. 2019), social isolation and poverty (Valenti et al. 2020), social rejection from family and friends (Stinchcombe et al. 2017), and barriers to maintaining SGM identity and selfhood in residential aged care facilities (Wilson, Kortes-Miller, and Stinchcombe 2018).

SGM patients also face barriers in accessing and utilizing quality healthcare in older adulthood (Nowakowski, Sumerau, and Lampe 2020). Most medical facilities are ill-equipped to identify and address older SGM patients' care needs (Hash and Rogers 2017). Examples include medical providers making inaccurate or insensitive assumptions about SGM patients' biographies, experiences, and bodies (Candrian and Cloyes 2021). SGM older adults may have a heightened need to formally appoint a healthcare power of attorney to protect their medical and legal wishes (e.g., a dying, SGM patient having their partner by their bedside) (Dickson et al. 2021). However, many SGM older adults do not have an appointed healthcare power of attorney due to financial and logistical barriers to advance care planning (Candrian and Cloyes 2021). Further, SGM older adults may need tailored community engagement for formalizing their advance care planning documents (Dickson et al. 2021) due to the lack of supportive and reliable family members whom they believe will make decisions with their best interests in mind (Allen and Lavender□Stott 2020). Such factors contribute to SGM aging and end-of-life disparities.

Interdisciplinary medical scholarship on chronic (Nowakowski et al. 2019), long-term (Caceres et al. 2020), palliative (Valenti et al. 2020), and end-of-life (Stinchcombe et al. 2017) care among SGM communities mainly consists of literature reviews. Although such reviews are helpful for the synthesis of existing research, further empirical investigation into SGM aged care needs, issues, and barriers is needed using primary data from SGM older patients and their family care partners. Prior research, for example, addresses how safe residential environments (Kortes-Miller et al. 2018), familial support (Allen and Lavender□Stott 2020), and technology access and use (Mock et al. 2020) may enhance aged care and support services for SGM older adults. Advances in public policy, such as the 2015 US Supreme Court ruling of *Obergefell v. Hodges,* which legalized marriage equality (for people in dyadic partnerships) in the US, could also enhance legal protections for SGM couples and families in preparation for end-of-life experiences (Candrian and Cloyes 2021).

There is a critical need to understand how SGM older adults engage and strategize end-of-life preparation while identifying aged care needs, issues, and barriers for SGM patient populations. For example, Thomeer and colleagues (2017:473) explain that despite sexual minority spouses "devot[ing] considerable attention to informal and formal end-of-life planning," sexual minority couples may not necessarily have better deaths than heterosexual couples. In other words, like those from other socially and medically disadvantaged communities, sexual minority people often do not have the privilege of gaining full control and choice over their dying experiences (Thomeer et al. 2017).

3.4 TNBI OLDER ADULTHOOD

An estimated 217,050 transgender adults 65+ reside in the US (Flores et al. 2016). As a medically and socially vulnerable sub-group within SGM communities, TNBI older adults have distinct healthcare access needs related to managing chronic illness (Nowakowski et al. 2019), long-term care (Caceres et al. 2020; Ing et al. 2018), and end-of-life care (Stinchcombe et al. 2017). The majority of transgender respondents 55+ from the Transgender MetLife Survey (n=1,963) reported feeling ill-prepared to navigate aging and end-of-life experiences, particularly preparing and formalizing advance directive documents for future use in medical settings. Some transgender older respondents also noted that they would rather choose suicide than experience transphobic discrimination in long-term care settings (Witten 2014). Additionally, special consideration should be given to TNBI older residents' advance care planning challenges such as (i) residential aged care staff refusing to refer to TNB residents by their chosen name or pronouns, (ii) family members refusing to accept healthcare power of attorney status, and (iii) residential aged care staff denying medical treatment and services (Arthur 2015).

Despite progress in providing SGM-competent care to TNBI older adults (Porter et al. 2016), there remains a lack of internationally and US recognized standards of care for older TNBI patients in palliative and hospice care settings (Stevens and Abrahm 2019). Comprehensive medical guidelines and standards of care for providing end-of-life care to TNBI older patients are important since TNBI people experience substantial aging and end-of-life inequities (Stinchcombe et al. 2017). Examples include managing chronic illness and disability (Witten 2014), experiencing poor overall physical and mental health outcomes (Fredriksen-Goldsen, Cook-Daniels, et al. 2014), and navigating barriers with end-of-life care planning (Henry et al. 2020). In the US, transgender Medicare beneficiaries also have higher rates of chronic disease burden, regardless of Medicare status, compared to cisgender Medicare beneficiaries (Dragon et al. 2017). These distinct needs highlight the multifaceted challenges TNBI people may face in older adulthood.

Sociological research primarily focuses on TNBI general adult populations or adolescent and young people (Sumerau and Mathers 2019), while remaining substantially limited in investigating how older age and adulthood impact TNBI people's navigation of cisgender (not transgender) interactions, settings, and institutions (shuster 2021). Older

TNBI people may have greater gaps in obtaining health services, resources, and forms of support, compared to their younger peers, due to increasing health and peer support needs (Ing et al. 2018). Despite an estimated 1.2 million non-binary SGM adults ages 18-60 residing in the US (Wilson and Meyer 2021), research on non-binary people's experiences managing aging and end-of-life needs is almost non-existent in the interdisciplinary medical sciences. To date, there are no population-based studies that report the estimated number of older TNBI adults residing in the US.[6] Research on older TNBI people's experiences managing aging and end-of-life needs is severely limited in the interdisciplinary medical sciences (Latham and Barrett 2015; Rosenwohl-Mack et al. 2020). Further investigation on how TNBI older adults perceive, plan, and experience end-of-life milestones is especially needed.

In terms of end-of-life experiences for TNBI people, a particular trope predominates: that, for TNBI people, death is most often both sudden and occurs early in the life course via suicide or homicide (Boyer et al. 2021). Because of disproportionately high rates of untimely death for TNBI people, especially among TNBI people of color, the aging process and natural death experiences of TNBI people are grossly under-researched and under-theorized (de Blok et al. 2021; Nowakowski, Sumerau, and Lampe 2020). Perceptions of social support and providers' SGM competency may help transgender people successfully meet their aging goals over the life course (Walker, Powers, and Witten 2017). Prior literature is not conclusive on how various social and

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[6] Blackless and colleagues (2020) estimate that about 1.7% of the general population have intersex variations.

medical conditions of TNBI older adults (e.g., prior mistreatment from medical providers) shape their perceptions and preparation for end-of-life experiences.

3.5 RATIONALE FOR THE PRESENT STUDY

While sociologists have examined perspectives of dominant good death definitions among underserved communities in healthcare (Cain and McCleskey 2019), there is much less empirical focus on bad death or the grey areas in between good and bad death. Examining this grey area between good and bad death among TNBI older Americans can further advance sociological research on possibilities for living and dying well among these understudied populations, address existing health and healthcare disparities among SGM older populations, and provide strategies for reducing or eliminating these disparities (Cain 2021).

The purpose of the present study is to analyze the current social, medical, and political state of TNBI older Americans by determining their unique needs for or barriers to advance care planning and end-of-life preparation. I ask the following research question: How do transgender, non-binary, and intersex older Americans perceive and plan for end-of-life experiences in the context of advance care planning? My research pinpoints what a good death might mean for older TNBI people, which is needed to begin to address existing aging disparities among SGM Americans. Such perspectives illuminate how existing social and medical conditions influence SGM older adults' perceptions of and experiences with end-of-life preparation, while assessing opportunities to incorporate structural competency for the purpose of advancing medical education and reducing older TNBI health and healthcare disparities (Donald et al. 2017; Metzl and Hansen 2014) by combating larger-scale social forces that drive barriers to care. Teasing apart and expanding conceptualization of good and bad deaths when examining SGM older adults’ perspectives is critically needed for enhancing SGM aged care and support services in the US.

3.6 DATA, METHOD, AND SAMPLE

Study eligibility and recruitment

This study was approved by the University of South Carolina Institutional Review Board (see Appendix A). Between September 2021 and January 2022, I conducted 50 semi-structured, individual interviews with TNBI older adults who reside in the US. I recruited TNBI older adults through social media, SGM and non-SGM health centers, aged care facilities, SGM-friendly faith communities, and SGM community leaders and organizations. Most respondents in my research sample did not have personal relationships with other TNBI adults 65 years of age or older. This meant that strategies traditionally used to recruit SGM research participants, such as purposive social network sampling (Pfeffer 2012) and snowball sampling strategies (Compton et al. 2018), were less effective in this qualitative study.

I recruited my research sample of TNBI older respondents by (a) being open about my TNBI identities during participant recruitment and answering any questions prospective research participants had about me or the study, (b) attending SGM-led community events and meetings (e.g., attending a faith worship service virtually and SGM lay leaders introducing me to faith community members before the start of worships service) to share more information about the study, (c) connecting with intersex activists in the US who shared the study information in private Facebook groups for intersex community members, and (d) connecting with SGM-friendly faith community clergy and lay leaders. Many non-SGM and SGM-led organizations, especially SGM-friendly faith communities, refrained from distributing my intersex participant recruitment flyers (located in Appendix C) but eagerly shared my TNB participant recruitment flyers (located in Appendix B) with their stakeholders through their social media accounts and programming. This hesitance to share research study information about intersex populations could be due to structural erasure, stigma, and discrimination of intersex experiences throughout US society.

Importantly, there are no large-scale or long-term quantitative health studies in the US that specifically examine the health management experiences of TNBI older adults. Thus, utilizing qualitative methodology was critical for me to employ in this research study to comprehensively examine TNBI health management in older adulthood. Eligibility included respondents who: (a) self-identified as transgender, non-binary, and/or intersex, (b) were 65 years of age or older at the time of the interview, (c) lived in the US at the time of the interview, and (d) consented to be audio-recorded during the interview (see Appendices E and F for participant demographics).

Instruments and interview procedure

I developed and pretested an interview guide with 3 TNBI older adults to ensure questions were insightful, affirming, and culturally appropriate (interview guide located in Appendix D). Due to participant safety concerns during the COVID-19 pandemic, I conducted 39 Zoom interviews and 11 telephone interviews during data collection. To fulfill respondents' accessibility needs, particularly for those who were hard of hearing, I offered automated closed captioning and lip-reading functionality for respondents who were interviewed through Zoom.

With ethics a key concern in research with a vulnerable aging population, I developed an interview instrument with the assistance of TNBI sociologists from Sociologists for Trans Justice (interview instrument located in Appendix D). I pretested the interview guide with 3TNBI adults to ensure that questions are insightful, sex and gender-affirming, and culturally appropriate. I approached respondents with questions concerning their (i) healthcare experiences, (ii) attitudes toward advance care planning, and (iii) health needs and management throughout each interview. This qualitative approach allowed me to build trust, comfort, and rapport with TNBI respondents. Each part of the interview contained several follow-ups or probes to ask for further information. I secured verbal consent from each participant before the start of each interview and before I asked about advance care planning experiences, which included various follow-up questions about aging and end-of-life perspectives in the context of advance care planning.

On average, interviews lasted 98 minutes (range: 30 to 346 minutes). Each TNBI older adult respondent received a $40 prepaid Mastercard debit card after completion of the interview to thank them for their time and contribution to the study. I audio-recorded interviews and used Nvivo transcription software to transcribe each interview. After the completion of each interview transcription, I fidelity checked each interview transcript to ensure accuracy, while making corrections as needed. I gave respondents pseudonyms and removed all identifying information during the fidelity checking process to ensure research participant confidentiality. I also wrote memos during qualitative data collection and analysis.

Researcher standpoint

My social standpoint as a white, non-Hispanic/Latinx, TNBI young adult living in the US Southeast certainly influenced my interview experiences with respondents. Many respondents expressed that they felt more comfortable with me interviewing them – as a TNBI interviewer – than they would be if a cisgender or endosex researcher interviewed them due to fear of negative or mediocre interview experiences (see also Sumerau and Mathers 2019). Despite me disclosing my sex and gender identities with respondents before each interview (as a TNBI person who was socially assigned female at birth), respondents perceived me as a cisgender woman, transgender man, or transgender woman in some cases (see also shuster 2021). My gender expression and respondents' assumptions about my sex and gender identities likely shaped our interactions. Additionally, my social location as a TNBI researcher residing in the US Southeast may have allowed some respondents who live in socially, politically, and/or religiously conservative areas to feel comfortable enough to be interviewed by me. My background as someone who grew up in a conservative, working-class household in the rural US Midwest also allowed me to connect with some respondents from rural and financially-disadvantaged backgrounds.

Although my social standpoints produced certain benefits in terms of recruitment, there were also limitations. First, my status as a young adult interviewer, at times, discounted my credibility as a TNBI aging researcher or made me a potential outsider (e.g., a respondent asked whether I was "old enough" to interview them) with some older respondents (see Charmaz 2014 for the importance of insider versus outsider perspectives in qualitative methodology). Second, recruiting and interviewing a racially and ethnically diverse sample for the study was limited due to my positionality as a white, non-Hispanic/Latinx interviewer. Having a skewed sample does not preclude qualitative researchers, however, from obtaining meaningful data on how racial, ethnic, and economic privilege shapes the reported experiences of research participants, regardless of sex and gender identity (Riggs et al. Forthcoming). Because TNBI people of color face multiple and intersecting forms of oppression and discrimination in the US (Buchanan and Ikuku 2022; Stryker 2017; Vidal-Ortiz 2009) and have experienced medical trauma at the hands of both researchers and clinicians (Karzakis 2008; Singh and McKleroy 2011; Sumerau and Mathers 2019), relying on SGM and SGM-friendly faith community leaders of color, as trusted community gatekeepers, was necessary for me to recruit and engage with TNBI respondents of color.

Data coding and analysis

My data analyses focused on how TNBI older Americans perceive and plan for end-of-life experiences in the context of advance care planning. I coded data using Nvivo (Release 1.6) software and analyzed inductively utilizing a constructivist grounded theory approach (Charmaz 2014). I engaged in initial or open coding, meaning I read a subset of transcripts to develop a general sense of the data and generated an initial list of codes. Subsequently, I engaged in focused or thematic coding, which involves the identification of coding overlaps and divergences, resulting in the combining and collapsing of open codes to form broader thematic codes/themes that are then placed in network relationships to one another. I also coded disconfirming evidence during the focused coding process. I then developed categories and themes from this coding scheme to discern emergent patterns and connections in the data. Finally, I engaged in axial coding, linking demographic attributes in the dataset (e.g., gender identity, socioeconomic status) to specific codes and themes, which provided information about particular patterns among and between various sub-groups of respondents.

Utilizing the analytic memos, recurring themes, and existing literature, I thematically analyzed these data while exploring emerging themes and codes concerning my research question: How do transgender, non-binary, and intersex older Americans perceive and plan for end-of-life experiences in the context of advance care planning? Data analysis revealed TNBI older adults' uncertainty of potentially experiencing a good death for themselves and their calculated strategies for reducing the possibility of experiencing a bad death. Existing biases within sociomedical systems reproduce aging and end-of-life disparities for TNB people and perpetuate inequality in US society.

Participant sample

Demographics of the participant sample are located in Appendices E and F. I conducted semi-structured, in-depth interviews with 50 TNBI older adults (65 years of age or over). Participants resided across 21 US states. Most respondents (60%) live in suburban areas, while 28% live in urban areas and 12% live in rural areas. Regarding sex as a social category, 32% self-identified as intersex and/or as someone with intersex variations. Regarding gender identity, over half of participants (54%) self-identified as transgender women. This research sample contained mostly endosex (not intersex) and intersex TNB people. Only three respondents in the participant sample self-identified as cisgender (not transgender) intersex people. Respondents ranged from 65 to 81 years of age (average age: 69 years).

The majority of respondents were white and non-Hispanic/Latinx (74%) with 26% from racial and/or ethnic minority backgrounds. Regarding social class, most self-reported as middle-class (58%) and 18% as from low-income backgrounds. Respondents reported diverse sexual identities, with most identifying as lesbian (33%) or bisexual (20%). Most respondents reported obtaining an associate's or more advanced college degree (62%), with 22% of respondents holding a graduate degree. Most respondents were single (64%) and had no children (34%). Respondents' identities and lived experiences shaped the research findings from this dissertation study. In what follows, I discuss how TNBI older Americans perceive and plan for end-of-life experiences in the context of advance care planning.

3.7 FINDINGS

Prior sociological research has pushed toward pinpointing what a good death might look like for underserved communities in healthcare, such as among those who are financially disadvantaged (Carr 2012), African American and Latino populations (Cain and McCleskey 2019), and older widowed populations (Carr 2003). Echoing Cain (2021), I call for further development within the interdisciplinary medical sciences of understandings of death and end-of-life that conceptually complicate binary understandings of good vs. bad death and provide a better understanding of in-between processes. Further, I argue that fulfilling some of the normative elements of achieving a good death in US society (e.g., having quality end-of-life care and familial support during death) is currently structurally unachievable for many older TNBI people given that existing social and medical practices in the US erase, neglect, and devalue TNBI lives.

Nearly all respondents expressed detailed wishes (e.g., social, healthcare, and legal) for themselves during future aging and end-of-life experiences. First, most respondents described great uncertainty around whether they would be able to access normative elements of having a good death for themselves in US society (e.g., having family members take care of them in later life). Second, respondents who expressed uncertainty around being able to have a good death consequently engaged in coping strategies engineered to make having a bad death less likely. However, these strategies are often not fully feasible due to existing social and medical practices that negatively shape TNBI older adults' aging and end-of-life experiences.

These findings reveal respondents' complex perspectives and uncertainty around the possibility of experiencing a good death, as well as their resourceful strategies and plans for preventing a bad death. I describe this as *satisficing around aging and death*, a process that involves being less able to access or be assured of a good aging process and death due to existing social, structural, health, and healthcare inequalities faced by TNBI people. I find that while many older TNBI adults must satisfice around aging and death, they simultaneously engage resourceful strategies to better ensure their ability to avoid a bad death by drawing upon existing and available social support and resources. Satisficing around aging and death, as a conceptualization, contributes to studies of structural competency and pathways toward improving TNBI health and healthcare in the future, while being grounded in TNBI patients' everyday lives and social realities.

3.8 UNCERTAINTY AROUND THE ABILITY TO HAVE A GOOD DEATH

Respondents described the importance of engaging in formalized advance care planning for themselves to help fulfill their aging and end-of-life wishes, regardless of support from their familial and intimate relationships. Most respondents described great uncertainty in fulfilling normative elements around having a good death in US society (e.g., maintaining family support, pain-free status, satisfactory relationships with medical providers) when discussing fears around future aged care and later life challenges. Respondents reported two primary fears that motivated their uncertainty around having a good death as an older TNBI person: (i) medical mistreatment and neglect in aged care settings and (ii) lack of social support.

Medical mistreatment and neglect in aged care settings

In the first sub-theme driving uncertainty for having a good death, respondents primarily expressed their fears of medical mistreatment and neglect in aged care settings. Specifically, respondents worried about themselves in later life and discussed how unsure they were about their future medical care in older adulthood as TNBI older adults. Respondents discussed how their positionality as older TNBI adults in aged care facilities may subject them to potential medical mistreatment and neglect, especially if medical providers and staff are aware of their TNBI identities. Jane, a white, working-class, endosex, bisexual, transgender woman, explained her recent concerns with the possibility of residing in a long-term care facility after the death of her brother:

> This experience with my brother dying has made it very, very important to me to get it [advance care planning] taken care of. I do not have anything prearranged… I'm concerned. Should my health require me to be in any kind of long-term care facility?... Will doctors treat me well as a trans female?... I don't know. The fact that I have fully medically transitioned I think would probably make that experience not as clunky as someone who chose to not fully medically transition.

Jane shared her bereavement experience and perceptions about the possibility of living in a long-care term facility in later life. Much like Jane's uncertainty around her possible future aged care for herself, most respondents described how the possibility of experiencing medical mistreatment and neglect in later life has complicated their perspectives of living and dying well.

As Jane illustrated, respondents were very much aware of the challenges that TNBI older adults face in aged care settings, such as TNBI-related stigma among medical providers or TNBI-incompetent medical training and practice. After describing her uncertainty with aging and end-of-life perceptions, Jane hypothesized that her positionality as a "fully medically transitioned" trans woman could enhance or better her experience in a long-term care setting compared to other trans and non-binary people who have not undergone gender-affirming medical interventions (e.g., hormone therapy, gender-affirmation surgeries) or followed the medical model of transgender identity (Johnson 2015). Indeed, the inability to be medically recognized as transgender in the US places substantial barriers on transgender and non-binary (TNB) populations seeking gender-affirming aged care services (Miller and Grollman 2015; Nowakowski, Sumerau, and Lampe 2020). However, Jane's framing around "choosing" gender-affirming medical interventions and "fully" medical transitioning is economically inaccessible for many trans people (shuster 2021; Sumerau and Mathers 2019), especially many trans women of color (Buchanan and Ikuku 2022; Vidal-Ortiz 2009).

Miguel, a Latino, middle-class, intersex, heterosexual, transgender man, described how he pleaded with his geriatric care team for hormone therapy services. Miguel described his worry with experiencing medical mistreatment and neglect in later life:

> I could read [sense or feel] a bit about their judgment… and the doctors could just make me feel so bad because they [would] tell me that I was crazy for thinking I was a boy. Instead of being like, "Miguel, what's really, really on your mind?"… At the end of the day, it became very, very awkward to be at their mercy of getting male hormones for me, despite me being a man. I don't know what the future will be like for me getting male hormones… what makes me a man.

Miguel shared his experience of navigating barriers to access testosterone therapy as an older trans man and how his medical providers framed his trans identity as a mental health condition. As Miguel emphasized, testosterone therapy helps him enhance his well-being and mental health as a transgender man. However, he is uncertain about whether he will be able to access hormone therapy services in later life due to prior experiences with medical mistreatment and neglect. Miguel's feelings of uncertainty in receiving gender-affirming health services in older adulthood further illustrate the structural and institutional limitations that TNBI older adults often face in preparation for a good death. Indeed, 70 percent of my sample respondents wondered whether they would receive quality and TNBI-competent medical care in later life.

Medical providers denying or delaying trans-specific health services produces uncertainty among many TNBI older adults that they will be able to experience a good death. In other words, there is no guarantee that TNBI older adults will live and die well given the crisis in contemporary TNBI medicine, with many medical providers in the US not being fully equipped to understand and treat TNBI patients' health and healthcare needs (shuster 2021). Normalizing cisgender and endosex experiences in medicine, and the concomitant neglect of TNBI experience, carry over in later life for TNBI older adults and systematically shapes their uncertainty around being able to have a good death.

Lack of social support

Most respondents described having no or limited social support from family members due to family members' rejection of them due to their TNBI status. One-third of respondents reported having no family member who could function as a healthcare agent for them in later life. When I asked them about their experiences with advance care planning, Andie, a white, low-income, intersex, asexual, pangenderfluid, androgynous, demi man, non-binary person responded:

> I don't have a current advance directive… I had my daughter [as a healthcare agent], but two years ago she became a born-again Christian and now hates [that] I'm non-binary and intersex. I'm gonna have to go back to square one. [long pause] It makes me uncertain about everything. [voice elevates] It makes me scared to have no one in my life who could take care of me during my final days.

Andie originally had their daughter as their healthcare agent, but Andie's daughter no longer supports Andie as a family caregiver due to non-binary- and intersex-related stigma. Andie's uncertainty in living and dying well in later life stems from having no support among family members that could offer additional ways to enhance their quality of life, positively mediate provider-patient interactions, and bolster confidence in their ability to have a good death.

While many respondents have other sources of social support, such as their friends, neighbors, or medical providers, some expressed that they do not have advance care planning documentation in place because they currently have no social support.

Valerio, a Latino, middle-class, endosex, bisexual, transgender man explained: “I have heard information about it [advance care planning], but never considered it ‘cause I have no one to take care of me in life or anyone who should be mindful about my health and future life.” Several challenges for TNBI older adults are reflected in Valerio’s narrative. Valerio does not currently have social support in place to prepare for later life or to have a trusted healthcare agent carry out his aging and end-of-life wishes. Valerio acknowledging that there is no social support currently available to him is an example of the logistical uncertainty and care gaps many TNBI older adults face when attempting to prepare for a good death.

Even when having family members and friends present in their lives, some TNBI respondents are hesitant to discuss advance care planning decisions with others due to mental health or safety reasons. When asked about whether she discussed her healthcare wishes with family members or friends, Lupita, a Black, working-class, endosex, bisexual, transgender woman, replied, “No. I really don’t think it’s safe to talk about it with them now, but I will in [the] future.” When I followed up with her response, Lupita briefly clarified: “I trust very few people in my life,” and then asked to take a break during the interview. Lupita is concerned with discussing healthcare wishes in later life with her family and friends and protected herself from potential harm by opting not to have such conservations with others in her life. Lupita demonstrated how preparing for a good death among TNBI people may be derailed through limited trust, safety, and social support due to pervasive structural and interpersonal stigma and violence against these communities. Some respondents, for example, were worried about the possibility of their healthcare agents having full control of their financial assets. Such conditions exacerbate and reproduce social and medical inequities against TNBI aging communities.

Existing social and medical conditions that erase, marginalize, and neglect TNBI experiences create much uncertainty surrounding TNBI older adults' ability to maintain social support, which may lead to greater health and healthcare inequities in later life. Respondents heavily weighed their access to social support and financial barriers when considering possibilities for legalizing advance care planning documents. Many respondents had uncertainties around having and maintaining social support in later life and their perspectives surrounding aging and end-of-life experiences often blurred the lines between planning for a good death and avoiding a bad death. These ambiguities were expressed among some respondents who currently had social support from family members and friends. Much like Andie's story of losing support from their daughter, respondents' uncertainty around being able to have a good death included fears of having no or limited social support in later life. Respondents' uncertainty makes sense given their frequent inability to follow dominant pathways toward a good death due to existing social, structural, and institutional inequities and barriers. In what follows, I explore how respondents address the potential inaccessibility of living and dying well through focus on their resourceful and pragmatic strategies as they satisfice to prevent a bad death.

3.9 SATISFICING AROUND AGING AND DEATH TO FURTHER PREVENT A BAD DEATH

Satisficing around aging and death is a process that involves being less able to access or be assured of a good aging process and death due to existing social, structural, health, and healthcare inequalities faced by TNBI people (Cain 2021; Dickson et al.

2021; Henry et al. 2020; Kortes-Miller et al. 2018). This conceptualization addresses structural competency by acknowledging systemic barriers to being able to access healthy aging and a good death among TNBI older populations, such as ensuring that TNBI older patients have their basic needs met (e.g., access to housing security, affordable medication, social support). Because respondents have a great deal of uncertainty around whether they will be able to have a good death, they reported engaging in resourceful strategies that might prevent them from experiencing a bad death. Specifically, respondents engage in pragmatic strategies (Pfeffer 2012) to avoid a bad death rather than pursuing idealized pathways to a good death that are socially and/or structurally inaccessible or unattainable to them.

Echoing findings from Thomeer and colleagues (2017), which focused on gay and lesbian couples seemingly better prepared for end-of-life challenges, I find that all respondents in the present study have engaged in at least one resourceful strategy aimed toward preventing a bad death. Unfortunately, their bad death prevention strategies can neither guarantee they will experience a good death nor avoid a bad death. As such, there remains great uncertainty for TNBI respondents around living and dying well in later life. Bad death prevention strategies included resourceful and pragmatic strategies such as: (i) formalizing their advance care planning documents and (ii) choosing non-family members as healthcare agents.

Formalizing advance care planning documents

Over half of respondents formalized their advance care planning documentation. Many respondents also drew on existing sociopolitical conditions against SGM communities (e.g., anti-transgender proposed and enacted legislation) to affirm their decision to formalize their advance care planning documents. In these narratives, respondents discussed their perspectives toward advance care planning before and after the US Supreme Court ruling of *Obergefell v. Hodges* (2015). Respondents described the importance of legally protecting themselves and their families from anti-SGM discrimination, especially before the *Obergefell v. Hodges* (2015) ruling, but expressed that discrimination against SGM individuals and families persists in the US.

When asked about her advance care planning experiences with her spouse Diana, Linda, a white, middle-class, endosex, lesbian, transgender woman, reported:

> [W]e're very tuned into advance care planning as a same-gender couple together for 30 years. Before there was marriage equality, we wanted to ensure that our wishes were carried out. You know, you heard all the horror stories about same-gender spouses not being allowed visitation rights and not being the designated care provider or designated surrogate…

Like Linda, about half of respondents had formalized their advance care planning documents to further protect themselves from anti-SGM discrimination. Respondents noted how formalizing their wishes through advance care planning might assist them in preventing a bad death for themselves as well as provide support for their families following their death. However, such resourceful strategy is a central example of satisficing around aging and death because legally formalizing advance care planning documentation does not structurally assure a good aging process and death given existing structural inequities faced by TNBI aging populations.

Yvette, a white, middle-class, endosex, lesbian, transgender woman, expressed how lucky she felt to have legally formalized her advance care planning documentation, with her wishes clearly outlined throughout and family members who she trusted to follow her wishes. When asked about how she felt with her current advance care planning documentation in place, Yvette responded by comparing other trans people's experiences to her own:

> I think I'm perhaps unusual, but definitely fortunate if not [in a] privileged position… It is very important to have to be sure that gender is understood and that the proper pronouns are used [for me]. Because good Lord, it's hard enough dying without having all this other stuff going on with respect by gender. You know when you… [long pause] when you're out… at death's door.

Yvette acknowledged and underlined her privileged position in having legally formalized advance care planning documentation to include all her specific wishes (e.g., medical providers using her correct pronouns and opting for a do-not-resuscitate status) while also noting the particular importance of honoring transgender people's wishes in later life. Yvette making sure that she had all of her wishes included in her advance care planning documentation made her feel more confident that she was as prepared as possible (and more so than many other TNBI people are able to be) for proactively preventing a bad death for herself. As such, respondents like Yvette satisfice around aging and death by engaging in resourceful strategies to better ensure their ability to avoid a bad death through existing and available social support and resources.

Isabel, a multiracial, Puerto Rican, middle-class, endosex, lesbian, transgender woman, described how she feels that she is in full control of her aging and end-of-life decisions because she and her spouse of 49 years (Sophie) formalized their advance care planning documentation. Isabel explained: "You know, we've had people go, "Oh, what are you going to do if Isabel passes away, Sophie?” And Sophie says, ‘Well, I've got my wishes wrote [sic]. Here it is.’ You know, I don't need anybody to make my decisions. These are my decisions.” Isabel’s response exemplified the importance of legally formalized advance care planning documentation for TNBI older adults by highlighting how legal protection via advance care planning preserves Sophie’s and Isabel’s wishes and financial assets in older adulthood – even in the case when one of them dies. Although SGM people often do not have the privilege of gaining full control and choice over their dying experiences (Thomeer et al. 2017), legalizing advance care planning documentation – as a resourceful strategy for satisficing around aging and death – better ensures their ability to avoid a bad death

Most respondents in my research sample who had advance care planning documentation in place also had middle-class and upper-class cultural capital and standing, whereby respondents who were from low-income and working-class backgrounds lacked not only the financial resources, but also the social connections, pathways, and knowledge required to access, complete, and legally formalize advance care planning – a process that can be particularly opaque, overwhelming, and inaccessible. Many respondents who have not legally formalized advance care planning documentation shared that financial barriers to paying for legal and administrative costs were the main reason. Some respondents were more concerned about attending to current financial challenges than paying for advance care planning to prepare for potential later life events and expenses.

When asked about his thoughts about advance care planning for aging and end-of-life experiences, Chris, a white, middle-class, intersex, flux, gender-questioning person said, “Well, I'm concerned about the financial aspect of it. For a number of reasons, I… do not have like [these] huge retirement savings. And that in itself is a long story, but so I worry about that… I worry about the finances of it all.” When asked the same question, James, a white, middle-class, endosex, queer, transgender man responded after a long silence: “[L]et’s just say that I’m not even sure if my current finances would pay for my own funeral. At least *I* don’t have to worry about it when it’s my time to go. [laughs]” Chris and James both express the social realities of many respondents who face financial challenges and barriers to formalizing their advance care planning documentation for aging and end-of-life care.

Other respondents expressed that they do not know how to go about formalizing advance care planning documentation. Most respondents from low-income and working-class backgrounds lacked not only the financial resources, but also the social connections, pathways, and knowledge in accessing, completing, and legally finalizing advance care planning. Some expressed how legally finalizing advance care planning documentation can be particularly opaque, overwhelming, and inaccessible. Summer, a multiracial, low income, endosex, heterosexual, transgender woman, explained:

> Well, to be honest, I don’t [long pause]… I don’t even know where to get something done up like that. I don’t know if that’s something you get up at the doctor’s office or at the hospital or if you go downtown to the, you know, the civil courts. I’m not sure where... where you would go for something like that. I’m not sure that, you know, what about if I if I put something down in... and I want to change it? Is that legal? You know? You don’t see much... You don’t see much information on things of that nature.

Those who are unable to afford advance care planning expenses, and/or do not know how to access advance care planning services, are in a particularly vulnerable position, facing heightened uncertainty about the possibility of being able to have a good death. Although formalizing advance care planning documentation was a common resourceful strategy for many respondents attempting to prevent a bad death, such strategies are limited due to existing economic, political, and social barriers that TNBI aging communities disproportionately face in US society (e.g., financial insecurity and anti-SGM legislation and bias). Thus, respondents' processes for satisficing around aging and death exemplify the systemic limitations of a good aging process and end-of-life preparation due to existing structural inequities faced by TNBI older Americans.

Selecting healthcare agents

The second strategy respondents reported using to prevent a bad death involved carefully selecting their healthcare agents or those who will make healthcare decisions for them if they cannot communicate with them on their own due to illness or injury. Overall, respondents offered diverse responses of who they would select as their healthcare agents. Many respondents chose a healthcare agent who would carry out their specific aging and end-of-life wishes, even if their healthcare agent personally disagreed with those wishes. Linda explained why her spouse, Diana, is currently her healthcare agent:

> She [Diana] knows very well my wishes… [T]he most important thing is that we've had discussions about this and we're very clear as to about what we want done, what we don't want done. So, we see eye to eye about that. She would still be my healthcare surrogate if we didn't see eye to eye, as long as she respected my wishes.

Several respondents explained that they have a healthcare agent, but do not have any intention to formalize advance care planning documentation to have their chosen person as their healthcare agent, such as establishing them as healthcare power of attorney. By satisficing around aging and death, respondents engage in resourceful strategies to better ensure their ability to avoid a bad death by drawing upon existing and available social support through family, friends, and medical providers.

Some respondents proclaimed that they do not need legal documentation for advance care planning because they trust their healthcare agents to make informed decisions about their aging and end-of-life wishes. However, such situations leave some respondents in precarious positions should someone legally challenge the decision-making capacities of an informally-designated healthcare agent (e.g., a family member disapproves of their older TNBI parent’s legally-unmarried life partner). Informal advance care planning may create further instability or uncertainty in honoring TNBI older adults’ social, legal, and medical wishes through satisficing around aging and death by being less able to access or be assured of a good aging process with legal security.

When asked about why Miguel chose his partner [Maria] as his healthcare agent, he said: “Because I really love her [Maria] and had known her long enough. And she has a list of things I would want for myself. I just have no true intentions for putting it down on paper legally.” Although Miguel is confident that Maria would enact his aging and end-of-life wishes if he is unable to communicate them on his own, Miguel and Maria are not legally married and have no advance care planning documentation in place. As an SGM couple, Miguel and Maria have no legal protection against challenging aging and end-of-life experiences that may put them in a difficult position (e.g., in the case of terminal illness). Their informal arrangement may also place them at greater risk for experiencing structural and institutional inequity in medical settings (e.g., not being able to see a life partner in the hospital due to medical gatekeeping). Further, this legal precarity can widen existing inequality for TNBI older Americans by not securing legal protection that honors their wishes in later life, which may place them in a more vulnerable state with legal, medical, and funeral authorities.

Similarly, Summer emphasized her confidence that her friends and family would conduct her healthcare wishes in later life despite not having advance care planning documentation in place:

> "Well, I don't have anything down on paper. But… [m]y friends and family also know that if I'm in the kind of condition, you know where I got to be on life support and there's no chance of me coming back, and if I'm just going to be a vegetable [in a persistent vegetative state], just to let me go… I don't want to be a burden to nobody. I [am] so independent, I just can't see myself like that."

Much like Summer's wishes, most respondents felt that their healthcare agents would focus support for their aging and end of life care around quality of life rather than quantity of life. Despite respondents' personal confidence in their non-formally-appointed healthcare agents and directives, there remains great structural uncertainty for Miguel, Summer, and other TNBI people who assume that informally selecting healthcare agents is enough to ensure their aging and end-of-life decisions.

Critical healthcare decisions (e.g., a person experiencing cardiac arrest) are often made under conditions of great uncertainty. Non-formalized medical directives may not offer full protection for TNBI older adults to further protect themselves against unwanted healthcare and end-of-life decisions. At the same time, many older adults from racial and ethnic minority communities, similar to those expressed in the quotes above, do not fully trust medical authorities to carry out their wishes due to structural and institutionalized racism (see Cain and McCleskey 2019). Specifically, historical and contemporary medical racism may substantially impact how TNBI people of color perceive whether medical providers would actually honor their wishes through formal advance care planning documentation (Cain 2021). Thus, the importance of Summer and Miguel both primarily relying on family members to informally carry out their aging and end-of-life wishes may reflect broader advance care planning inequities among TNBI older adults of color and their family care partners (i.e., family caregivers).

Such dynamics shape the social and medical landscape of advance care planning by reproducing structural vulnerabilities and insecurities among TNBI communities, which may contribute to aging and end-of-life disparities for TNBI patients (Donald et al. 2017; Metzl and Hansen 2014). Structural competency education and training within US healthcare systems are needed to further promote greater equity in emergency services for TNBI older adults from racial and ethnic minority communities (Willging et al. 2019).

Despite many respondents having a clear idea of who their healthcare agent would be, and holding great trust in these agents' willingness to enact their aging and end-of-life wishes, other respondents were unsure who they might select as a healthcare agent or if they would be able to fully trust them. As Scott, a multiracial, low-income, endosex, heterosexual, transgender man, stated: “Do I trust somebody completely right now [as my healthcare agent]? No, I don't. And that includes my older sister, who lives right down the road from me in a different trailer park… If she can't even get my pronouns right, how can I trust her to make those serious decisions for me?" Scott recognizes that he is unable to fully trust anyone to be his healthcare agent due to the limited regard that even his sister has for him, along with her capacity to personally capitalize on his death. Such conditions made it difficult to confidently prevent a bad death for respondents who lack trust in and social support from family members as TNBI older adults. Thus, a good death is not structurally guaranteed and consequently TNBI older respondents sacrifice around aging and death to maximize their chances of aging and dying well.

Overall, preventing a bad death among respondents involves obtaining resources that require privilege in the forms of money, social capital, social support from family and non-family members, and access to aged care and support services that many TNBI older adults and families simply do not have. As such, navigating aging and end-of-life care challenges generated blurred pathways between a good and bad death for many TNBI older adults in the present study. Much like other underserved communities in healthcare, there is great uncertainty when it comes to aging, end-of-life, and dying well when faced with systemic inequities in US society. My conceptualization of satisficing around aging and death explains how TNBI older adults' perspectives exemplify the systematic limitations of aging and end-of-life preparation, while they engage in resourceful strategies to better ensure their ability to avoid a bad death by drawing upon existing and available social support and resources.

3.10 DISCUSSION

Introducing a *satisficing around aging and death* perspective that provides an alternative to the binary good vs. bad death framework predominant in research on aging and end of life health research, this work assesses how TNBI older adults perceive and plan for aging and end-of-life care experiences using resourceful and pragmatic (though certainly not ideal) strategies. While sociologists have examined perspectives of dominant good death definitions among underserved communities in healthcare (Cain and McCleskey 2019), my analysis reveals TNBI older adults' uncertainty around experiencing a good death, along with their calculated strategies for reducing the possibility of a bad death. Such uncertainties both reflect and reproduce health and aging inequities among TNBI older adult populations. Overall, these findings prompt consideration of how perceptions of a good death and a bad death are extremely complicated among TNBI older adults and require more careful consideration of in-between approaches and outcomes produced at the intersection of experiencing multiple social, institutional, and systemic inequities. Examining older TNBI adults' resourceful approaches around managing aging, advance care planning, and end death offers fruitful opportunities for expanding SGM scholarship on aging and end-of-life experiences while pinpointing how social, economic, political, and medical structural inequities negatively impact TNBI older adults' chances of living and dying well (Cain 2021).

My findings suggest that interdisciplinary medical scholarship could benefit from closer consideration of aging and death processes that exist between good and bad binary conceptualization, while pinpointing how TNBI older adults use resourceful and pragmatic strategies to satisfice around aging and death. This conceptualization contributes to theorizing about structural competence in ways that healthcare providers can meaningfully learn from (Donald et al. 2017; Metzl and Hansen 2014). Although sociologists have explored how various underserved communities in healthcare have diverse constructions of living and dying well (Cain and McCleskey 2019; Carr 2003), researchers know very little about how structural conditions and biases against TNBI older Americans, specifically, produce challenges around living and dying well.

In the case of public policy, we also know little about how sociohistorical context, like recent anti-SGM enacted and proposed legislation, affects SGM older adults' perspectives on aging and end-of-life experiences. Further, we have even less information about these perspectives among TNBI older adults in US society in particular. This research examines TNBI older adults' perspectives on aging and end-of-life experiences in the context of advance care planning. I call for structurally competent interventions that specifically target aged care services, outreach, and support training for TNBI older populations. My research contributions allow researchers and clinicians to better address systemic inequities experienced by TNBI people in older adulthood, while examining how TNBI older Americans draw upon existing and available social support and resources to migrate bad aging and death experiences.

Respondents in this study illustrate satisficing around aging and death, a process that involves being less able to access or be assured of a good aging process and death due to existing social, structural, health, and healthcare inequalities faced by TNBI aging populations. I further extend this work by articulating how a good death for TNBI older adults is not structurally guaranteed and outlining the multiple resourceful and pragmatic strategies used by respondents in their attempts to prevent a bad death and minimize the impacts of experiencing structural inequality. Research findings can guide direct improvement of aged care and end-of-life preparedness for TNBI people and support research identifying additional opportunities for SGM communities to age well. I join other sociologists (Cain 2021; Cain and McCleskey 2019; Nowakowski et al. 2019) in calling for new growth and development in this emerging line of scholarship to investigate how medically and socially underserved communities experience uncertainties in their aging, advance care planning, and death processes and how such processes reflect and reproduce health and aging inequities among SGM older adult populations more broadly.

CHAPTER 4: “NO ONE CARES ABOUT MY HEALTH.”: HEALTH MANAGEMENT DURING COVID-19 AMONG TRANSGENDER, NON-BINARY, AND INTERSEX OLDER ADULTS

4.1 INTRODUCTION

An estimated 2.7 million sexual and gender minority (SGM) adults 50+ reside in the United States (US) with this number projected to increase to more than 5 million by 2060 (Flatt et al. 2022; Fredriksen-Goldsen and Kim 2017). The Coronavirus Disease 2019 (COVID-19) pandemic poses unique challenges in health management among SGM older Americans (65 years or over), as a medically and socially vulnerable population in US society (Jen, Stewart, and Woody 2020). As many US healthcare systems and providers continue to struggle with providing structurally-competent SGM care (Hsieh and shuster 2021), researchers have demonstrated how the COVID-19 pandemic has exacerbated existing health and healthcare inequities among SGM Americans (Candrian, Sills, and Lowers 2020; Hsieh and shuster 2021; Jen et al. 2020; van der Miesen, Raaijmakers, and van de Grift 2020) such as delayed or denial of gender-affirming medical interventions (van der Miesen et al. 2020), mental health challenges during COVID-19 isolation (Candrian et al. 2020), and limited access to adequate health resources (Salerno, Williams, and Gattamorta 2020). Metzl and Hansen (2014:5) define *structural competency* as “the trained ability to discern how a host of issues define clinically as symptoms, attitudes, or diseases [e.g., clinical depression and anxiety symptoms]… also represent the downstream implications of a number of upstream decisions about such matters" [e.g., experiences with sex, gender, and sexual discrimination]. Integrating structural competencies of TNBI older patient populations into medical education, training, and practice is essential to fully meet the health and healthcare needs of SGM older Americans during the COVID-19 pandemic (Donald et al. 2017; Flatt et al. 2022; Grimstad et al. 2021).

At the same time, older adult populations (65 years or over) show a heightened risk of COVID-19-related severe illness, hospitalization, and death compared to their younger counterparts (Centers for Disease Control and Prevention 2022). The Centers for Disease Control and Prevention also found that about 1 in 4 older Americans had at least one potential long-COVID health problem up to a year after an initial COVID-19 infection (Associated Press 2022; Bull-Otterson et al. 2022).While previous research has notably examined SGM health and healthcare disparities during the COVID-19 pandemic (Hsieh and shuster 2021; van der Miesen et al. 2020; Salerno et al. 2020), less is known about how SGM people manage such conditions in older adulthood (see Candrian et al. 2020; Flatt et al. 2022; Jen et al. 2020 for exceptions).

Using a life course perspective (Elder 1994; Elder and Giele 2009), I extend interdisciplinary health research by investigating how transgender, non-binary, and/or intersex (TNBI) older Americans – as a medically and socially vulnerable SGM sub-population – manage and maintain their health during the COVID-19 pandemic, while pinpointing opportunities to improve healthcare providers' responses through structural competency education, training, and practice (Donald et al. 2017; Grimstad et al. 2021;

Metzl and Hansen 2014). *A life course perspective* is a theoretical framework that allows researchers to analyze how macro and meso-level social pathways vis-à-vis social conditions and interactions shape people's lives over time (Elder 1994; Elder and Giele 2009). Utilizing data from 50 semi-structured individual interviews with TNBI older Americans, I show how key life course transitions shape how TNBI older adults respond to the COVID-19 pandemic and make decisions about their health management. My analysis also pinpoints what barriers and resources TNBI older adults encounter while managing their health during the COVID-19 pandemic, which are key ingredients for providing a comprehensive foundation for structurally-competent medicine aiding TNBI older patient populations. In so doing, I call for greater attention to the social conditions that aid in the reproduction of health and healthcare disparities of TNBI older Americans during the COVID-19 pandemic. My findings can usefully inform and steer healthcare providers about the particular social, structural, and institutional conditions to consider when providing care and recommending treatment for TNBI older populations in the US.

4.2 HEALTH MANAGEMENT IN SGM OLDER ADULTHOOD

Many SGM older Americans face challenging social conditions when managing their health (Handlovsky et al. 2020; Hash and Rogers 2017; Orel and Fruhauf 2015). SGM older adults, for example, disproportionately report lower socioeconomic status and higher rates of chronic illness compared to the general US population (Fredriksen Goldsen, Jen, and Muraco 2019). SGM people often face mental health challenges over the life course due to stigma, discrimination, and violence against SGM individuals and communities (Meyer 2003; van der Miesen, Raaijmakers, and van de Grift 2020; Su et al. 2016). SGM populations are at risk for experiencing high rates of depression, anxiety, and violence and multiple health risk behaviors such as suicide ideation and attempt, substance and alcohol use, and eating disorders (Fredriksen-Goldsen, Simoni, et al. 2014; Rice et al. 2021; Su et al. 2016). Older gay, bisexual, and queer cisgender men and trans individuals have a relatively high risk of HIV and other STIs compared to their counterparts (Emlet 2006; Fredriksen-Goldsen et al. 2013; Ing et al. 2018). Additionally, SGM older adults often experience greater challenges in managing their health due to intersectional marginalization in the forms of racism, heterosexism, cissexism, and endosexism (Crenshaw 1989; Fredriksen Goldsen et al. 2019). Consequently, SGM older adults continue to experience health inequalities in older adulthood (Fredriksen Goldsen et al. 2019). Taken as a whole, SGM older people constitute a medically-vulnerable population with substantial health and healthcare disparities (Hash and Rogers 2017).

At the same time, these social conditions make it difficult for SGM older Americans to receive adequate social support and resources in managing their health (Torres and Lacy 2021). For example, family caregiving of older SGM adults can assist with SGM health and healthcare management (Anderson and Flatt 2018; Nowakowski and Sumerau 2017). However, researchers have demonstrated the social and health challenges SGM caregivers face when caring for a loved one (Nowakowski et al. 2019; Nowakowski and Sumerau 2019a; Pfeffer 2017). SGM caregivers, for example, frequently perform more healthcare management tasks than their non-SGM counterparts (Orel and Fruhauf 2015). SGM caregivers often report increased employment and income insecurity due to their informal caregiving responsibilities and commitments (Bookwala 2016). Researchers have also established connections between chronic illness management among SGM couples and families (Nowakowski et al. 2019; Pfeffer 2012, 2017). Most importantly, many SGM older adults do not have access to informal and formal caregiver support systems in US society (Czaja et al. 2016). Relevant directions of future research inquiry should address effective support and resource provision strategies for SGM older adults and their family care partners to further reduce or eliminate SGM health and healthcare disparities.

Few studies directly examine the health, aging, and care needs of TNBI populations 65 years and over (Fredriksen Goldsen et al. 2019). Most medical knowledge and practices follow Western sex and gender binary systems (e.g., female/male and women/men) in healthcare planning, prevention, and treatment services (Liang et al. 2017) while erasing patients with sex and gender variations. Additionally, TNBI people often experience challenges in accessing and utilizing quality care in the US (Davis et al. 2016; Witten 2004). For example, there is a paucity of literature on long-term care challenges for older trans people living with HIV (Ing et al. 2018). Literature is also scarce on the social and health consequences of intersex people experiencing medical trauma over the life course (Davis 2015). Older TNBI adults face multiple social and health disadvantages in society (Feder 2014; Ing et al. 2018). However, prior literature is not conclusive on how TNBI people navigate and manage their health in older adulthood.

4.3 A LIFE COURSE PERSPECTIVE

To further examine the health management experiences of TNBI older adults, it is particularly important to understand how these communities manage their health and aging over the life course, so US healthcare systems and providers can create structurally-competent practices in offering quality, effective care to TNBI older patients that address the actual sources of TNBI health and aging disparities. Utilizing a life course perspective allows researchers to analyze macro and meso-level social pathways that define sequences of events, transition roles, and experiences of individuals and communities over time (Elder and Giele 2009). After reviewing 66 articles on SGM aging research, Fredriksen-Goldsen and colleagues (2019) noted the scarcity of health disparities and inequalities research on SGM older adults. Their review calls for future methodological, theoretical, and empirical directions of SGM aging research, which includes the need to examine the experiences of transgender older adults and how cisnormative assumptions of gender may negatively impact their aging experiences (Fredriksen Goldsen et al. 2019). Health and aging both co-operate as social processes which occur over the life course and are often shaped by one's new understandings of the social world (Nowakowski, Sumerau, and Lampe 2020). Therefore, studying TNBI older adults while using a life course perspective offers fruitful avenues for researchers to further understand how these communities navigate social passages and life events over time concerning health management.

Five major principles shape a life course perspective: (i) *the interplay of time and place*, (ii) *life-span development*, (iii) *the timing of lives*, (iv) *human agency in choice making*, and (v) *linked lives* (Elder 1994; Elder, Johnson, and Crosnoe 2003). First, *the interplay of time and place* influences the social conditions of human lives (Elder 1994), especially in the case of health management of socially and medically underserved communities (for examples see Lu et al. 2010; MacLean and Elder 2007; Smith 2007) like SGM Americans (Fredriksen Goldsen et al. 2019; Rosenwohl-Mack et al. 2020). Medicalization of TNBI people, bodies, and experiences has expanded since the early

20th century (Davis 2015; Preves 2003; shuster 2021), which fundamentally shapes how medical authorities and institutions control TNBI healthcare access (Davis et al. 2016), utilization (Davis 2013; shuster 2016), and delivery (shuster 2021). Many transgender and non-binary (TNB) Americans, for example, have experienced and/or continue to experience substantial delayed or limited access to gender-affirming medical care services, resources, and support during the COVID-19 pandemic (Jarrett et al. 2021; van der Miesen et al. 2020). Therefore, when assessing health management resources during the COVID-19 pandemic, understanding the crucial interplay of time and place is a fundamental element in life course research on TNBI aging populations.

Second, the *life span development* principle illustrates how people socially develop in meaningful ways throughout adulthood via new trajectories, transitions, and conditions (Elder 1994; Elder et al. 2003). Approaches of and experiences with new situations throughout adulthood shape life span development individually (Elder and Giele 2009) and collectively (Bockting et al. 2016). For example, a transgender person socially, medically, and/or legally transitioning will be shaped by their previous social interactions, relationships, and engagement with institutions, such as prior positive, mediocre, and negative experiences with medical providers and staff. It is critical to examine the life span development of TNBI older communities to assess how their health management strategies and experiences during the COVID-19 pandemic are affected by their prior health management histories.

Third, *the timing of lives* principle highlights how the chronological timing of events may affect people's social expectations and beliefs over the life course (Bengtson, Elder, Jr., and Putney 2005; Elder 1994). In the case of TNB experiences, there may be social expectations for a TNB person to socially, legally, and/or medically transition in early adulthood versus in older adulthood (Sumerau and Mathers 2019). If transitioning experience is chronologically out of sequence with age-related normative expectations in US society (e.g., a transgender person transitioning during older adulthood), such situations may act as a barrier or structurally disrupt TNB older adults' access to gender-affirming care resources, support, and services (Auldridge et al. 2012). Thus, social timing is influential in TNBI people's health management over the life course.

Fourth, the *human agency in choice making* principle emphasizes the importance of how people's decision-making choices and processes influence their life course (Elder 1994). Decisions shape our positionality in social situations, which may have short-term and long-term consequences (Bengtson et al. 2005; MacLean and Elder 2007). At the same time, social resourcefulness (or lack thereof) also shapes human agency in decision-making processes and outcomes (e.g., no or limited health insurance coverage) (Smith 2007), especially among medically and socially underserved communities in US society (Lu et al. 2010; Torres and Lacy 2021). Human agency is an especially important element in the case of how TNBI older adults manage their health. TNBI older adults make strategic choices in their everyday lives (e.g., seeking out TNBI-contempt long-term care services) to better manage their overall health and quality of life (Caceres et al. 2020).

Fifth, the *linked lives* principle – a central element in life course research (Elder 1994) – underscores how human lives are not fully independent, but socially "linked" or integrated with others from social relationships, networks, and influences (Halfon and Hochstein 2002; Settersten 2015). Social linkages go beyond formal relationships and often shape individual and collective interpretations of the social world (Mayer 2009).

For example, many SGM older adults have family care partners (i.e., family caregivers) who help them better manage their chronic health conditions (Anderson and Flatt 2018; Flatt et al. 2022). SGM older adults and their family care partners both contribute to maintaining their social linkages, which may further influence life course pathways. Social linkages can also be discontinued and disrupted over the life course, such as the COVID-19 pandemic disrupting prior family care partnerships and responsibilities (Gauthier et al. 2021). Little research explains how TNBI older adults' social relationships and support systems have changed during the COVID-19 pandemic and how such changes shape their health management possibilities and strategies.

Using a life course perspective (Elder 1994; Elder and Giele 2009), I focused on how TNBI older Americans in my research sample made decisions about their health management during the COVID-19 pandemic as a specific sociohistorical event that actively disrupted US healthcare access, utilization, and delivery. I further pinpoint which specific barriers and resources TNBI older adults drew upon to adequately maintain their health during the COVID-19 pandemic, which will meaningfully inform healthcare providers and staff opportunities for improvement in providing structurally-competent services to TNBI older patients. Finally, I illustrate how key principles of the life course shape how TNBI older adults respond to the COVID-19 pandemic and make decisions about their health management. Such findings have the potential to enhance intervention research on TNBI older adults' health management experiences and further reduce SGM health and aging disparities.

4.4 DATA, METHOD, AND SAMPLE

Study eligibility and recruitment

This study was approved by the University of South Carolina Institutional Review Board (see Appendix A). Between September 2021 and January 2022, I conducted 50 semi-structured, individual interviews with TNBI older adults who reside in the US. I recruited TNBI older adults through social media, SGM and non-SGM health centers, aged care facilities, SGM-friendly faith communities, and SGM community leaders and organizations. Most respondents in my research sample did not have personal relationships with other TNBI adults 65 years of age or older. This meant that strategies traditionally used to recruit SGM research participants, such as purposive social network sampling (Pfeffer 2012) and snowball sampling strategies (Compton et al. 2018), were less effective in this qualitative study.

I recruited my research sample of TNBI older respondents by (a) being open about my TNBI identities during participant recruitment and answering any questions prospective research participants had about me or the study, (b) attending SGM-led community events and meetings (e.g., attending a faith worship service virtually and SGM lay leaders introducing me to faith community members before the start of worships service) to share more information about the study, (c) connecting with intersex activists in the US who shared the study information in private Facebook groups for intersex community members, and (d) connecting with SGM-friendly faith community clergy and lay leaders. Many non-SGM and SGM-led organizations, especially SGM-friendly faith communities, refrained from distributing my intersex participant recruitment flyers (located in Appendix C) but eagerly shared my TNB participant recruitment flyers (located in Appendix B) with their stakeholders through their social media accounts and programming. This hesitance to share research study information about intersex populations could be due to structural erasure, stigma, and discrimination of intersex experiences throughout US society.

Importantly, there are no large-scale or long-term quantitative health studies in the US that specifically examine the health management experiences of TNBI older adults. Thus, utilizing qualitative methodology was critical for me to employ in this research study to comprehensively examine TNBI health management in older adulthood. Eligibility included respondents who: (a) self-identified as transgender, non-binary, and/or intersex, (b) were 65 years of age or older at the time of the interview, (c) lived in the US at the time of the interview, and (d) consented to be audio-recorded during the interview (see Appendices E and F for participant demographics).

Instruments and interview procedure

I developed and pretested an interview guide with 3 TNBI older adults to ensure questions were insightful, affirming, and culturally appropriate (interview guide located in Appendix D). Due to participant safety concerns during the COVID-19 pandemic, I conducted 39 Zoom interviews and 11 telephone interviews during data collection. To fulfill respondents' accessibility needs, particularly for those who were hard of hearing, I offered automated closed captioning and lip-reading functionality for respondents who were interviewed through Zoom.

With ethics a key concern in research with a vulnerable aging population, I developed an interview instrument with the assistance of TNBI sociologists from Sociologists for Trans Justice (interview instrument located in Appendix D). I pretested the interview guide with 3TNBI adults to ensure that questions are insightful, sex and gender-affirming, and culturally appropriate. I approached respondents with questions concerning their (i) healthcare experiences, (ii) attitudes toward advance care planning, and (iii) health needs and management throughout each interview. This qualitative approach allowed me to build trust, comfort, and rapport with TNBI respondents. Each part of the interview contained several follow-ups or probes to ask for further information. I secured verbal consent from each participant before the start of each interview and before I asked about health needs and management experiences, which included various follow-up questions about self-reported health, health management experiences, social support, and resources before and during the COVID-19 pandemic.

On average, interviews lasted 98 minutes (range: 30 to 346 minutes). Each TNBI older adult respondent received a $40 prepaid Mastercard debit card after completion of the interview to thank them for their time and contribution to the study. I audio-recorded interviews and used Nvivo transcription software to transcribe each interview. After the completion of each interview transcription, I fidelity checked each interview transcript to ensure accuracy, while making corrections as needed. I gave respondents pseudonyms and removed all identifying information during the fidelity checking process to ensure research participant confidentiality. I also wrote memos during qualitative data collection and analysis.

Researcher standpoint

My social standpoint as a white, non-Hispanic/Latinx, TNBI young adult living in the US Southeast certainly influenced my interview experiences with respondents. Many respondents expressed that they felt more comfortable with me interviewing them – as a

TNBI interviewer – than they would be if a cisgender or endosex researcher interviewed them due to fear of negative or mediocre interview experiences (see also Sumerau and Mathers 2019). Despite me disclosing my sex and gender identities with respondents before each interview (as a TNBI person who was socially assigned female at birth), respondents perceived me as a cisgender woman, transgender man, or transgender woman in some cases (see also shuster 2021). My gender expression and respondents' assumptions about my sex and gender identities likely shaped our interactions. Additionally, my social location as a TNBI researcher residing in the US Southeast may have allowed some respondents who live in socially, politically, and/or religiously conservative areas to feel comfortable enough to be interviewed by me. My background as someone who grew up in a conservative, working-class household in the rural US Midwest also allowed me to connect with some respondents from rural and financially-disadvantaged backgrounds.

Although my social standpoints produced certain benefits in terms of recruitment, there were also limitations. First, my status as a young adult interviewer, at times, discounted my credibility as a TNBI aging researcher or made me a potential outsider (e.g., a respondent asked whether I was "old enough" to interview them) with some older respondents (see Charmaz 2014 for the importance of insider versus outsider perspectives in qualitative methodology). Second, recruiting and interviewing a racially and ethnically diverse sample for the study was limited due to my positionality as a white, non-Hispanic/Latinx interviewer. Having a skewed sample does not preclude qualitative researchers, however, from obtaining meaningful data on how racial, ethnic, and economic privilege shapes the reported experiences of research participants, regardless of sex and gender identity (Riggs et al. Forthcoming). Because TNBI people of color face multiple and intersecting forms of oppression and discrimination in the US (Buchanan and Ikuku 2022; Stryker 2017; Vidal-Ortiz 2009) and have experienced medical trauma at the hands of both researchers and clinicians (Karzakis 2008; Singh and McKleroy 2011; Sumerau and Mathers 2019), relying on SGM and SGM-friendly faith community leaders of color, as trusted community gatekeepers, was necessary for me to recruit and engage with TNBI respondents of color.

Data coding and analysis

My data analyses focused on how TNBI older Americans manage and maintain their health during the COVID-19 pandemic. I coded data using Nvivo (Release 1.6) software and analyzed inductively utilizing a constructivist grounded theory approach (Charmaz 2014). I engaged in initial or open coding, meaning I read a subset of transcripts to develop a general sense of the data and generated an initial list of codes. Subsequently, I engaged in focused or thematic coding, which involves the identification of coding overlaps and divergences, resulting in the combining and collapsing of open codes to form broader thematic codes/themes that are then placed in network relationships to one another. I also coded disconfirming evidence during the focused coding process. I then developed categories and themes from this coding scheme to discern emergent patterns and connections in the data. Finally, I engaged in axial coding, linking demographic attributes in the dataset (e.g., gender identity, socioeconomic status) to specific codes and themes, which provided information about particular patterns among and between various sub-groups of respondents. Utilizing the analytic memos, recurring themes, and existing literature, I thematically analyzed these data while exploring emerging themes and codes concerning my research question: How do TNBI older Americans manage and maintain their health during the COVID-19 pandemic?

Participant sample

Demographics of the participant sample are located in Appendices E and F. I conducted semi-structured, in-depth interviews with 50 TNBI older adults (65 years or over). Participants resided across 21 US states. Most respondents (60%) live in suburban areas, while 28% live in urban areas and 12% live in rural areas. Regarding sex as a social category, 32% self-identified as intersex and/or as someone with intersex variations. Regarding gender identity, over half of participants (54%) self-identified as transgender women. This research sample contained mostly endosex (not intersex) and intersex TNB people. Only three respondents in the participant sample self-identified as cisgender (not transgender) intersex people. Respondents ranged from 65 to 81 years of age (average age: 69 years).

The majority of respondents were white and non-Hispanic/Latinx (74%) with 26% from racial and/or ethnic minority backgrounds. Regarding social class, most self-reported as middle-class (58%) and 18% as from low-income backgrounds. Respondents reported diverse sexual identities, with most identifying as lesbian (33%) or bisexual (20%). Most respondents reported obtaining an associate's or more advanced college degree (62%), with 22% of respondents holding a graduate degree. Most respondents were single (64%) and had no children (34%). Respondents' identities and lived experiences shaped the research findings from this dissertation study. In what follows, I discuss how TNBI older Americans manage and maintain their health during COVID-19.

4.5 FINDINGS

Overall, TNBI older adults' narratives from my research sample revealed that the COVID-19 pandemic was an unanticipated life course disturbance that drastically impacted their health management attitudes and experiences. For example, regardless of respondents' demographic and social backgrounds (e.g., political and religious affiliation), most respondents reported socially distancing themselves from others outside of their household during the early stages of the COVID-19 pandemic. However, respondents had various reasons why they chose to physically distance themselves from others outside of their household, aside from the US government stay-at-home orders (e.g., benefits of working from home, social responsibility to not spread COVID-19 infection, spending more time with spouses/partners, peer pressure from family members and friends). The primary explanation for why respondents physically distanced from others was due to the fear of being exposed to and managing COVID-19 infection. This specific fear often constructed TNBI respondents' decisions in managing their physical and mental health.

Summer, a multiracial, low- income, endosex, heterosexual, transgender woman, who reported managing chronic neck and back pain for most of her adult life, described how her fear of experiencing COVID-19-related illness made her choose not to seek medical care for her chronic pain symptoms:

> Summer: I've had [sic] to be honest, I stayed home a lot. That kind of stuff scares me... I had a couple of aches and pains during the... during the pandemic that I wasn't able... I wasn't able to go. My fear took over.
>
> NL: The fear of getting sick or...?

Summer: The fear of catching COVID.

Summer expressed how her fear of becoming ill with the COVID-19 virus acted as a barrier to receiving medical services for her chronic pain symptoms.

Aging researchers have described maintaining human agency as an important principle that may enhance health management over the life course (Elder 1994; Elder and Giele 2009; Settersten 2018). However, many respondents expressed fears similar to Summer's during the early stages of the COVID-19 pandemic (e.g., fear of COVID-19-related death and of not being able to see family members and friends again), which severely limited their human agency with maintaining their health and well-being. Indeed, many TNBI older respondents described having limited or no control in managing and maintaining their health, such as feeling "powerless," "limited," or "restricted," while some respondents expressed that they took health management during the COVID-19 pandemic "one day at a time."

Nearly all TNBI older adults from my research sample described their health management decisions and experiences during the COVID-19 pandemic through two, primary themes: (i) coping with COVID-19 related social isolation and (ii) navigating disrupted medical care. Such experiences were heavily influenced by respondents' social and structural advantages and disadvantages, such as financial security (or lack thereof), informal and/or formal care partnerships, and reliable access to technology. While these research findings cannot be generalized to the SGM older adult population, they are suggestive that broader patterns of social and health inequity affect how TNBI older adults manage their health during the COVID-19 pandemic. For the remainder of this analysis, I will demonstrate how respondents resourcefully circumnavigate social isolation and disrupted access to medical care that impact their health management during the COVID-19 pandemic and how such insights should be incorporated in structurally-competent medical education, training, and practice.

4.6 COPING WITH COVID-19 RELATED SOCIAL ISOLATION

TNBI older adults in my research example described the substantial challenges they endured with managing social isolation due to the COVID-19 pandemic, regardless of whether they lived with others in their household. Most respondents described their coping processes when managing COVID-19-related social distancing and isolation (e.g., temporarily living with family members, playing bingo with friends virtually). Respondents reported two primary health management challenges that influenced their feelings and experiences with social isolation during the COVID-19 pandemic: (i) exacerbated mental health challenges and (ii) disrupted social relationships and support.

Exacerbated mental health challenges

Respondents primarily reported exacerbated mental health challenges while coping with social isolation during the COVID-19 pandemic – a global and unanticipated life course disturbance. Specifically, respondents expressed increased, negative aspects of their mental health symptoms (e.g., a self-reported increase in loneliness, anxiety, and depression) during the COVID-19 pandemic and discussed more limited agency to make quality health management decisions for themselves and their family care partners. Respondents who lived by themselves discussed how their single-person household status was a notable contributor to their exacerbated mental health challenges, especially if they needed additional caregiving support during the COVID-19 pandemic.

Amari, a Black, middle-class, intersex, lesbian, transgender man explained why he underwent substantial mental health challenges during the first six months of the COVID-19 pandemic: “I think it [COVID-19-related social isolation] was lonely because, at that point, my caregiver was not around. And my kids, they live far away, they don't stay in my house. So, it was lonely. Just think[ing] I was alone. I could barely take care of myself at that point because of it… Yeah, it was hard.” Amari shared his experience of being socially isolated during the COVID-19 pandemic without any caregiver assistance and support. Amari further acknowledged that he “could barely take care of” himself because of his elevated feelings of loneliness during COVID-19-related social isolation periods. Amari’s children did later hire a full-time, formal caregiver to care for Amari after he finally disclosed his mental health challenges to them months later. Much like Amari’s description of how his feelings of loneliness created issues in his ability to take care of himself during the COVID-19 pandemic, most respondents described how their exacerbated mental health challenges during COVID-19 acted as major barriers in maintaining their prior health management routines before the COVID-19 pandemic began. Respondents were very much aware of their mental health challenges influencing how they managed their physical health during COVID-19, such as more frequent alcohol and/or smoking use or regularly forgetting to take their chronic illness medication (e.g., prescribed medication for managing high blood pressure).

As a US health disparity population that also has a higher risk for serious illness from COVID-19 due to older age, it is important to recognize how the effects of the COVID-19 pandemic reproduce broader patterns of mental health inequity among TNBI older Americans. Researchers have demonstrated, for example, how TNBI patient populations face various challenges related to TNBI-related stigma, discrimination, and violence in public spaces from cisgender (not transgender) and endosex (not intersex) others, which can negatively impact their mental health and well-being (Nowakowski, Sumerau, and Lampe 2020; Sumerau and Mathers 2019). For respondents with underlying mental health conditions such as anxiety and depression, experiencing social isolation during the COVID-19 pandemic can structurally limit their ability to achieve health management goals or at least maintain basic wellness. This examination of TNBI older adults' exacerbated mental health challenges informs structural competency in medicine by pinpointing the conditions that TNBI older Americans experience as short- and long-term effects of health management challenges during the COVID-19 pandemic.

Antonio, a Latino, low income, intersex, gay, transgender man, described how he experienced immense changes in his physical and mental health after his state's COVID-19 stay-at-home order went into effect:

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

Antonio – who lives alone - shared his health management experiences of coping with COVID-19-related social isolation and how he underwent notable physical and mental health issues, such as "the loss of self-motivation" and stress-related weight loss. As Antonio emphasized with his need to "rid[e] everything one day at a time," managing health during a pandemic was uncharted territory for respondents that had not been encountered during earlier experiences throughout their life course. Respondents like Antonio felt they were not able to meaningfully maintain a consistent routine to maintain good overall health. Antonio's feelings of loss and regret around previous life decisions made in adulthood further illustrate associations between the COVID-19 pandemic mental health challenges among TNBI older adults. As a medically and socially vulnerable population, with limited peer support services and resources dedicated to them, these populations may experience new (or considerable exacerbations of existing) mental health issues during COVID-19.

The COVID-19 pandemic posed noteworthy barriers among TNBI older adults in managing and maintaining their mental health, especially while coping with social isolation. Existing social conditions further hinder TNBI older adults' ability to maintain basic wellness and high quality of life in older adulthood. Reducing mental health disparities among TNBI older adults will require better efforts to reduce social isolation through intervention research and affordable peer support services and resources tailored to them. The concomitant neglect of TNBI people through medicine and other social institutions (e.g., families, religion) in US society also structurally limits TNBI older adults' ability to make comprehensive health management decisions for their unique health and healthcare needs during the COVID-19 pandemic. Structural competency training and education within healthcare systems is necessary to mitigate COVID-19-related challenges that TNBI older adults are facing in US society (Donald et al. 2017; Metzl and Hansen 2014).

Disrupted social relationships and support

Most respondents described having disrupted social relationships and support during the COVID-19 pandemic, which influenced their health management goals and experiences. One-third of respondents reported losing contact with other SGM friends, acquaintances, and community leaders during the COVID-19 pandemic. When I asked about maintaining friendships during the COVID-19 pandemic, Mary, a white, middle-class, endosex, lesbian, transgender woman explained: "I used to be friends with a lady who [is] trans, but I haven't seen her for a couple... three years because of the pandemic and we just lost touch. That wasn't great for me… health-wise." Mary originally had met her friend through a drag queen bingo event and, over the years, they bonded over common interests such as baking desserts and taking cross-country road trips together. Mary described how they lost touch after the pandemic began and she had difficulty "health-wise" not having her friend's social support and presence in her life, which helped her to maintain her emotional and social health. Mary's narrative about her disrupted social relationship with her friend highlights the importance of TNBI older adults maintaining social support networks to boost their mental health and well-being.

While many respondents reported disrupted social relationships and support when coping with COVID-19-related social isolation, some expressed how they resourcefully drew upon such situations as a way to focus on themselves and better their health management as TNBI people. Helen, a white, lower-middle-class, endosex, bisexual, transgender woman illustrated how she reevaluated her life after her spouse's death and wanted to move forward with the transitioning process to better her overall health and quality of life as a trans woman:

> What happened was my wife was sick for a long time, she had severe dementia and, you know, I was the primary caregiver and she passed away last July… It was, you know, weeks after weeks after she passed on, then, "OK, what do I do now?" And, you know, I started thinking about this stuff and everything. I had lots of time to be myself and thinking everything through because of COVID. And then a couple of days later, I said to myself, "Wait a second before you decide what we do now. Who the hell are you?" And I did a deep introspective into myself and how I felt my entire life and everything. And it just came to the conclusion that, hey, this is something you know, I got to look into. And I started doing a lot of research and everything and long about mid-December, I decided, you know, "OK, now it's time to talk to a therapist, you know, just to make sure you know you're not crazy and that you're thinking clearly."

Several life course transitions are reflected in Helen's experience. After Helen's spouse passed away during the early stages of the COVID-19 pandemic, Helen sought out mental health support from a therapist to begin the medical transitioning process and focus on her emotional health during these life changes. Much like Helen's experience, some TNBI respondents had family members (all of whom were cisgender and endosex) who became estranged or passed away in 2020, which encouraged TNBI respondents to center their health and seek out gender-affirming medical care and resources. Such a pattern is an example of how TNBI respondents resourcefully manage their health when navigating disrupted social relationships during the COVID-19 pandemic.

Even when trying to navigate disrupted social relationships and support during COVID-19 by relying on technology access and resources (e.g., connecting with others using telephones, social media messaging apps, and video conferencing software), some TNBI respondents described the difficulty of maintaining social relationships and support while managing their mental health during the pandemic. When asked whether she experienced social isolation during the COVID-19 pandemic, Summer said:

> Absolutely. No friends to visit and no friends... I was not... Letting any friends come over, but we do have Facebook and I do that Messenger. So, I did a lot of Messenger and video chats on Facebook. So, I was still able to keep in contact, you know. But it's not the same as having in-person contact. It still affected me mentally and not in a good way.

Summer emphasized how she was still able to maintain contact with friends over Facebook when the federal and state social distancing mandates were enforced. However, Summer still experienced mental health challenges during that time because virtual communication is "not the same as having in-person contact."

When I followed up with Summer by asking her how that experience made her feel, she explained:

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

As someone who lives by herself and emotionally thrives on maintaining in-person social interactions, Summer's mental health worsened while being physically isolated due to COVID-19. Summer demonstrated the vulnerable mental and social health states that many TNBI older Americans experienced during COVID-19 physical distancing. Some respondents, for example, were worried about the possibility of never physically being able to spend time with their close family members and friends again due to the worsening of COVID-19 pandemic conditions locally and globally.

Disrupted social relationships and support during the COVID-19 pandemic notably shaped TNBI older adults' health management goals and challenges. Not having adequate social support and resources for health management during the COVID-19 pandemic posed unique obstacles to respondents' ability to maintain quality social relationships and mitigate mental health concerns, which may lead to experiencing greater social and health inequities in later life. Such social conditions simultaneously reflect and reproduce mental and physical health disparities among TNBI older adults as the COVID-19 pandemic continues. In what follows, I explore how respondents navigate disrupted medical care and how they manage their health through these challenges.

4.7 NAVIGATING DISRUPTED MEDICAL CARE

Because the COVID-19 pandemic exacerbated healthcare workforce challenges in the US and created a shortage of healthcare resources, respondents reported how they navigated disrupted access to medical care as TNBI older adults. All respondents in the present study reported barriers concerning healthcare access and utilization due to the COVID-19 pandemic (e.g., needing to purchase WIFI to access telehealth visits, being afraid to receive emergency care). However, such experiences greatly depended on respondents' ability to receive material and social support from family care partners and to access social resources to further maintain their health during the COVID-19 pandemic. As such, there remain considerable structural inequities in health management among TNBI respondents from single-person and/or financially disadvantaged households. Resourceful health management strategies that TNBI respondents reported included: (i) adopting cost-effective strategies for health management and (ii) incorporating family care partners in chronicity management.

Adopting cost-effective strategies for health management

Over half of respondents reported adopting cost-effective strategies for resourcefully managing and maintaining their health during the COVID-19 pandemic. Many respondents reported that their financial concerns and insecurity worsened during the pandemic (e.g., losing employment, retiring earlier than planned, providing financial support to family members) and that this was the primary reason for shifts in their health management capacity or priorities. Respondents discussed how they resourcefully shifted to using more cost-effective health resources to enhance their health management (e.g., outdoor or at-home rather than gym exercise activities, reducing food intake or meals at restaurants, using free mindfulness and relaxation telephone apps) as self-health management strategies during the pandemic.

When asked about her health management experiences during the COVID-19 pandemic, Dominique, a Black, middle-class, intersex, bisexual transgender adult, described how she moved in with her child and grandchild due to financial and health concerns after the World Health Organization declared the COVID-19 outbreak a pandemic. Dominique lived in an independent assisted living facility before the pandemic. She further explained that she was able to better manage her health with her family members than previously: “[W]e've been doing the exercises in the house the whole time with them [child and grandchild], we've… we've done some yoga, we've watched some movies, so it's like bonding time. And then my grandson is in school. So, I would help out with his homework once in a while." Dominique and her family members were able to participate in fun, enjoyable, and cost-effective activities together while they were in lockdown. Dominique explained how her family members' recent involvement in her health management routines provided fruitful opportunities to maintain her physical and mental wellness, while also supporting her family members with family caregiver responsibilities such as helping Dominique's grandchild with his homework. Dominique's narrative emphasizes the importance of familial support for some TNBI adults' cost-effective, health management strategies during the COVID-19 pandemic.

One-third of respondents reported regularly engaging in outdoor exercise and recreation activities to mitigate negative health effects due to the COVID-19 pandemic. Respondents described how visiting national and state parks and participating in park activities with others (e.g., fishing, camping, hiking, swimming) during the COVID-19 pandemic assisted them in better managing their physical health. When asked about her physical health status, Yvette, a white, middle-class, endosex, lesbian, transgender woman, recounted her recent hiking trip with a friend:

> Well, for my age, I'm good to excellent. No lung issues or heart issues. I walk three and a half miles a day or more. I was backpacking in April in the [US national park] wilderness for six days, five nights, 40 miles. We tracked 40-pound packs. Something you'd enjoy, I'm sure. Sleeping in our tents on the ground. We had ice one morning, which is what happens at that time of year. And we were in T-shirts and shorts in the middle of the afternoon.

Yvette reported her "good to excellent" physical health status and described how she was able to complete a long-distance hiking trip with heavy camping equipment and difficult weather conditions. Much like Yvette, many respondents who regularly engaged in outdoor exercise and recreation activities felt that they better managed their physical health during the COVID-19 pandemic.

At the same time, over a third of TNBI respondents in my research sample shared that financial insecurity imposed unique barriers to their health management during the COVID-19 pandemic. Some respondents, most of whom were from racial, ethnic, and/or social class minority communities, were more concerned about addressing immediate needs (e.g., being financially able to purchase groceries or pay rent) than engaging in cost-effective health management approaches during the pandemic. When asked about his health management experiences during the COVID-19 pandemic, Kojo, a Black, middle-class, endosex, bisexual, transgender man, explained that he almost died from COVID-19, which completely depleted his finances.

> Kojo: It has been tough. I was actually sick with it [COVID-19] for a couple of months in the beginning and almost died. It was quite awful.
>
> NL: What do you think… could have helped you with any kinds of resources or forms of support during the COVID 19 pandemic? Are there things that could have been more helpful for you to navigate all of this?
>
> Kojo: More money and more access to doctors. I lost a lot of money [while] trying to get better.

Kojo illuminated the social conditions of many respondents who experienced significant financial challenges that resulted in barriers to maintaining their health and wellness during the COVID-19 pandemic.

Respondents from racial, ethnic, and/or social class minority communities also reported need for additional resources from medical and social service agencies to better manage their immediate health needs and quality of life during the COVID-19 pandemic. Lupita, a Black, working-class, endosex, bisexual, transgender woman, explained: "COVID-19 resulted in major changes in my expenditure and overall health. I am glad that I survived it. But I really could of used a lot of help during early COVID days – like a social worker to make sure I continue to have food on the table and a roof over my head." Indeed, TNBI older adults who do not have adequate social resources and support systems during the COVID-19 pandemic are in a particularly vulnerable position to comprehensively manage their health, which may worsen existing health inequities among these aging communities. Although adopting cost-effective resourceful strategies for health management (e.g., outdoor exercise and recreational activities, using mindfulness and relaxation apps) was a common method for many respondents aiming to better their health and quality of life during COVID-19, such approaches are structurally limited due to their inability to fully address TNBI older adults' immediate everyday living and health needs in US society (e.g., food and housing assistance, safe TNBI-welcoming spaces to engage in outdoor exercise and recreational activities).

Incorporating family care partners in health management

The second approach respondents reported when navigating disrupted medical care during the COVID-19 pandemic is incorporating family care partners (family caregivers) in health management. Almost all TNBI older respondents managed acute and/or chronic health conditions. Overall, respondents with chronic health conditions shifted their health management strategies to have family care partners assist them with daily living tasks, such as medication management and cooking nutritious meals. Many respondents also reported their family care partners advocating for them during healthcare appointments. Miguel, a Latino, middle-class, intersex, heterosexual, transgender man, recalled his children's recent involvement during Miguel's telehealth appointments with his doctors: "[T]hey [Miguel's children] really give me a lot… My children sometimes now translate for me when I'm tired of doctors who don't understand me through the computer [telehealth] when I tell them my meds aren't working."

Echoing Nowakowski and Sumerau (2017) on the importance of centering family care partnerships in health management, several TNBI respondents expressed their appreciation for maintaining strong family care partnerships with their significant others (i.e., partners and/or spouses) to better manage their health during the COVID-19 pandemic. Some respondents discussed the emotional value of both receiving care from and providing care for their family care partners – especially respondents who have similar health management needs and expertise as their family care partners. Linda, a white, middle-class, endosex, lesbian, transgender woman, and a retired medical provider, offered an example of how she and her spouse, Diana, provided care for one another rather than seeing a medical provider during the COVID-19 pandemic:

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

Much like Linda’s narrative, but even without formal medical training, most respondents felt that some health needs could be easily managed with the assistance of their family care partners during COVID-19.

Despite respondents’ mostly positive experiences with incorporating family care partnerships into their health management practices, there remain structural barriers to care among TNBI older respondents who do not have family care partners to help manage their health during the COVID-19 pandemic. Having regular access to family care partners is a social privilege in the US that many TNBI older Americans simply do not have due to existing social, familial, and institutional stigma, discrimination, and neglect of TNBI aging communities in US society. At the same time, family caregiving can be a valuable, resourceful, and cost-effective strategy for health management (Nowakowski and Sumerau 2017) that allowed many TNBI older respondents to reduce formal medical care during the COVID-19 pandemic while maintaining their overall health and well-being. Such social support dynamics shape the health management decisions and experiences of TNBI aging communities.

Despite most respondents reporting having adequate social support for their health management, other respondents reported having no or very limited social support with their health management challenges (e.g., polypharmacy, high fall risk, clinical depression) throughout the COVID-19 pandemic. Although he lived with his children because of COVID-19, Kojo disclosed that he has no social support in managing his health and healthcare. When I followed up with Kojo about his social support from medical providers in managing his health during the COVID-19 pandemic, he explained:

> Yeah, I initially had a really, really, bad experience… [T]hey were really punishing me – I think - for being male [a trans man]… [T]hey [medical providers] gave me an incorrect supply of medication and information about the medication… They didn't help me manage my medication, even though I asked many times. I called them many times. No one returned my calls. No one cares about my health. Not my children. They didn't want to help me even though I brought them into this world… Not my doctor and nurses…. When they finally gave the correct amount [of medication], like I already had hypertension and I lost blood flow and almost died from a stroke… The doctor said I really, really can't blame them because the medication they gave me was basically helping my heart and I didn't tell them I was on other medications for me being male... Maybe the doctor or doctors could have been more… more… asking those kinds of questions or answered the fuckin' phone, I would of opened up with more information.

In addition to Kojo almost dying from COVID-19 in 2020, he also experienced a life-threatening medical emergency because his medical providers did not provide adequate social support and communication in counseling Kojo with his medication management. These medical providers also did not ask Kojo for his comprehensive patient history (i.e., past or recent use of medications), which could have prevented the harmful side effects that Kojo experienced. Additionally, Kojo reported that his children did not provide him with social support and assistance with his medication management challenges. Such social conditions make it difficult to effectively manage health during COVID-19 for respondents who lack social support as TNBI older adults.

Overall, resourcefully adopting cost-effective strategies and incorporating family care partners in health management practices requires both privilege among TNBI older adults (e.g., financial security, social support, access to health information and resources) and access to tailored health and peer support services. Those who do not have such privilege and access continue to struggle to manage their health during the COVID-19 pandemic. As such, navigating health management during COVID-19 posed many new challenges for TNBI older adults in the present study, which could have been potentially mediated through structurally-competent medical care (Donald et al. 2017; Grimstad et al. 2021). Some potential resourceful strategies that may have been offered in these circumstances for TNBI older respondents during the COVID-19 pandemic include structurally-competent approaches such as offering reliable formal caregiving services, medication assistance programs, and age-tailored web-based resources that respondents could utilize to connect with other community members and find medical referrals and resources. Thus, these existing social and health challenges are fundamentally preventable with TNBI older adult structural competency in healthcare and peer-support services. Creating more structurally-competent healthcare practice (or reducing structural incompetency) would allow TNBI older patients to have greater likelihoods of receiving quality, effective care that addresses the macro-level sources of their health disparities.

4.8 DISCUSSION

Using a life course perspective, this work assesses how TNBI older adults manage and maintain their health during the COVID-19 pandemic. The life course perspective provides a useful framework for better understanding how the COVID-19 pandemic – as an unanticipated life course disturbance – dynamically shapes TNBI older adults' health management decisions, practices, and challenges. Currently, there is limited empirical research addressing individual and collaborative health management that pays particular attention to TNBI older adults and how they respond to the challenges imposed by the COVID-19 pandemic while working to maintain, protect, or better their health (Nowakowski and Sumerau 2017). These research findings reveal the social and structural barriers (e.g., lack of financial security, access to resources, and social support) to achieving TNBI older adults' health management goals. These critical issues must be further examined and addressed in future sociomedical scholarship focusing on TNBI older adults. Understanding TNBI people's health management practices in older adulthood as dynamic interactive processes influenced by privilege, social location, and life course disruptions (such as COVID-19) is a critical step toward reducing and eliminating health disparities among SGM older adult Americans.

My findings suggest that sociomedical scholarship would benefit from greater attention to the unique vulnerabilities and challenges SGM older adults experience in protecting their health during the COVID-19 pandemic. Although previous research has explored how various underserved communities in healthcare have responded to the COVID-19 pandemic (Gauthier et al. 2021; Jarrett et al. 2021), researchers know very little about how structural conditions and stigma against TNBI aging communities reproduce patterns of inequality during COVID-19. In the case of public policy, SGM people have faced recent anti-SGM legislation (e.g., transgender youth healthcare bans) in the US. However, we know little about how health might differ among SGM people who reside in US states with anti-SGM or SGM non-discrimination laws across the life course. Further, we have little to no evidence-based knowledge on the perspectives of

TNBI older adults during the COVID-19 pandemic. This research begins to fill that gap. Future interdisciplinary medical scholarship should examine health management needs, behaviors, and experiences among TNBI older adults and implement interventions that specifically target aged care services, outreach, and support training. Such research will allow researchers, practitioners, and policymakers to better address systemic social, health, and healthcare inequities existing among TNBI people in older adulthood.

Respondents in this study illustrate experiences of social inequity among TNBI people within the specific context of health management during the COVID-19 pandemic. I further extend this work by articulating how TNBI older adults protect or struggle with their health management while responding to the COVID-19 pandemic and minimizing the impacts of experiencing disruptions in medical care. Research findings can guide direct improvement of health and peer-support services for TNBI people and identify additional opportunities for SGM communities to live and age well. I call for new growth and development in this emerging research area to investigate how medically and socially underserved communities respond to the COVID-19 pandemic, assess access to social and healthcare resources, and determine how various access and care strategies may ameliorate or exacerbate existing health, aging, and healthcare inequities among SGM older adult populations.

CHAPTER 5: CONCLUSION

5.1 SUMMARY OF RESEARCH FINDINGS

To date, there is limited sociological research focusing on the lived experiences of TNBI patient populations over 65 years of age. As a socially and medically vulnerable aging population in the United States, there is a critical need for researchers and clinicians to maintain structural competency by adequately addressing the macro-level forces that influence TNBI older people's health and healthcare needs, such as offering opportunities to receive free legal services for formal advance care planning documentation. Metzl and Hansen (2014:5) define structural competency as "the trained ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases [e.g., clinical depression and anxiety symptoms]… also represent the downstream implications of a number of upstream decisions about such matters" [e.g., experiences with sex, gender, and sexual discrimination]. Medical professionals must recognize the complexity of the specific healthcare needs (Davis 2015; Witten 2017), access (Davis et al. 2016; Gooren and T'Sjoen 2018), utilization (Caceres et al. 2020; Simmons 2020), experiences (Feder 2014; Porter et al. 2016), and barriers (Johnson et al. 2020) among TNBI people, and how these experiences differ by the structural constraints that TNBI people with various socially privileged and/or marginalized standpoints face in US society (Davis 2015; Sumerau and Mathers 2019).

Using data from 50 semi-structured, individual interviews with TNBI older Americans, I address these substantial gaps in the empirical knowledge base by examining three primary research areas. First, I examine how TNBI older Americans access and experience reproductive and sexual health services. Second, I investigate how TNBI older Americans perceive and plan for end-of-life experiences in the context of advance care planning. Third, I assess how TNBI older Americans manage and maintain their health within the context of the COVID-19 pandemic. In the following, I summarize my research findings and explain their implications and limitations, while offering potential future directions for creating TNBI older adult structural competency in interdisciplinary medical research and practice.

Summary of the first study

Advancing the conceptualization of minority stress and resilience (Hash and Rogers 2013; Meyer 2003, 2015), I examine how TNBI older adults – as a medically and socially vulnerable sub-group within SGM communities – perceive, access, and utilize reproductive and sexual health services through *resourcefulness*. Resourcefulness, or implementing resourceful strategies, is a tactical process by which socially and medically vulnerable communities obtain and use resources (e.g., access to reliable, social support) to improve their social and health challenges. Resourcefulness is different from resiliency insofar as it acknowledges the necessity of social privilege, material and social capital, and resources to overcome difficult situations, rather than successfully using individual, psychological coping strategies alone. Attending to such processes is an example of structural competency – or considering how macro-level systems, institutions, and structures reproduce barriers to appropriate care and interventions at the meso level.

Attending to resourcefulness makes clear the necessity of providing direct resources in order to meaningfully address and reduce SGM health disparities.

First, most respondents described medical provider ignorance in providing (i) SGM-competent and (ii) age-friendly care in reproductive and sexual healthcare settings. Consequently, TNBI older respondents reported the use of resourceful strategies for combatting medical provider ignorance and incompetence when accessing and/or utilizing reproductive and sexual health services. Specifically, I found a bifurcation in respondents' narratives in using resourceful strategies to combat medical provider ignorance with (i) trans men respondents opting out of receiving sexual and reproductive health services and (ii) trans women and non-binary respondents seeking out SGM-competent care providers, services, and resources. However, these strategies required respondents to assume individual responsibility for receiving (or avoiding entirely) quality reproductive and sexual health services. Such approaches within reproductive and sexual healthcare systems are not structurally sustainable for maintaining SGM-affirming and age-inclusive care for older TNBI adults in US society.

Summary of the second study

Introducing the concept of *satisficing around aging and death*, I urge health and aging researchers to move beyond binary good vs bad aging and death framework to more fully account for the systemic barriers to initiating, completing, and legally formalizing advance care planning among TNBI aging communities. Further, I underline the need to develop structurally- competent care practices for SGM older patient populations through focus on provision of necessary resources. Satisficing around aging and death is a process that involves being less able to access or be assured of a good aging process and death due to existing social, structural, health, and healthcare inequalities faced by TNBI people (Cain 2021; Dickson et al. 2021; Henry et al. 2020; Kortes-Miller et al. 2018). This conceptualization aids in the maintenance of TNBI older adult structural competency by acknowledging systemic barriers to being able to access healthy aging and a good death among TNBI older populations (e.g., lack of standards of care for TNBI patients in end-of-life care settings).

I analyze the current social, medical, and political state of TNBI older Americans by determining their unique needs for (and barriers to) advance care planning and end-of-life preparation, while pinpointing what a good death might mean for older TNBI people. While sociologists have examined perspectives of dominant good death definitions among underserved communities in healthcare (Cain 2021; Carr 2003), my analysis reveals TNBI older adults' uncertainties around their ability to experience a good death, along with their resourceful strategies for reducing the possibility of a bad death.

First, respondents reported two primary fears that motivated their uncertainty around having a good death as an older TNBI person: (i) medical mistreatment and neglect in aged care settings and (ii) lack of social support. And second, because respondents have a great deal of uncertainty around whether they will be able to have a good death, they reported engaging in resourceful strategies that might prevent them from experiencing a bad death: (i) formalizing advance care planning documents and (ii) selecting healthcare agents. Specifically, respondents report engaging in pragmatic strategies (Pfeffer 2012) to avoid a bad death rather than pursuing idealized pathways to a good death that are socially and/or structurally inaccessible or unattainable to them. Examining TNBI older adults' uncertainties around having a good death offers fruitful opportunities for expanding SGM scholarship on aging and end-of-life experiences while pinpointing how social, economic, political, and medical structural inequities negatively impact TNBI older adults' chances of living and dying well.

Summary of the third study

Older adulthood is a crucial time in the health management journeys of TNBI people. Understanding how the COVID-19 pandemic has impacted TNBI older patients offers critical guidance for successful health services reform and continued delivery systems change. Advancing a life course perspective, I investigate how TNB older Americans – as a medically and socially vulnerable population in the United States – manage their health during COVID-19. TNBI older adults' narratives from my research sample revealed that the COVID-19 pandemic was an unanticipated life course disturbance that drastically impacted their health management attitudes and experiences. Results also indicate a need for enhancing health services and resources for TNB older adults while creating a culture of age-inclusive and gender-affirming healthcare. Two primary themes emerged among respondents' health management experiences during the COVID-19 pandemic: (i) coping with COVID-19 related social isolation and (ii) navigating disrupted medical care. Such themes were shaped by respondents' social advantages and disadvantages, such as access to financial security, social support, and adequate medical care. Respondents from racial, ethnic, and/or social class minority communities also reported need for additional resources from medical and social service agencies to better manage their immediate health needs and quality of life during the COVID-19 pandemic.

Respondents reported two primary health management challenges that influenced their feelings and experiences with social isolation during the COVID-19 pandemic: (i) exacerbated mental health challenges and (ii) disrupted social relationships and support. My analysis also pinpoints how respondents utilize resourceful strategies via (i) adopting cost-effective strategies and (ii) incorporating family care partners (i.e., family caregivers) in their health management during the COVID-19 pandemic, which are key ingredients for providing a comprehensive foundation for structurally-competent medicine among TNBI older patient populations. While these research findings cannot be generalized to the sexual and gender minority (SGM) older population, they suggest that broader patterns of inequity affect how TNBI older Americans manage their health during COVID-19.

Significance of overall research findings

Throughout this dissertation, I examine how current empirical knowledge regarding the reproductive and sexual healthcare experiences, attitudes towards advance care planning, and health needs and management of TNBI older adults is very limited in the social and medical sciences. In addition to beginning to fill these empirical knowledge gaps, this dissertation also offers insights and contributions to the sociology of health, aging, and medicine literatures. Examining TNBI older adults' experiences in sociology is critical for understanding how cisnormativity (normalization of cisgender experiences) and endonormativity (normalization of endosex experiences) both impact older adulthood for TNBI aging populations in US society. Additionally, this dissertation offers empirical, conceptual, and theoretical innovations and contributions to the sociological literature across the following areas: (i) satisficing around aging and death in the context of advance care planning and end-of-life preparation, (ii) resourcefulness or resourceful strategies in the context of reproductive and sexual healthcare access and utilization, and (iii) evidence of the need for greater structural competency among providers of TNBI older adult health care. These contributions are significant because they allow researchers, clinicians, and policymakers to better understand the health, aging, and healthcare experiences of TNBI people over the life course, which will enable more informed approaches toward reducing and eradicating social, institutional, health, and healthcare inequities among TNBI populations.

Researchers have demonstrated how TNBI people (Davis et al. 2016) and SGM older adult populations (Flatt et al. 2022) face substantial disadvantages in US healthcare systems. Yet, sociologists rarely examine the experiences and lives of older TNBI adults, making it difficult to understand how cisnormativity and endonormativity negatively impact TNBI people in older adulthood. By examining TNBI older patient narratives, my research: advocates for greater sex and gender diversity and inclusion in the sociomedical sciences; calls for advancing TNBI-competency and age-friendliness within US healthcare systems and interactions; and outlines key ingredients for ensuring greater structural competence among healthcare providers who work with TNBI older patients.

5.2 LIMITATIONS AND SUGGESTIONS FOR FUTURE RESEARCH

Qualitative research provides rich, descriptive data that offers pathways for understanding social processes and interactions. In general, such research is not intended for the purposes of generalization to the broader population or even the subpopulations from which its samples are drawn. In this dissertation, I have focused on how TNBI older Americans (i) access and experience reproductive and sexual health services, (ii) perceive and plan for end-of-life experiences in the context of advance care planning, and (iii) manage and maintain their health during the COVID-19 pandemic. My motivation for studying and carefully evaluating existing aging, aged care, and end-of-life care disparities among older TNBI Americans focuses on their socially and medically disadvantaged status in US society as an SGM aging population that often reports acute and chronic health conditions with limited social support in managing health, advance care planning, and end-of-life preparation needs (Nowakowski et al. 2019).

While findings from this dissertation may not be considered representative of the entire population of older TNBI adults in the US, future research should pinpoint opportunities for improving TNBI community-dwelling older adults and older residents' experiences in residential aged care settings through structural competency of TNBI-specific community issues and macro-level barriers to care (Donald et al. 2017; Grimstad et al. 2021; Metzl and Hansen 2014). Examining TNBI aged and end-of-life care disparities in the context of COVID-19 may also provide valuable information for medical practitioners with implications beyond the pandemic and with extension into other social conditions that TNBI older adults may navigate as instability within US society increases.

TNBI older adults face various forms of stigma, discrimination, and violence in US society (Sumerau and Mathers 2019), especially in the form of intersectional marginalization among those with racial, ethnic, and/or social class minority backgrounds (Bauer et al. 2009; Nowakowski et al. 2019). Because of my privileged social standpoint as a white, non-Hispanic/Latinx researcher at a research-intensive university, it was particularly difficult to meaningfully recruit and engage with TNBI older adults whose racial, ethnic, and educational backgrounds differed from my own. Like most SGM health research in the US (Fredriksen Goldsen et al. 2019), most respondents in my research sample were white and not Hispanic/Latinx, able-bodied, and/or lived in financially-advantaged households.

While this research sample of 50 participants is not generalizable to the US general population, my research sample of Black respondents (12%) comes close to reaching the percentage of Black Americans in the US (12.4%), but not the US South (Jones et al. 2021). Engaging with Black TNBI community advocates, clergy, and lay leaders from faith communities, with medical professionals from SGM and non-SGM health centers, and being affiliated with a South Carolina public university, may have shaped the percentage of Black respondents in my research sample. Future clinical and empirical research with SGM older adult populations from Black, Indigenous, and people of color (BIPOC), disability, and financially-disadvantaged communities (Orel and Fruhauf 2015; Porter et al. 2016) is needed. Such lack of attention with engaging these SGM subpopulations reproduces structural incompetency, or the failure to understand how macro-level systems, institutions, and structures reproduce barriers to appropriate care and interventions at the meso level, such as the failure to provide direct material, social, and medical resources to SGM older adults from BIPOC communities.

Another important limitation of this research study is the difficulty of recruiting and engaging intersex Americans 65 years or older for research participation. While I was able to interview 16 older intersex Americans for this dissertation research study, this population comprised only 32% of the total research sample. There are two main reasons why intersex older adults may be hesitant to engage in (or completely avoid) research participation that researchers must be mindful about. I explore these factors below.

First, although intersex people (much like transgender and non-binary populations) have existed throughout recorded human history, intersex activism and civil rights movements in the US have been centered primarily on the fight against medical providers performing unnecessary surgeries on intersex infants and youth to "correct" their intersex variations (Carpenter 2018; Stryker 2017). Intersex advocacy organizations in the US (like InterACT: Advocates for Intersex Youth) have actively worked toward human rights advocacy and better healthcare for intersex youth. Intersex research and activism, however, rarely pivot toward discovering opportunities to engage and potentially help older intersex adults (Talley and Casper 2012). Thus, older intersex adults may feel erased, medicalized, and/or tokenized when considering research participation focusing their unique health, aging, and healthcare experiences.

Second, intersex older adults may perceive their intersex variations as a medical condition and thus not utilize intersex-specific terminology or engage in intersex identity work to further understand their bodies and experiences (i.e., referring to intersex variations as differences or disorders of sex development (DSD)). Blackless and colleagues (2020) estimate that about 1.7% of the general population have intersex variations, which is equivalent to the percentage of those in the general population with red hair or green eyes. However, most intersex people are often unaware of their intersex status or traits unless they are experiencing health challenges related to their intersex traits or their intersex traits are externally noticeable (e.g., genitals that do not conform to female/male endosex binary norms). Because of these factors, researchers have substantial difficulty with recruiting and engaging intersex older adults as a medically-vulnerable and invisible aging population in the US.

Despite these notable limitations, utilizing a qualitative research design was a necessary methodological choice for this dissertation study to further examine patient narratives among TNBI older Americans (Compton et al. 2018). Specifically, integrating gender variation and diversity into sociological research through qualitative approaches can transform patient-centered healthcare for TNBI aging populations, while creating opportunities to fill existing gaps at the intersection of social science and medical scholarship (Charmaz 2014). Conducting and analyzing 50 in-depth interviews of TNBI older Americans in a semi-structured format created enough structure and flexibility for respondents to meaningfully convey information they deemed important while providing rich data that meaningfully answered my key research questions and fruitfully provoked many additional avenues of inquiry.

Important to note, there are no large-scale or long-term quantitative health studies in the US that specifically examine the health, aging, and healthcare experiences of TNBI older Americans. Importantly, this qualitative study may inform future development of quantitative instruments to obtain larger-scale data with older TNBI populations. Despite some tension among the diverse membership of TNBI communities about whether or not they should be grouped together (particularly from the perspective of intersex communities in the US), it is particularly challenging to combine a sociological study of these aging populations to further examine aged care and health research focusing on those who live between and beyond sex and gender binary systems (Nowakowski, Sumerau, and Lampe 2020). TNBI communities face similar challenges when navigating

US healthcare systems with providers unable to provide quality care due to existing cisnormative and endonormative assumptions in medicine and existing barriers to age-inclusive and sex and gender-affirming health services. Overall, the potential benefits of using a qualitative research design for this study outweighed its potential limitations.

5.3 CONCLUSIONS

There are many ways to usefully expand sociological research among TNBI older adult populations. Actively recruiting and including narratives and reported experiences from TNBI older adults is a necessary first step in sociological health and aging research. Inclusion of TNBI aging population narratives will offer comparative cases for existing research on SGM, cisgender, and/or endosex aging populations. While the design of this project is not explicitly internally comparative by design, it relies upon external comparison to the existing research literatures referenced herein. Such approaches are both common and important in sociological studies of under-researched populations in health and medicine.

For example, shuster (2021) analyzed medical providers' attitudes of and experiences with transgender patients in the US, while comparing how these medical providers used the medicalization and standardization of intersex bodies as a justification for delaying medical interventions for transgender patients (Davis et al. 2016; shuster 2021). Through such comparisons, sociologists can pinpoint the barriers and resources that TNBI older adults face in their interactions with healthcare and other social systems. This approach differs from others that might situate TNBI aging populations as separate study populations (and generating extremely small sample sizes) or that combine them with the general US adult population or the SGM aging population (often eliding their distinctiveness). Utilizing mixed-methodologies in sociological research can meaningfully address existing methodological and empirical research challenges such as under-sampling, limited literature, and failure to focus on TNBI older adult populations within existing research (Davis 2015; Pfeffer 2017).

Future directions in sociological research should also address the substantial gaps on aging processes and elderly SGM people in the following areas: (1) studies on the chronic, long-term, palliative, and end-of-life care experiences of SGM older patient populations, (2) SGM caregivers and caregiving experiences, (3) studies on racial, ethnic, and social class inequalities among SGM older populations, and (4) studies on health and healthcare experiences among SGM older people globally. By conducting 50 semi-structured interviews with TNBI older Americans in this dissertation, I addressed substantial existing gaps in the sociological literature while gleaning an in-depth understanding of respondents' health and healthcare needs, resources, and barriers in relation to achieving healthy aging. Findings from this study will inform the development of more structurally-competent health research and evidenced-based interventions with medical providers whose patient populations include TNBI older people. Overall, I examined the implications that existing social and medical conditions and structures have on TNBI healthy aging over the life course in relation to TNBI older adulthood. Through this research, interdisciplinary medical researchers, clinicians, and policymakers can benefit from empirical insights into how TNBI older patients populations face and navigate social processes in the context of healthcare interactions and systems – and how such social processes are similar and/or different from those experiences among broader SGM and non-SGM older adult populations.

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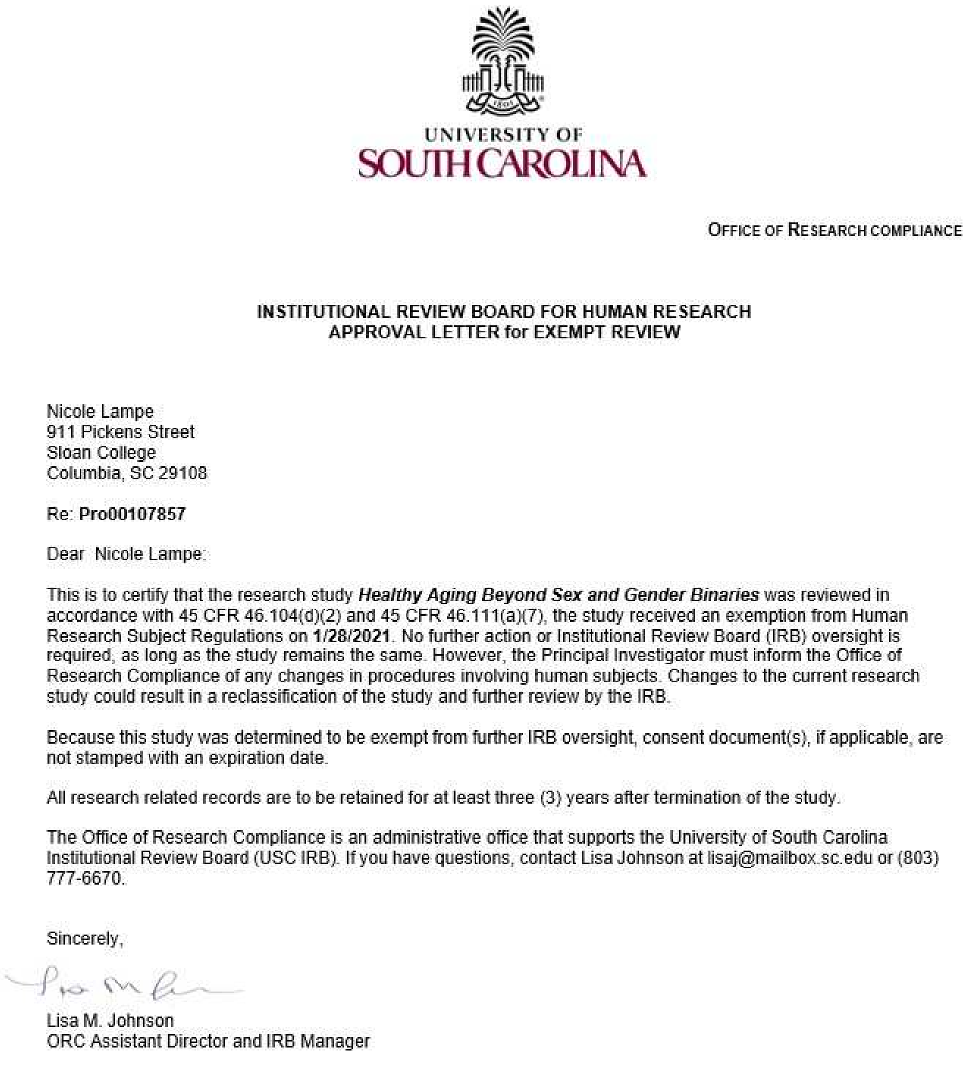
APPENDIX A: IRB APPROVAL LETTER



UNIVERSITY OF
SOUTH CAROLINA

OFFICE OF RESEARCH COMPLIANCE

INSTITUTIONAL REVIEW BOARD FOR HUMAN RESEARCH
APPROVAL LETTER for EXEMPT REVIEW

Nicole Lampe
911 Pickens Street
Sloan College
Columbia, SC 29108

Re: **Pro00107857**

Dear Nicole Lampe:

This is to certify that the research study ***Healthy Aging Beyond Sex and Gender Binaries*** was reviewed in accordance with 45 CFR 46.104(d)(2) and 45 CFR 46.111(a)(7), the study received an exemption from Human Research Subject Regulations on **1/28/2021**. No further action or Institutional Review Board (IRB) oversight is required, as long as the study remains the same. However, the Principal Investigator must inform the Office of Research Compliance of any changes in procedures involving human subjects. Changes to the current research study could result in a reclassification of the study and further review by the IRB.

Because this study was determined to be exempt from further IRB oversight, consent document(s), if applicable, are not stamped with an expiration date.

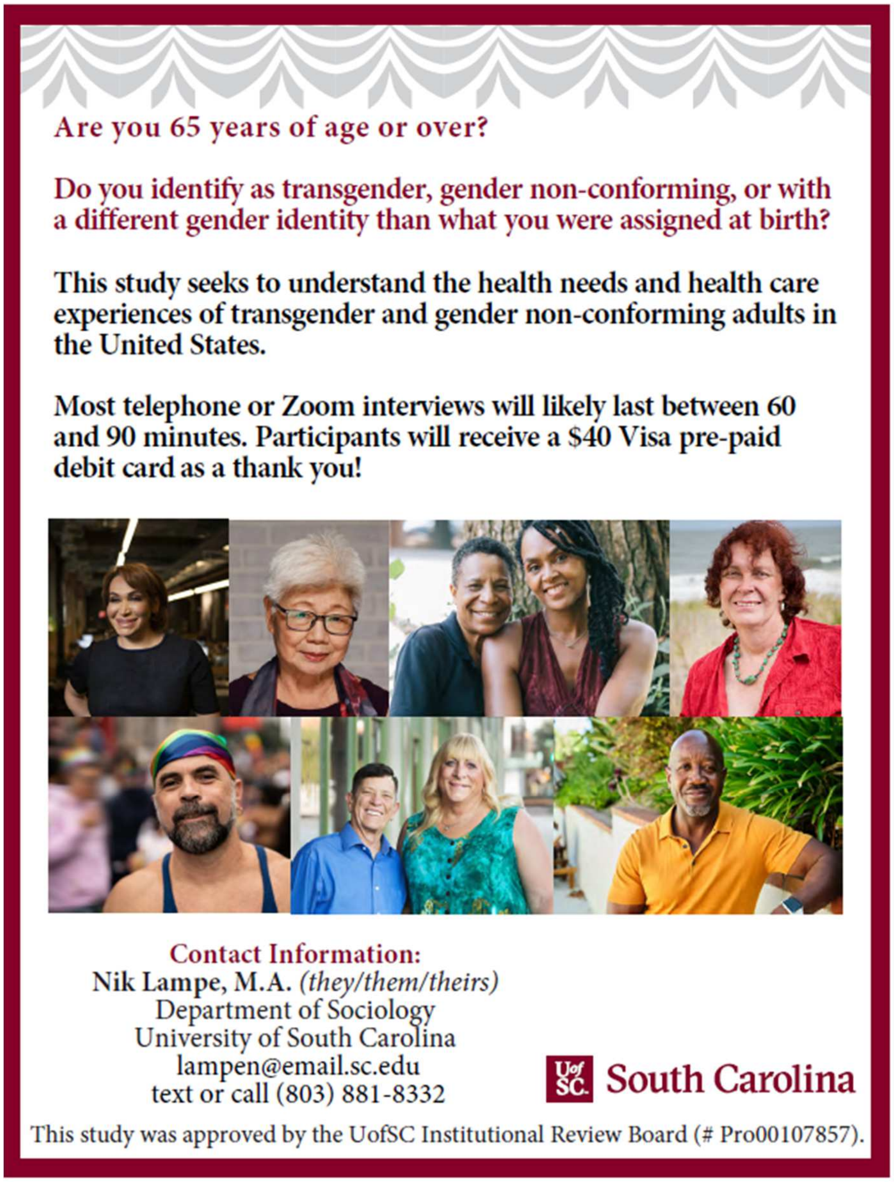
All research related records are to be retained for at least three (3) years after termination of the study.

The Office of Research Compliance is an administrative office that supports the University of South Carolina Institutional Review Board (USC IRB). If you have questions, contact Lisa Johnson at lisaj@mailbox.sc.edu or (803) 777-6670.

Sincerely,

Lisa M. Johnson
ORC Assistant Director and IRB Manager

APPENDIX B: RECRUITMENT FLYER FOR TRANSGENDER AND NON-BINARY AMERICANS 65+



Are you 65 years of age or over?

Do you identify as transgender, gender non-conforming, or with a different gender identity than what you were assigned at birth?

This study seeks to understand the health needs and health care experiences of transgender and gender non-conforming adults in the United States.

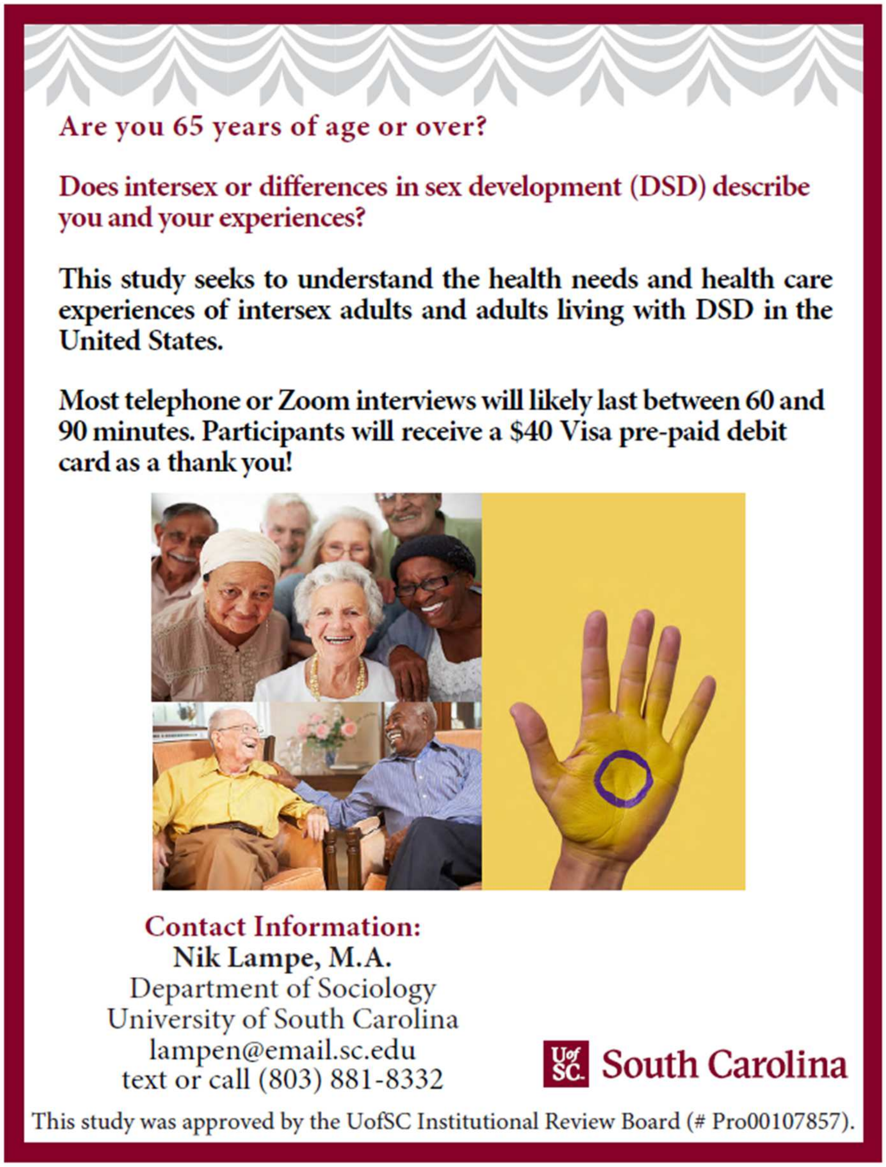
Most telephone or Zoom interviews will likely last between 60 and 90 minutes. Participants will receive a $40 Visa pre-paid debit card as a thank you!

Contact Information:
Nik Lampe, M.A. *(they/them/theirs)*
Department of Sociology
University of South Carolina
lampen@email.sc.edu
text or call (803) 881-8332

UofSC South Carolina

This study was approved by the UofSC Institutional Review Board (# Pro00107857).

APPENDIX C: RECRUITMENT FLYER FOR INTERSEX AMERICANS 65+



Are you 65 years of age or over?

Does intersex or differences in sex development (DSD) describe you and your experiences?

This study seeks to understand the health needs and health care experiences of intersex adults and adults living with DSD in the United States.

Most telephone or Zoom interviews will likely last between 60 and 90 minutes. Participants will receive a $40 Visa pre-paid debit card as a thank you!

Contact Information:
Nik Lampe, M.A.
Department of Sociology
University of South Carolina
lampen@email.sc.edu
text or call (803) 881-8332

UofSC South Carolina

This study was approved by the UofSC Institutional Review Board (# Pro00107857).

APPENDIX D: INTERVIEW GUIDE

VERBAL ASSENT SCRIPT

Introduction and Purpose: My name is Nik Lampe, and I am a Sociology Ph.D. student at the University of South Carolina. The purpose of this research is to investigate the health and healthcare experiences of Americans 65 years and over who identify as transgender, non-binary, gender non-conforming, intersex, someone living with differences in sex development (DSD), or someone who identifies with a different sex or gender identity than what they were assigned at birth. To be transparent with my own background, I identify as trans, non-binary, and intersex.

Description of Study Procedures: If you agree to participate, we will discuss your healthcare experiences and health needs. Some questions will be personal, and you can participate without having to answer any questions that you do not wish to answer. Our conversation will take place over [telephone or video call using Zoom software]. Most interviews will likely last between 60 and 90 minutes. If you give me permission, our interview will be digitally recorded so that I can accurately transcribe what is discussed.

Confidentiality: Participation is confidential, meaning that your identity will not be revealed to others. Your information will be kept in a secure location and no one else other than me will know your personal information. A transcript of this interview will only be reviewed by me and my faculty advisor and destroyed upon completion of the study. The results of the study may be published or presented at professional meetings, but your identity will not be revealed.

Voluntary Participation: Your involvement in this study is completely voluntary and you are under no obligation to participate. You may skip any questions that you do not wish to answer. There are no negative consequences if you choose to end your participation in the study at any time. After the completion of this interview, you will receive a $40 pre-paid Visa gift card for your time and effort. [Need verbal assent to proceed.]

Questions: If you have any questions about your rights as a research participant you may contact me any time at lampen@email.sc.edu or 803-881-8332, my faculty advisor Dr. Carla Pfeffer at (pfefferc@mailbox.sc.edu), or the University of South Carolina's Office of Research Compliance at (803) 777-6670. If you are interested, I can provide some information or support resources for different challenges we cover after our interview. Do you have any questions about this study before we begin? Do you agree to participate in this interview? [Need verbal assent to proceed] May I begin recording our conversation? [Start recording if you receive verbal assent].

PARTICIPANT DEMOGRAPHIC QUESTIONS

a) I would like to start by getting some basic information about you. [Respondents will answer Questions 1 to 19 verbally during the interview or by filling out an electronic, demographics survey prior to the interview.] What year were you born?
b) How do you identify in terms of gender?
c) What are your pronouns?
d) When you were born, what sex was initially listed on your birth certificate?
e) Do you identify as someone who is intersex or someone who was born with a difference of sex development or DSD?
f) How would you describe your race and ethnicity?
g) How would you describe your sexuality?
h) What is the highest level of education you received?
i) Are you currently employed? [If no: Retired? Volunteering?]
j) Do you receive SSI/SSDI/SNAP/public assistance benefits?
k) What is your social class?
l) What is your relationship status?
m) Do you have any children? [If yes: How many?]
n) What state do you currently live in?
o) Do you currently live in an urban, suburban, or rural area?
p) What type of housing do you live in? [E.g., A group home or communal living and care environment]
q) Who currently lives in your household?
r) What is your health insurance status? (Employer-sponsored, government-sponsored, self-funded)
s) Are you a veteran?
t) What is your religious affiliation?

Thank you for answering these questions. I would now like to ask you a few questions about your healthcare experience.

INTERVIEW QUESTIONS

Healthcare Experience

1) I'd like to start by having you think back to the first time you identified as_______/found out about your intersex [or DSD status]. When was that? How old were you and what was going on in your life at that point?
2) If respondent is intersex: How did you find out about your intersex [or DSD] status?
3) What other interactions in healthcare settings stand out to you?
4) Please describe your healthcare experiences with healthcare providers since you have [identified as ______/or found out about your intersex [or DSD] status].

5) Have you spoken to a primary care provider or physician since you have [identified as ______/or found out about your intersex [or DSD] status]? If so, please describe your experiences with your primary care provider.
6) Have you spoken to a mental healthcare provider or a counselor since you have [identified as ______/or found out about your intersex [or DSD] status]? If so, please describe your experiences with your mental health provider.
7) Have you spoken to a reproductive healthcare provider or an OB/GYN since you have [identified as ______/or found out about your intersex [or DSD] status]? If so, please describe your experiences with your reproductive healthcare provider.
8) What kind of healthcare providers are you going to currently?
9) How do you select a provider?
10) How would you describe the doctor's offices you have been in? How comfortable were you in those healthcare environments?
11) How do you feel when you're in a doctor's office? How does your body feel? What sorts of emotions do you experience while there? What sorts of things are you thinking about?
12) Can you tell me about a positive or encouraging experience that you've had while seeking or receiving medical care?
13) Can you tell me about a negative or discouraging experience that you've had while seeking or receiving medical care?
14) Have you ever talked about your gender identity/intersex [or DSD] status with a healthcare provider before?

Advance Care Planning (ACP)

I would now like to ask you questions about advance care planning. For context, advance care planning helps your loved ones gain a better sense of your values, preferences, and wishes related to healthcare. It provides information to others about your healthcare wishes in case of illness or injury that prevents you from telling them yourself.

I recognize that this can be a sensitive topic for some people though, so please let me know if we need to skip some questions or this part of the interview. Is it okay if I ask you some questions about advance care planning?

[If yes: Continue with this section of the interview guide. If no: Skip this whole section.]

15) Have you had any experiences with advance care planning?
16) Healthcare agents are those who make healthcare decisions for you if you cannot communicate them on your own.
17) Do you have someone in your life who can act as your healthcare agent?
18) Have you legally formalized your healthcare agent(s) through establishments like healthcare power of attorney, advance directives, etc.?
19) Are there people in your life that you trust who can do this? Who are those people?
20) What feelings do you have about possible future medical care for yourself? If applicable: How about for your partner/spouse?

21) What personal or religious/spiritual beliefs and values shape how you make choices about your healthcare wishes?

Health Needs and Management

I would now like to ask you questions about your health needs and how you manage your health.

22) Please tell me about your health. How are you doing physically? How about your current health in general?
23) Have there been any big changes in your physical or emotional health in your life?
24) How much support would you say you have in managing your health?
25) Do you rely on family members for support in managing your health? Friends? Significant others? Providers?
26) Do you rely on support from your community? Neighborhoods? Community health centers?
27) What kinds of resources do you have that you feel help you manage your health?
28) What additional resources do you think you need? What do you wish you had, or had more of, to better manage your health?
29) Have your health priorities changed during the COVID-19 pandemic?
30) Have your resources changed during the COVID-19 pandemic?
31) Have you experienced social isolation during the pandemic?
32) In the future, how do you hope that healthcare might be different for people like you, people with your background or experiences?

Closing Remarks

I appreciate you taking the time to answer all my questions. Is there anything else you would like to add that I have not asked about, perhaps something I'm not asking but that I should be asking?

Do you know any other adults 65 years or over in the US who identify as transgender, non-binary, gender non-conforming, intersex, someone living with differences in sex development (DSD), or someone who identifies with a different sex or gender identity than what they were assigned at birth and who might be willing to participate in this research study?

If yes: Please let them know about this study and send them my email address (remind them of what it is). I am happy to answer any questions they may have.

Please do not hesitate to contact me if there is anything else that you would like to add that you have not had a chance to say during this interview. Thank you so much for your time! It was great hearing about your experiences.

APPENDIX E: TABLE 1 OF INTERVIEW RESPONDENT DEMOGRAPHIC CHARACTERISTICS (N=50)

Broad Demographic Category	Specific Demographic Identification	Number of Respondents	Percentage of Respondents
Gender Identity	Transgender Woman*	27	54.0
	Transsexual Woman	1	2.0
	Transgender Man	10	20.0
	Transgender	1	2.0
	Non-Binary	8	16.0
	Non-Binary	3	6.0
	Blended-Gender	1	2.0
	Pangenderfluid	1	2.0
	Two-Spirit	2	4.0
	Questioning	1	2.0
	Cisgender Woman	2	4.0
	Cisgender Man	1	2.0
Age	65-69*	34	68.0
	70-74	8	16.0
	75-79	7	14.0
	80-84	1	2.0
Sex	Intersex	16	32.0
	Endosex (Not Intersex)*	34	68.0
Sexuality	Lesbian*	16	32.0
	Bisexual	10	20.0
	Heterosexual	9	18.0
	Asexual	4	8.0
	Gay	4	8.0
	Pansexual	3	6.0
	Queer	3	6.0
	Flux	1	2.0
Race/Ethnicity	Black, Non-Hispanic/Latinx	6	12.0
	White, Hispanic/Latinx	3	6.0
	Multiracial and Indigenous	1	2.0
	Multiracial, Hispanic/Latinx	1	2.0
	Multiracial, Non-Hispanic/Latinx	2	4.0

* Modal category for each demographic measure.

APPENDIX F: TABLE 2 OF INTERVIEW RESPONDENT DEMOGRAPHIC CHARACTERISTICS (N=50)

Broad Demographic Category	Specific Demographic Identification	Number of Respondents	Percentage of Respondents
Social Class	Low Income	9	18.0
	Working Class	9	18.0
	Middle Class*	29	58.0
	Upper Class	1	2.0
	Opted Not to Answer	2	4.0
Formal Education	Middle School Graduate	1	2.0
	Some High School	1	2.0
	High School/G.E.D. Graduate	2	4.0
	Some college	15	30.0
	Associate's Degree	4	8.0
	Bachelor's Degree*	16	32.0
	Master's Degree	6	12.0
	Doctoral Degree	5	10.0
Relationship Status	Single*	32	64.0
	Single, Never Married	13	26.0
	Single, Divorced	12	24.0
	Single, Widowed	7	14.0
	Married	16	32.0
	Married	14	28.0
	Remarried, Divorced	1	2.0
	Married, Separated	1	2.0
	Partnered	4	8.0
	Partnered	1	2.0
	Partnered, Divorced	3	6.0
Number of Children	Child-Free/No Children*	17	34.0
	One Child	10	20.0
	Two Children	15	30.0
	Three Children	3	9.0
	Four Children	3	9.0
	Five Children	1	2.0
	Nine Children	1	2.0

* Modal category for each demographic measure.