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Genealogy Tells: Informing Health and Aging Policies Using East Tennessean Older Women's Family Histories, Perceptions, and Experiences of Health Inequity

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To the Graduate Council:

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Solange Munoz, Major Professor

We have read this dissertation and recommend its acceptance:

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Accepted for the Council:

Dixie L. Thompson

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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GENEALOGY TELLS: INFORMING HEALTH AND AGING POLICIES USING EAST TENNESSEAN OLDER WOMEN’S FAMILY HISTORIES, PERCEPTIONS, AND EXPERIENCES OF HEALTH INEQUITY

A Dissertation Presented for the

Doctor of Philosophy

Degree

The University of Tennessee, Knoxville

Heather A. Davis

December 2022

DEDICATION

Thank you to the women who participated in this study, for their courage, and their willingness to share their stories, thoughts, and voices. They are inspirations.

Thank you to my sister and best friend, whom my parents rightly named Hope, because that is what she is to me. To my mother, whose sense of humor and acts of service bring great joy and keep me on my toes. To my father, who passed away during my PhD journey, whose deep bass voice I still hear singing, and who would have been so proud.

Thank you to two special teachers and a friend’s gracious mother who encouraged and helped me, a first-generation college student on both sides of my family, apply to and get into university while I was in my last semester of high school. I never dreamed I could go to college, but they dreamed I could. They changed my life.

Thank you to my friends, extended family, and the best animal family I could ever dream of having.

Finally, thank you to the nurses, doctors, and all healthcare staff who saved my life when I was diagnosed with cancer, and to those who continue to work to heal me since then.

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ABSTRACT

Older women face unique health inequities challenges. This study aims to provide an understanding of older women’s perceptions and situated experiences regarding the gendered health inequities they face and the social determinants (SDOH) thereof. It examines how these health inequities are situated in older women’s genealogical (familial) and geographical health and mortality outcomes histories and how their perceptions and experiences of health inequities and their familial mortality outcomes histories are characterized by the geopolitical and social norms in which they live. The purpose of this project is to present policy and decision-makers with insights about and recommendations from older women on their needs and wants in order to mitigate those health inequities. The data for this study was collected through semi-structured interviews with twelve women in Appalachian East Tennessee. Areas examined include: the women’s perceived impact of federal, state, and local policies and interventions on the participants; the role of social norming and health narratives, particularly stigmatization and discrimination around ageism, sexism, and health marginalization of older women, and the resultant older women’s internalization of health norms; the familial role in health inequities; the usage of family health histories and older women’s genealogies of health and mortality outcomes; and the role of place and place-effects. This study also aimed to examine the place-based and temporal geopolitical, social, and cultural norming and social conditioning of older women in relation to their perceptions, attitudes, and beliefs. This study sought to determine if these norms impact the participants’ awareness or lack of awareness of their family health histories. This study showed that internalization of these norms, and the replicating of beliefs, attitudes, and perceptions that older women have around health inequities and familial mortality outcomes may be reproduced in their own families. The women provided their own recommendations for ways to mitigate the health inequities they face. This has implications for policymaking and intervention design in co-production with older women in order to mitigate older women’s health inequities.

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CHAPTER ONE

INTRODUCTION AND GENERAL INFORMATION

In this dissertation you will meet twelve women: Anita (now age 76), Mary (now age 75), Sharon, Margaret, and Ruth (all now age 71), Deborah and Sylvia (both now age 70), Peggy and Barbara (both now age 69), Kathryn (now age 68), Carolyn (now age 67), and Cynthia (now age 66)[1]. They are older women living ‘ordinary’ lives in East Tennessee, and, like millions of other older women across the United States, they have overcome incredible familial, individual, social, cultural, and geopolitical challenges to reach older age. They have traveled and worked around the U.S. and the world, created careers in male dominated industries, started their own businesses, completed their education ranging from high school to PhD, married, divorced, raised families, lost parents, spouses, and children, become caretakers of family members, fought battles for the healthcare of their loved ones, and contributed their time, effort, and skills to volunteering in and supporting their communities. They poured themselves into the places in which they lived, some doing all of this while growing up in the Jim Crow American South[2] and living through the imposed norms, discrimination, and systems designed to limit women’s rights in the mid-20th century United States. In other words, they did this in communities and a country they loved that did not necessarily love them

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[1] The interviews took place nearly one year prior to the publication of this dissertation. The women were one year younger at the time of the interviews.

[2] The Jim Crow South refers to the U.S. southern geographic area and its involvement in the enactment of social and cultural norms, laws, and policies which established a caste system based on race against BIPOC people, particularly Black people (Pilgrim, 2012).

back, especially minoritized women. In fact, through that lens, some might call older women extraordinary. I do.

Much has changed in their lifetimes. Yet, their experience today is that of getting older in a country that has never considered healthcare a human right (Heeb et al., 2021), of living in a state that does not accept federal funding to fill gaps in insurance coverage that would allow many of them to receive financial support / resources they currently don’t have (Park, 2021; Rosenbaum et al., 2016), and who face extraordinary pressuring and stigmatizing geopolitical and social norms that exacerbate the health inequities they may face as older women in southern Appalachia (Arber, 2006; Bierman & Clancy, 2001; CAB, 2017; McGuire et al., 2008; Miller & Vasan, 2021a; Velez et al., 2019; WHO, 2007).

This study was undertaken in order to gather and examine these women’s situated experiences of the circumstances in which they were born, grew up, and live, as well as to learn how they perceive those circumstances (i.e., determinants) in relation to their and their families’ health, illnesses, and deaths. One purpose was to learn what they knew about the social determinants of health and the systemic factors impacting their health inequities as well as how these determinants had played out genealogically across their families. Another purpose was to learn what they wanted policymakers and decisionmakers to know about them, and what they need. It turns out, that what these women wanted, more than anything, was to be heard - to have someone listen to what they are going through and what they have endured, what they historically needed and need today regarding their health, how joy and tragedy entered and impacted their and their families’ health, and how other people (and systems) have treated them. They were asked to tell, in-depth, what they perceived and experienced of the health and mortality outcomes – of life and death - that have run through their families and that have led to the health inequities they have faced and continue to face. They want their elected representatives, their doctors, researchers, and those who have power over decisions which affect them, to also hear them and have these conversations with them. They have generational, accumulated, and intimate knowledge about health and mortality that should be incorporated into any policies, clinical care, or interventions affecting them. They are right. Researchers should not only listen but should act upon and heed their recommendations.

Background

Age is the most important determinant of health (UNDESA, 2018). Health inequities evident in old age not only exist due to the intersectional disadvantages long noted in the social determinants of health, but also, in the accumulated effects of these disadvantages over the life course. Combined with socially stigmatizing ageist attitudes and beliefs, laws, and policies that are often inadequate for their health needs, and practices which marginalize the aged, older people face unique health equity challenges (Afshar et al., 2015; UNDESA, 2018).

Women make up the majority of people aged 65 years and over, and this is especially true for those in the oldest age categories (UNDESA, 2020). Older women live longer lives, but they do not necessarily live healthier lives than older men (EuroHealthNet, 2017). They are also affected by factors such as stigmatization, the double jeopardy effects of sexism and ageism (Sen, 2001; WHO, 2007), other disparities within the social determinants of health, and a lack of policies directed at alleviating intersectional inequities for older women (Sen, 2001; WHO, 2007), irrespective of country, region, city, or state / province (Carmel, 2019; Morgan et al., 2018; WHO, 2007).

While health equity research is making strides in capturing and sharing older women's lived health inequity experiences, more research needs to be done, especially through a health geographies lens which locates the experience of this demographic group in specific contexts and places, to translate those experiences into awareness raising, participant-led research, policy recommendations, and attainable empowerment steps to allow older women, as individuals, to participate in health inequities mitigation policies and intervention processes more fully. Studies on older women and health have tended to focus on quantitative measures of older populations' health outcomes and the impact of or recommendations for socioeconomic or health policies. There are some notable early exceptions, including, but not limited to, (Tannenbaum et al., 2005), whose research on the Canadian Wellbeing of Women (WOW) survey focused on older women's perceptions about care delivery; the Nun Study (S. M. Butler & Snowdon, 1996), a longitudinal study of several aspects of aging of women aged 75 years and older; Mitchell's qualitative study of older women's perceptions of health and aging in relation to control (Mitchell, 1996); and the research on aging women conducted by the WHO and other major health organizations (WHO, 2007). Recently, gerontological and other researchers, have started to fill this research gap across a range of health issues (Carmel, 2019; S. R. Meyer et al., 2020; Tuohy & Cooney, 2019; van Ee et al., 2019; Wang et al., 2020). Yet, qualitative studies specifically focusing on older women and health remain lacking in the field of health geography. This research will seek to add to the body of health geography research examining older women’s perceptions and experiences of health inequities and policies and interventions impacting older women’s health.

Pearce (2012, p. 2), in referencing Takahashi (1997) stated, “It is argued that places can inherit the stigma attached to the groups who occupy those spaces”, and, in doing so, shape population health. Not only have the older women in this study experienced historical inequity, but living in East Tennessee (located in the middle of what (Fenelon, 2013) calls the worst of “Southern Disadvantage” states[3]) has situated them in a region steeped in geographically-based, place-rooted discrimination (Fifolt & McCormick, 2020; Hsiung, 2014). Comparing older women’s health perceptions and experiences through a geographic / spatial lens is important because research shows that health inequity is greatly influenced by geographical factors. In fact, (Arora et al., 2016) has stated that inequities in life expectancy, for example, are “not fully explained by differences in race and socioeconomic status” (p. 2075). This is indicative of environment’s inclusion as a social determinant of health, and the large body of literature on place-based health inequity research (Bambra et al., 2010; Marmot et al., 2012; Marmot & Wilkinson, 2005; Montez et al., 2016; Wilkinson & Marmot, 2003) demonstrated deep inequities in women’s mortality between U.S. states, with Tennessee having the third highest age-standardized annual probability of death for women aged 45-89 years in the US. Current research also identifies the American South as having “poorer health and mortality outcomes …with respect to many measures of health and well-being”, (Fenelon, 2013), and that the “Southern

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[3] The Southern Disadvantage states are made up of the central Southern states of Alabama, Kentucky, Mississippi, and Tennessee.

disadvantage" phenomenon is at its worst in the Central Southern states of Alabama, Kentucky, Mississippi, and Tennessee, with rural areas in these four states being worst (Dollar et al., 2020; Fenelon, 2013; Montez & Berkman, 2014).

Tennessee's state and local legislatures, in part, have seemingly reacted by embracing a patriarchal neoliberal policymaking culture, having been swept up in the move towards ever-increasing faith-based conservatist politics (Elisha, 2008; Sager & Bentele, 2016). Charles et al. (2018) argue that this means that regardless of whether women are born in Tennessee or relocate to Tennessee, they will face the highest level of sexism and misogynistic attitudes towards women in the U.S., on par with only four other states: Arkansas, Utah, Alabama, and West Virginia.

This has created a policy and intervention context at odds with eradicating the inequities they face (Deakin, 2021; Navarro, 2020; Rotarou & Sakellariou, 2017). The cumulative effect of this reality is the consistent ranking of Tennessee in the lowest categories for several outcomes as well as for retiree or older American's health with increased impacts on older women (Hoover et al., 2020; LaPick, 2021; McCann, 2021a a, 2021b b; Melton, 2018; Pellegrin, 2018a a; UHF, 2021). These include: the third worst state in the U.S. for women across several health factors (IFWPR, 2015); as the fifth worst state for women's life expectancy at birth in 2021 (McCann, 2021c); regarding the health of its older citizens, as 44th out of the 50 states for consistently higher premature deaths than the rest of the US between 2011 and 2019.(UHF, 2021); as 45th for community support expenditures for those aged 60 years and over; 48th for the number of home health care workers per 1,000 adults aged 65 years and over with a disability; 42nd for hospice care for the percentage of Medicare decedents; 49th for those

65 years and over who smoke; 43rd for those 65 years and over in fair or better health with physical inactivity; 46th for percentage of those 65 years and over in frequent mental distress; and 47th for those in frequent physical distress (UHF, 2021). Tables 1-3 in Appendix 1 shows a more in-depth review of health rankings and outcomes for the participant counties represented in this study.

Problem

While there are numerous federal, state, and local policies and interventions designed to support older people, most are inadequate to meet the specific needs and wants of older women, especially those women who fall into the gap of assistance ineligibility and who are at low and lower-middle levels of income in the USA (Garfield et al., 2021; KFF, 2013; Morton & Dunn, n.d.) This is due, in part, to how policies and interventions are shaped (or in the case of federal policies, how they are blocked or adapted) by state decision-makers who are antagonistic to federal government oversight of health policy. Additionally, patriarchal norms and beliefs, as well as culturally conservative and libertarian neoliberal ideas regarding health—such as individual responsibility, market primacy, and limited government intervention—are prominent in the area and often strongly internalized by older women. (Cruikshank, 2013; Rubinstein & Medeiros, 2015; Tincknell, 2011). These and many other structural and individual causes exacerbate older women's health inequities in Appalachian regions (Rubinstein & Medeiros, 2015). While health equity research is making strides in capturing and sharing older women's lived health inequity experiences (Arber, 2006; Bierman & Clancy, 2001; EuroHealthNet, 2017; S. R. Meyer et al., 2020; Mitchell, 1996; E. Phelan & LoGerfo, 2005; Phillips & Carver, 2015; Rostad et al., 2009; Sen, 2001;

Tannenbaum et al., 2005; Tuohy & Cooney, 2019; Wang et al., 2020; WHO, 2007; Young et al., 2019), there remains a gap in relation to women's perceptions and experiences of policies and interventions designed to mitigate the health inequities they face (Chrisler et al., 2016). This is particularly true within health geography research, which brings a particular focus on the cogency of place, where research in this area is lacking.

Theoretical Framework

The theoretical framework for this dissertation is Krieger's ecosocial theory which links the social and biological determinants of health and the nature of embodiment (Krieger, 1994, 2001, 2012, 2021) as the theoretical framework for this dissertation. In ecosocial theory, health may best be understood through the lens of embodiment – the incorporation of the social and environmental world into individual's bodies. This is done by looking at the intersectional and spatio-temporal scales of pathways of embodiment, of agency and accountability of disease patterning (systematic, structural), and of the cumulative interplay of outcomes of health on individual's life-course histories and experiences. These interplays can occur intergenerationally as well as at global, national, societal, familial, and molecular scale (Krieger, 1994, 2001, 2012). Because this dissertation focuses on intersectional inequities and is interdisciplinary in nature, ecosocial theory is well suited as a framework underpinning this study.

Focus

This paper draws on qualitative research, conducted in the summer of 2021, in which 12 women, aged 65 years and older who live in East Tennessee in and around the counties of Blount, Knox, and Sevier, were interviewed about their perceptions and experiences of health inequities, as defined above, in the region.

Focusing on structural health inequities, policies, perceptions, and personal experiences, this research asks:

Research Questions

For older women in East Tennessee,

a. how are perceptions of and lived experiences with health inequities at the intersections of age, gender, race, and socioeconomic status, and the social determinants (SDOH) thereof, situated in their genealogical (familial) and geographic health and mortality outcomes histories and
b. how are their perceptions and experiences of health inequities and their familial mortality outcomes histories characterized by the geopolitical and social norms in which they live?

This study examines several possible factors to answer these questions including:

- Federal, state, and local policy and intervention impact on older women in East Tennessee
- Social norming and health narratives, particularly ageism, sexism, health marginalization of older women, health promotion and the rise of the health behavior / individual responsibility narrative
- Older women and health norm internalization
- Stigmatization, marginalization, and “low control”
- Familial role in health inequities

    - While ecosocial theory is the primary theoretical framework for this dissertation, because the role of family is imperative to the factors examined in this study, a very brief look at several foundational theoretical frameworks of the familial role in health inequities is also included: ecosocial theory; family systems theoretical approach; life course approach; fundamental cause framework; intersectionality theory – including family systems; family diversity perspectives; family-composition based health disparities; family social contagion; and downstream / upstream effects of health education
- Family health history and genealogies of older women's familial health and mortality outcomes
- Place and older women's health inequities

Those aged 65 years and over are the fastest growing population in the United States (Roberts et al., 2018). This paper argues for the need for policies and interventions that are co-created, sustainable, fit-for-purpose, participant-led, place and population-based, and intersectional in order to support our oldest members of society (R. M. Li et al., 2017; Sharp et al., 2020) – what (Coelho, 2021) calls patient-led policymaking. This paper will contribute to efforts to translate older women's experiences into health inequity mitigation policy recommendations designed to address the needs and wants of older women. By doing so, it will add to the body of policy and intervention recommendations, particularly in health geography, which address appropriate and effective measures, resources, and services to mitigate situated health inequities for older women.

The health policy and intervention needs and wants expressed by the women in this study are framed by the geopolitical, cultural, and geographical environments in which they reside. In East Tennessee (and Tennessee overall), this includes the primacy of neoliberal and paternalistic principles. Neoliberalism emphasizes inequality, diminishes concepts of social justice or ties these concepts to free market principles. Additionally, it restructures economic, employment, and institutional resources to favor business interests, privatization, deregulation, redistribution of wealth towards the rich, and less government involvement and oversight (C. Collins et al., 2016). It also often normalizes, in many societies, including the United States, a culture of individual responsibility which for health inequities is often equated to personal fault for ill health (Sparke, 2016), and incorporates the issues of gender legacy / gender penalty / gender disadvantage. These include women's historical legacy of poverty; inequitable and less pay / income; financial stress; less earning capacity and contribution to and from social security and pensions due to traditional care roles; and less housing security. This creates a "privileging of profitability over human needs" (Darab et al., 2018, p. 538). These long-term and structural conditions can have devastating consequences on the mitigation of older women's health inequities, especially those who are most vulnerable, not only due to neoliberal policymaking but also because of older women's possible internalization of these principles (B. J. Brown & Baker, 2012). This paper has implications for research on the health inequities experienced by older women, and for policymaking and interventions to address these.

This paper proceeds by first summarizing the literature on aging and older women's health inequities. This includes a short synopsis of the unique challenges faced by older women within the historical context of health inequities and policymaking Also included are a look at the social determinants of ageism and gender-bias, and the impacts of stigma and discrimination on older women's health inequities. A review of the place-based context and relevant major policies that impact older women in East Tennessee situates the responses by participants regarding their perceived health needs and demands. This is followed by an examination of how the intersectional nature of those determinants lend themselves to the types of health inequities policymaking currently seen in the U.S., Tennessee, and the local East Tennessee counties of Blount, Knox, and Sevier, as well as the phenomenon of the internalization of cultural and geopolitical normative policies. An ecosocial theoretical framework is applied to a thematic analysis of the participants' interviews and my own field notes. A description of the methodology used is provided and includes a demographic overview of the participants. A comparison is undertaken of the policies and interventions currently in place with the perceptions, wants, needs, and experiences of the women involved in the study. Finally, a comparison of the policy gaps at the gender, socioeconomic, and age intersections which impact older women's health inequities. This is followed by the participants' recommendations of what they believe would inform policies and interventions to help mitigate the impact of the health inequities they experience.

Key Terms / Definitions

Older women are defined here as those aged 65 years and over (CDC, 2015). This paper uses the term health inequities as opposed to health inequalities or health disparities unless quoting a paper that uses inequalities or disparities.

Health Equity

Health equity is defined by the U.S. National Academy of Sciences, Engineering, and Medicine (NASEM) as the individual’s opportunity for full health potential and the prevention of socially defined circumstances that disadvantage individuals from taking full advantage of that opportunity (NASEM, 2017, p. xxiv). The factors that bring about health inequity include structural, environmental, and socioeconomic factors that are inequitably distributed in societies and, therefore, impact health. (NASEM, 2017, p. 1).

Health Inequities

Braveman et al. (2018) has pointed out that there are many definitions of health inequities. Health inequities is the term used by the World Health Organization (WHO) and are defined as systematic, unjust, preventable, and avoidable health status differences between groups of people (WHO, 2017a). The WHO includes in their definition systematic differences in health outcomes and the distribution of health resources and considers social conditions to include several place-based factors, such as where one is born, raised, lives, works, and ages (WHO, 2017a). The Centers for Disease Control and Prevention (CDC) provides a similar definition of health inequities (R. Klein & Huang, n.d.). The causes of health inequities include structural, environmental, and socioeconomic factors that are inequitably distributed in societies and thus unevenly impact health (NASEM, 2017). In this dissertation, health inequities are defined as the "systematic, avoidable, and unfair differences in health outcomes that can be observed between populations, between social groups within the same population, or as a gradient across a population ranked by social position" (McCartney et al., 2019). Older women in East Tennessee (and the U.S.) can help us to see into the processes that create and prop up health inequities. Their life experiences and perceptions of the geopolitical, social, and cultural norms and contexts in which they live can give us insights into how better to understand the impact these processes have on them. It should be noted that worse health outcomes are not experienced by all older women, and that health inequities may not be applicable to all age group differences in health outcomes, but older women have often been left out of academic research, public enquiry, policy and decision-making, and intervention design. Because of this and the stigma and discrimination, including gender-bias and sexism, racism, and ageism, they face in health and other areas of social life, it is imperative to include their experiences, thoughts, needs, desires, attitudes, and beliefs when examining the processes involved in creating and sustaining health inequities.

Health Inequalities

Health inequalities are defined as systematic, unjust, preventable, and avoidable health status differences between groups of people based upon their socio-economic position (McCartney et al., 2013).

Health Disparities

Health disparities are defined by the CDC as “preventable differences in the burden of disease, injury, violence or in opportunities to achieve optimal health experienced by disadvantaged racial, ethnic, and other population groups, and communities. Health disparities exist in all age groups, including older adults (CDC, 2017). The U.S. National Academy of Sciences, Engineering, and Medicine (NASEM) defines health disparities as “differences among specific population groups that prevent the attainment of full health potential that can be measured by differences in incidence, prevalence, mortality, burden of disease, and other adverse health conditions” (NASEM, 2017, p. xxiii).

Social Determinants of Health

The social determinants of health are “the conditions in which people are born, grow, work, live, and age” (WHO, 2022, para. 1), and these conditions are molded by systemic and structural factors which then impact people’s health outcomes (WHO, 2022).

Healthy Life Expectancy

Healthy life expectancy (HLE), as defined by the CDC, is a population health measure which combines mortality and morbidity (or health status) to “estimate years of life in good health at a given age”, and includes quantity and quality of life (P. Meyer et al., 2013, p. 561). It differs from health-adjusted life expectancy (HALE) in that HALE refers to healthy life expectancy at birth (UN, 2007; WHO, 2007).

Mortality

Mortality measures a defined population’s frequency of death during a specific time interval (CDC, 2019). While mortality measures are applied across a range of populations (for example, cause-specific death rates, post-neonatal mortality, infant mortality, maternal mortality, age / sex / race -specific mortality, age-adjusted mortality, and more (CDC, 2019), for the purposes of this research, the participants were asked how they defined mortality overall.

Good Health

Definitions of good health vary in health geography, medicine, and in public health. It is difficult to come to agreement on one definition of good health (Fred, 2013).

According to the WHO, good health isn’t solely defined by absence of disease but consists of community member’s social and mental well-being (Howard & Bogh, 2002; WHO, 1946). Sartorius (2006) added coping ability and an internal state of balance to these definitions. Indeed, recently, Fallon and Karlawish called for a change to the WHO’s / CDC’s definition of health altogether (2019).

Poor Health

There is no standardized definition of poor health. However, utilizing the definition of good health (above) from the WHO’s constitution, poor health could be defined as an state of incomplete “physical, mental and social well-being” (WHO, 1946, p. 1), and could or could not include disease or infirmity absence (WHO, 1946). Some scholars and clinicians refer to ill health, explained by Boyd (2000) as an inner, personal experience of ‘unhealth’ whether it accompanies disease or not (p. 10).

With this in mind, and in keeping with both the lack of consensus in the medical, research and public health fields on the definition of poor health, and most of the other ‘definitions’ related to health above, all of the women discussed poor health in terms of its component parts.

Wellbeing

Wellbeing also has no standardized definition. Instead, it, too, is made up of component parts to help craft a more encompassing way of thinking about wellbeing in terms of health. The CDC has collated a set of aspects from a number of researchers and schools of thought, to include physical, economic, social, emotional, and psychological aspects of a person’s life, as well as life satisfaction, fulfillment and positive functioning in a number of ways (CDC, 2018). The Association of Faculties of

Medicine of Canada (AFMC) incorporated spiritual life as part of their wellbeing definition (AFMC, 2018).

Geopolitical

I acknowledge that, in the discipline of Geography, “geopolitical” is a contested, controversial term, having been shunned and avoided for a long period of time, due to the often ideological misappropriation of the usage of the term (Atkinson & Dodds, 2000). In this dissertation, geopolitical refers to a critical geopolitics focus, with a view to “the way in which ideas about places are constructed” (Novak, 2021, p. 5), and how examining those ideas allow for establishing “patterns that help to explain how those ideas shape political behaviour and how agendas are set, as well as how those ideas affect the everyday lives of ordinary people” (Novak, 2021, p. 5).

Conclusion

In this introductory chapter, a short overview of this study of older women and health inequities that will be explored throughout this dissertation is provided. The research questions are presented as well as the theoretical framework, research methods, and evidence that will be explored in the dissertation to answer those questions and to support the aims of this research. Finally, descriptions are provided of the focus, gaps, scope, considerations, impacts, study layout and key terms and definitions that will be covered in supporting this paper’s conclusions, recommendations, and contributions to the topic of the health inequities older women face.

This study aims, through an ecosocial lens, to provide an understanding of older women’s perceptions and situated experiences regarding the gendered health inequities they face and the social determinants thereof. The dissertation discusses how these health inequities are situated in their genealogical (familial) and geographical health and mortality outcomes histories and how their perceptions and experiences of health inequities and their familial mortality outcomes histories are characterized by the geopolitical – federal, state, and local levels – and social, cultural, and familial norms in which they grew up and live. The primary aim in this study is examining the women's understandings of health inequities. This includes examining what causal factors, including social determinants of health and / or structural factors, if any, they identify or attribute to their own and their familial health and mortality outcomes, and what their recommendations would be to mitigate or improve policies and interventions related to the health inequities they face. This study explores that context as well as whether these policies and interventions are adequate to meet the health needs and wants of older women in East Tennessee. By incorporating some family systems-based theories, this study expounds upon the importance of situated genealogical health and death experiences in families across the life course of older women and how these experiences influence older women's understandings and experience of health inequities.

Understanding the geopolitical, geographical, and cultural context of East Tennessee is important to this study because of the area's unique history within the United States, and its continued struggles across several social determinants. Moreover, Tennessee's geopolitical norms and legislative actions contribute to the exacerbation of older women's health inequities alongside those of other highly conservative, neoliberal, and Christian-fundamentalist-leaning state legislative bodies.

Because age is the most important determinant of health, aging in the United States and other countries can be exacerbated by stigmatized norms which impact health inequities, and limited research has been done on older women and health inequities, particularly in the East Tennessee Appalachian region, this study aims to add to this much needed body of literature.

CHAPTER TWO

LITERATURE REVIEW

As an interdisciplinary health inequities research project, this study examines the barriers to older women's ways of understanding the social determinants of health and the structural drivers that underpin health inequities. In Chapter Four, a look at the geopolitical, policy and intervention, access, and funding drivers as well as the literature on those issues is provided. In this chapter, an examination of the literature on ecosocial theory as well as the literature regarding psychosocial and structural discrimination factors involved in older women's ways of knowing is also provided. These include drivers that formulate social norming and health narratives (ageism, sexism, and the rise of the health movement (locus of control / health behavior / individual responsibility / health promotion)). A brief review of the literature on the role and impact of families on health inequities is given. Finally, a review of the role of family health histories in genealogical (pedigree) health and mortality outcomes as a tool to help examine familial health inequities rather than solely examining risk is undertaken.

Ecosocial Theory

Ecosocial theory links health with its social and biological determinants of health using the concept of embodiment (Krieger, 1994, 2001). Embodiment is the literal incorporation of the social and environmental world into individual's bodies. This is done by looking at various scales of intersectional and spatio-temporal levels and pathways including: embodiment and its pathways; systemic and structural factors relating to the agency and accountability of disease patterning; and the cumulative interplay of outcomes of health on individual’s histories and life-course experiences. These interplays can occur inter-generationally as well as at global, national, societal, familial, and molecular scale (Krieger, 1994, 2020).

Krieger’s seminal work on ecosocial theory (Krieger, 1994) is premised on the combination of the social view of human health and the ecological view of human and more-than-human interconnectedness. This was a response to biomedical and individualized theories of health which emphasized individual responsibility and health behaviors (such as diet, smoking, alcohol intake) in shaping health (Porter, 2006). Krieger sought to challenge this traditional biomedical model, beginning with a look at the “web of causation” theories which had come to the fore in the 1960s’ (Krieger, 1994). Krieger was concerned about understanding the origins of illness and the social dynamics involved in these causes (Krieger, 1994 citing Friedman, 1974; Macmahon & Pugh, 1970; Mausner & Bahn, 1974). She felt that epidemiology lacked significant investment in theoretical frameworks. Her solution was to develop an ecosocial theoretical framework. Ecosocial theory tells us that society exists spatially and temporally and is intertwined, affecting and affected by individuals at all levels, from “sub-cellular to society” i.e., the human ecosystem (Krieger, 1994, p. 896, 2020), and over the life-course (i.e., historical generation into which they were born). These levels and pathways include micro, meso, and macro levels – from individual to global – and include the primary causal drivers of income, wealth, and power which influence and create injustice at all levels (Krieger, 1994, 2020). This, in turn, impacts population (and individual) health (Krieger, 1994, 2020). Therefore, the social patterning of health must be recognized as an interactional and intersectional phenomenon. Individual health or mortality outcomes cannot be separated from social drivers (Krieger, 1994), and must be accounted for when designing policies to mitigate or prevent disease and ill health.

Of paramount importance in ecosocial theory is Krieger's questioning of whether equal responsibility for shaping our human environment is held by everyone across population stratifications and why certain groups of people seem to have not equally benefited from or have actually suffered harm as a result of the traditional way policies have been designed (Krieger, 1994). She emphasized the need for researchers and clinicians (and in her case, epidemiologists) to incorporate the social, political, and economic determinates of health in their theories of and policymaking on how to tackle health inequities, embracing 'social production of disease' and 'political economy of health' and 'embodiment' models for policy and intervention design (Krieger, 1994, p. 894, 2001, 2012). This includes recognizing intersectional social determinants / drivers of health, such as socioeconomic status, race, ethnicity, and gender, which, at the time of the writing of Krieger's paper, were still not equally represented in research, policy, or healthcare decision-making. It also rejects theories of health behavior as a sole causal factor, and rejects perpetuating the norms of research and policymaking focus and language on white, male health outcomes.

Ecosocial theory is an action-based theory and has established a paradigm by which policymakers, clinicians, health researchers, practitioners, and health activists and advocates are called to challenge the injustices brought about by health inequities (Krieger, 2012). It has become the basis of much community health inequities advocacy work across the globe, from the Spiritof1848 group established by Krieger herself[4]

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[4] The Spirit of 1848 group was introduced to me by my PhD co-advisor, Dr. Gerry McCartney in 2017.

which connects health inequities scholars, activists, and clinicians for cross-working purposes, to the monumental current U.S. health justice work of Reverend Dr. William J. Barber II and Reverend Dr. Liz Theoharis and their teams at Repairers of the Breach and the Poor People's Campaign.[5] Ecosocial theory encapsulates much of what this study entails, particularly the interconnected and intersectional lifespan experiences of older women's health inequities and mortality outcomes. Therefore, it is the primary theoretical framework on which this dissertation is built.

Health Literacy

Health literacy, a social determinant of health itself, is associated with a number health indicators that impact health outcomes and status, including access, diagnosis and screening, medication adherence, and communication between clinician and patient (Dadaczynski et al., 2022; Malen et al., 2016). Low health literacy is correlated with low participant uptake across a range of health services. (Dadaczynski et al., 2022). Health literacy, at a population-level approach is an ecosocial matter, bringing the focus from traditionally individual-level to community, regional, state, or national level (multi-spatial) (Dadaczynski et al., 2022). Ecosocial theory and social ecological approaches situate these experiences at meso and macro-levels in addition to micro / individual levels. This allows us to understand the wider context of how women with lived experiences across very different states, but within one country, may or may not respond similarly to one another regarding health inequities (Ross et al., 2009).

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[5] Reverend Dr. Barber's daughter, Dr. Sharrelle Barber received her Doctor of Science in Social Epidemiology from the Harvard T.H. Chan School of Public Health (Drexel University, 2022), which Krieger herself informed me of during an email exchange between she and I about Reverend Dr. Barber's work. It was from Sharrelle and through Krieger that Reverend Dr. Barber learned about social epidemiology to build his health inequities social justice work (Bennett College, 2019).

Social Norming and Health Narratives

Social Norming of Older Women and Health

The social and moral norming of individual responsibility for our health has permeated the lives of people in the United States and elsewhere, including justification through codification of these norms into legislation and policymaking (Galvin, 2002). In a country like the U.S. where distrust of government is high, shifting responsibility for health onto the individual helps to justify the alleviation of government's responsibility for the health of its population (Hook & Markus, 2020; Yoder, 2002). In neoliberal systems, if the government is not responsible for its citizens, and individuals are, healthcare, like any other service, is open to commodification and monetization (Fourcade, 2018; Sengupta et al., 2018). Corporations, organizations, and insurance and care bodies determine what healthcare services are available and how much to charge, and, most importantly, who has access to large parts of healthcare provision. In fact, some of the first large genealogical studies of family health histories were by insurance companies at the turn of the 20th Century in order to determine the concept of risk in insurance, and to determine whom to charge what, and to whom to deny or allow coverage (B. H. Cohen, 1964). If someone is sick, disabled, older, or has a 'bad' health behavior, then one is undeserving of coverage, nor should anyone else who is not sick, disabled, or participating in "bad" health behaviors have to pay for one who is (Hook & Markus, 2020). The only way to guarantee this is to make sure that those in the business of paying for healthcare align with and co-create the systems which empower, enable, and embed individual responsibility into societal structures. It goes something like this - people can take their healthcare needs to another healthcare provider, who matches their beliefs about health (if they can afford to and the provider accepts their type of insurance or takes people who self-pay), but they can't take their healthcare needs to another government. And most importantly, if their federal government leadership changes every four to eight years and their state and local leadership every two to four years, they run the risk of having leadership who will dismantle healthcare provision which supports their needs or will create healthcare provision which acts against their needs. Of course, businesses do this all the time, but this belief system allows the illusion of control and of opportunity. For example, if an insurance company denies pre-authorization for a procedure, anyone can take their health 'business' anywhere else – they can apply to another health insurance company on the hopes of getting approval, they can apply for support from care organizations who supplement those in need, or they can pay for the procedure out of their own pockets, or even through fundraising to help with costs. The moral norm of health in the U.S. (and many other countries, including the UK) is that only those at fault due to lifestyle choices end up relying on the government (those 'benefit scroungers'), a morally and socially repugnant situation, in which no "good" person would allow themselves to be (Hook & Markus, 2020).

The norming of health care goes further – stigmatizing some types of ill health (HIV / AIDS, obesity, sexually transmitted diseases, for example) and accommodating select issues seen to be truly outside of a person's responsibilities (accidents, for example) (Hook & Markus, 2020; Yoder, 2002). Yoder (2002) argues that it is important to understand what is meant when researchers say 'responsibility' and how 'responsibility' is conflated not only with blame, but also with causality i.e., physical, moral, or social liability (the social policy arm of causality) (p. 24). Additionally, determinations of responsibility, causality, and liability come with decision-maker (governments, insurance companies, providers) bias as well as beliefs about agency which both shape and are shaped by social and moral health norms. This is no different for social / health policymaking, despite efforts to develop policies and interventions meant to mitigate bias (Yoder, 2002). Yoder (2002) also argues that facts cannot be extrapolated (in this case causality, responsibility, or liability) without recognizing who and what those facts serve, the spatial and temporal context in which those facts are established, and that the context (and therefore causality, responsibility, and liability) can and does change. Responsibility (blame) is established considering human goals, values, and social practices, and cannot be divorced from these, no matter how objective researchers and policymakers intend to be in policymaking. Because of this, it is important to consider the social (and moral) norming around health, and the health of older women, when examining their perceptions and beliefs and statements (or lack of) about their familial health and mortality outcomes, their own health, and the health inequities they face.

“We assign blame not only for behaviors that cause or increase the risk of illness and injury – smoking or excessive alcohol consumption, for example – but also for failing to act in ways that might have prevented illness or injury…” (Yoder, 2002, p. 26). For example, is it obesity itself, obesogenic environments, structural determinants, or health behaviors that cause ‘obesity-related’ illnesses? Because people decide what factors are causal, people also decide the morality of those factors - which ones should be normalized as “good” and which ones should be normalized as “bad”, and offload responsibility onto individuals for making those good and bad choices. Through this, people embed normalization, as well, as stigmatization (ageism, ableism, sexism), discrimination, and bias – individually and structurally.

For the older women in this study, the social norming of health must be seen within not only the individual responsibility context and bias within the U.S. but also within the timeframe in which they grew up, and the deeply religious moral coding within legislative and policymaking in Tennessee (as discussed in Chapter Four). If, as (Yoder, 2002) argues, human beings hold people morally accountable for not only causing risk, but for creating the potential for risk, governments, organizations, companies, health bodies and providers are as responsible for causing and creating risk as individuals. However, it is in the best financial and governance interest of these groups to offload responsibility onto individuals. If corporations can prevent the onus of responsibility for public health measures, such as mandatory seat belt wearing, from resting on their shoulders, they can save themselves the financial costs and regulatory constraints of complying with laws that require building their goods with mandated equipment (Yoder, 2002). In the U.S., this argument is heavily discouraged - in a monetized and capitalistic healthcare system, if people cannot trust their government for their healthcare and cannot trust businesses for their healthcare and cannot believe themselves solely at fault when they become sick, who can they trust?

Social and moral norming of individual responsibility comes replete with issues around the understanding of voluntary action, decision-making and free will and are beyond the scope of this dissertation. But they lie outside the scope of the assigning of social and moral responsibility to health, affecting our understanding of science, evidence, and our actions in social practice, and must be kept in mind, particularly because they are used for the basis of the imposition of individual responsibility as a causal factor in the U.S. neoliberalist health system. (Hook & Markus, 2020; Huzum, 2010; Vallgårda, 2011; Yoder, 2002).

The broader determinants of health are important to note here in addition to the system of healthcare provision and access. As noted throughout this dissertation, older women face a number of factors that contribute to the social norming they face and that exacerbate their health inequities: discrimination (ageism, gender-bias and sexism, racism, health marginalization, and more); geopolitical norms that affect many things in their life, including their socioeconomic status and, in the generation explored in this study, their agency to a certain degree; familial and socio-cultural norms that may drive their own attitudes, beliefs, and perceptions of health norms; and more (Potter et al., 2019).

Ageism, Sexism and Health Marginalization of Older Women

For more than a century, medical, economic, political, and population health interventions have successfully increased life expectancy (Callahan, 1998). The fact that, worldwide, those aged 65 years and over make up 9.3% of the world's population (UNDESA, 2020), shows our commitment to healthier longer living. Health bodies like the World Health Organization (WHO) have repeatedly stated that the area of aging, and specifically health equity for older women, is an under-studied research area, and have called for additional studies to help enable better intervention and policy recommendations (WHO, 2007).

It may be said that older people, with their lived experiences, skills, and knowledge, have contributed as equally to society throughout their life course as those under 65 years. Unfortunately, aging is often no longer viewed as a positive accomplishment hard won over more than one-hundred years of effort in increasing healthy life expectancy and longevity. Having accomplished this goal in the U.S., aging is now framed in a ‘fear language’ where older people are seen as a burden, a social and economic cost, a ‘drain on the system’, and a thing of disgust (Cruikshank, 2013). This is despite the reality that even though aging is a physical process, societies determine what “old” and “young” mean.

However, on some level, age itself is a social construct (A. A. Cohen et al., 2020; Cruikshank, 2013; LibreTexts, 2021; Peto & Doll, 1997) with inequitable and stigmatized barriers, particularly for women aged 65 years and over (Arber, 2006; Bierman & Clancy, 2001; CAB, 2017; Velez et al., 2019; WHO, 2007). McGuire et al.’s (2008) study, revealed that 84% of the 247 community-dwelling older adults they surveyed in East Tennessee had experience at least one type of ageism, despite the knowledge those perpetrating this type of discrimination may live long enough to experience it themselves. At the same time, in many societies, particularly the United States, neoliberal policies have long set social expectations for a ‘rugged individualism’, i.e., minimization of public support and maximization of individual effort and productivity, even in old age (Cruikshank, 2013). As a result, to encourage these expectations and to mitigate the social stigma associated with aging, policies and interventions are framed around concepts such as ‘healthy’ aging, ‘successful’ aging, ‘productive’ aging, and ‘responsible’ aging (Cruikshank, 2013). These framings have been particularly detrimental to older women’s self-perceptions about who and what is responsible for their health, and the internalized stigmas they have developed as a result (B. J. Brown & Baker, 2012).

Like all other forms of discrimination, this language (and resultant policies and interventions) situates marginalization or ‘unworthiness’ of people within the body, a result of bodily difference (be it physical or mental health), with the onus on the individual to conform to non-aging health norms. Additionally, in cultural and social settings where older people may be viewed as irrelevant, and with expectations that their lives and deaths are less important than other age groups because they have ‘already lived their lives’, policies and interventions may follow, which codify these social constructions of worthiness.

In the United States, and in East Tennessee, this dynamic plays out as an ideological and policymaking concept of health care as a privilege and not a right (Hoffman, 2012; Maruthappu et al., 2013). Lack of universal health care, combined with neoliberal policymaking, allows for a systemic-wide market-based stratifying of who is worthy of care and who is not, such as those who are poor, racialized, gendered-marginalized, disabled, and / or older. As a result, marginalized women, like the women in this study, face multiple intersectional areas of jeopardy in the social ‘determinants spectrum’.(R. A. Hahn et al., 2018; Hailemariam et al., 2020; Hoffman, 2012; Sakellariou & Rotarou, 2017; Witter et al., 2017).

Silences

The silences framework (also known as “screaming silences”) (Janes et al., 2019; Serrant-Green, 2011) “define[s] areas of research and experience which are little researched, understood, or silenced” (Serrant-Green, 2011, p. 347), “reflect the unsaid or unshared aspects of how beliefs, values, and experiences of (or about) some groups affect their health and life chances” (Serrant-Green, 2011, p. 347), and expose “issues which shape, influence and inform both individual and group understandings of health and health behaviour” (Serrant-Green, 2011, p. 347). It is a framework which helps researchers to examine these silent spaces for additional perceptions and discourses by marginalized people. This is helpful when examining internalization of norms which exacerbate the health inequities people face but also when people are the subject themselves of stigmatizing social norms, as older women may be. Because marginalized people, including older women, are often silenced, their experiences and perceptions are also often neglected and go untold (Janes et al., 2019; Serrant-Green, 2011).

Older Women and Health Norm Internalization

A discussion about health inequities should consider the psychosocial drivers involved. Perpetuation of inequities cannot happen without the attitudes, beliefs, and perceptions that create inequities in the first place (Horne, 2014). In ecosocial theory, the pathway to norm internalization comes through adverse exposure to forms of systemic and personal discrimination (referred to as “isms” by Krieger) (Krieger, 2020) including geopolitical, social, and cultural, narratives, social and other forms of trauma, stigmatizing marketing, and poor clinical care (Krieger, 2020)The responses of the women in this study have prompted a look at the possibility of the internalization of health norms, especially in light of the U.S. neoliberal stance on health, and the conservative, fundamentalist neoliberal policymaking currently happening in Tennessee.

Internalization of anything is a tricky subject to parse. How can researchers be sure that someone has internalized anything? Could their behavior, verbal repetition, or silences regarding a norm prove their internalization of it? This has been debated for centuries, in both scholarship, and literature, such as Thomas Hobbes' *Leviathan*, written in 1651, and by early scholars including Judith Blake and Kingsley Davis, (1964), Peter M. Blau, (1964), George Herbert Mead, (1956), Talcott Parsons, (1937 & 1952); Robert M. MacIver, (1937), Max Weber, (1930), and Émile Durkheim, (1915 & [1903] (1953) (as cited by Horne, (2003)).

Certain Ideas around social norming are predicated on arguments that human beings are either "naturally social beings or…inherently self-interested." (Horne, 2003, p. 335). Some researchers argue that if people are inherently self-interested beings, they require external pressure to adhere to norms, since those norms may go against what they want to do. This external pressure can come in many ways. Other researchers argue that people, as social beings, voluntarily act against their own desires, for the greater good – a choice which could be made due to any number of reasons, but arguably because of norm internalization (Cislaghi & Heise, 2018; Horne, 2003; Morris et al., 2015). For this dissertation, relational pressure in the form of peers or groups such as families, organizations, and policy and other decision-makers through group norm enforcement (Cislaghi & Heise, 2018; Edmonds & Xenitidou, 2014; Horne, 2014) and structurally / systematically in the form of incentives (rewards / punishments) through structural systems is examined (Horne, 2003).

"Behaviours that are dictated by social norms become the ends that individuals desire and there is no discrepancy between the interests of the individual and those of the group" (Horne, 2003 citing Elster, 1989). Internalized norms, sometimes called personal values or morals, overlap with socially constructed (sanctioned) norms, both constructing and being constructed by social 'rules', 'mores' and laws (Horne, 2014). Intertwined with internalized norming and group norm enforcement, systems, structures, policymaking, and laws are set up to codify rewards and punishments for individual adherence and non-adherence (Cislaghi & Heise, 2018; Horne, 2014). Tremendous intragroup and intergroup pressure on individuals to conform to social norms may exist within a given society or social group (known as group norm enforcement) which can result in positive social cohesion, a phenomenon recognized as one of the most important factors in mitigating health inequities (Emerson, 1962; Horne, 2014). However, it can also result in not only oppression of minorities, but also in negative social cohesion where there is pressure to conform to or stay silent about factors which worsen health outcomes or health inequities. For societies, such as the U.S., embracing the norm enforcement of individual responsibility as a way to control people provides the platform for the internalization of health behavior as the main driver of health and mortality.

Horne (2014) states "[ ]…when individuals are dependent on those around them, their well-being is tied to the well-being of others" (p. 107). Since people are complex, social beings who are dependent upon one another for survival, this can lead to people agreeing to norms that go against their best interests or that they don't agree with in order to retain perceived security and positive relationships within social groups (family, friends, work colleagues, society). Moreover, if people internalize norms, they and those around them choose which norms carry the most weight depending upon the social context in which they are (Edmonds & Xenitidou, 2014; Horne, 2014). This means they are influenced by their temporal, place-based, situated norms. If a group of people give the most weight to individual responsibility, they (and their policymakers, health bodies, corporations, friends, and family) feel justified in choosing to support those who adhere to the norm, and not support those who don't. In the case of health, if individuals are at fault for being sick, other people need not feel responsible for making sure that an individual receives care. Indeed, some societies set up systems to ensure that individuals are to blame (Horne, 2014). Since individuals are normed to accept sole blame for their health or other circumstances, they can readily understand why systems not only don't work for them, but actively work against them and believe ill health is a "punishment" they "deserve".

While U.S. social awareness and attitudes about systemic and structural influences on health and mortality outcomes has begun to change since the Affordable Care Act (ACA) came into force in 2014 (McIntyre & Song, 2019), for those 65 years and over, the women in this study have lived with the pressure to adhere to norms of individual responsibility for their health outcomes. This also includes norms around silences on perceptions, attitudes, and beliefs about systemic or structural determinants, even when these norms appear to have gone against evidence-based health and social care programs designed to improve their health and mortality outcomes and mitigate health inequities (Cislaghi & Heise, 2018).

In addition to the other social determinants that older women face, which exacerbate health inequities, researchers must also consider the impact of issues of internalized norms, and group, and systemic norm enforcements when examining older women’s temporal, situated internalized and externally compelled beliefs, perceptions, and attitudes.

Familial Role in Health Inequities

This dissertation’s examination of the genealogy of older women’s familial health and mortality outcomes in relation to the health inequities they face, merits a consideration of the role families play in health inequities. Families are affected by and can contribute to health inequities. The long history of research on families and family life show multiple factors that impact health inequities, particularly because of the class and financial stratification of families within society, and the inequitable distribution of resources across families (Thomeer et al., 2020). Families as an institution, and the individuals within them, influence and are affected by public policy and institutional decision-making, and by the events (environment) in which they live or are experiencing. This exacerbates health inequities as driven by the “isms” which Krieger discusses and, which as Thomeer et al. (2020) argues, are “shaped by families and by the public policies, organizational decisions, and concurrent events that also impact families and health” (p. 448). Therefore, as Thomeer et al. argue (2020) argue, families[6], influenced by public and organizational policy and decision-making, are a major route to reducing health inequities.

Theoretical Frameworks of Familial Roles

A short look at some foundational theories which examine the role of families in health inequities and how family dynamics may interact with health, mortality, and

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[6] Thomeer, Yahirum & Cólon-Lófapez indicate that their definition of families is connected groups, not solely by biology, and can include legal, emotional, or biological. For the purposes of this dissertation only, the familial focus is on biological intergenerational ties, while at the same time acknowledging the wider context of familial connected groups.

health inequities is helpful for this study. Each has its own merits, and all intersect with theories of the social and commercial determinants of health. Thomeer et al. (2020) provide a non-exhaustive list of many of the foundational theories, from which this study draws.

While this dissertation emphasizes ecosocial theory and its focus on personal and environmental interrelationships in relation to health inequities (Bronfenbrenner, 1986; Krieger, 1994, 2001, 2012), the role of family / genealogy is not prominent, and so it would be remiss to not include some of the other primary theories which intersect with this study.

Family Systems Theory

For decades, studies looking at familial health, mortality, and life expectancy outcomes have relied on family systems theoretical approach, which emphasizes how an individual’s health is affected by their families due to interdependency among family members (Broderick, 1993; Fingerman & Bermann, 2000; Haefner, 2014; Thomeer et al., 2020; Umberson & Thomeer, 2020; Utz et al., 2017). This includes structures in interdependency (such as family ties, family resilience, patterns of interaction, social identity), strong or absent relationships among family members, length of contact among family members, and geographical proximity to one another (Thomeer et al., 2020). It also includes the role of family culture and environment in the well-being (both emotional and physical) for all members of the family (Fingerman & Bermann, 2000) and generationally embedded behavior patterns (Haefner, 2014). Family systems, therefore, are affected by social determinants of health and also can create and reiterate systems, at the meso-level, that shape determinants of health – including familial-level contributions to attitudes, behavior, and beliefs about discrimination, health and social norms, economic and class stratification, perceptions of health and aging, and more (Utz et al., 2017). Because family units are a system (in whatever form they occur), they face the same possibility of creating inequity as all other systems. This means they can act as one pathway in which embodiment of health inequities can occur.

Life Course Approach

More recently, health inequities research has also incorporated Carr's (2018), life course approach, which also emphasizes the interrelationships between family members and the impact on family member's health over the course of an individual's life, especially because many families have long periods of sharing spaces and time (Zick et al., 2014). In addition to the social determinants of health which shape the participant's attitudes and beliefs around health inequities, this study also focuses on the family systems of older women, and how they not only also contribute to those attitudes and beliefs, but how they 'pass on' these beliefs, behaviors, and attitudes from generation to generation.

Fundamental Cause Framework

Many studies on social determinants of health and health inequities build from Phelan et al.'s (2010) fundamental cause framework and its emphasis on spatial and temporal social conditions as a determinant of health. These include what J.C. Phelan et al.(2010, p. S29) call "flexible resources" – the fundamental causes of power, income, wealth, knowledge, prestige, and social cohesion and their impact on health across time, even if a society's disease, risk, and protective factors change. These flexible resources are used by individuals, to the extent that they have each of these resources, to mitigate poor health outcomes. Because this study looks to examine whether place, time, social, geopolitical, and cultural surroundings counteract or solidify the participants' familial health, it is imperative to look at not only their family history and health history, but where they grew up, where they work or have worked, why they chose to relocate to East Tennessee, what social systems and social networks they were and are surrounded by.

Intersectionality Theory

Because so many factors interact with familial health, embedding intersectionality and critical theories in this study are needed. Adding to Crenshaw's (1989) intersectionality theory, P.H. Collins (1998) expanded this to family systems. The State has traditionally and continues to attempt to define what and whom constitutes 'family' (Thomeer et al., 2020). This is certainly the case in Tennessee, with the recently failed legislation introduced in the state house of representatives for special permits for heterosexual marriages to give advantages to those types of families who match the state's criterion while attempting to marginalize those family units which do not meet this criterion (M. Brown, 2022). This can impact a family's health and wellbeing and exacerbate their health inequities because it removes resources that may be available to individuals to mitigate the health inequities they face, and because the systemic nature of discrimination and withholding of resources creates the systematic, preventable, and unjust differences between groups (such as families) that cause health inequities. This has been a factor in the lives of some of the women in this study who fall outside of traditional family structures.

Family Diversity Perspectives Theory

Looking at family diversity perspectives P.H. Collins (1998) argues that families that have been traditionally marginalized may have developed coping strategies which may help mitigate the social, cultural, and political norming that exacerbates the health inequities they face. This can be the case especially for those families who face additional impacts to their health outcomes (Thomeer et al., 2020) such as those facing discrimination of any kind, those who are institutionalized, refugees, asylum seekers, deportees, prisoners and ex-prisoners, those who have had sudden traumatic deaths or illnesses of a loved one, those who have had loved ones with a stigmatized illness, or because of deaths perceived to have been preventable by individual behavior changes (Thomeer et al., 2020). This resonates with the experiences that some of the participants in this study have had, particularly Black and Brown, and non-cis gendered participants.

Family Composition Based Health Disparities

Familial stigmatization and marginalization of certain family members can happen for a number of reasons, including illness and disease, which creates inequities within the family, adding another layer of inequity upon individual and familial health outcomes. These issues are studied through theories that look at family-composition based health disparities (Thomeer et al., 2020). Stigmatization and marginalization can contribute to social isolation, even within their own households. This is also particularly true for older women who tend to live alone at a much higher rate than older men (Thomeer et al., 2020). Older family members may have low control within the family, including regarding the choices affecting their own bodies (Thomeer et al., 2020), and control of their own body comes up again and again in the responses of the older women in this study. In a country where individual responsibility and control is the cornerstone of policymaking and intervention design, this loss of control compounds the burden of health inequities and can set the stage for their health outcomes, and their perceptions of or speaking about their and their family members' health.

Family Social Contagion Studies

Finally, the field of family social contagion studies (Christakis & Fowler, 2009) is of unique relevance for this study. It argues that more than infectious disease 'spreads' within families, but that chronic health conditions and habits can spread as well. This phenomenon is often referred to as the downstream / upstream effects of health education (Thomeer et al., 2020), with parents teaching children and children teaching parents. Take, for instance, a child who learns about a 'health behavior' habit from seeing a parent partake in that action, then begins doing that action too. Likewise, adult children, especially older women, are often parental caretakers, and may have some influence on parents regarding healthcare access and health behaviors (Thomeer et al., 2020). Because it is known that families influence each other's political, religious, and geographical location beliefs and attitudes (Thomeer et al., 2020), the idea that families spread these beliefs and attitudes about health and mortality outcomes to other family members is of major importance for this study.

Each of the theories above interweave with one another to paint a fuller picture of how family dynamics may interact with health, mortality, life expectancy, and health inequities across the generations.

Family Health History

There is something enticing about the feeling of being in control. It shapes life's ambiguity, makes people cling to ideas of agency, helps make meaning out of the unpredictable cruelty seen in daily living. When applied to illness prevention, as (Davison et al., 1992) examined in their seminal work on fatalism, it gives rise to dominant framework such as the healthy lifestyle / health behavior movement and the preventative health paradigm that argues that people can, at the very least, have some semblance of control over minimizing their health risks of death or illness. It also allows people to construct beliefs and attitudes which explain away and help them to cope with the randomness of illness and death (Davison et al., 1992).

As advances in tackling infectious disease increased, life expectancy increased, and a change in the primary causes of mortality and morbidity shifted to those caused by chronic diseases (Remington & Brownson, 2011). The construction of risk came about in the 20th century as this focus shifted (Davison et al., 1992). In the 1970's, 'health locus of control' theory was developed. It places knowledge of health harms, specifically through personal choices, squarely on the shoulders of individuals (Davison et al., 1992; Wallston et al., 1978). Health locus of control theory contributed to the emphasis in medicine and public health on individual responsibility for health behavior as a way to mitigate the risk associated with chronic diseases, and as a way to educate the public about known causal factors that were within an individual's supposed agency to control through behavior change (Davison et al., 1992).

Alongside the rise in the narrative of personal responsibility for health behavior, was an increase in the use of family health history (FHH) as a means of predicting, life expectancy and health risks, and to establish the inequitable practice of basing insurance coverage on family mortality history and pre-existing conditions (B. H. Cohen, 1964).

Family health history is now commonly used in medical settings, to gather an individual’s history of chronic and acute disease information across their immediate family members (up to grandparents) (Davison et al., 1992; Walter & Emery, 2006). Sometimes called a pedigree (hence the referral in this study to the ‘genealogy’ of familial health and mortality outcomes), family health history “is a valuable method in capturing the relationship between genetic susceptibilities, common behaviors, and shared environment” (Vogel et al., 2007, p. 352) and, therefore, is considered the bedrock of clinical genetic medicine. This, in turn, has brought family health history into primary care practice (Guttmacher et al., 2004; Vogel et al., 2007; Yoon et al., 2002). Family health history is a major component in this study since it is a way to trace the ‘genealogies’ of health and mortality outcomes within familial generations, in order to map the clustering and patterning of health and mortality in families.

As a result of the dominant narrative created through the convergence of health locus of control theory and the medicine and public health focus on individual responsibility many individuals attribute their family health history, health risk of disease, illness, or mortality outcomes to their health behavior (Hunt et al., 2000).

However, many researchers of family health histories found that even though health education has seemed to work for individual behavior risk awareness given the substantial corporate and political investment in health behaviorism, some people are also aware of other factors that affect their health or may contribute to their health risk such as: genetics for “well-known” diseases like certain types of cancer, heart disease, diabetes, etc., in relation mortality and morbidity outcomes (Davison et al., 1992; Hunt et al., 2000); geopolitical; social; cultural; racial; ethnic; personal; and natural environments, all of which constitute drivers (determinants) of health (Davison et al., 1992; Walter & Emery, 2006).

Therefore, this study examines the women’s awareness of and perceptions of their family health histories. A major aim of this study is on the social norming of these attitudes and beliefs about health, risk, health behavior, fatalism, etc., and other drivers of health that deeply impact awareness or lack of awareness of family health history, and therefore, of the health inequities burden carried generationally, potentially passed down from ancestors to descendants.

It may be helpful to review how particular social determinants impact an individual’s awareness of their family health history:

- access – to health insurance, clinicians, and health care facilities (AHRQ, 2016; AMA, 2022; Cyr et al., 2019; Douthit et al., 2015; Lavizzo-Mourey et al., 2021; McMaughan et al., 2020; Ndugga & Artiga, 2021; ODPHP, 2022; Riley, 2012; Trinh et al., 2017) gender (women tend to gather FHH more than men) (Hughes Halbert et al., 2016; Hunt et al., 2000; Vogel et al., 2007)
- education (those more highly educated collect FHH more than those less educated) (Hughes Halbert et al., 2016; Vogel et al., 2007)
- sphere of influence - who is influencing individuals to gather FHH (such as trusted community or religious leaders) (Vogel et al., 2007)

- secrecy (familial and cultural), stigma, fear, embarrassment, and denial – causing family members not to discuss FHH within the family or to share information with healthcare professionals (Malen et al., 2016). This has implications regarding health information sharing intra-socially and culturally versus inter-socially and culturally.
- immigration (those who immigrant to the U.S. may come from countries that do not make use of family health histories, or that have lower acculturation and may not know that FHH is related to genetics or is used in relation to health risk) (Malen et al., 2016)
- lack of genetic literacy - understanding regarding inherited disease risk for certain demographic groups (which may be related to healthcare access) (Malen et al., 2016)

Additionally, several studies indicate particular psychosocial, family dynamic variables influencing awareness or lack of awareness of family health history. These include:

- the experiences of other family members, particularly those who are immediate family members, who have recently gone through a difficult illness or have died;
- who are family members that are particularly emotionally close to or resemble the individual involved;
- whether individuals were socially isolated from family members;
- individuals' own experiences, expectations, and salience (how likely they are to perceive the risk of getting an illness themselves);

- individuals’ perceptions of diseases and disease outcomes (such as ‘cancer always kills’);
- whether a family member died suddenly, unexpectedly, or traumatically;
- culturally influenced family teachings about specific diseases

(Hughes Halbert et al., 2016; Hunt et al., 2000; Malen et al., 2016; Petty & Briñol, 2015; Rodríguez et al., 2016; Walter & Emery, 2006).

Studies show that most people in national samples had not collected their family health history (Hughes Halbert et al., 2016). Women may tend to know or collect FHH more than men because of traditional caring roles within the family, their roles in health care seeking, and their wider healthcare consumerist knowledge (Vogel et al., 2007). For older women, however, studies differ. Some, like Hughes Halbert et al. (2016), show that older people were even less likely than others to know or to have collected their family health history (though Black people were more likely to have than white people). However, other studies show that older people are more likely to know their FHH (Ashida et al., 2011; Yoon et al., 2002). Access may play a large part here as well because the common use of FHH in clinical settings today, and the development national level FHH health campaigns and publicly available FHH collection tools such as the CDC’s online “My Family Health Portrait” (CDC, 2022; Hughes Halbert et al., 2016) all rely on access to clinical care, healthcare facilities, or access to the internet.

There may be the phenomena of people not taking the older members of their family into account when outlining their family health history. In turn, older people discount themselves and their perceptions that they have any family health histories of any given disease (Hunt et al., 2000). It may be that the social norming of ageism plays a role here, as does norming around health, resulting in normed internalizations of beliefs, attitudes, and perceptions (K. Hunt et al., 2000, citing (Backett & Davison, 1995; C. C. Butler et al., 1998; Kreuter & Strecher, 1995), for older people that they may reproduce in their own families, and that may keep them from awareness of structural drivers of health. (Hunt et al., 2000) also found that people ascribe social determinants of health such as housing and living conditions as less important to family health history than health behavior and family 'tendencies', and that visible risks (such as weight, smoking, etc.) are factored as more important by individuals than hidden risks (blood pressure, for example). Additionally, families tend to know more about familial health and mortality generalities than specifics, e.g., "I think he had something with his heart" rather than "He had congenital heart failure". In relation to subjective life expectancy (SLE) (when individuals estimate their own life expectancy), which is a predictor of individual behaviors in relation to health, parental longevity is the dominant factor in the assessment by individuals in relation to SLE. However, individuals were also more likely to relate the experiences of first-degree same sex relatives than second-degree or non-same sex relatives (Zick et al., 2014). This is important for this study which focuses on self-reported first and second-degree familial health and mortality histories among older women born with the sex of female, and any gender-specific effects thereof.

While the time period of some of the early research on family health history must be considered, and, therefore, the prevalence of health promotion models as the focus of Global North governments health and economic policymaking (Hunt et al., 2000), it could be said that the health promotion model remains the primary 'way of doing health' in the United States.

Place and Older Women's Health Inequities

The research on place-effects of health and mortality is long and established (Finkelstein et al., 2021; Kuuire & Dassah, 2020; Macintyre et al., 2002). Comparing area variables through a geographic / spatial lens is important because research shows that people's health inequities across the social determinants are greatly influenced by geographical factors. In fact, when looking at life expectancy of males and females at the county level across all U.S. states, Arora et al. (2016) stated that "geographic disparities in life expectancy are substantial and are not fully explained by differences in race and socioeconomic status" (p. 2075). This is indicative of environment's inclusion as a social determinant of health, and the large body of literature on place-based mortality and health inequity research (Bambra et al., 2010; Marmot et al., 2012; Marmot & Wilkinson, 2005; Wilkinson & Marmot, 2003).

Montez, et al. (2016) demonstrated substantial inequalities in women's mortality between U.S. states. Research also identifies the American South as having "poorer health and mortality outcomes …with respect to many measures of health and well-being", (Fenelon, 2013, p. 2) and that the, "Southern disadvantage", phenomenon is at its worst in the Central Southern states of Alabama, Kentucky, Mississippi, and Tennessee, with rural areas in these four states being worst (Fenelon, 2013). Appalachian areas of the U.S., of which East Tennessee is a part, have been shown to have deeply ingrained geo-cultural norms which impact health also. This includes strong ties to religious beliefs and local social networks, as well as "distrust of outsiders, and distrust of formalized medical systems" (McGarvey et al., 2011, pp. 348–349). These factors are discussed in the internalization of norms section of this chapter (pages 30-

34), in Chapter Six on older women’s perceptions, attitudes, and beliefs of health, mortality and health inequalities, and Chapter Seven, the findings of the interviews with this study’s participants.

For East Tennessee, geographic isolation is also a major factor (Behringer & Friedell, 2006). Appalachia is largely defined by its mountain chain, and mountain / mountain foothill communities, large parts of which have low population density, are rural, and isolated (Behringer & Friedell, 2006; Huttlinger et al., 2004; McGarvey et al., 2011; Studts et al., 2013; Thompson et al., 2021). The rurality of areas, like East Tennessee, also deeply affects health outcomes and inequities, with well-established evidence showing that rural areas, as opposed to urban areas, suffer from the “rural health mortality penalty” (Miller & Vasan, 2021b, p. 267) with East Tennessee being part of “Southern rural mortality penalty” (Miller & Vasan, 2021b, p. 267). Additionally, its geographic location as part of the East South Central Region of Appalachia, makes it one of the rural Southern states with the lowest life expectancy and highest mortality rates in the U.S. (Miller & Vasan, 2021b). The rural mortality penalty is due to several intersectional factors, such as “geospatial clustering of individual risk factors” (Miller & Vasan, 2021b, p. 268), structural and historical racism and Jim Crow segregation laws, higher poverty, less education, greater lack of access to healthcare, healthy food, recreational facilities, higher levels of unemployment, and greater lack of care-seeking (McGarvey et al., 2011; Miller & Vasan, 2021b). Regions like East Tennessee tend to have the worst of the worst rural penalty outcomes. When areas are this deeply affected by health inequities, combined with geographic isolation, shared attitudes and beliefs about health and healthcare are so strong that some researchers have identified the need for cultural competency training for doctors practicing in Appalachian areas (Huttlinger et al., 2004).

Researchers today often identify places as ‘deprived areas’ or ‘health disparity regions’, and Appalachia is almost always included (APA, 2018; Marshall et al., 2017; McGarvey et al., 2011; RHIH, 2019). While this helps researchers, health bodies, and governments qualify areas for economic aid, policymaking and intervention design, it adds to internalization of norms by creating or reinforcing place-stigmatization (Studts et al., 2013). People living in or near stigmatized places, such as certain areas of Appalachia, compared to non-stigmatized places, have a much more normed resistance to, fear and worry of, or shame about health and clinical intervention, are more fatalistic about health, have worse health outcomes, higher premature mortality, poorer self-reported health, poorer perceived relative deprivation, and, as noted in the previous paragraph, greater health inequities (Behringer & Friedell, 2006; McGarvey et al., 2011; Miller & Vasan, 2021b; Studts et al., 2013). Most of the women in this study were not born or raised in Appalachian regions but have lived in East Tennessee for more than half their lives. One major purpose of this study was to determine if they perceived place as mattering or making a difference in their health, and if they perceived a difference in health effects, outcomes or attitudes and beliefs depending upon the areas in which they lived and worked. For a breakdown on the women’s residence places by city, state, and number of the women who lived in each, see Table 5 in Appendix 1.

CHAPTER THREE

MATERIALS AND METHODS

Introduction

In order to mitigate the health inequities that older women face, it is necessary to engage with and examine their perceptions, attitudes and beliefs about those inequities and component parts such as mortality outcomes (Bécares & Zhang, 2018; Hosseinpoor et al., 2012; E. Phelan & LoGerfo, 2005; Pinquart & Sörensen, 2001; Tannenbaum et al., 2005). As noted in earlier chapters, older women face several factors which exacerbate the health inequities they face (Arber, 2006; Bierman & Clancy, 2001; CAB, 2017; McGuire et al., 2008; Velez et al., 2019; WHO, 2007). Older women in the United States have also historically and continue to face deeply influential social health norming pressures, particularly around narrative of individual responsibility and health behavior being the key causes of health and mortality outcomes (Cruikshank, 2013; Horne, 2014). This has impacted the health and mortality perceptions and experiences of older women in the U.S. (Cruikshank, 2013; Horne, 2014). Additionally, place and geopolitics attenuates these impacts, especially in highly conservative, neoliberal areas of the U.S. such as East Tennessee (Galvin, 2002; Hook & Markus, 2020; Yoder, 2002).

This chapter presents an examination of these factors in relation to older women's genealogical (familial) and geographical health and mortality outcomes histories. It describes the research philosophy, research strategy, sampling and interview technique and design, sample size, data analysis framework, and coding strategy, used in this study.

Research Philosophy

Because the purpose of this study is to gather and explore participants' lived experiences and their perceptions of health inequities and mortality outcomes within a complex, inter-generational, interrelated socially constructed health 'world', this research is undertaken from a critical and feminist geographies approach. Critical geographies work to not only challenge and influence the general public, but policy and decision-makers as well (Fuller & Kitchin, 2004). As such, they make space for researcher-activists and researcher-activist geographies (Blomley, 2008) and for participatory research and engagement (Fuller & Kitchin, 2004). Critical geographers sometimes attempt to dissolve the walls between academia and participants, what is sometimes called participant action research or activist research and allows the researcher to engage in direct action on social justice issues alongside those they study. Likewise, feminist geographies encourage researchers to examine the patriarchal and power-relations inherent to older women's health inequities (Fuller & Kitchin, 2004). Both encourage researchers to question all aspects of research and praxis, and to be self-reflexive – questioning a researcher's own positionality and bias (Fuller & Kitchin, 2004). These methodological philosophies compliment ecosocial theory in that all challenge researchers to carefully consider the relationship between themselves and the people they are researching, and to work to not 'objectify' the people / participants with whom they engage (Fuller & Kitchin, 2004). While these methodologies continue to have challenges, such as closing the gap for academics between using the language of social justice and issuing calls to action in our research or on being “impartial” scholars, these methodologies embrace the ‘messiness’ and nuances of people’s experiences and perceptions which result in complicated and complex research studies and outcomes such as this study.

Research Strategy

This qualitative study undertakes research of older women in East Tennessee through purposive sampling in order to examine a) how their perceptions of and lived experiences with gendered health inequities, and the social determinants (SDOH) thereof, are situated in their genealogical (familial) and geographical health and mortality outcomes and b) how their perceptions and experiences of health inequities and their familial mortality outcomes histories are characterized by the geopolitical and social norms in which they live. One-hour long semi-structured interviews were conducted in the Spring and Summer of 2021. In keeping with Rice & Ezzy’s (2001) interpretive rigor in qualitative research criteria, the recordings of interviews were transcribed and reviewed for accuracy.

Geographical and Health Profile of Participant Counties

East Tennessee, the southeastern region of Tennessee, along the Appalachian mountain chain, is approximately 180 miles east of Nashville. It is part of southern Appalachia, historically considered one of the most socioeconomically deprived areas within the United States (Fenelon, 2013; Woolf et al., 2019).[7] The participants in this

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[7] Tennessee has 95 counties, with 89 mainly rural health departments that are appointed by the Tennessee Health Department (TDOH) Commissioner. Six which are larger and more urban, are appointed by their county leaders, and operated under local governance (TDOH, 2021) until November 2021, when the state’s republican supermajority and the republican Governor, in reaction against federal COVID-19 public health measures, removed the rights of the six urban public health boards to make certain public health decisions and placed it in the hands of the governor, county mayors, and state appointed health commissioner (T.C.A. 14 COVID-19 19 of 2021). The counties are divided by TDOH into

study reside in three counties – Blount, Sevier, and Knox which are located in the foothills of the Smoky Mountains[8]. All three counties have majority “white” populations[9]. This majority is expected to remain through 2070, though population increases are expected in those who identify as Hispanic, Other Non-Hispanic, and Black Non-Hispanic in all three counties (UT Boyd Center, 2021). See Tables 1-3 in Appendix 1 for county-level population characteristics and statistics, and a county-level snapshot of additional selected county indicators.

Data Analysis Framework

Data analysis of this study was undertaken using critical discourse analysis (CDA). Like ecosocial theory and critical and feminist geographies, critical discourse analysis centers on meaning-making, the inter-relationships between people and the contexts in which they are situated, how they perceive and experience those contexts, what fundamental causes may be at play in discursive practices, and how power shapes the ideologies surrounding these issues (Mogashoa, 2014). It is interdisciplinary, adductive, and historically contextual, allowing for a wide range of data

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eight regions, one of which is East Tennessee, with two additional regions known as Northeast Tennessee and Southeast Tennessee. For public health purposes, the East Tennessee region is divided into sixteen counties, all of which have rural health departments with the exception of Knox County which is one of the state’s six urban health departments.

[8] All counties in the study are located in and/or along the Great Smoky Mountains range, an international biosphere reserve and UNESCO World Heritage Site, situated between the Tennessee and North Carolina borders. The Great Smoky Mountains National Park, the most visited national park in the United States, is located within the Smokies and is maintained by the U.S. National Park Service. (NPS, 2021). Blount County is considered part of the Knox County metropolitan area while Sevier County (home of Dolly Parton) is considered a micropolitan area (TDC of Knox County, 2021). According to Waldorf’s Index of Relative Rurality (IRR), Blount and Sevier counties are considered to be mixed rural counties and Knox County is considered a mixed urban county, while at the same time the IRR considers Knox and Blount are in the top quartile of most urban counties in the US (TACIR, 2021). This belies the complicated nature of socially qualifying these three counties within a region traditionally thought of as a rural Appalachian region.

[9] Blount and Sevier showing well over 90% (Knox – 76.3%; Blount – 93.7%; Sevier – 95.0%) (U.S. Census Bureau, 2021b).

collection methods across a wide range of issues and spaces. It is also disruptive, which fits with research intended to disrupt the status quo of traditional ways of understanding and treating older women (Mogashoa, 2014, pp. 110–111).

This study collects and examines the words (and silences) of older women regarding extremely sensitive subjects – health and death – covering their and their families' lifespans. It tries to convey the power relationships under which older women have formed their perceptions of health inequities and mortality outcomes and how those relationships (socially, structurally, individually) have shaped their experiences, thoughts and beliefs. Critical discourse analysis allows me to question not only the women's speech patterns but also the patterns they adhere or do not adhere to regarding socially constructed health norms. Understanding norms as a causal factor in determining their understandings of the social determinants of health or any systemic factors involved in theirs and their family's health and mortality outcomes is imperative to examining their perceptions of policy and other decision-making processes which shape their health and mitigate or exacerbate their health inequities. Critical discourse analysis provides the mechanism to examine "the underlying meaning of words" (Mogashoa, 2014, p. 105). For a generation of women brought up in a patriarchal Jim Crow dominated society, who were normed into silences or beliefs that their health inequities and outcomes were their fault, piecing together the underlying meaning of their words, in light of the social context in which they were formed, is of the utmost importance.

While there are those who find critical discourse analysis to be too interpretive, too complicated in keeping track of each academic field's epistemological approaches to CDA, or not neutral enough, for the purposes of this study (Grochalska, 2020; Mogashoa, 2014), the advantages of CDA outweigh any complications.

Sampling Process

Women aged 65 years and over from counties in East Tennessee were invited to participate in one screening survey and one in-depth interview. They were recruited via an email and flyer circulated by local organizations on behalf of the researcher and well as by word-of-mouth. The researcher sent a letter or email of introduction and a flyer to each identified organization for which clients or members were recruited. The organizations consisted of those whose primary members or clients are people aged 65 years and older, or whose services provide for a large number of people aged 65 years and over. The researcher had a good relationship with each of the organizations to whom a request to circulate the recruitment materials was submitted. The letter or email of introduction to the organizations explained that the researcher was contacting them to ask for their assistance in disseminating the flyer and information about the study. The researcher explained that the organization would not be asked to recruit potential participants, but only to share the information with their members or clients. The researcher specified that potential participants would be asked to contact the researcher if they were interested in participating in the study.

Potential participants who heard about the study through word-of-mouth either contacted the researcher directly or were contacted via phone or email by the researcher. Potential participants who did contact the researcher (whether by email or phone), including those who had heard of the study by word-of-mouth, were emailed or mailed a set of three screening questions, which they returned by email or mail.

The screening survey consisted of three criteria questions: confirmation that the potential participants were over the age of 65 years; that they usually reside in one of a set of counties typically referred to as “East Tennessee” counties; and that they were born with the biological sex of female. Women were excluded from the research interview if all three of those criteria were not met. If they met the screening requirements, they were then emailed or mailed the main consent form along with an audio recording consent form, detailing the aims and scope of the research and their rights regarding withdrawing, stopping the interview at any time, asking questions, or choosing not to participate, as well as ensuring both confidentiality and their anonymity. Consent forms were then either returned via the university’s secured Vault virtual private network (VPN) or mailed to the researcher using a self-addressed stamped envelope provided by the researcher. All research materials including introduction emails, the flyer, the screening survey, and the consent form were sent to the organizations and to potential participants via the university’s secure VPN email server and storage vault or via postal mail and stored securely in a lockbox in the researcher’s home.

Interviewing and Interview Process

Interviewing provides many advantages long noted in the literature, including the development of thick descriptions and meaning interpretation; a more holistic view of participants answers in the situated context in which they are currently placed; greater insight into the participant’s perceptions, thoughts, feelings, attitudes, and beliefs; the capture of participant’s literal and metaphorical voices and words; an allowance for adaptation to participant needs regarding time and space to respond; an allowance for the researcher to examine their own bias in asking questions and expectations around answers; the opportunity for researchers to seek clarification from participants in real-time or in follow-up conversations; the ability to see the participant's physical reactions (body language); and the opportunity to record interviews among others (Alshenqeeti, 2014; Berg & Lune, 2017; J. B. Hamilton, 2020; Kirsch & Brandt, 2002; Nathan et al., 2019).

Because these interviews took place during the Covid-19 pandemic, the use of video conferencing software allowed for face-to-face video chatting and recording. Telephone interviews accommodated for those who do not have access to computer technology (Kirsch & Brandt, 2002). Both video conferencing and telephone interviews remove travel obstacles and costs for participants, allow for a greater reach in accessing participants in various geographical locations and at various times and time zones (Khan & MacEachen, 2022; Kirsch & Brandt, 2002). I used Zoom software to conduct most of the interviews in the study because Zoom provides transcripts that allow researchers to review and correct them while reviewing and listening back to the interview. I also used a recording device for the telephone interviews I conducted as well as the one in-person interview I conducted.

However, interviewing as a method comes with concerns as well. These include establishing the validity and reliability of participant responses; the subjectivity of respondents, who opinions may change over time; possible misinterpretation by the researcher; the power dynamic between the researcher and the participant; the positionality and the potential subconscious bias of the researcher; and, in cases of structured or semi-structured interviews, the shaping of the study through the types of and layout of the questions asked (Alshenqeeti, 2014; J. B. Hamilton, 2020; Khan & MacEachen, 2022; Nathan et al., 2019). For telephone interviews, there is the lack of ability to see the body language of the participant, and one must rely on the voice affect and the capturing of pauses, sighs, stutters, etc., (Kirsch & Brandt, 2002). Telephone interviews also require strong note-taking skills and, sometimes, shorter time spaces in which to interview participants (Kirsch & Brandt, 2002). This was not the case for me because all of my participants were retired and were able to set up the interviews at a time that was most convenient for them. Still, it is a consideration. There is also debate among some scholars that the small sample sizes often required by one-on-one interviews or done because of the time-consuming nature of one-on-one interviews may lead to a lack of generalizability (Alshenqeeti, 2014; Hammersley, 2008, 2021; Kaliber, 2019).

Given these factors, the benefits of semi-structured interviews for the purposes of this study far outweighed any disadvantages. While there are instances in which allowing participants to review the transcripts for accuracy and agreement is best, in the case of this study, I made the decision not to do that. This is because of several concerns I had. The first is because I was seeking first responses regarding the women's perceptions at the given time of the interview – what they knew right then and there. Since this study was looking at what the women did and did not know or did and did not report in explaining their perceptions about health inequity, policies and interventions, and social determinants of health, had I allowed them to review the interview transcripts, I ran the risk of the women adapting their answers based on any research or conversations with family members, peers, etc., since the time of their interview. For example, I ran the risk of them researching information about health inequities or federal, state, and local policies, or asking their family members about their genealogical illness and mortality outcomes, and correcting their answers based on that updated information. There were also considerations to be made about the arousal of negative emotions in the participants when reading their transcripts (Mero-Jaffe, 2011). This meant that their updated answers may reflect updated transcripts that were not necessarily information that they recalled or knew at the time of interview. This could potentially change the results of the study as noted in the literature regarding this possibility (Hagens et al., 2009). Therefore, in weighing these options, not providing the participants a chance to review the transcripts seemed to be the most prudent decision.

Because I also took notes during the interview process, observing their body language, silences, conflicting statements and pauses, I was able to match their responses in the transcript to the observations I made in my notes. This allowed me to confirm that their non-language responses were matching or conflicting what they were saying and provided validity and reliability to my analysis of what the women said (FitzPatrick, 2019). Moreover, the transferability (FitzPatrick, 2019) of the study was helped by the fact that, while all of the women were located in one region during the time of the interview, nearly all of them were born, lived, and grew up in various areas of the country and internationally.

Finally, my positionality as a researcher must be taken into consideration. Because I have worked in communications, marketing, public relations, and broadcasting, I have extensive experience interviewing individuals. This means I have strong skills in establishing rapport quickly, taking notes in difficult circumstances on difficult topics, and in recording and reporting on interview answers.

Once they signed the consent form, participants were given the option to undertake the interview either in-person, via secured VPN video call, or via telephone. The semi-structured interviews were conducted over several months in the Spring and Summer of 2021 and lasted approximately one hour. Because these interviews took place during the pandemic, only one participant chose to participate in a face-to-face interview. Standard health and safety precautions, as prescribed by the CDC, were put into place in order to conduct that interview, including social distancing and wearing of masks during the interview. The remainder of the interviews took place via video call or telephone call. The researcher ensured that all call interviews took place in the privacy of a locked-door, selected room within her home and that no one else was present in the room or within hearing distance of the call. All calls, including telephone calls, were recorded using the university's secure sign-in Zoom software, and stored in the university's secure file system.

The first round of potential participants consisted of twenty women ranging in age from 65 years to 80 years. However, due to complications with health and with complications from the pandemic, several initial potential participants, many who had already signed consent forms, were unable to continue to the interview stage. Their consent forms and communications were securely destroyed or deleted, and the researcher undertook a round of snowball sampling which resulted in additional new participants.

The interview consisted of 26 questions which fell under broad categories, including introductory questions, and questions on life experience; health inequities perceptions of women aged 65 years and over; daily life experiences and perceptions of women aged 65 years and over regarding health overall; trends in mortality and healthy life experience; policies and services related to health; and what they wanted policymakers and clinicians to know about their health wants and needs. They were also asked how they defined concepts such as health inequities, healthy life expectancy, mortality, good health, poor health, and wellbeing. They were asked to describe where they grew up, where they were born, how long they have lived in East Tennessee. They were asked how health was viewed in their home growing up as well as amongst their peers, and if they perceived any differences in views of health in the places they had lived. They were also asked to recall, to the best of their knowledge, family health history questions, including mortality, causes of death, specific illnesses or conditions that ‘run in their family’, what they thought caused these conditions or illnesses, and how these conditions and illnesses were viewed by family members and by themselves. I asked them questions related to their own health care, clinical care, and insurance experiences. Finally, they were asked to describe their knowledge and perceptions of local, state or federal laws or policies that affect women 65 years and over, and what they would like policymakers, healthcare researchers, and services providers to know about what they think women aged 65 years and over need and want regarding their health. These questions were designed to capture their experiences growing up in these circumstances. This allows for an examination of any sub (or un) conscious beliefs, attitudes, non-answers, and silences that may not be apparent to them and that may support or contrast with their answers to the direct questions about their understandings of health, mortality, and health inequities. They were purposefully not asked the question, “What are the social determinants of health (SDOH)?” in order to see if they would mention ‘social determinants of health’ themselves. While it would not confirm the women’s knowledge or awareness of SDOH if they did not mention the phrase, it would act as an alert to the silences around the SDOH as a health term. Field notes on their demeanor, voice affect, body language, and expressions of emotion during the interview were also taken for the same purpose.

In keeping with Rice & Ezzy’s (2001) interpretive rigor in qualitative research criteria, the recordings of interviews were transcribed and reviewed for accuracy. Coding was completed by the researcher using a manual, inductive coding process. A thematic analysis approach was used when analyzing the data. Each interview was transcribed by the researcher herself, then re-read for accuracy and for entering into a coding framework spreadsheet. Each transcript was used in the first stage of analysis to apply overarching categories to the participant’s answers, followed by a second round of analysis to identify patterns and themes across participants’ interviews. A third round of analysis identified participant response outliers, where participant answers were in opposition to most of the responses. To assist with the accuracy of the findings, the researcher clarified responses with participants and followed up with additional questions, particularly around age of participants, as needed. The researcher also maintained field notes for interviews which were noted in the coding framework spreadsheet.

Coding

The coding was completed using a manual, inductive coding process. Inductive coding, which allows for coding to be created from the data (i.e., in qualitative studies using interview questions, from the participant's wording), is particularly useful for research whose aim is to 'give voice' to the participants, in providing prominence of the words of the participants in the study, and in examining meaning in the participant's perceptions. It helps to provide credibility in observational data construction of studies involving empirical data (Gioia et al., 2013; Kyngäs, 2020; Skjott Linneberg & Korsgaard, 2019). Inductive coding was best suited to the purposes of this study because this study is qualitative and was conducted using semi-structured interviews.

The data was analyzed using a thematic analysis approach whereby the themes emerged from the interviews. Each interview was transcribed by me, then re-read for accuracy and for entering into a coding framework spreadsheet. Each transcript was used in the first stage of analysis to apply overarching categories to the participant's answers, followed by a second round of analysis to identify patterns and themes across participants' interviews. A third round of analysis identified participant response outliers, where participant answers were in opposition to most responses. The women's perceptions and experiences were recorded using a bespoke coding Excel spreadsheet which is saved in University of Tennessee encrypted software systems. To assist with the accuracy of the findings, the responses were clarified with participants and followed up with additional questions, particularly around age of participants, as needed. Field notes for interviews which were included in the coding framework spreadsheet were also maintained. Pseudonyms are used for the participants and the data has been de-identified. The women’s interview responses are meant to assist with the credibility of this qualitative data.

Individual and Collective Memory

A note must be added regarding memory in relation to participant’s interview answers. Memory and collective memory are both a strength and a challenge when undertaking research on perceptions, particularly when examining the influence of social norms, since memory-meaning is socially constructed as well (Johnson (Ed.), 2018; O’Connor, 2022b; Roediger III, 2021; Wertsch & Roediger, 2008).

While this study relied on individual’s memories, caution must be taken in relation to memory bias, mis-recollection, and distortion (Huffman et al., 2022) both at an individual level and a collective level (O’Connor, 2022a; Roediger III, 2021). This is particularly true when looking at social norming and socially constructed meaning (Johnson (Ed.), 2018). One proposed solution to this is Keightley and Pickering’s (2012) call to examine the interaction between identified groups and cultural memories at interscalar levels – micro, meso, and macro – which Van de Putte (2022) has built on by proposing measurable observational tools in which to do so. Calls for addressing collective memory as relational provides the opportunity to see memory as a negotiated space, and allows qualitative researchers to accommodate for this (Gensburger, 2019; Johnson (Ed.), 2018; Kansteiner, 2002; Van de Putte, 2022). This dissertation study also examines the macro, meso, and micro scales of social norming – from geopolitical to familial - on the women involved and looks at their memories and lived experiences of the SDOH factors as relating to the health inequities they face at these scales, from childhood to adulthood.

Conclusion

Older women have unique health inequity challenges (AARP, 2022; Bierman & Clancy, 2001; NIA, n.d.). A look at their genealogical histories of health and mortality outcomes, social norming pressures, the discrimination and stigmatization they face, and other social determinants helps to contextualize the impacts older women experience regarding these health inequities. This dissertation examines those factors as well as the women’s identified wants, needs, and recommendations to policy, clinicians, and other decision-makers to create engaged partnerships upon which more effective solutions can be found to mitigate their health inequities. Ecosocial theory, critical and feminist geographies theories, and critical discourse analysis are used to examine the women’s interviews and determine patterns of perceptions, experiences, and influences. Reporting of the findings will show the health inequities, policy, and genealogical health history perceptions and experiences of older women in East Tennessee and their recommendations for mitigating these health inequities.

CHAPTER FOUR

PARTICIPANT CONTEXT: THE GEOPOLITICAL CULTURE OF EAST TENNESSEE

Temporal and spatial impacts of policymaking on older women's perceptions and experiences of health inequities policies and interventions.

In this chapter, I explore the geopolitical cultural norms of East Tennessee and how it has impacted participants' perceptions and experiences of health inequity policies and interventions over time and legislative level (state, regional, local) is undertaken. This chapter provides a background to policymaking in East Tennessee because a primary aim of this research is to examine what the women know about social determinants and drivers of health, including what they know of the laws, acts, and policies which codify these. It may be said that Tennessee's brand of Appalachian neoliberal, small government focused, ultra-conservative (and religiously based) policies that affect health are a strong influence in the norming of the women's perceptions of not only health inequities, but of the policies, services, and interventions available or not available to support them (L. Hamilton et al., 2022; Walton, 2017). In other words, they are a barrier to alleviating the women's health inequities and a barrier to their liberation from social, cultural, and political norming of attitudes about health and mortality (e.g., reinforcement of individual responsibility, shaming and blaming, health behaviorism). Reviewing their residencies in East Tennessee and the other states and areas in which they have lived (detailed in Chapter Five), will help in determining at what spatial level place seems to have on the women's perceptions of health inequities and familial mortality outcomes.

Federal, State and Local Policy and Intervention Impact on Older Women in East Tennessee

A review of Tennessee's state and local county policies, as well as how Tennessee's legislature has chosen to implement federal policies (and funding) is vital to understanding how systemic health inequities are built into the fabric of older women's situated and lived experiences, and how they shape older women's perceptions.

Federal to State Funding and Policymaking

In the United States, policies and interventions are made at the federal, state, regional, and local level, all of which impact older women's health and health inequities. For brevity's sake, this paper focuses mainly on major what is sometimes known as "pipeline" legislation and funding, which is to say, from federal to state to local implementation - such as the myriad provisions in the Older Americans Act of 1965[10] (OAA) as well as Medicare and Medicaid and the relevant Tennessee and local level legislation and services. Additional brief details of the provisions in any policies and services mentioned are provided in the footnote and appendices sections of the paper.

Since the 1920 Civil Service Retirement Act, which established retirement benefits for particular U.S. federal employees (U.S. OPM, n.d.), several acts have been passed at the Federal level for older people, covering a range of issue areas[11] (ACL,

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[10] The Older Americans Act of 1965 was enacted to provide services to people aged 60 years and over (Colello & Napili, 2022). Provisions in the Older Americans Act include, but are not limited to, home and community-based infrastructure programs such as "protective services, homemaker services, transportation services, adult day care services, training for employment, information and referral, nutrition assistance, and health supports" (Dillingham, 2019).

[11] Including social security, disability, and social service programs; housing; nutrition; transportation; adult day care and congregate independent living services; special needs; foster grandparenting; counseling; volunteering; employment; in-home care services and caregiver's community development; Medicare and

History, 2022). Many of these programs were enacted within the 1965 Older Americans Act (OAA) which created state and area agencies, often called Offices on Aging (housed alone or within county action committees), to coordinate community-based services for older people. The Act has legislatively amended or extended over the years to modify and improve the services and supports to older people (ACL, History, 2022). Most recently, the American Rescue Plan Act of 2021 was passed at the federal level which makes provisions to boost public health and economic supports in an effort to mitigate the effects of COVID-19, included a funding boost for many of the services provided to older people in the Older American Act (AARP, 2021; Bedlin, 2021; S. M. Brown, 2021). However, funding provisions for federal programs that impact older people, such as Medicare, Medicaid, Social Security Income, Earned Income Tax Credit, the Family Medical Leave Act, and several of the programs included in the Older Americans Act, come with limitations. These funds can provide states with 69-80% of federal funds to assist with state and local program costs for older people's care. Several of the programs allow for funds that provide for expansion of service provisions. This requires states, in turn, to fund a portion of the program costs themselves. However, residents of states like Tennessee, whose legislators are unwilling to fill the funding gap despite having the funds to do so, are unable to partake in the level of services which may be available in other states or localities (E. Park, 2021; Rosenbaum et al., 2016), as in the case with Medicaid expansion. Tennessee's lawmakers have also consistently opted out of the federal funding expansion of TennCare / Medicaid (and in 2021 the extension of pandemic-related unemployment benefits), despite

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Medicaid; age discrimination; legal services; nursing home reform; special needs assistance; elder abuse prevention; and much more.

several studies showing the benefits of expansion (Guth et al., 2020). This means additional or expanded benefits, such as those related to providing health coverage to more low-income residents or benefits to better support caregivers, are unavailable or are limited for those older Tennesseans who are part of the 300,000 people in Tennessee who quality for Medicare but whose supplemental insurance does not cover certain care needs or who may otherwise qualify for both Medicare and Medicaid (Garfield et al., 2021). Though Tennessee has used its TennCare CHOICES program for expansion of aging-in-place home and community-based services (HBCS), it has restricted some types of benefits older people receive. For older Tennesseans, this had been primarily done through a requirement to meet both state and federal Medicare requirements and “increasing medical eligibility requirements for nursing facility services and for more comprehensive home and community-based services” (Mattson & Bergfeld, 2017, p. ii) with certain exceptions for those at-risk individuals who may need higher levels of care.

Additionally, alternative funding for some of these programs is via a “block grant”, a funding system which provides less federal government oversight and more flexibility for state and local governments to determine how, where, when, and to whom, they will provide services within their communities. As a result, in the U.S., block grants are often acknowledged as an economic driver for the establishment of inequities (Brumfield et al., 2019; Schapiro, 2020; Serrato, 2013). Additionally, block grants have become what are known colloquially in the U.S. as “political hot potatoes”. This is because of the potential that states might accept block grant money that is intended for Medicaid expansion, for example, and, instead, misuse these federal funds, such as using them for non-Medicaid expansion programs, not disbursing the funds, attempting to cap Medicaid funding, or impose more stringent eligibility requirements. (TN Justice Center, 2020). All of these options would result in less benefit to, or even downright harm to, a state's residents. Yet, Tennessee's state government has a history of engaging in these acts (Dreyfus, 2021; TN Justice Center, 2020). For example, it placed its portion of American Recovery and Reinvestment Act of 2009 federal funds, enacted during the Great Recession in order to assist low-income people and their providers with additional Medicaid funding, into a state reserve fund against explicit requirements by the federal government not to do so (TN Justice Center, 2020). Until 2022, it did the same for the federal funds provided for the Temporary Assistant for Needy Families to support children in poverty (TN Justice Center, 2020). Block grants are such a political 'hot potato' and carry such potential for negatively impacting a state's residents, that no state has agreed to convert its Medicaid program into a block grant – except Tennessee (TN Justice Center, 2020). For these reasons block grants are often acknowledged as an economic driver for the establishment of inequities (Brumfield et al., 2019; Schapiro, 2020; Serrato, 2013).

The federal government stipulates mandatory coverage for certain groups of individuals in particular programs, such as Medicaid, but allows states the right to determine what will constitute remaining coverage eligibility for any of these programs. Therefore, many older women may be disqualified, such as those whose income is not sufficient to provide for services they need but is too high for income-based programs, (% of poverty-level); those who don't meet mobility or physical need requirements, yet still need assistance with certain aspects of daily living (TN TennCare, n.d.); and those who give up sometimes much needed older-age working in order to assume the role of familial caregiver, resulting in income loss (Navaie-Waliser et al., 2002). Because older women, once retired, are most often on a fixed-income, they may additionally be going without the added income support of their deceased spouses, the impact of not expanding Medicaid or other federal programs can mean that they go without the federal services they otherwise may have had in another state (Garfield et al., 2021).

Tennessee's policies and interventions are, like all governments, tied to their funding structure, which includes all federal funding provided for health and care services. Tennessee's state constitution requires that its budget must be balanced annually and that this must be done within strict revenue and expenditure guidelines (State of Tennessee, 2014). All policy and economic decisions in Tennessee are made with that requirement in mind, even when it means that other services, such as health, education, and infrastructure must sustain cuts (The Sycamore Institute, 2018). With regards to policies and interventions impacting older women in Tennessee, following the pipeline from the federal government to the state, Tennessee provides the standard range of federally funded services[12] as well as the state's version of Medicaid, known as TennCare (and as the TennCare CHOICES Act of 2008 which provides for long-term care services (LTSS)) (Mattson & Bergfeld, 2017; TN TennCare, n.d.), and the Options program. TennCare, as Tennessee's Medicaid program, provides healthcare services to those who meet the State's stringent eligibility requirements, including those older people who are low-income and who are receiving Medicare. TennCare CHOICES is

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[12] For a full list of services, visit https://comptroller.tn.gov/office-functions/research-and-education-accountability/publications/other-topics/content/senior-long-term-care-in-tennessee--trends-and-options0.html (TN Comptroller, 2022).

Tennessee’s state and federally funded Medicaid long-term services and support (LTSS) program for low-income older adults who have little remaining assets and who also meet stringent eligibility requirements. CHOICES provides a variety of homecare, community-based and nursing home care services available under the Older Americans Act. CHOICES covers the top-tier higher cost level of services needed by older people and comes into play when all other options are no longer able to provide the necessary level of care a person needs. Once a person dies, if there are any remaining assets or funds from their estate, the government can seek to recoup the costs from participant’s estates. Options is Tennessee’s state-funded program aimed at helping those aged 65 years and over who are at risk of becoming Medicaid eligible and who don’t qualify for federal-state support to stay in their homes as long as possible (Mattson & Bergfeld, 2017). The Options program, passed via legislation in 1999, supports those who are at-risk of becoming Medicaid eligible, and who don’t qualify for TennCare services, including older women (Mattson & Bergfeld, 2017). Additionally, for those who meet TennCare’s eligibility requirements, TennCare provides a mix of coverage, including long-term care and services supports (LTSS), some of which offer more service coverage than is required under federal law and makes use of the optional federal flexibilities that extend LTSS (Pellegrin, 2021).

Prior to 2021, federal government administration priorities resulted in drastic decreases in state funding for several federal health services and programs due to reduced participation and caseload (TDFA, 2019). While state funding went into all of its Health and Social Services Agencies, only four of those agencies were majority funded by the state: the Departments of Children’s Services, Mental Health & Substance Abuse

Services, the Tennessee Commission on Children and Youth, and the Health Services Development Agency (which oversees the regulation of healthcare facilities, institutions and services). The Tennessee Commission on Aging and Disability only received 34% of the state's funding allocation (Pellegrin, 2018b).

This means additional or expanded benefits, such as those related to providing health coverage to more low-income residents or benefits to better support caregivers, are unavailable or are limited for older Tennesseans who may be in the coverage gap or who may otherwise qualify for both Medicare and Medicaid (Garfield et al., 2021). This leaves the State's older women without some services they could have otherwise been provided. By creating stringent eligibility requirements for care and community-based services, older Tennesseans face a gap in the services they most need. For older women in Tennessee, who have longer life expectancies but may spend that time in poorer health, this is especially difficult.

State to Local Funding and Policymaking

Tennessee provides discretionary local government grants to cities and towns which are then allocated as determined by local (county, municipal) governments. East Tennessee policies and services related to older people are also administered through the East Tennessee Human Resource Agency (ETHRA), and the East Tennessee Area Agency on Aging and Disability, established by the Older Americans Act. Their 2019-20 plan included usage of Older American Act federal funds to support elder justice; assisted transportation for improving HCBS's, which have rolled out in local county area agencies and offices on aging; building stronger community-based organizational and clinical care partnerships; and the other component parts of the OAA. Direct state funds cover TennCare Options, Public Guardianship for those 65 years and over and the state health insurance assistance program (SHIP) which helps older Tennesseans with Medicare enrollment (ETHRA & East TN AAAD, 2019). ETHRA also administers funds from other federal funding programs such as the Supplemental Nutrition Assistance (SNAP) program (through the U.S. Department of Human Services) and the Collaborative Response to Elder and Vulnerable Adult Abuse (CREVAA) program (ETHRA & East TN AAAD, 2019). In Blount, Knox, and Sevier counties, these flow through to local community action agencies with offices on aging.

Local governments also generate their own revenues and expenditures. Much of their revenue comes from tax dollars. In Tennessee, local governments raise 67.5% of their tax dollars from property taxes, 20.5% from local general sales tax and 12.0% from all other taxes (PEW, 2021). Local governments may work together, or with the state, to establish several regional or local authorities which may collect revenue via revenue bonds or various types of charges which regulate and undertake the operation of services within local areas (U.S. Census Bureau, 2021b). These authorities can include several systems which impact health. These include but are not limited to: health facilities; hospitals; public health departments; education; transportation; housing; energy and water and other utilities; recreation and environment; economic, neighborhood, residential and commercial development; and more (U.S. Census Bureau, 2021b).

While these authorities can be created locally, they must have governing bodies, which rarely include at large members. Most are governed without direct community input by a combination of local mayors, local senate and house representatives, state commissioners, or those appointed by any of the above. For older women in East Tennessee, this can mean very little representation on issues that affect their health or the health inequities they face, especially for racialized and other marginalized older women since all East Tennessee counties except two are majority white (Schaeffer, 2019) and all of the state's county commissions are majority male (CTAS, 2021).

As noted earlier, local governments (and non-profits) provide boosted funding and fundraise for these services where they can, as well as work to fill in the gaps that the OAA funding does not provide or does not fully cover. One example includes the OAA Title IIIC Nutrition Services program, contracted out to vendor providers, which is suffering from increases in labor and meal costs and lack of regional coordination. (ETHRA & East TN AAAD, 2019). This makes it more difficult to provide older community members the meals they need. Likewise, in 2019-2020, ETHRA could not add any new TennCare Options clients due to lack of state funding, despite a long-waiting list. This means that older Tennesseans on waiting lists for services in the East Tennessee area continue to not receive much needed services for which they are eligible. Some remain on the waiting list for years, a problem which could be resolved through the State undertaking expansion of federally funded program dollars in which it currently does not participate, as well as the usage of some of its high reserve / rainy day monies (Pellegrin, 2018b).

Conclusion

The geopolitical context in which these women live provides an understanding of the structural and systemic issues which mold the policies and interventions that impact the health inequities they face. Tennessee's geopolitical and geocultural environment, along with other neoliberal, and highly conservative states within the U.S., restricts some provisions, funding, and services that would perhaps otherwise be available to these women if they lived in a non-highly neoliberal, conservative state. Moreover, Tennessee’s state legislative members, governor and most local government elected officials often overlay fundamentalist Christian values with the policymaking decisions they make. Tennessee’s health norms and neoliberalism favor the ‘individual responsibility’ narrative around health outcomes and around investment in healthcare. This can mean that older women in East Tennessee are also affected by social and cultural norms that permeate decision-making around health inequities issues and therefore, may harm them or exacerbate the inequities they face. As a result, older women in Tennessee encounter several barriers to mitigating the effects of health inequities on their lives and, indeed, may face worsening of the health inequities they face as a result of living in a geopolitical environment such as that in Tennessee.

CHAPTER FIVE

PARTICIPANT CONTEXT – LIVED EXPERIENCE AND NORMS

The women in this cohort were born and spent their early childhood during extremely adversarial geopolitical circumstances, in the immediate years following World War II, followed by a return to war in every subsequent decade since the 1950’s. They grew up in the 1950s’ misogynistic ideals of womanhood (Dimitrieska & Efremova, 2020; Guglielmo, 2018; PBS, n.d.), born into a history of laws, policies and interventions that stripped women of social rights, including: being explicitly identified as a ‘person’ in the U.S. Constitution (though several people argue that women were implicitly included as persons) (Lewis, n.d.; Rohlinger, 2018); being allowed to vote (DuBois, 2020; M. S. Jones, 2020; MAR, n.d.; National Archives, 2021; Ware, 2019); experiencing employment without gender-based discrimination (Banks, 2019; Dworkin et al., 2018); receiving governmental social benefits support as a single mother (Gordon & Batlan, 2011; Lundberg, 1926); right of entrance to certain establishments, including certain educational institutions (Freedman, 2014; Hill, 2020); having non-subordinate marital status (Sultana, 2010); and much more (Hill, 2020). They were raised in systemic, generationally inequitable, traumatic policies that went to war against their bodies – from abortion rights to lack of “comprehensive family planning and related preventative health services” (Shattuck & Risse, 2021, p. 5) to contraception, and rights not to be raped by their spouses. A look at any timeline of women’s legal rights in the United States will show the deeply traumatic policy and intervention climate these women have endured (NWHA, 2021), and even more so for racially and ethnically marginalized women, LGBTQ women, and others. As a result, decades of discriminatory practices have deeply impacted these participant's health and their opinions, experiences, and perceptions in relation to their own health and to health inequities.

In this chapter, the participant context of the women's lived experiences and the norms faced by them throughout these experiences is explored. An examination of how the cyclical nature between the norms they've encountered, their experiences, and their familial health and deaths influence their perceptions about these issues as well as health inequities is undertaken.

A number of dimensions including: place (state and town residences); family and youth experiences ('good' and 'bad' childhood memories, adverse childhood experiences, positive childhood experiences, and people they felt influenced them); and their genealogies of health and mortality (participant childhood health, participant adulthood health, and family health and mortality, specifically family member illnesses and deaths and participants' perceptions of the causes of those illnesses and deaths) are examined.

In addition to geopolitical environment and norms, these social, cultural and familial variables are important indicators of how the women's perceptions were shaped over their lifespan regarding health inequities, health and illness in general, and mortality (Broderick, 1993; Carr, 2018; Christakis & Fowler, 2009; P. H. Collins, 1998; Crenshaw, 1989; Krieger, 1994, 2001, 2012; J. C. Phelan et al., 2010; Thomeer et al., 2020). These variables shed significant light on why the women think these illnesses and deaths have happened throughout their genealogical timeline (family history). By knowing what the women think and believe about causes of health inequities and mortality outcomes in their family, researchers can develop translational and implementation health science protocols in order to help older women, clinicians, researchers, policymakers and others develop more appropriate policies and interventions to meet the health needs of older women and to mitigate their health inequities.

Places of Residence[13]

Although all of the women interviewed currently reside in East Tennessee, all except Deborah and Anita were born in other states prior to relocating to East Tennessee. All but one had resided in other states or countries. Of those who relocated to East Tennessee, none had lived in the area less than seven years. The places the women were born and lived in show a U.S. north mid-and-east geographical concentration of participant's birthplaces and the lack of U.S. northern mid-west and, surprisingly to me, southeast, lived-in places. This may be important because it shows a concentration of north-eastern and western immigration to East Tennessee, which will allow an examination of whether a cultural norm difference in primarily non-Appalachian attitudes, beliefs, and perceptions of health, health inequalities, and mortality manifests in the participants' responses (Hege et al., 2018; McGarvey et al., 2011; Morrone et al., 2021). It allows us to see where residence overlap occurred in participant residency locations including the states of California, Illinois, New York, Texas, Virginia, and the counties / cities of Ann Arbor (Michigan), Davis, (California), Nashville (Tennessee), New York City, (New York), and Westchester Co (New York) (for a full breakdown of

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[13] World Bank size classification and Best Places politics & voting data are used here (Best Places data is compiled using Federal Election Commission data) (Best Places, n.d).

city and state locations by number of participant residences, see Table 4 in Appendix 1). It also allows us to see if the women who unrelatedly lived in the same states, counties, or cities outside of Tennessee, share some of the same attitudes, beliefs or perceptions. Finally, by examining the breadth and diversity of residency locations of these twelve women, it is possible to argue that their geopolitical, social, and cultural place experiences were not limited in scope, and allow for a wider understanding of place, health, and policy experiences across the U.S.

To provide context to the geopolitical similarities or differences of various areas the women have lived in compared to East Tennessee, and to build a life course approach (Carr, 2018) connection to the geopolitical and social place environments they have encountered prior to living in the Tennessee and East Tennessee geopolitical and social place environment, a short comparison synopsis of the areas in which the women lived outside of East Tennessee to the three counties within the study counties of residence is undertaken. A review the social determinants of political environment, race-majority make-up percentages, and age 65 years and over population percentage as well as a comparison of non-East Tennessee areas against the major population areas within the East Tennessee study counties of residence: Knoxville (Knox County), Maryville & Alcoa (Blount County), and Sevierville (Sevier County) (birthplace of Dolly Parton) is also undertaken. Knoxville is, relatively speaking, a more racially diverse area than much of the U.S with a 68% white-majority population. Fourteen percent of its population is 65 years and over. The city itself has a mixed history of democrat-liberalism with republican-conservatism and is currently democrat-liberal within a conservative county, metro area, and state. Maryville is a strongly white-majority population with a just over 91% white-majority population and just over an 18% population of those 65 years and over. Alcoa has a 74% white-majority population and just over 17% of its population is 65 years and over. Sevierville has a 73% white majority population, and just over 20% of its population is 65 years and over. All Blount County and Sevier County areas are conservative with conservative counties, metro areas, and state.

Short Synopsis

- Deborah has only ever lived in East Tennessee, highly white-majority population areas, and in majority republican-conservative political environments.
- Cynthia, Anita, Sharon, Ruth, Sylvia, Carolyn, Kathryn all have the experience of living in non-white-majority population areas.
- Cynthia, Anita, Sharon, Margaret, Sylvia have the experience of living in both majority democrat-liberal and republican-conservative areas.
- Carolyn had only ever lived in democrat-liberal areas until moving to East Tennessee.
- Cynthia and Kathryn had only ever lived in democrat-liberal areas with the exception of one republican-conservative area in their lives before relocating to East Tennessee.
- All areas in which they have lived have been just over 50% female population majority
- The area with the highest 65 years and over population in which any of the women lived had 22.5 percent of residents 65 years and over.

- The women lived in a wide range of racially diverse areas. The area with the least racial diversity had 98% white majority population while the area with the most racial diversity had just over 12% white majority population. Half (six) of the women lived in non-white majority areas for some period in their lives.

Family and Youth Experiences

The women were asked about their childhood and young adult experiences in order to understand and uncover any social determinant and family systems, family diversity, and family composition norm patterns that may be running through these women's childhoods and young adulthoods (Broderick, 1993; P. H. Collins, 1998; Thomeer et al., 2020). Some stated that they'd had very good child and young-adult hoods. Some had extremely difficult ones with several adverse childhood events. In the sense of what illnesses and deaths occurred in their families, familial health and death histories (FHDH), surprisingly, differed very little, nor did attitudes and beliefs about the causes of these histories. There were, of course, some exceptions. Some women were very knowledgeable about their FHDH, some knew very little at all or reported very little at all, in keeping with attitudes and beliefs about secrecy and stigma. Many were very frank about the shortcomings of their familial attitudes and beliefs while others often chalked these up to the times in which they were raised. The findings of these inputs on the participant's health inequities perceptions, attitudes and beliefs will be explored in Chapter Seven. All of the women reported being deeply impacted, positively or negatively, by parents, family members, friends, school, or home environments. The literature is well established on the impacts or influences on health inequities on these determinants (Allison et al., 2019; N. L. Jones et al., 2019; Kuhlman et al., 2018; S. R. Liu et al., 2019; Umberson & Thomeer, 2020).

Adverse Childhood Events

Alcoholism, Abuse, Neglect, Abandonment

The adverse childhood experiences the women reported were many. Peggy, Barbara, Cynthia, and Margaret spoke about the impact they suffered because of parental or familial / generational alcoholism, even if they felt they did not suffer parental abuse because of this. However, Mary, Peggy, and Barbara talked about the abuse, neglect, isolation, and silences they suffered in the home as children by family members or other caretakers (Thomeer et al., 2020). Both Mary and Peggy were treated as pariahs by certain family members, reflecting deep levels of family social contagion effects upon their health (Christakis & Fowler, 2009).

Mary said, when speaking about her mother:

> “It seemed like I was always a problem to her…and I see now that I was, kind of the way she got rid of things she didn’t want. I was kind of like the sacrificial lamb…so I was very anxious, very nervous, um, terribly frightened about everything and, [developed] digestive problems…and I think the anxiety had a lot to do with my heart issues. I started having those in the eighth grade.”

Barbara’s mother left the family (“abandoned” as Barbara says) when Barbara was young. Both of her parents were alcoholics, so she and her underage siblings were removed from the family and placed into foster care while her two “of age” siblings were left to find their own places to live and to care for themselves. Having returned to live with her father and his new wife when she was fourteen, she ran away from home. The local police gave her a choice to return home to her father or to stay in jail for two weeks. She chose jail, which she said she felt provided more semblance of safety compared to living with her father. Kathryn experienced an incident with an instructor so inappropriate that she stated that she has “blocked out” the details of it. Peggy was moved from home to home because of her mother’s life-threatening illness.

Parental Illness

Peggy was traumatized by her mother’s illness because of the decision her father made to resettle her with family in another state until she was two, making her mother a stranger to her. Peggy feels this pattern of shuttling Peggy back and forth between family members, followed by punishments by her father if Peggy upset her mother, and non-allowance by the family to discuss both her mother’s illness and the punishments she received deeply affected her health. When Sharon was a teenager, her mother had breast cancer. She recalls visiting her mother in the hospital and nearly fainting from distress.

Loss of Loved Ones in Childhood

As young people, Sylvia discussed the impact of the loss of her grandparents, which affected her due to their close relationship, as did the sudden and shocking loss of her older sister’s fiancé to an unexpected, sudden illness. Margaret lost four of her childhood friends within a very short time of one another. Kathryn lost her father, Peggy eventually lost her mother due to her mother’s life-long illness, and Sharon lost her sister. This is explored more further in this chapter. Deborah and Kathryn, who are extremely attached to pets and animals, spoke of the devastation of losing their childhood pets. Deborah remembered this loss and this pet all of her life and was affected deeply enough to remember it as part of her responses in relation to the question about “bad childhood memories”. It is important to consider that the bonding that happens between children / young adults and their pets is an area that is often overlooked when looking at ACEs and health inequities. At the University of Tennessee, this has been recognized through the establishment of the veterinary social work program and the pet loss support group services (UT Vet Social Work, 2022b, 2022a).

School

Carolyn was bullied at “regular” school, and it was only when she transferred to a performance arts school that she felt accepted, was able to build friendships and felt at home (even though the performance arts school was not in her home city). Sharon started a protest movement at school regarding restrictive school uniforms, which was successful, but she accidentally struck a fellow student while waving her hand and received a punishment from the school, the effects of which have stayed with her even now.

Racism, Segregation, and the Jim Crow South

Anita, a Black woman, spoke openly about her health care access experiences growing up as a Black child in the Jim Crow American South.

> “Some of…my memories aren’t so favorable, you know. It involved, you know, the fact that you didn’t realize that your status in life was different than that of some of your white counterparts…I remember the segregation, I remember ‘colored’ fountains, I remember, “you can eat here, you can’t eat there”, I remember traveling and, you know, you could only travel during certain…times of day, in particular at night when you know there’s not a lot of folks around. You

> know, there were certain places you could not stop. You had to be sure you had enough gas and liquid, whatever, to get through this particular town."

She detailed the segregation of health care access as a child and of only being able to receive dental and medical care after regular office hours. She spoke of only being allowed to enter at the backdoor of the offices of providers who were willing to treat Black people. She also spoke at length about what Collins (1998) terms a family diversity coping strategy (extended to the 'community family' as well) - the need for Black families and Black communities to develop their own in-home medical services which her family and neighbors did, teaching the next generation how to provide midwifery services in each other's homes, as an example.

> "My mother gave birth to me at home because, you know, during those times Blacks [sic] or 'Coloreds' [sic] could not go to the hospital. So, most of your care was in your house, and it was the neighbors and, you know, their different preventative, you know, ideas, okay? [laughs] It wasn't necessarily grounded in medical knowledge, but it was those stories and those treatments that were passed down through generations."

Anita recounted her and her community's experiences and the daily fear for their lives and was very careful about displaying emotion in her voice when recalling this.

Positive Childhood Experiences

Even in the midst of traumatic relationships, most of the women recalled good memories with their family or friends or particular situations. Peggy's good experiences centered around being outside, away from the home, and with drastically different female influencers – the nuns at the school she attended, and the sex workers in the dark hideaway alleys she frequented in her city in order to escape the difficulties at home. When asked what her good childhood memories were, Barbara stated with little voice or body emotion, “Not very many. I hate to say that, but I can’t think of any really good memories. There just weren’t any.” Barbara’s statement was surprising, not because of her answer, which, given the circumstances in which she grew up, made complete sense, but because she had the courage to say this. The fact that her openness about her lack of good childhood memories required a self-reflection on my part regarding self-internalized social norms around being silent in public or to others about bad childhood experiences.

Deborah, Cynthia, Sylvia, and Kathryn cited being with their family as one of their main good experiences growing up, while Carolyn, Barbara, and Anita specifically mentioned being with their parents as a good experience. Cynthia, Ruth, Sylvia, and Kathryn stated that family events, celebrations, holidays, and vacations were positive experiences for them. Mary, Deborah, and Cynthia recalled good experiences with one or both of their grandparents. Mary specifically mentioned good times with her brother. Mary and Deborah also spoke at length about spending good times with their aunts. For Mary, this was an interesting revelation because she was speaking about her maternal aunt and highlighting the stark differences between her mother, who she spoke about as being abusive to her, and her mother’s sister, who she saw as kind to her. This is a further area of research that future researchers can examine – what differences in health, mental health, and health inequities exist, if any, between siblings who grow up together in the same home, and present very differently to their children or relatives.

Anita unequivocally stated that her community and neighborhood camaraderie were essential to her positive experiences growing up. She included teachers as part of that community, and said she had good teachers who got involved in and were supportive of the lives of the children in their school. Cynthia had good memories of high school and making new friends in school each time she moved. Sharon had good memories of her neighborhood friends. She also stated that school was a positive memory for her. This conflicts with her earlier statements about the negative lifelong emotional effects of the punishment she received for mounting a school uniform protest movement. Margaret also relished her neighborhood friendships, and “getting into mischief”. Sylvia referenced her good times with her friends as well.

For Mary and Carolyn, dancing was and remains a major joy in life. Likewise, Sharon enjoyed playing piano. Animals and pets played a positive role in Mary’s, Peggy’s, Deborah’s, Ruth’s, and Sylvia’s lives – so much so that Peggy, Ruth, and Sylvia went on to work in the animal health field as adults. Peggy and Sylvia said that Nature provided good experiences for them, while Deborah remembers being happy being part of groups like the Girl Scouts and Brownies. When Ruth answered what her good experiences were, she cited “food overall” as her most positive experience, outside of family vacations and holidays.

Ruth, Carolyn, and Kathryn said that they had good childhoods, and had very few negative experiences in childhood. In fact, Ruth gave no negative examples of childhood experiences at all. Sharon surprised me, as I’ve mentioned, when she said she’d had a good childhood overall and that nothing negative had happened to her – despite her mother’s cancer and the death of her young sister. Like others in this study, very often when traumatic experiences were discussed, Sharon responded showing little voice or body emotion, which may be a conditioned, normed response. When discussing her mother's cancer, she said:

> "I was in my sophomore year, my mother came down with breast cancer, and she had a major operation, and they decided to keep her another couple of weeks, to do a…hysterectomy because they weren't sure how far the cancer had travelled. I went to visit her and nearly fainted."

When discussing her sister's death, Sharon said:

> "Oh, I had a sister a couple years [sic] younger than I, when I was [age] and she was [age in relation to school year]. She died from [pause]…some kind of [illness]. She had two or three different things going on, and she had sixteen operations and…they had to take her all the way to [name of area] for the children's hospital. Even when I went there, they wouldn't let me see her, you had to be at least sixteen to see a patient, so that was sad."

In the interview, Sharon recalled this information about her sister almost as a second thought, prompted in her memory of it only after speaking of her mother and her mother's illness. Her responses reflect what appear to be silences and disconnects in her responses regarding the traumatic loss of her sister and of her distress of her mother's cancer. Sharon could not readily recall what illness her sister had and, instead, made a reference to the area of the body her sister's illness was located, nor did she mention what the other 'things going on' were. Sharon, of course, was not the only woman in the study to respond to the difficult events she endured in this way, but she provided conflicting statements more than once when speaking of difficult events.

Influencers

Most of the women named their influencers as the people that provided them good memories in childhood (noted above). Barbara, who experienced extreme parental abuse and neglect, cited her caseworker / social worker, and the philanthropist who was her college scholarship provider as the people who most influenced her:

> "I had a really…fantastic caseworker… she was very helpful and such a positive person and kind and everything, so as a matter of fact, when I went…to college…I got another degree in social work just because of that."

This was interesting because it speaks to Barbara's efforts and willingness to find those people who played a part in building a sense of social cohesion for her, given difficult circumstances. As is well documented, social cohesion can have a mitigating effect on health inequities (Gómez et al., 2021; Martin et al., 2021; Zhang et al., 2019). Although Mary and Cynthia didn't speak about good experiences with siblings specifically, both stated that they were positively influenced by their brothers. Likewise, for Margaret, it was her best friend, though she didn't specifically reference her in any of her childhood experiences, and for Kathryn it was her school peers and one classmate in particular. Anita stated that church was a major influencer in her life.

Participant Genealogies of Self and Familial Ill Health and Familial Death

To ask a person to recall, describe and expound upon their own ill health and the illnesses and deaths of family members is a profound experience. It is, perhaps, the most intimate part of examining the role of family systems in a person's health (Broderick, 1993).

At the beginning of this section of the interview, the participants were warned that this was ‘one of the most difficult parts of the interview’ and reminded that they could withdraw from the interview if and whenever they wanted and that they only had to answer questions they felt comfortable answering. None of them did. Most were stoic, some were extremely honest about their bitterness and disappointment, some were grateful for their faith. Looking at their experiences of self and familial illness, death, their perceived causes of death, and what they had to say about them, provides a researcher the fundamental context they need in which to understand why these older women perceive health inequities the way they do, and why they make the suggestions they make. This has implications for policy and for research on older women’s health inequities across the inter-disciplines.

Childhood Health

The women were asked about their childhood health, health conditions, and their understanding of the causes of any illnesses or accidents they may have had, some of the women spoke at length about the illnesses and injuries they suffered during childhood, and some did not refer to any childhood illnesses or injuries. Mary had scarlet fever as a child, causing complications including ear infections, temporary deafness and breathing problems. She also suffered from debilitating anxiety and digestive disorders, which she believes were caused by the parental abuse she endured and the resultant home environment in which she was raised. Likewise, Peggy identified parental abuse as the cause of her broken bones and cuts and believes their abuse is the cause of her stomach ulcers which began at the age of twelve.

Referring to her young childhood, Peggy said:

> “It was a time of uncertainty, all my life, you know, I never knew where I was going to be, where abuse was gonna come from. I had ulcers by the time I was 12, stomach ulcers. The pediatricians were beyond useless. Like sometimes I’d end up in the hospital from broken bones or things that needed to be sutured up or whatever, and they’d say, “You know, you shouldn’t get your dad upset, he’s got a temper” [laughs]. I just cracked up at that ‘cause now it’s like, “yeah, right, that wouldn’t be happening” or hopefully it wouldn’t…I never felt that there was anyone that I could feel really…supported by, so I was, I was a tense kid…”

Barbara discussed the hunger, malnutrition, and cavities she endured as a result of parental abuse and neglect of healthcare. She also described a leg injury due to an accident that cut her leg nearly to the bone, and the battle between her father who refused to allow her to seek care for it, and her mother who fought to take her to the hospital.

> "I don't know this, but I'm assuming my parents couldn't afford...to take us to a doctor. I can remember as a very young child going to the health department to get my illness shot [sic]. I don't know if everybody did that, or we just did it because we were poor. I had a really bad accident, when I was a little girl...really bad, and my dad would not allow my mother to take me to the hospital. My brother also had a pretty bad accident and [my dad] wouldn't let him go to the hospital. I just don't ever remember us receiving any kind of health care, besides mercurochrome and turpentine from my mom. Like I said, I don't know if we couldn't afford it or…what but we just didn't...get seen by doctors and dentists."

Both Anita and Carolyn also had issues with cavities, though for drastically different reasons. Carolyn stated that she inherited issues with her teeth from her mother. Anita was, as always, unemotional when recalling that her cavities and poor teeth issues were a result of the racism and the segregated care that Black people received while she was growing up. She also spoke at length about the poor teeth issues that were endemic to Black people in her community during those days, and that how, as an adult, the first thing she did with her wages was to get the dental work done that she needed on her teeth (P. H. Collins, 1998).

Like Sharon’s response regarding her mother’s and sister’s illnesses, Margaret’s response regarding her childhood illnesses experience seems to suggest a disconnect in her perception of her childhood health:

> “Well, growing up, no, there was really no [life experiences] impact on my health because my health was good. Hardly ever got sick. But if I got sick, I had, like, the flu. Caught the flu when I was 15 or 16, getting ready to go back to work. My mother told me to get back in bed. She'd called the doctor. House doctors over there made house calls, and I think they still do. It turns out, I had the German measles [laughs]. But that's the only kind of children's diseases. I've had the measles, the mumps, the chicken pox, tonsillitis, but other than that, my health was great."

Margaret’s perception that having had several contagious diseases equated to hardly ever getting sick, and that these diseases were part of childhood, it may be said, is indicative of social and familial norms regarding how illness was seen in her childhood years. This is explored further in Chapter Six.

Adulthood Health

In adulthood, some of the women have suffered catastrophic, life-threatening illness. Mary developed a life-threatening neurological disorder, which left her temporarily unable to walk or breathe deeply; a heart condition; a blood clot; and urinary retention under anesthesia. She has undergone several surgeries. She attributes all of these to the anxiety and stress she suffered in childhood (Christakis & Fowler, 2009; Thomeer et al., 2020). She even cites the ACEs she endured as the cause of a tooth infection. Peggy has had several heart attacks, which she feels is just a family inheritance / norm, though she referred also to parental abuse and family norms of silence about health as affecting her over her life course. She contracted a life-threatening disease due to the nature of the work she did. She had a detached retina of which she doesn't know a cause. Deborah mentioned that she now has allergies and acid reflux, but not why that might be. She has also had a broken arm, a damaged rotator cuff, and now has back and neck degeneration due to an accidental injury. She has concerns over the long-term effects of this injury as she ages and stated that she was more afraid of those effects than she is of having a heart attack. Cynthia also has degenerative arthritis in her feet, which she attributes to doing "stupid" things when she was a child, such as walking around on her toes. Ruth has chronic pain due to arthritis, which she says is genetic, inherited from maternal and paternal grandmothers. She has also had two hip replacements as well as several accidental falls, resulting in a pulled hamstring, broken leg, broken ribs, and broken transverse processes. Carolyn nearly died in a car accident in mid-life, which required hospitalization and on-going care for several years. She believed that her life may have been saved during the wreck because she danced professionally for a time when younger, and was, therefore, at elite athletic ability (with very good bone density, flexibility, and muscle strength). Although she quit smoking thirty or so years ago, she stated that she is having some effects from smoking. She began smoking as a teenager, having learned it from her mother, and had withdrawals after leaving home as a young person because she was exposed to so much smoke. Sylvia discussed non-specified health issues she believes were brought on by the stress she endured because of sexism at work, beginning in her middle age. She also stated that almost all her health problems can be traced back to genetics, her parents, and their backgrounds.

Familial Health, Illness and Death

Examining the women's family health histories (genealogies) is the crux of the genealogical part of this study. It helps to determine patterns in the passing on of familial health norms, beliefs, attitudes, and health ways of life, across diasporas, landscapes, places, spaces. It also helps to determine patterns of perceived (or real) illness and death within the families of these women. For the purposes of this study, participants' genealogical (familial) health histories on both sides of participants' family members (maternally and paternally) were tracked. Their family health histories of participants' spouses / partners, if provided, in order to map out the illness and mortality genealogy of the next generation were also recorded. Not all participants answered questions about their family health history, or did not fully answer the questions, or could not recall some information about their familial illnesses and mortality histories. Nevertheless, the information provided gives us a clear insight into the genealogical patterns of illness and mortality in older women's lives in East Tennessee.

The patterns of illness and mortality (Broderick, 1993) help to see which determinants may have played a role in the participant's responses to what they perceived to be the causes of illness and mortality in their family health and death histories. An exploration of participants' family illness and mortality histories and what the participants perceived the causes to be is undertaken in Chapter Six.

Illnesses

By far, the most common illness within the women's families was cancer. Deborah, Barbara, Anita, Sharon, Margaret, Ruth, Sylvia, Carolyn, and Kathryn had family members who had cancer, while Anita, Sharon, and Carolyn had more than one family member who had cancer. Cancer was followed by heart disease and diabetes as the top illnesses within these women's families. Heart disease appeared in immediate family member connections (parent to child) for Mary and Deborah. Diabetes appeared in the families of Deborah, Anita, Ruth, Sylvia, and Kathryn. For Deborah and Ruth's families, diabetes also appeared in immediate family member connections (parent to child). Other diseases that, as far as the women can recollect, have traveled genealogically through their families are Alzheimer's (which has devastated Sylvia's family), high blood pressure, stroke, arthritis, mental ill health, obesity, and thyroid disease.

Deaths

Asking people to talk about the deaths of their loved ones is a fearful experience. As noted above, the more questions like this that the women were asked, the more I understood not only the power imbalance research such as this has between researcher and participant, but also how researchers can and do have their own internalized norms. For each interview, it was clarified several times that the women did not have to answer these questions. It turned out they wanted to talk about this, to share what they had been through, who and how much they had lost. Most were unemotional when discussing these issues. Others were very emotional still deeply traumatized and shocked to their core by sudden and unexpected deaths, like Deborah with the loss of her mother and her husband, Sharon with the loss of her mother, Carolyn with the loss of her father and her husband, Kathryn with the loss of her brother, and Mary with the loss of her aunt and uncle.

Deborah's comments about her mother's death highlight several of the challenges older women face across multiple social determinants of health:

> "My mother was healthy, hardly ever got anything, cold or anything. She did have breast cancer, and then about five years later develops [sic] leukemia. We don't know how on earth that happened. Our [mother] was always a person that...went to the doctor and took care of herself, and my dad did too. It just seemed really unfair for her to get that. She had breast cancer at about seventy...and supposedly...they got it all. It was at the end of the breast, and she hadn't had any problems. Never even took anything but a Tylenol...but you wonder if the cancer cells didn't get loose somewhere because then I lost her at seventy-five...to leukemia. It was really hard. My mother was really, really good. In fact, I was furious at the doctor. They thought she had some...Alzheimer's type stuff, but he should have been catching that because the spleen was enlarged and, to me, he should have been knowing something bad was going on because by the time we got to the cancer doctor...he said. "Well, people can live...ten years with

> this." Well she didn't even make it a year, and I just boohooed at the ten years [mark]. I feel like the primary care let us down. I would not go to him, ever, because he didn't catch, he should have caught what my mother was having going on."

Of the deaths disclosed, cancer had the highest number of perceived causes of death for the women's family members. Cynthia, Carolyn, Deborah, Peggy, Anita, Kathryn, Ruth, and Sharon had family members they perceived as having died from cancer: Cynthia, Debbie, Peggy, Anita, and Sharon had more than one family member die from cancer; Anita lost both of her parents and several cousins; Cynthia lost two of her maternal aunts who also lost their father; Peggy lost both of her wives; Sharon lost several unspecified family members, going so far as to say it is the most common cause of death in her family.

Heart attack was the second leading perceived cause of death for the women's family members. Mary, Peggy, Deborah, Barbara, Cynthia, Sylvia, Carolyn, and Kathryn had family members who have died (or are believed to have died) from heart attacks: Mary's maternal grandmother; Cynthia's father and she assumed her paternal grandfather; Barbara's father, as told to her by her children, since she had lost contact with her father; all four of Peggy's grandparents, to the best of her knowledge; possibly Carolyn's father; Sylvia paternal uncle at a young age; Kathryn's brother; Deborah's husband, who died tragically of what is known colloquially as a "widowmaker" heart attack at age 52 years. Deborah's husband died in the garage while the family was in the house preparing to do some work together. She cried throughout the interview when discussing her husband. Again, an offer was made to stop the interview, but she wished to continue, to share the horrific loss of her husband, the discovery of her children's own heart related conditions, and the subsequent health actions her children have undertaken to mitigate the impact of those conditions.

Several of the women referred to "heart issues" as a cause of death for their family members: Sylvia's father; Deborah's maternal grandparents; Cynthia' maternal grandmother; possibly Margaret's mother; and Kathryn's maternal grandmother who she stated died of congestive heart failure.

Mary, Deborah, Carolyn, and Sharon had family members who died of stroke and stroke complications: Mary's maternal grandmother; Deborah's paternal grandmother and possibly her father; Carolyn's maternal grandmother; and several unspecified members of Sharon's family. Although alcoholism affected several of the women's families, only Peggy and Margaret reported alcoholism as a cause of death for family members. Alzheimer's caused the death of two of Sylvia's aunts who were sisters, a disease which Sylvia perceives as genetic within her family. Both Mary and Margaret lost their fathers to sepsis. Mary's father's sepsis was due to an IV after a pacemaker installation surgery. "It took him 82 days to die," she said, and stated that her brother had to fight the hospital to keep their father in the hospital after sepsis set in rather than the hospital transferring him to a nursing home. Mary spoke with bitterness and anger about what happened to her father, having also lost a maternal great-grandfather to surgery complications.

Mary and Peggy lost family members to secondary blood clots, one caused by a fall and the other after a surgery. Anita also believed that several of her unspecified cousin's deaths were due to 'blood issues'. A brain embolism caused Cynthia's paternal grandmother’s death, while a brain tumor caused Sylvia’s paternal uncle’s death at a young age. Diabetes complications were the cause of Sylvia’s paternal grandfather’s death as well as several unspecified members of Sharon’s family. Ruth’s father died from internal bleeding from a fall. Barbara’s mother died from pneumonia. Peggy’s mother, having battled illness her entire adult life, succumbed to renal failure due to post-illness syndrome.

Mary’s family suffered three particularly poignant family deaths, all involving paternal and maternal uncles. Like Deborah’s story about her husband, Mary’s stories about her uncles have stayed with me. Mary stated that she believes one paternal uncle died of heartbreak six months after the death of his wife. He was 94 years old and had known his wife since the second grade (around age seven). Another paternal uncle died during World War II, killed in the Battle of the Bulge at age 17. Her maternal uncle, at 88, had fallen and required permanent care. He was afraid to go into a nursing home and didn’t want to take family members up on an offer of living with them.

“[uncle’s name] shot himself when he was 88 because he had fallen, and he was afraid of going into a nursing home, and my mother had called him after he had fallen and said, “What do you need?”, and I told him he could come and live with me, and I would come down and get him. He lived in [name of town] and, um, instead, he chose that, and it’s hard not to go through second by second what happened.” When recounting this death, in particular, Mary spoke of how she understood his decision, though it devastated the family.

As noted, this study happened during the time of the COVID-19 pandemic. Just prior to these interviews, Sylvia lost her maternal aunt, aged 93 years, to COVID-19, while Anita stated that she lost her brother to respiratory illness causing him to be "unable to breathe", which she suspects may have been COVID-19. Anita expressed hesitation in sharing with me that she thought COVID-19 might be the cause of her brother's death, as if she was worried her brother would be judged for this. This made sense, given the stigmatized, highly politicized, and deeply divided opinions in the U.S. over COVID-19, but once she did not receive an adverse reaction from me to her discussion, she spoke more openly about her thoughts and beliefs about the loss of her brother.

Barbara, Ruth, and Carolyn attributed several of their grandparents, aunts, and uncles' deaths to "old age". Ruth used this term most of all, attributing old age as the cause of death for older family members for whom she was unsure of the cause. This term is important because it indicates a health belief (which will be discussed in the next chapter), one that has been normed and can discredit or even perpetuate stigma for older people's mortality (Dionigi, 2015; Stewart et al., 2012). By no means did Ruth appear to be intentionally discrediting or wishing to perpetuate stigma, nor portray any negative judgment about old age. However, it's precisely perceptions and beliefs – or guesses – that permeate social norms around age and health and contribute to health inequities (WHO, 2016; Wurm et al., 2017). This is not to say that reaching an 'old age' precludes concepts of 'dying of old age' as a natural end or a non-stigmatized conclusion to life. Still, by lumping older age death into a catchall phrase that doesn't explain or expand upon the causes of older people's illnesses and mortality, the opportunity to the chance of learning what older people are enduring, what the reality-on-the-ground is of the health risks they face, and of mitigating their health inequalities and mortality outcomes is lost.

Finally, the remaining two responses to causes of illness and death – “unsure” and “participant did not state” - are the ones that I most expected to encounter. This showed a bias on my part about older people, prompting an exploration, as a researcher, about self-biases regarding people’s knowledge of their family health, illness, and death histories in general. Mary, Barbara, Margaret, Carolyn, and Kathryn stated that they had certain family members who died but that they were unsure of theirs cause of death while Mary, Deborah, Anita, Sharon, Sylvia, Carolyn, and Kathryn had family members who were ill or who had died but did not talk about the causes of illness or death for those family members.

Conclusion

I expected higher rates of lack of knowledge on causes of death, only to be shown that these expectations, at least in this cohort, were wrong. The women’s knowledge of their familial health, illnesses, and deaths (and their causes) confirms Vogel et al.’s (2007) argument that women may tend to know or collect FHH more than men due women’s traditional caring roles within the family, their roles in health care seeking, and their wider healthcare consumerist knowledge.

Again, as when they discuss familial illnesses, it is difficult to know whether the women chose not to disclose the causes of death of particular family members or whether they simply forgot to mention what they knew during the interview. The silences in these instances were almost always about grandparents or aunts and uncles, with two notable exceptions: both Sharon and Carolyn did not discuss the cause of their mother’s deaths. Carolyn spoke briefly about her mother, who moved in with Carolyn when her mother was in her 80’s and who was a smoker until Carolyn insisted that she stop once she moved in. Carolyn did not speak harshly or negatively about her mother – only sharing the smoking story because she was explaining how she, herself, had been a long-time smoker. Likewise, given that Sharon remarked that she had a wonderful childhood and no bad remarks about her mother, that she was looking forward to spending more time with her mother upon her own retirement, and that she was shocked at her mother’s death, her lack of discussion around her mother’s cause of death was surprising.

These women’s responses revealed the complicated nature of tracking familial health and mortality histories. More than biological health self-reporting, examining the intersectional nature of these histories means listening for the silences as well as what is told. It means gleaning what one can from the fuller picture of a person’s life course story, gleaning what one can from a person’s body language, tone of voice, choice of words they use (and don’t use), references to abuse, bitterness, loss, policy, and political opinions. It means asking oneself from what positionality one is coming, what normed interpretations one is putting into the women’s responses and silences, and what values, thoughts, and opinions one is trying to express. By the end of this chapter, it could be said that, as a researcher, a feeling of the weight of the pressure on clinicians, policymakers, and researchers on how to gather all of this information in very short periods of time and to provide older women with some sense of authentic caring about them as women who have waited a long time to have their story heard, their needs met, and their inequities mitigated in some form.

How did these women, who had lost both parents and all of the generations they knew growing up, cope? What stories did they tell themselves, or believe and repeat from what they had heard growing up from their parents, family members, peers, and society, that got them through these health crises and deaths? What were the findings of these illnesses, deaths, health beliefs and perceptions, policies on the genealogies of health for these women, and the recommendations they would make to clinicians and policymakers in order to mitigate the health inequities they face?

This is explored in the next chapter.

CHAPTER SIX

PARTICIPANT CONTEXT: FAMILIAL AND PEER INFLUENCES ON PARTICIPANT PERCEPTIONS OF SELF, HEALTH, ILLNESS, AND DEATH

In understanding the impact of the health environment in which these women grew up, it may be said that researchers must understand the influence of family members and peers on our own thoughts and beliefs about health and mortality (Broderick, 1993; P. H. Collins, 1998). To this end, much of the women's family and childhood experiences are discussed in Chapter Five. Research shows that family and friends play a large role in shaping an individual's attitudes towards a given issue (W. Park, 2019; Telzer et al., 2018). This is the 'genealogical' nature of health beliefs, behaviors, and attitudes.

This chapter discusses the women's perceptions of and lived experiences with gendered health inequities, and the social determinants thereof; how they perceive those as situated in their genealogical (familial) and geographical and mortality outcomes histories; and how they perceive their experiences of these outcomes histories and health inequities as characterized by the geopolitical and social norms in which they live. Their responses help shape an understanding of the time and places which developed their health story, the knowing of which centers them in the solution to the health inequities that affect them.

Self-Perception: Telling About Themselves

As detailed in Chapter Three (Methods), I asked the participants to tell: about themselves; young self, familial, and young peer beliefs and views about the causes of ill or good health or mortality both within the family and in general; and thoughts about the health impact of their life experiences on their health. These questions were designed to capture their experiences growing up in these circumstances. This allows for an examination of any sub (or un) conscious beliefs, attitudes, non-answers, and silences that may not be apparent to them and that may support or contrast with their answers to direct questions about their understandings of health, mortality, and health inequities.

While the participants had a range of views about themselves, they most often described themselves via an external focus - in terms of their marital / partnership and children status, their jobs and retirement status, their current and childhood socioeconomic status, their educational status, and their hobbies and interests. This was particularly interesting because I purposefully did not ask about their social status in order to not influence their describing themselves with an external or internal focus. Instead, I asked them to tell me a little bit about themselves and what they liked to do (hobbies / interests). Some of the women reflected on their personal traits, allowing an inside view of how they perceive their internalized selves, and how this may interact with their views on gendered and genealogical health, health inequities, and mortality. Two described themselves as introverts, three as activists for social justice (one of who said she ‘speaks truth to power’ and one who said, as the carer for her husband, father-in-law and mother-in-law, that she is the health advocate for the family), some as spiritual people, some as religious people, and two as having had a good or great lives growing up. Still, a review of the women’s external experiences provides a strong context (in relation to social determinants of health) to understand their health’. Family relationships are integral to this study, since this study examines the role of families in the passing on of family attitudes, perceptions and beliefs about health, death, and health inequities.

For example, Mary described herself in relation to her family status and how her family plays board games together now, rather than eating together, and her pride around the 100-pound weight loss of both her daughter and grandson. This was one of her opening comments to me, which became a theme throughout her interview. In fact, in one of the field notes about this interview, it was noted that her interview answers were so heavily peppered with references to weight as a health indicator, that, for me, it became uncomfortable in the interview. Many of the women referred to weight and their weight which was not surprising given the large evidence-body of women's weight as a major clinical and social stigmatizing issue in all things women's health (Ciciurkaite & Perry, 2018; Forbes & Donovan, 2019; Mensinger et al., 2018; Puhl et al., 2020).

While I did not ask them to name their race or ethnicity, Anita, whose interview was conducted over the phone, stated that she was Black, and discussed her experiences growing up in the Jim Crow South. The other participants did not disclose their race or ethnicity. For those women who chose to tell me their marital or partnership status, Cynthia and Kathryn are currently married; Peggy, widowed twice, is currently and "happily" single; Deborah and Carolyn are widowed; Barbara is divorced, having married at 18; Ruth never married. Peggy disclosed that she is LGBTQ, identifying as lesbian. No other woman disclosed their sexual orientation nor their gender identity. For those who spoke of their parenthood status, Mary, Peggy, Barbara, Cynthia, and Ruth have children; Carolyn has stepchildren; Peggy, Deborah, and Barbara have grandchildren; and Mary had been a single mother early in her life, while Peggy currently is. Of those who provided their educational status, Margaret and Kathryn received a high school education; Mary, Peggy, Barbara, Anita, Sharon, Ruth, Sylvia had received their bachelor's degrees; Anita and Sharon had received their master's degrees; and Peggy, Janet, Ruth, and Sylvia had received their Ph.D., Ed.S., or other professional degree. Margaret and Anita went to public primary schools and Peggy, Carolyn, Kathryn went to private, religious or professional performance schools. At least one worked full-time while at university to help pay for her degree.

Barbara mentioned that, as a child, she grew up in poverty, while Cynthia stated that she had grown up middle-class and 'had never wanted for anything'. All of the women had worked in their middle and later lives. Barbara mentioned that she was "forced by her husband to be a stay-at-home mother" when she was younger, but after she divorced him, broke and homeless, she moved to another state. She found work, and eventually became self-employed for many years before retiring. Mary had also been unemployed after a divorce at a young age, a situation which caused her a lot of stress because she was also single parent and unable to find a job even though she has a bachelor's degree. Peggy continues to work full-time, and Sylvia is semi-retired, still working part-time. Both of those women are self-employed, running their own businesses. In addition to Barbara, Deborah, Anita, Sharon, Carolyn, and Kathryn, mentioned that they are retired, and Cynthia disclosed that she had been retired, went back to work, then retired again because she initially found it difficult to not work. The remaining women did not mention whether they are retired. The women work(ed) in a variety of industries, including education, manufacturing, corporate, printing / editing / publishing, government, and as professional artists / musicians / dancers / performers.

While most of the women did not disclose specifics about their spiritual or religious preferences, Peggy, Sharon, and Sylvia stated that they were raised Catholic. Sylvia recalls how her community and her Catholic church helped people with caretaking and finances if people were in need due to health issues. Deborah said that church is very important to her, that she likes going to church and participating in church activities. Anita said she was greatly influenced by church. Peggy stated that her spirituality now was nature. Margaret and Cynthia stressed the positive impact in their lives of the good friendships they have.

Hobbies included exercise, writing, watching movies, dancing, science, nature, gardening, medicine, travel, scrapbooking, sewing, quilting, crochet, games, going to church, swimming & other water activities, reading, walking, all things Christmas, animals, computers / internet / phones, social justice activism, volunteering, bicycling / road bicycling, hiking, and being outdoors.

Childhood Peer and Familial Perceptions of Health, Illness, and Death

To ascertain the women's thoughts of the impact familial and peer perceptions had on their own perceptions of health and mortality, I asked the women to recall what their family members' and peers' perceptions of 'health' and 'mortality (death)' when the women were young.

Several spoke about their families having silence norms or "do not discuss" rules regarding familial illness or death, which meant they were left, as young people, growing up without guidance or understanding or an outlet for discussion of what was happening to their parents or relatives who were ill or had died. This did not mean that they were not aware of illness or death in their family, and certainly not regarding their parents -

they were very aware of familial illness and death. It meant, in some of the women's cases, that they filled in the blanks of their perceptions with familial norms, including fatalism, pragmatism, and stoicism. This was the case for Margaret, Carolyn, Cynthia, Anita, and Kathryn. Others, like Sylvia, cited their familial stoicism as stemming from the placed-based regional, cultural norms that come from the Midwest.

Carolyn said, "If you live long enough, you're going to get some form of cancer." This was perhaps the most fatalistic response to any question asked during the entire study. The belief that older age brings with it an unescapable disease matches Ruth and Barbara's beliefs that family members died of "old age." This belief can be seen as stigmatizing aging (Bodner et al., 2015), though by no means was the impression made that Carolyn, Ruth or Barbara were intentionally disparaging of old age. Instead, these comments spoke more to the fatalism norm encountered through the U.S. when speaking of old age, illness and mortality (Davison et al., 1992).

Ruth and her siblings combined beliefs of familial inheritance of illness with fatalism and fear, which have profoundly impacted the decisions family members have made about their lives:

> "Well, my brother was concerned, if we could, if there's a way to figure out if the type of stroke that mom had, the bleeding stroke...did run in the family because he was concerned about his three sons...but there's nothing we can do about it. When you have a weak blood vessel, you have a weak blood vessel, and at this point, science hasn't...gone past that thing, but he was concerned about his three kids obviously. Other than that, we're just waiting and seeing. Then...the adult-onset diabetes, we knew about because...my father's sister had it also, as well as

> his mother, and then...my dad, so we've all been watching that. My sister has some mental health problems, but she has that well under control, and we think that she inherited that from my father's mother...because my father's mother did have some mood swings and things like that, but it's hard because things like that weren't diagnosed back then. She was born in 1894, and lived...to 92 in the 1980's. My sister doesn't have any children, so it'll end there type of thing."

It is striking that Ruth has come to believe and feels relieved that mental ill health will not be passed on through her sister because her sister does not have children.

For those with parents who shamed, neglected, or abused them, some perpetuated their parental norms of stigmatizing illness and death, referring to other family members as hypochondriacs or as suffering psychosomatic illnesses.

Peggy’s mother’s illness profoundly impacted Peggy and her siblings. She recalls, "I wanted to be a doctor, I was gonna cure my mom,” and, indeed, she did grow up and went to work in a health field. That may be why, as an adult, she vacillated into concern that she, her siblings and family members, and peers (who also grew up with a parent who had illness) became overly concerned with their health. Still, it was shocking to me to hear Peggy say:

> "In some ways we [peers and family] were too conscious about our health…my brother became just a hypochondriac. He's still a hypochondriac."

Peggy is not the only participant to use a stigmatizing word – hypochondriac – when referring to family members. Carolyn also did this. It is synonymous today with another stigmatizing word – psychosomatic. It may be that this shows a familial or social norming of expected silences and individual ‘toughness’ (i.e., responsibility) around health. Peggy, who is trained in healthcare and indicated during the interview that she is versed in mental ill health and trauma responses. However, instead of expressing her brother’s response to health seeking as possibly hypervigilance from being traumatized at their mother’s illness and death and the abuse by their father in the home, Peggy responds with what is sometimes referred to as a normed, stigmatizing, and inequity-perpetuating answer (O’Sullivan, 2021; Willis & Malcolmm, 2015). This is not a judgement of Peggy or of Carolyn, but rather an example of how people can, despite their best intentions, consciously or unconsciously, express discriminatory health beliefs and language. It is an example of how ingrained norms can be, and how people may be working hard to mitigate the inequities they face, while, at the same time, still working from an internalized emancipation barrier.

Carolyn, like Peggy, seemed to echo her perceptions of her family’s attitude toward ill health. While Carolyn was not a healthcare professional, she exhibited extreme compassion for certain members of society, particularly the poor. In fact, she cried at one point during the interview (as you will read further in this chapter) when discussing wellbeing and those in the Global North. But when relaying her frustration at her stepson for his hypervigilance about her health and other family members’ health, she stated that she does not tell him when she has health issues or is going to the doctor because his over-concern has "affected my life to the point where I don't tell him anything because I don't want it blown out of proportion as to what it is." It must be noted that his father, Carolyn’s husband, died just seven years ago, and may have impacted her stepson (her husband’s son) deeply.

Some of the women explained how their families had fears based on false beliefs about causes of illness or death or about how illness developed, and this fear prevented their family members from seeking care. These women most often referred to cancer when discussing this fear.

Cynthia, talking about her family said:

> "As far as cancer goes, they don't even want to hear the word. Some of my family members had used [sic] to say that once…they operate, the air gets in there, and the cancer spreads. I'm like "Mom, I don't think that's true." But that's the way they thought. I don't necessarily think that, but it's almost a given that once it's in your family, you just feel like, okay, which am I getting? I do my mammograms every...year. I do my colonoscopies. I try to keep on top of things. But when you feel like there's something wrong in your body, and several of my aunts were [like],"You don't want to go there [to the doctor] because you feel like they're going to tell you something you don't want to hear which is so true for many people."

Some mentioned that, as young people, they saw the parental “non-discussion” norm play out among their peers as well.

Ruth said:

"I don't think we even thought about it, as we were growing up to tell you the truth because I can't remember any discussions, particularly about health. I think at that point in your life, you're not really thinking about it. You notice the examples of what...your parents said.”

Some like Sylvia, however, said that their parental attitude towards health – and the community involvement in supporting other members of the community in need – helped to make her and her peers grow up unafraid of illness and death.

It is important to keep in mind, that these peers were children, and that the purpose of examining whether or not the participant felt that their peers (children) were discussing familial health or death was to see if there was a pattern amongst the children in what they were being told and were repeating from their own families, parents, or other social authority figures. It was not expected that children would necessarily discuss health and death with one another, but it is important to get the women's perceptions of how health was viewed outside of their family amongst peers.

Many also spoke about the profound effect parental or other family member's illness or death had on their perceptions of health, illness, and death. Many believed their parents and family members suffered and died due to individual responsibility (e.g., choosing not to adhere to a proscribed health behavior), and, as a result, they themselves adjusted their own health behavior in order to mitigate the chances of them getting ill with or dying of the same illnesses or causes of death their parents or family members had. This was the case for Anita and her siblings who are all non-smokers after watching both of their parents, who were smokers, die of lung cancer, as well as for Cynthia, Peggy, and Ruth.

Cynthia, however, did not shy away from expressing the fear and anxiety that the illnesses and causes of death that their parents and family members suffered would also happen to her:

"It's…scary. You get a little anxious thinking about it. Like I said, my dad being 66 and I'm coming up on that age. You know, it's like, uhhhhh [anxious sounds], okay...trying...to make sure that I don't do any wrong things to push the bucket, so to speak."

Cynthia's solution, at least in part, then has been to rely on individual behavior modification to attempt to avoid her genealogies of illness and death. She did not speak about any systemic things that may have led her father to alcoholism or for the family to have ill health. She saw her father as having made choices individually that profoundly affected her and her family – particularly when she referred to her father as having "decided to take himself off of his medicine and…drink himself to death." The fear that Cynthia has resonated with me, the way that death resonates with people when they feel an illness or death was 'preventable', and when parents make choices that change their children's lives. Her comment about her father has also stayed with me well beyond the interview process. Perhaps Cynthia saw her father's death and her familial illnesses in the way that she was taught and normed to think. Of course, her silence around social determinants does not mean she did not think of them or know of them, rather than their silences about them were noticeable and worth examining, though there may have been many reasons she chose not to mention any determinants.

Some felt that having parents or other family members who worked in healthcare helped to make the family more aware of health, healthcare, illness, and death. In these cases, these women felt there was a difference in the openness about these topics in their families compared to their peers.

Anita said:

> "[they viewed it] differently because…I know some of the things that mother would insist that we do…some of [the things] my peers didn't do because it was just…knowledge-based. You know, if you were around an environment where health is discussed, health is important. She knew about exams or tests or whatever that other folks were getting...that white folks were getting. She'd say "Hey, [laughs] if they gettin' it [sic], must be pretty good" [laughs], so she would make sure that we...would undergo the same kinds of examinations and things like that…"

The answers given by the women affirm the need for investment in education at early ages about the drivers of our health and mortality. Their answers help to clarify the idea that norms seemed to be for some families to not discuss health or mortality matters with children or young adults so that some children and young adults did not learn or think about health or death. Their answers also confirm the need to balance some adult perspectives of not introducing young people to these concepts, with those who have designed and delivered age-appropriate learning tools on how to make young people aware of health, death, health inequities and similar subjects (Health Equity Initiative (HEI), 2021).

Participant Perceptions of the Causes of Childhood Self-Health and of Family Members' Health, Illness, and Deaths

Having some understanding of the geopolitical, cultural, social, familial, and peer health milieu and of participant's familial and peer health and mortality perceptions, helps build the base of understanding and examining the health and familial illnesses /

mortality perceptions of the participants themselves. Here patterns among the women that emerged from their thoughts, as children, about health and about what impacted them (or didn’t) about illness and death in their family are examined.

By far, individual responsibility, in one form or another, was the main response regarding the participants’ perceptions as to the causes of family illnesses and deaths.

As noted above, many of the women were profoundly affected by the illnesses and deaths of their parents and other family members and expressed concern for their own health as a result, even expressing fear of certain types of diseases, even if there was no history in the family of those diseases.

When speaking about her perception of her family’s illnesses, Deborah stated that she felt so many of the illnesses were unexpected. Deborah’s statements about the unexpected nature of her family’s illnesses were poignant - particularly because her husband’s death was so unexpected and traumatic. Deborah stated that much of the unexpectedness she experienced was because she and her family were uneducated in health matters:

> "Most of the other stuff [referring to family illnesses not mentioned by Deborah] just kind of came on more suddenly I guess because it was not something they could just necessarily…do some things to prevent. They…didn't know that kind of thing, a lot of it. And I think, again, healthcare's improved so much that we catch things a lot easier than we did...a long time ago… It's hard to know what caused [illnesses] other than the diabetes, you kinda got that coming on. But looking back, you see the things that I didn't know to watch [in reference to husband's diabetes]...that I do now. Watch for going to the bathroom more, drinking a lot

> more, those kinds of things. That I'm a lot more conscious of stuff now. I wish I'd paid close[r attention]."

Not only were they profoundly affected by their illnesses and deaths, but they saw their parents' and family members' individual health behavior choices as the culprit in not preventing or mitigating their illnesses and causes of death.

Anita's responses to the questions about her perceptions of health as a child and of her family's health and deaths, was surprising in that she, too, focused on individual responsibility, unlike many of her other answers which incorporated social determinants and systemic discriminatory practices. She said:

> "Well, I don't smoke, okay [laughs]. I try and get regular check-ups...and I try to do the things that [are healthy]...except I know sugar is an issue [laughs]...I drink too many sodas, and I'm trying to cut back on sweets. It's hard, but I know what I should be doing, not necessarily what I'm doing, but I know what…I should be doing."

It was as if by asking her about her view of her own health, she felt the need to self-blame, to take on the mantle of individual responsibility / behavior as the means of her family's health outcomes and her own. Anita's responses show the complicated nature of health inequities and how the social dominance of one of the drivers of the determinants of health (health behaviors) can drown out all of the others in moments when people feel pressured or react in ways they've been taught or shamed to act about their health. It cannot be known for sure why Anita answered the way she did, but it is important to critically examine responses which are incongruent with other answers provided by a participant, especially if they may indicate a normed response or a powerinduced response (such as a participant thinking this is what the researcher wants to hear).

Only Carolyn and Sylvia perceived any systemic or social determinants of health at play in their family’s illnesses or deaths.

Carolyn, whose family are Russian Ashkenazi Jews, also spoke at length about the role she perceives genetics has formed in her family’s health:

> "First of all, I’m sure it's genetic. I know that Ashkenazi Jews carry a lot of genetics...and it's probably because it wasn't a huge pool of people, and they didn't tend to marry outside of [one another]...and, in fact, genetically if you have even a small percentage of Ashkenazi Jew in your genetics, you're related to everyone else that has it. So, I'm satisfied that...that's part of it because my parents were Russian. My father and his family, the man who raised me and his family were Russian Jews and came over from Russia. Depending upon what year they came, it had been Poland [laughs], so I...think that cancer is a genetic...you do have a genetic tendency towards it. I'm sure that I feel...cancer's a combination of two things: you have a genetic tendency or leaning tendency, lean that way. Then there's an external environmental thing that triggers it, and if a whole family remains in the same area of the country or in the same profession as everyone else, it may be they're there with a trigger, so that's why each one of them is then getting the cancer or a form of cancer. That's my theory. No medical background for what it's worth [laughs]”.

Hearing Carolyn’s thoughts about the role genetics has played in cancer in her family, helps to widen the understanding of why she thinks cancer and old age go hand in hand. She also references environmental triggers – place-based and job-based. She refers to her explanations as to why her family members have suffered from cancer as her theory. This could indicate that Carolyn understood the social determinants of health and the role genetics played in her family without understanding that she understood them. As conflicting as Carolyn's responses are, they go to show what much of this study shows about older women (and people in general) - that people can hold several beliefs and attitudes about health, health inequities and mortality at the same time. They can know what they think they don't know about health inequities. It may be said that this is why researchers must take the time to do in-depth qualitative health research – to get deeper, "thicker" information from the very people they are trying to build policies and interventions for, and to build more inclusive policies and interventions with their seemingly incongruent perceptions in mind.

Sylvia, who worked in healthcare for many years, viewed her family illnesses as mostly genetic. She also examined her thoughts about her uncle's death from a brain tumor and what environmental factors, such as job stress, may have been involved:

> "We've not really had a problem, like obesity. In our family...the cause of my grandfather's diabetes, and since his father also had diabetes, I suspect that was genetically driven. I think the heart disease and the Alzheimer's is. The one uncle who died of a brain tumor, we often worried that he was an air traffic controller during some of the most stressful times for that profession, and we worried about whether or not his health in general, you know, was affected, and the stress of that...perhaps didn't necessarily cause the tumor, but maybe didn't allow him to fight it as well as he should. We didn't experience any of the exposures...to toxins

> that...some industries...would have or to respiratory...inhalant...irritants that some industries would. Not like the friends, I know who got sarcoma on their…arm because they were exposed to Agent Orange in Vietnam, or anything like that, so I don't really know of any real environmental triggers to the health problems."

Prior to hearing the participant’s answers to these particular sets of questions, I would have attributed Sylvia’s answer up to her healthcare professional experiences. But the other healthcare professionals in this study have proven that theory of mine wrong. It was encouraging to hear Sylvia refer to possible genetic and environmental factors as well as the impact stress can have on the body. Having diseases in her family such as diabetes and Alzheimer’s which have strong genetic propensities, it makes sense that she refers to genetics as a consideration for her. Having friends who developed cancer due to Agent Orange has given her a familiarity with environmental factors that other people may not have. Sylvia is also highly active in community groups which tackle various ‘social ills’ and may also have much to do with her knowledge and referral to environmental factors.

Some also perceived the ‘silence about health’ norm in their families as leading to replication of normed behavior in their lives and in their passing on of these norms to their own children. For some, like Margaret, who had replicated the silence norm, this led to anger with their parents and other older family members for the health risks that she and her children may have unnecessarily endured. Importantly, Margaret is an immigrant and was raised with this norm in another country, not in the U.S. This is important because this research shows that certain norms may be spatially, temporally and generationally significant.

Others, like Ruth, felt her family’s “silence about health” norm led to ignorance about healthcare access and provision overall. She did not fully understand what healthcare services were available to her or others in general until much later in life:

"....at each place [she lived], was I aware of what they had for others? No. But I was able to find what I needed. I mean, until I...served on [organization’s board in East Tennessee], I really didn't have an understanding of...all of the healthcare things that are available."

Those who suffered abuse, neglect, incarceration, or other forms of violent adverse childhood experiences, most often expressed the perception of health, illness, and death in terms of individual responsibility. This makes sense for young people who have not been able to rely on caretakers and, therefore, may have developed views of mitigating ill-health as relying solely on self.

Barbara’s incredible experiences of abuse, neglect, and time spent in jail as a teenager, profoundly impacted her view of health. As a result, she subscribed to the individual responsibility view - working to keep her health was as well as she could make it and being vigilant to the environment around her as one means to the end of ensuring she could change her life:

> "I had been in jail, and it was a pretty scary place, so I pretty much put my nose to the grindstone and thought...I better keep my nose clean and do the best I can so that I don't have to live like this anymore…. Just taking care of my health and paying attention to what's around me"

When speaking about her family conditions and illnesses, she spoke of her father's intentional unwillingness to provide access to healthcare for her and her brother, and his abusive behavior around illness or accidents:

> "Even as a kid, it concerned me. I told you I had a pretty severe injury. I wrenched my leg open through the bone, and I was in a wagon, one of those little radio flyer wagons, and the whole bottom of that wagon was full of blood, and...I can remember thinking..."I need to go to get this sewn up." I knew what that was all about. I knew there was that such [sic] procedure, but I can remember not understanding why my dad would not let my mother take me to the hospital...I probably was five years old, but it still looked to me like a lot of blood. The same thing happened when...my brother had a pretty severe incident. My dad drug him behind a car on a dirt road for about half a mile, and ...he was bleeding all over, he was all scratched up. I thought "he needs to go to the hospital". Instead of taking him to the hospital, he wanted to spank him or beat him for falling off the car and that was very confusing for me as a child. I remember that very well."

Not only did Barbara develop a perception of health and healthcare as one of individual responsibility in part because of the ACEs she experienced in the home, her first experiences of lack of access to healthcare began in her home as well, with her parent. When Krieger speaks of the pathways of embodiment regarding health as being the literal incorporation of the social and environmental world into individuals' bodies, this is a clear example of which she speaks. Barbara and her brother experienced physical injury to the body – and in the case of her brother, injured by their father – in the social and environmental world of their home where healthcare was denied to them.

They incorporated, bodily, the norms of their father’s attitudes toward healthcare within the systemic and structural factors that impacted their father and subsequently impacted them and their health outcomes.

Conclusion

This chapter examined the role and impact of familial and peer influence on the women’s attitudes, beliefs and perceptions of health, ill health, and mortality.

Most of the participants grew up in an environment of silences around health, healthcare, illness, and death. These silences were familial, socially, and culturally constructed, most often resulting in the reinforcement of not learning or speaking about health or death as young people. The absence of open discussion or challenges to normed health messages may have helped to ‘open the door’ for the perception that individual responsibility and health behavior choices were causal factors in theirs and their familial health and mortality outcomes. Certainly, many expressed developing fear and anxiety in the home which they felt impacted their health. Their perceptions of their own childhood illnesses and the family illnesses and deaths they witnessed as children support this argument.

Some seem to have internalized their familial health norms, some understood the genealogical (and genetic) factors involved, and some understood certain environmental factors were involved, most commonly noted as place-based and job-based. Parental choices profoundly impacted their health outcomes and perceptions. As a result, several reported that they changed their attitudes and beliefs toward health when they grew up. Some replicated their parental and familial stigmatized perceptions regarding individual health-seeking. Others adopted parental and social norms of fatalism. But all were focused on what their or other individual responsibility factors were involved in their perceptions of health, illness, and death, and on what changes they could make themselves, as ‘responsible individuals’, to mitigate health and mortality outcomes. The norming of individual responsibility for these outcomes, rather than the social norming of an awareness of and assigning some responsibility to the social determinants of health helps to create a perfect storm of misplaced perceptions contributing to health inequities.

CHAPTER SEVEN

PARTICIPANT CONTEXT: INSIGHTS INTO AND EXCEPTIONS OF UNDERSTANDING OF HEALTH INEQUITIES AND THE SOCIAL DETERMINANTS OF HEALTH

This chapter discusses the women's answers to the interview questions. Their responses help shape an understanding of the time and places which developed their health story, the knowing of which centers them in the solution to the health inequities that affect them. Ecosocial theory is the framework for the analysis of the findings of the study. These findings are grouped in sections indicating a category of the social determinants of health. Each of the findings confirms the systemic socio-ecological context in which they occur and shows the interrelationships of the findings at the macro, meso, and micro spatial levels.

Health Definitions

By gathering participants' perceptions and experiences with health inequities / inequalities / disparities, healthy life expectancy, mortality, good health, poor health, and, wellbeing, the objective was to both understand and bridge the gap between what their upbringing and their experiences as younger people growing up in a particular moment and place and their current perceptions and understanding about health, illness, mortality, etc., at the time of the interviews. In effect, it was to determine if they know what health inequities are; if their understanding of health and mortality grew or changed from when they were younger; if their understandings of component parts of health inequities constitute their de facto understanding of the social determinants of health; and what, if any, silences may appear in their discussions of these terms. As expected, the women were varied in their understandings of each definition and how their own conditions are reflected in these definitions.

In Chapters Five and Six, the participant’s lived experiences in relation to select social determinants of health and health inequities, theirs and their family’s illnesses and deaths, their adverse and positive childhood experiences, and who they considered to have the greatest influence on them were examined. Their perceptions of their family members’ and peers’ perceptions about health, illness, and death were also examined. This was in order to gather context about which factors, in addition to geopolitical culture, may have shaped their perceptions about health inequities. People’s understanding of common components that make up ‘health’ is one part of the societal drivers of health within an ecosocial framework (Svalastog et al., 2017). In this study, it has been an invaluable approach to understanding the women’s perceptions of some of the health literacy elements of health inequities, given that none of them mentioned the phrase “social determinants of health” and only Ruth and Sylvia mentioned “system” or “systemic” in their definitions. By seeing how they define those component parts - how they have become embodied in the women – researchers may gain a better understanding of how they perceive health, healthcare and health inequities as well as what has influenced their perceptions (Pallai & Tran, 2019). Furthermore, by understanding how older women perceive health inequities and define these elements of the social determinants of health, researchers, those who provide support to older women, and others who work in areas related to older women’s health, may continue to shape health inequities awareness-raising efforts for older women and mitigate the impact of social determinants on their health (Fletcher, 2022).

Health Inequities / Inequalities / Disparities

Because the terms health inequities, health inequalities, and health disparities are often (erroneously) used interchangeably (Meyer, Yoon, & Kaufmann, 2013), all three terms were used simultaneously when asking the participants their definition of health inequities / health inequalities / health disparities. While a few stated they were unsure of what health inequities is, all but one provided their thoughts on what definitions of health inequalities might be.

Several of the women referred to health behavior in the form of lack of self-control as health disparity. Cynthia, for example, used weight as proof of her lack of self-care (and, therefore, her individual responsibility), referring to it as a disparity, then followed her comments about this by stating she did not know what “equality” (i.e., health inequities / disparities) is:

> “When you look back on life, and…I am a good representation of, I was a chubby child, I've never been a thin person, and, unfortunately, after two babies, and menopause, it's…taken, it's disparity because I didn't take care of myself earlier in life. I don't really know how to define equality [sic]."

Cynthia’s answer confirms this study’s finding that though the women may not provide a textbook definition of health inequities – and there may be many reasons they do not provide this - they do know different component parts that make up the social determinants of health. Through an analysis of the data presented in earlier chapters, this chapter addresses the broader research findings and responds to the three main research questions of this dissertation:

What are the women’s perceptions and lived experiences with gender health inequities?

How do the older women perceive social determinants as situated in their genealogical (familial), geographical, and mortality outcome histories?

How do the geopolitical and social norms in which the women live impact how they perceive their experiences with outcome histories and health inequities?

Health inequities: lack of access, bias, and discrimination

Almost all of the women mentioned lack of access to healthcare and particular component parts of healthcare, as part of their definition of health inequities including lack of access to healthy food / diet / nutrition; to clinical care; to affordable and equal healthcare costs; to sufficient Medicare ‘gap’ provision for health insurance; to representative clinicians (race, gender); and to place-based care (particularly rural care). They also mentioned lack of access to health education. This confirms the literature on access as a primary component of the social determinants of health which people identify as health inequities. (AHRQ, 2016; AMA, 2022; Cyr et al., 2019; Douthit et al., 2015; Lavizzo-Mourey et al., 2021; McMaughan et al., 2020; Ndugga & Artiga, 2021; ODPHP, 2022; Riley, 2012; Trinh et al., 2017).

Barbara discussed health disparities in relation to access, including job, income, and parity, as well as the lack of health awareness and health education she sees around her:

> "Health disparities, I think it's…. You know, I think without a good job and good health care, people cannot take care of themselves because there's just too many...things influencing health nowadays and so...if you don't have access to

> healthcare…I just…think it's criminal...I live in Tennessee, so you know even people that receive TennCare, I'm not sure they get the same level of health care that...I got when I paid for my health. It's just the inequalities in access to health care.… It's just inequalities...understanding what is a healthy life, and what do we do, how do we maintain it. It bothers me a lot that everybody doesn't have that same level of knowledge."

For Sylvia, access to healthcare incorporated the social determinants of income, gender, and racial inequalities. She said: "I think when access to the same level of health care is not available to all…is a major inequality. I think when...certain groups are forced to pay more for health care and, historically, you know, that's been women versus men...at least in my experience. I think when coverage is…different for different parties…that's a problem. I think when you have…physicians that you cannot find of the same sex or the same race…is an inequity."

Kathryn spoke about the differences in access to healthcare for herself now that she was eligible for Medicare, and also discussed placed-based (regional) inequities:

> "Well, I think, I'm…lucky now because I'm on Medicare, and I have access to good…affordable health care, but I know there have been times when I didn't. There have been times when I didn't have the money. I think that's just the pathetic thing, that money is what means health. Access to healthcare, affordable health care is not available for everybody. That's just sad and pathetic. A lot of it is financial. I think, definitely, there's a racial inequality. There's also probably regional [sic], and if you're rural, you know hospitals are closing…There's an economic inequality."

Barbara’s, Sylvia’s, and Kathryn’s explanations of what their definition of health inequities / inequalities / disparities is shows the complicated, contextualized, and overlapping nature of how people may describe health inequities. Their definitions include social determinants of health, from jobs to health literacy to access to spatial (place-based), income, gender, and racial inequalities, without ever defining health inequities in the terms the medical profession and researchers use. These are strong examples, as will be seen throughout these findings, of the both the gap and the common ground between the way medical professionals and researchers define and create policies and interventions around health inequities, and the way ‘laypeople’ – in this case older women – understand them and perceive them in their daily lives.

Most of the women also mentioned inequitable treatment via systemic discrimination (sexism, racism, ageism, classism; ableism; economics) against women, especially poor and / or racialized women which confirms Krieger’s ecosocial theory arguments on the nature of health inequities, the causal factors thereof, and embodied injustice (Krieger, 2021). Peggy said, "We're [women] all supposed to shut up and get back in the kitchen or back in the servant's quarters.”

Some spoke about clinician / medical professional profiling regarding one’s knowledge, capability and understanding of their own bodies and health or health issues in general, an issue which has also been discussed in recent literature regarding the need for more gender-focused medical education (Yang, 2020). Anita spoke about this as a Black woman who experiences gender-and-race-based inequitable clinical treatment, highlighting what has been well-cited in the literature on inequitable and discriminatory barriers to care for older women, especially racialized women (Arber, 2006; Bierman & Clancy, 2001; CAB, 2017; McGuire et al., 2008; Velez et al., 2019; WHO, 2007).

> "I tend to think …health inequities or disparities is when you go to…medical…professions. Sometimes they make assumptions about your knowledge or your capability or your understanding, and they don't give you, as your first choice, things that really would resolve the issue. They tend to assume that they know what's best, and on that best list is never the best technologies. That's just...my experience, based on...my encounters. I think too many...physicians…believe that... you don't really understand what's going on, with your own body. I think what has happened because Blacks [sic] additionally don't trust the physicians because...[there are] too many stories are out there about encounters that have not gone well. I try and be straightforward, so when it comes to my health or anything, I'm going to do my homework, and then I'm going to, engage in a conversation until I understand what you're trying to...tell me, and that doesn't necessarily occur all the time in a relationship with Blacks [sic] and other whites. I think there is a belief that...your best interests are not necessarily, you know, what's the agenda for them …where people have been taken advantage of because they are believed to [not] have any…influence…"

Anita's comments illustrate how relationships of gendered, class and racialized power, one of the three major components of the drivers of inequities, in which both patient and doctor assume specific roles and make particular assumptions from their positionality, can create a dynamic of distrust and the threat of potential abuse

(Kentikelenis & Rochford, 2019; Kim, 2021; McCartney et al., 2013; Moon, 2019; Plamondon et al., 2020).

Deborah also discussed her experience with the gender-bias women receive from some clinicians when she said: “women's heart examples [sic] are not the same as men's and sometimes I think…those issues might have been kind of just brushed off because we didn't have the same symptoms, but I think things...are beginning to turn around." Deborah’s words illustrate how men’s symptoms are often used as the norm to determine a health condition and that when women describe their symptoms, which might be different or experienced differently, they are then not diagnosed or misdiagnosed.

Similarly, others spoke about the lack of health research tailored specifically to older women’s bodies. Carolyn said:

> "Well, I guess I could start by saying that almost all the research has been done on men when it comes to how heart attacks and everything else that happens to…people, health wise. Whenever they did studies, until recently, it was just always on men, assuming that it would be the same for women...not even caring how it affected women, so I call that a health inequity. That's the way I define it."

Carolyn’s response reflects what ecosocial theory identifies as ‘pathways of embodiment’. Carolyn has developed an understanding of one or more of what Krieger calls “unjust isms” which she may have developed through her life course (Krieger, 2020, p. 47). Carolyn is able to discuss areas or elements of the social determinants of health, in this case gender-based health research, without necessarily identifying specific “social determinants of health” and can therefore attribute discriminatory health research practices as health inequities.

Barbara spoke of the working poor not receiving free or reduced care costs compared to those on Medicaid and the shame she felt for being ‘bothered’ by her thoughts on disparities in eligibility for services:

> “My sister is…retired now, but she spent 43 years in orthodontics. The…government would pay for children's braces if they were indigent or couldn't afford it, and that kind of bothered me the other way, sometimes. I thought, my [relative] needed braces, but I couldn't afford it, and they got it for free, and I paid for it. I hated that that bothered me. I'm a little embarrassed to tell you that, but it did.”

Barbara’s perception that the working poor are penalized with regard to receiving benefits, while people who are indigent are able to receive government welfare reflects a social norm or common way of thinking in the United States due to the lack of universal health care. It also highlights one of the main challenges to alleviating health inequities, and the struggle between ‘moral’ determinants and neoliberal structures and attitudes (Berwick, 2020).

While some of the women’s responses, like those included here, show an understanding of component parts of the drivers of health inequities, with some of the women sharing their comprehension of structural factors such as poverty, racism, and differences between members of in-population groups, some of the other women interviewed could not offer a definition. For example, Cynthia said, “I don’t really know how to define equality,” and Margaret simply said, “I don’t know.”

Overall, while some of the women were able to communicate a vague understanding of the component parts of the social determinants of health, the majority revealed a lack of awareness or understanding of the health literacy surrounding them. This next section identifies some of the ways that the women engaged in a conversation about some of the social determinants of health. It should be kept in mind that the women may have felt pressure or felt intimidated to answer “correctly”, which may have also prompted their silences or efforts to answer.

Healthy Life Expectancy

I asked participants what their understanding of “healthy life expectancy” was. As with their answers to the other health term definitions, most of the women referred to components that made up what they considered to be a healthy life expectancy. Kathryn defined it as how healthy one is no matter how long one lives, even with underlying health conditions, and incorporated quality of life, access to treatment or support systems, and place and environmental justice, e.g., the impact of environment on the human body and mental health. Barbara described HLE in terms of predicting how long she was going to live as she was undertaking financial planning for old age, while Anita declared that a HLE was not being able to statistically differentiate life expectancy based on race or socio-economic status. Cynthia and Sharon referred to physical good health, good physical and cognitive ability and maintaining mobility and activity. Deborah and Ruth mentioned living well in addition to enjoyment of life, as well as their individual responsibility to ensure their health behavior was as best as it could be to mitigate and prevent illness. Ruth also mentioned the role of genetics and aging gracefully.

Carolyn mentioned living well until death, and as noted by Dr. Gerry McCartney, in a review of this dissertation, Carolyn’s definition is an excellent definition of compressed mortality, which is a key component of healthy life expectancy:

> "You mean put an age bracket on it? I'm not sure exactly how. I mean I'm not quite grasping the end outcome, not the answer per se, but how you quantify it…healthy life expectancy. The ability to live well until you're not living. [laughs]. I don't know how else to put it” [laughs].

Mary, however, gave one of the most telling answers. Having mainly discussed early years prevention in term of instilling “good” health behaviors, she answered with a form of fatalism:

> “There are a lot of things that you can find out about people when they are children….so I think good life expectancy starts with young...with good health practices being explained and also with a family who does that to the best of their ability. My [relative] weighed well over 300 pounds...my [relative] weighed well over 200...so I knew that wasn't healthy, and they would go on these crash diets and lose weight, but then they would go back to the old habits. My grandmother was a wonderful cook but...the only person who really exercised was my [relative]. He walked to work, and he went fishing all the time...but he was the youngest to die.”

Mary’s response confirms, for her at least, Davison et al.’s (1992) arguments on fatalism, illness prevention and ideologies around lifestyle or health behavior movements. Although she understands that health and life expectancy outcomes start in the early years, she indicates health behavior and lifestyle choice as the determinant of importance in this matter. For Mary, this fatalism appeared in her argument that regardless of his health-promoting health behavior and lifestyle choices, her relative still died young, while her other relatives continued to live despite their behavior and choices.

Again, most were unsure how to define healthy life expectancy or kept silent about their understanding of it for reasons identified in the health inequities section above. What is important to note in this section is Carolyn's very clear definition of compressed mortality, even though she stated that she did not know what health life expectancy was and that she was only guessing, and Mary's reverting to fatalism in her answer, confirming the literature discussed earlier in this dissertation regarding fatalism's role in many people's view of illness and death within neoliberal geopolitical systems (Davison et al., 1992). Additionally, Mary seemed to revert also to stigma and health norms about obesity and health versus thinness, insinuating that thinness equates to good health, despite the fact that thin people can also be ill.

Mortality

Mary, Anita, Sharon, Sylvia, and Kathryn referred to mortality as death rate or likelihood of death while Sharon included average age: "Mortality is the rate, I mean, let's see, the…average age of…death, I guess," and others included mentions of mortality as age-related.

Kathryn stated that it is a demographic / population rate / population-based metric, noting that certain demographics have lower chances of dying at certain ages, that mortality is dependent upon many factors, and that the chances of dying are all different.

> Kathryn said: "…that's an acute condition, lack of life. Well, mortality to me, because I used to do like demographics, is a rate, certain demographics have lower [mortality] at a certain age, your chances of dying are…different and it's all dependent on a lot of different factors. So, mortality, I think of as a more population-based statistic. Yeah, that's how I would define mortality."

In Kathryn's case, it seems her job has helped her to expand her understanding of mortality, from individual level to population-level, even if she cannot completely offer a definition. This illustrates how education, even outside of health education, can contribute to health literacy.

As with healthy life expectancy, Anita spoke about mortality rate as affected by racially inequitable rates, with mortality rates higher for Black people than white people, given certain circumstances; as affected by clinical care relationships; and as affected by systemic economic issues and access to information and resources.

> Anita said: " I would tend to think that the mortality rate of Blacks [sic] is higher than that of whites, given similar circumstances. And a lot of that mortality is, I think, somewhat dependent upon your relationship with your...physicians or your health professionals. [This] can be associated with economics, you know, knowledge base. A lot of it has to do, I believe, with your race and your ability to access the kind of...information or the kinds of resources that are necessary."

Anita's perception of mortality indicates her understanding of structural factors at play in determining mortality outcomes, including racism, clinical-bias, economic inequalities, and health literacy, but she does not define mortality itself.

Mary, Cynthia, and Ruth discussed aspects of illness and physical incapacity as a kind of mortality – death in relation to illness, mortality as encompassing quality of life prior to death as well as death itself, physical incapacity as a kind of mortality. Barbara and Margaret did not know what mortality is. Cynthia, however, spoke about her family's health and mortality genealogy, and expressed concerns about her own death relative to their ages and causes of death.

Peggy referred to mortality as "cause of death" or as death itself. Deborah and Ruth also referred to it as death. For some, death was the end of life, but for others, it was not the end of life. Deborah, for example, qualified mortality in relation to her faith, "Well, it's death, but it's not the end because I'm a Christian, so I know me and my family are going to get to see each other again one day." Carolyn also qualified it in terms of her personal spiritual (though non-religious) beliefs, referring to it as death, its inevitability, and explaining that she thinks of our souls as energy returning to collective energy. However, she also had a striking comment about mortality:

> "I'm getting into strangely philosophical things I don't think about much. People don't ask these questions, and if they do, they don't usually want to know your answer truly...[laughs]".

Carolyn's statement that mortality (for her, death) was not something she thought much about was also echoed by Margaret. Indeed, there was a general consensus throughout the women's responses that most of them tried not to think about mortality, but when most did, it was at an individual level (e.g., death) and not at population level. However, her response regarding people not asking questions about mortality and other health terms, and that people do not truly want to know other people's answers illustrates the impact of the norms of silences may have on older women’s perceptions of their thoughts, needs and wants not being considered by policy and decision-makers. It also illustrates how fatalism thrives in societies where people do not feel valued or heard by those in power.

Carolyn’s observation that people do not ask questions about mortality or other health definitions, and that people don’t really want to hear other’s answers was exactly one of the reasons this study was undertaken. As simple as it sounds, without hearing older women’s answers to these questions, researchers, clinicians, and policymakers cannot know what they know of or want and need in relation to health, mortality, health inequities, the policies, geopolitical environment, or social norms which shape their perceptions. It should be noted that Carolyn’s surprise at being asked these questions and the embarrassment by other participants in not knowing how to answer some of these “health definition” questions may reflect experiences of invisibility, marginalization, and health norming or may reflect, as stated earlier, efforts to define these terms ‘correctly’, or a desire to not appear that they were ignorant of these definitions.

Good Health

Again, most of the participants did not define good health, but instead identified component parts of good health. By far, the most identified components were ability to maintain mobility, activity, control of one’s circumstances, choice, and independence.

Anita said:

> "Every day my feet hit the floor, that's good health [laughs]. The fact that I woke up, that's good health [laughs]. I may wake up in the morning, and I've got a few aches and pains, but I walk it out, it gets better, until I, literally, don't even think

> about it...until the next morning when I get up. That's still good health, 'cause I got up. Good health is, you know, you're able to do the things that you would like to do. Now, you may be doing it at a slower pace because of the aging process, but you're still able to do the things that you want to do. Oh, because I'm looking at my age…and we all have similar kinds of things happening to us and...it's [sic]...the kind of things that are happening to most older people in our age category.

Anita’s explanation seems to suggest that good health is relative to one’s age, so that if you are older, you can be in good health, but it will not protect you from some of the challenges that many older individuals experience.

The issues of individual responsibility for maintaining “good health” were also discussed in relation to weight, healthy diet / nutrition and exercise. Some had specific aspects of physical good health which they identified through their own personal concerns and difficulties – such as inability to breathe fully or losing their eyesight. Some mentioned lack of pain, and some mentioned physical safety. Some included good mental and cognitive health. Sylvia, whose two aunts died of Alzheimer’s, said:

> “When you have…good mental health, in terms of not dealing with dementia…and not dealing with other forms of mental health disease like depression or bipolar or schizophrenia."

Cynthia and Carolyn also identified enjoyment of life and quality of life as components of good health

Carolyn also identified the ability to maintain joking and laughter in one’s life by saying that good health was [being] “a 25-year-old”. Interestingly, she did identify not being able to enjoy one’s environment in terms of mental ill health, although she never explicitly discussed mental health. Therefore, it is unclear as to whether or not she identifies mental health (as opposed to enjoyment of a person’s environment) as a component of good health. Because of her lack of reference to mental health, it is difficult to know if Carolyn understands or just remained silent about the relationship of mental health, the social determinants of health, and health inequities. Further, she identifies good health with age, seeming to say that youth (age 25) is equivalent to good health. This is a strong example of an internalized social norm around aging which neglects the fact that people at age 25 years can have poor health, and that growing older may equate to no longer being able to have good health. Sharon identified good health as incorporating spiritual health:

Kathryn differentiated between individual good health and community good health. For good community health, she identified that the majority of the population’s health issues are addressed; that the population isn’t facing environmental causes of ill health; and that community members have well-functioning mental health:

> "Good health for an individual or good health for a population? Good health for an individual to me would be, you know, you feel good to think straight…You can overcome whatever physical...challenge you might have. Your good health is that you can function physically and mentally…without…a lot of drag, you know, like it's not everyday living…is a terrible, terrible challenge and painful. Good health for a community or population would be that same sort of thing. Your people in your community are functioning well physically and mentally."

Although Kathryn did not explicitly mention health inequities, in this comment she was able to link component parts of social determinants of health, including the role of place (e.g., community), with the relationship between population health and individual health, and to recommend possible solutions for policy and interventions regarding health inequities. Her response is another good example of the consistent thread throughout this study of how the women were able to identify component parts of the social determinants of health and of health inequities, without necessarily having a clear understanding of the concepts.

Poor Health

Most of the women cited poor physical health, physical impairment, poor cognitive health, lack of enjoyment, and the lack of mobility or lack of ability to undertake activities as poor health. Mary mentioned that fear, harm, and lack of safety were component parts of poor health.

Some described needing care support, having limited mobility, or losing independence as poor health indicators. Barbara said:

> “For me, it would be being wheelchair bound. Being…in a home somewhere. Not being able to…do anything on my own. For me…that's pretty…poor. Having to take medications out the wazoo, you know, I don't like to take pills…”

Carolyn indicated that mental health is a concern also for those who are experiencing poor health and said:

> "When I'm no longer able to enjoy my environment, that is poor health. Are there other things that are poor health? Well, there's…the gradual loss of abilities that...aren't so drastic that they totally affect your ability to...enjoy things, but still

> limit [us] as...we get older. I'm not sure how to answer this. [Someone] can get poor health...and I've watched it with many people. As your physical health declines, so does your mental health. Whether people are aware of it or not, they become depressed, they turn inwards, they isolate themselves because of physical conditions that make life difficult.”

Interestingly, Carolyn recognizes not being able to enjoy her environment as a definition of poor health. She linked physical health to poor mental health, going so far as to say that people with poor physical health would be depressed whether they knew it or not. This makes sense given that Carolyn was a professional performer in elite athletic physical condition which she believes helped her survive a devastating car wreck. Carolyn seems to be indicating that losing her physical health will lead to poor mental health for her. She generalizes this to the wider population when she states that people, when they lose their physical good health become depressed whether they know it or not.

Unlike Carolyn’s thoughts about declining physical health resulting in poor mental health, Kathryn argued that people with poor physical health could have good mental health and that people adapt to their circumstances and conditions:

> "Anything less than good health…. but people's bodies and minds adapt to where you are... if you cannot function, if you're in such pain, that you cannot think straight, if you are addicted, so you can't control what you're doing… if you can't walk or…anything, I mean, if you can't walk, [that] doesn't mean you're in poor health. That means maybe, if you're paralyzed from the waist down, it's...very unfortunate, it's tragic, but you...could still be healthy in the body that you have.”

Deborah, Sharon, and Margaret all discussed individual responsibility as a factor in poor health, highlighting the neoliberal social norms that characterized the women's responses, and the ways they viewed the consequences of poor health behaviors and choices. When referring to addiction as a form of poor health Deborah explained: "I've never done that. I don't understand how they get there…I guess, they have problems to where [sic] they feel like there's an outlet, but I've never gotten to that point emotionally or physically, where I needed those kinds of things. Bad habits."

Similarly, Sharon shared a story, saying:

> "Well, I have an example of somebody, well several examples in my family...that I married into that, where you have a condition, perhaps, diabetes, and you don't take the medicine properly, you break all the rules, all the recommendations for food, you know, diet and exercise and all that. So, poor health and when you're run down, when you drink or eat to excess, and everything's out of whack, that's what it is - poor health."

Unlike Sharon and Deborah, Margaret discussed how, oftentimes, certain conditions were beyond people's control and alluded to people not feeling in control or being capable of making certain decisions or engaging in certain behaviors. She explained, "Not doing anything but sitting on your butt all day. Not being able to do certain things. That's beyond your control. Not…trying to take care of yourself. But then that can be not your choice either. Right now, I can't think of anything else. I've never really thought about it."

Kathryn referred to poor health as being dependent upon where we start in life:

> “…everybody's bodies have health issues at some point in their life. That's just life [laughs]…[It]…kind of makes it hard to answer because everybody’s health condition is different. I mean where you’re starting from is different.”

In keeping with Kathryn’s consistent perceptions of component parts of the social determinants of health, she clearly understood the impact of childhood / early years on the health outcomes and the health inequalities people face later in life, instinctively confirming what much of the literature on these determinants argues (Dannefer, 2020; Gee et al., 2019; Hoffmann et al., 2022; N. L. Jones et al., 2019; Pearce, 2012; Pickett et al., 2022; Vaccarella et al., 2020).

Interestingly, very few of the women identified themselves as currently being in poor health, other than references to being overweight or past illnesses. Whether the women perceive poor health through the normed view of individual responsibility to prevent their own poor health or as the reason other people have poor health, or they perceived and identified some determinant or injustice factor as influencing poor health, they all spoke clearly about their fear of having poor health in older age and of the emphasis they have on ensuring that they do their best to avoid or mitigate it.

Wellbeing

As noted in the key terms and definitions, this section of the findings reflects that there is, currently, no standard definition of wellbeing. While some participants referred back to aspects of good physical and mental health as well as good mobility, most participants mentioned balance in life, enjoyment of life, happiness with environment and with self, contentment, and peace of mind as the component parts of wellbeing.

Recall that Peggy spoke about being abused as a child and of the impact her mother’s illness had on her early childhood. She referred to nature as her source of spirituality and that she found her wellbeing through nature, “...the only place I felt safe was out in nature or in the dark.”. Anita included financial security (see quote further down in this section) and Barbara, who had endured years of financial hardship after her early divorce, mentioned happiness, but also financial security. Barbara said: "For me, well-being would be happiness. In a state that I don't have to worry about paying my bills.”

Three mentioned the role mental health plays in wellbeing:

> Anita said: "Wellbeing is not really thinking about, your health issues. You're not thinking about your economic issues [laughs]. Wellbeing is just a state of mind, I think. You just feel good about being here. You don't have any overriding issues that make you...weary of life. You know, you just embrace life...you don't dwell on all the things that have been bad in your life. You dwell on the things that you have accomplished, however big or small....and if you were to leave tomorrow, you will have...this feeling that "I lived". I didn't just occupy space, but I lived. It's tranquility. You just feel tranquil. It’s that peace of mind. You’re just at peace with the world. You’re just at ease with the world. It’s just a comfort. You just feel comfortable with who you are, what you have become…"

> Sharon said: "You just…feel pretty good about yourself because your life is going well, and …you're not fighting against anything."

Both Anita and Sharon reference wellbeing as being at peace - not thinking or fighting against anything negative. It is important to note because their definitions of wellbeing are powerful, but also reflect a sort of utopian vision - that wellbeing is sustained only through lack of conflict. In fact, Anita states that wellbeing means one is not thinking of their health issues. As difficult as it may be to think about when reading such beautiful statements, this may illustrate a normed response to social ideals of health, and a non-acceptance of having wellbeing in spite of one having health issues or other issues. Still, their comments about wellbeing are indicative of what one can hope wellbeing can be, the subjective nature of wellbeing, and that there is currently no standard definition of wellbeing in the scientific community.

Sylvia mentioned good, sustaining relationships, including her lifelong relationships with animals. Ruth mentioned being able to help oneself to manage one’s problems to the best of one’s ability, to get the best quality of life that one can, and to depend on oneself for happiness. Barbara and Carolyn mentioned that wellbeing is place-based and reliant on the environment in which you live:

Carolyn, who cried out of empathy as she responded to this question, said wellbeing is

> "Transitory [laughs]. It depends upon the day. Wellbeing is a…very personalized scenario. It depends upon your external environment. It depends upon how you're internalizing it. That's a luxury of being an American because, if you are in a third world country, those things don't affect you as much because all you're worried about is eating and surviving the bullets, and all those things that he [sic] shouldn't be subjected to” [cries].

Carolyn’s comments reflect the intersectional nature of wellbeing, reaching across the personal, the environmental, socio-economic, temporal, and spatial aspects of this part of human health. She saw the impact that the geopolitical plays, often, in shaping (and being shaped by) all other determinants: war (violence), famine, and poverty supersede personal concerns about ill health, in the moment. For example, war may not be currently happening within the U.S. borders, but many must choose between eating, paying bills, or affording a doctor or medicine. These choices start at the macro, systemic, international, geopolitical level (Sturm et al., 2021), filtering down, in the U.S., into the destructive norms of believing these choices are individual (micro-level). Carolyn saw the impact this had on people in the Global South. The findings, likewise, illustrate that geopolitical norms established as part of neoliberalism impact the way older women understand health inequities.

Conclusion

Examining the women’s perceptions of health definitions provides a basis for being able to understand their health literacy and what they know about health inequities and the social determinants of health. As can be seen throughout this chapter, many of the women were able to identify component parts of the definitions, even if they did not provide definitions as medical professionals and health researchers would. However, the women’s responses also showed that their understandings were either limited, did not exist, or were held in silence. Any of these would be a reason to do further research into the differences in how clinicians, policymakers, decisionmakers, and researchers view and speak about health inequities terminology compared to how older women do. Additionally, examining older women’s definitions may provide insight into their perceptions that may not be shared by them in telling their histories or opinions elsewhere. Their responses to questions about health terms builds a fuller picture of their health awareness and education, and where, as researchers, clinicians, and policymakers, we can start to bridge this gap. This is imperative because health inequities mitigation requires – or should require – the development of policies and interventions which meet the needs and wants of older women. Understanding what older women do and do not understand (or voice) about health inequities or other health terms also provides insight into how older women may or may not have developed internalized norms of the environments in which they were born, raised, and aged. Simply put, it is vital to know what older women perceive about health terms, in order to understand where to start in co-production with them of policymaking and intervention / services design.

CHAPTER EIGHT

FINDINGS AND ANALYSIS

This research has found that despite differences in political affiliation, the women who participated in this study articulate similar opinions and desires about what they want and need regarding their health, even when they are on opposite sides of the political spectrum, and irrespective of similarities or differences in the social determinants of their health. The most common areas of concern were:

- the systemic and individual discrimination and inequitable treatment they face as older women in East Tennessee;
- access to healthcare and the systemic drivers related to healthcare access, including, but not limited to, economic, geopolitical, place-based / geographical, and discriminatory determinants;
- lack of health literacy, e.g., awareness of and education around health inequities;
- gender-bias in clinical care and health research tailored to older women;
- and the geopolitical cultural norming in areas like East Tennessee that perpetuate the development of attitudes, beliefs, policies, and services regarding older women's health.

As noted in the literature review, much research has been done on the preferences of older women and health inequities in relation to particular health conditions, social determinants such as housing, or older women as part of research on older people in general. Because little has been done in relation to older women's health inequities and policy preferences, a review of the literature was expanded to capture general preferences themes arising across these areas. By far, most studies show that older women's preferences, in all health circumstances, are to maintain their independence and agency, followed by other preferences such as quality of life over quantity of life, proximity to family in order to maintain relationships, co-partnerships with clinicians, financial independence, and safety (Dostalova, et al., 2021; Teater & Chonody, 2020; Barken, 2019; Darab, et al., 2018). Some of these themes match this study's participants' preferences.

As can be seen throughout this chapter, these findings are interrelated, interdependent, and intersectional, overlapping with one another. This shows the nature of the difficulty in separating one determinant from another and, therefore, calls for a holistic approach in translating solutions into effective policy and interventions in mitigating the health inequities older women face.

Systemic Discrimination and Inequitable Treatment

Systemic and individual discrimination in the forms of paternalism, sexism, racism, ageism, classism, and ableism against women, especially poor and / or (Black, Indigenous, and People Of Color (BIPOC)) women, was the most stated concern by the women in this study. For many of the participants, this was perceived as profiling by clinical / medical staff or by legislators regarding their knowledge, capability and understanding of their own health and of health inequities (Chrisler et al., 2016). This is in line with the answers provided by the women when asked about their definitions of health inequities (see Chapter Seven) and with the literature on this topic as cited in the literature review (Arber, 2006; Bierman & Clancy, 2001; CAB, 2017; Cruikshank, 2013; McGuire et al., 2008; Velez et al., 2019).

Peggy, who presents with white skin but who did not mention her race or ethnicity (again, I did not ask for participants what they identify their race or ethnicity as), talked about her perceptions of Tennessee's gendered healthcare culture. When asked what she wanted policymakers to know, her concerns were around equal treatment for women, older people, and BIPOC people in relation to policymaking, clinical care, and interventions. She mentioned that policy- and decisionmakers should "listen to women, take more time to hear what they're saying" and that they should treat everyone respectfully across the board, especially older Americans and "not just if they have a penis...and they're white." Anita echoed this sentiment when speaking of her need to establish a firm understanding of the policies and interventions affecting her, especially as they play out in the clinical setting, because of Tennessee's inequitable legislative treatment of her as a Black woman (see Anita's comment in Chapter Seven (page 126).

As noted at the start of this chapter, the women in this study did not share the same political views, but they all perceived that living in Tennessee meant living where their policymakers were not making decisions that helped or supported them. Peggy said: "There's no real protection for women…especially in this state" (referring to Tennessee), and Barbara, who talked at length about her fears of lack of good nursing and care home facilities in her county, said:

> "…I hope I never have to experience…getting to the end of life and not having any resources to take care of myself or anything because I don't think Tennessee really takes good care of their elderly people."

The women’s comments show that they understand that they have experienced and are experiencing individual and systemic discrimination. Anita consistently spoke throughout her interview about the impact that systemic racism has had on her health experiences and perceptions. Peggy has worked in a position of leadership and decision-making (and, therefore, power) in healthcare most of her career. Both of these women came from what could be called opposite ends of the power dynamic in clinical experience, yet have the same perception of how older women, particularly women of color, receive discriminatory treatment from clinicians and policymakers. Peggy’s experience is important because, although she has been a decision-maker for healthcare provision, she has also experienced gender-based discrimination as a patient.

Peggy and Barbara’s comments are just some of the comments made by the participants regarding their concerns about how Tennessee’s state policymakers were not making decisions in favor of older women. Their perceptions confirm the arguments in Chapter Four regarding the negative impact of the geopolitical culture and policy-making environment in Tennessee / East Tennessee for older women. These women experienced Tennessee’s political culture and policymakers’ decisions not only as discriminatory and out of touch with their needs, but as harmful to them. It was clear that many of them worry about their own circumstances should they find themselves in need of resources, and that they do not feel they will get what they need should that be the case. Like many of the findings in this study, the issue of inequitable treatment is intertwined with other findings, one of which, at least for these women, is the issue of access.

Healthcare access

As discussed in earlier chapters, lack of access to healthcare is a major driver of health inequities (AHRQ, 2016; AMA, 2022; Cyr et al., 2019; Douthit et al., 2015; Lavizzo-Mourey et al., 2021; McMaughan et al., 2020; Ndugga & Artiga, 2021; ODPHP, 2022; Trinh et al., 2017) and the rights of who has healthcare access, in the U.S., have been socially normed as a moral and financial issue (Hook & Markus, 2020; Krieger, 1994, 2001; Yoder, 2002). Moreover, gender disparity in access to and quality of healthcare has been shown to be associated with state-level sexism (Rapp et al., 2022), an issue discussed in-depth regarding Tennessee in Chapter Four.

As noted in Chapter Seven when discussing their understandings of the definition of health inequities and their perceptions of health inequities, almost all of the women mentioned lack of access - to healthy food / diet / nutrition; clinical care; affordable and equal costs; older-age employment; health education; living wages; employer provision or sufficient provision for health insurance; representative clinicians (race, gender); and appropriate place-based care (particularly rural care). None of the women in this study qualify for TennCare, placing several of them in the “Medicare gap”. Only some of them can afford supplemental health insurance, leaving those who can’t without the ability to afford services they need. For these women, concerns around Tennessee’s funding of services (or lack of it) and refusal to expand federal services such as Medicaid contributed to their responses of access as their major concern of the health inequities they face.

This includes Ruth, who, despite agreeing with the other women’s concerns around access, was also able to provide insights she experienced while sitting on a major local health-related board. She spoke about seeing the issue of access from both an individual level and a provider / system level. She said:

> ”It's basically the inequality of not being able to get the care, or not being able to get there, to the care. [Local area] has a pretty good safety net in place between the hospitals and...the health department, but it's not always easily accessible to everybody, nor do they necessarily know about...it being accessible …”

Ruth’s comment illustrates not only the issues of lack of access in East Tennessee, but also the lack of awareness of services (health education) in the local areas amongst the residents. Often, at least amongst these women, lack of access went hand in hand with lack of awareness and health education.

Kathryn, Mary, Ruth, and Sylvia, all spoke about the specific impacts some older women suffer due to their lack of access to healthcare because of falling into the Medicare gap or because the level of income they receive based on their social security contributions is insufficient.

> Kathryn said: “I think there are plenty of women over 65 that don't make…much or nothing when they were in the workforce, and now they're on a pittance of social security, and that's not enough to afford health care...and Medicare doesn't cover everything. So, I think that...there are women without enough income to...feed themselves healthfully and have access to other things that you can do to help your physical self.”

Mary said, “…my heart goes out to women who are living on much less social security and... and [who are] taking care of somebody else because … they can't afford to...get somebody [to help].” Sharon, having gone through the devastating, unexpected losses of her mother and sister, expressed concerns about the impact of state legislative decision-making on access to care, “I’m just aware that …our state of Tennessee has not accepted care, the Medicaid expansion idea, and that’s causing hospitals to close.” Sylvia said, "People should not have to leave their community to get [healthcare].". She also spoke about the need for Medicare and supplemental insurance to cover dental, eye and hearing costs, affordable prescription drugs, and adequate home health services, "… they're very expensive and they're not covered…It's a huge financial burden”.

Sylvia’s response illustrates the issue covered earlier in this dissertation regarding the coverage ‘gap’ for Medicare recipients who cannot afford supplemental insurance or who do not receive the parts of Medicare which help to cover some costs related to the areas mentioned in Sylvia’s quote. Like Kathryn, Sylvia also identifies geographic / spatial inequalities as a factor in the lack of access to healthcare in the U.S. when she speaks of those who live in areas where healthcare is not available and who must travel to other areas to receive it. This is important not only because she identifies lack of access as an issue, but that affordability then becomes an issue for those who cannot afford to travel outside of their area.

In her response, Kathryn identified racial, economic, and spatial inequalities in her statement as the causes behind lack of access and affordability while Mary identified the impact low income has on older women and on caregivers. Throughout the study, Kathryn consistently identifies component parts of the social determinants of health, and even refers to inequalities, showing she has some familiarity with the terminology. Mary’s response is notable not only because of her identification of socioeconomic status as a factor in lack of access and inability to afford healthcare or care resources, but also because she is openly concerned for caregivers like Kathryn, while Kathryn does not express this concern for herself. Instead, Kathryn expresses concerns for other groups who cannot afford healthcare. Both Kathryn and Mary have experienced lack of access to healthcare themselves due to affordability. Their direct experience helps to confirm that lived experience can inform a person's perceptions or understandings of health inequities.

What these women have experienced and perceive confirms the established theories of discrimination, access and affordability as primary social determinants leading to health inequities (Link & Phelan, 1995; Phelan et al., 2010). Their perceptions and recommendations also match the identification of intersectional discrimination, access and affordability as major areas in which governments, global health organizations, and health research bodies have long made recommendations and established policies, but that continue to fall short of older people's needs (Burn, et al., 2020; Gulliford, 2019; de Carvalho et al., 2017).

Health Literacy

The findings of this study in relation to health literacy are that an interdisciplinary ecosocial approach to understanding the women's comments and silences about health literacy is needed (Sentell et al., 2020). This is because the women in this study were born, lived, and worked in multiple places across the U.S. and abroad which indicates that their health literacy may have been produced at macro-level. Some mentioned systemic lack of healthcare education and knowledge both on the part of decision-makers and older women.

> Ruth said: “The other thing is when...a lot of people just don't pay attention, and they don't have a lot of money, so they don't know about health care, and they don't know how to take care of themselves. I think one of the biggest problems that I see, too, with the health disparity is the schools…They have cut back on physical education, and I had ‘phys ed’ [physical education] in junior high and high school four days a week and the fifth day was health...classes. It's not just the lower income people that are suffering… it's...systemic. And then it comes into play later in life on that type of thing. There's only so much the medical care community can do, but education has got to go back and swing the pendulum back the other way. They're putting academics over phys ed, over physical well-being, and in health class, we learned good nutrition, had home ec (home economics), learned good nutrition. They don't teach any of that anymore… so there's a lot of inequalities, all the way up the line, and part of it's to do with economics, but part of it's to do with education."

The inclusion of Ruth’s comment almost in entirety is because it shows the complicated nature of how some of the women perceived drivers of health inequities. Ruth understood that lack of health literacy (not knowing about healthcare, not knowing how to take care of oneself) was a part of health inequities. But Ruth switched then to a solution-oriented approach to solving the health literacy through reintroduction of physical education in the Tennessee school systems – placing physical education over academics. However, Ruth’s referral to the removal of health education classes and home economics classes in today’s Tennessee school system, and the impact that this may have had on (presumably) young people today, does speak to the removal of some prior avenues of health literacy provision in the state. Nevertheless, Ruth's comments reflect her awareness of the lack of health literacy she has encountered in those around her contributes to health inequities and confirms the literature that health education and awareness is a driver of health inequities.

Gender Bias in Clinical Care and Health Research Tailored to (Older) Women

The literature confirms that gender-bias exists in clinical diagnosis, medical care and health research approaches to women (Alcalde-Rubio et al., 2020; Burrowes, 2021; Hui et al., 2020; K. A. Liu & Mager, 2016; Maas & Appelman, 2010; Mazure & Jones, 2015; Reynolds et al., 2020; Rios et al., 2020; Salles et al., 2019). This means that older women face the double jeopardy of ageism and sexism in relation to healthcare interventions and research design which incorporate the unique needs of older women (Chrisler et al., 2016). Some of the women in this study were acutely aware of this. Ecosocial theory captures gender bias in healthcare provision and health research as a structural and systemic issue at all spatial levels (Homan et al., 2021).

As noted earlier in Chapter Seven, both Carolyn and Deborah identified gender-bias in cardiac care as examples of gender-bias in clinical care. Deborah's statement (page 127) that women's heart issues were brushed off because women didn't have the same symptoms related to heart disease as men do was a fantastic example of gender bias in clinical care, and she could not have stated it more effectively than if she had written it for a journal herself. Compare the statement from senior researcher, Kelly Burrowes in the March 7, 2021 edition of The Conversation (Burrowes, 2021):

> "Heart disease is another example where sex — or perhaps sexism — still plays a huge determining factor. Women are less likely to experience the "classic"

> symptoms of a heart attack — symptoms that were discovered in research led by men, in which most of the participants were men. But because the diagnosis method still favours male biology, many women experience a delayed diagnosis or a misdiagnosis. Women's most common heart attack symptom, as with men, is chest pain or discomfort. But women are more likely than men to experience some of the other common symptoms, particularly shortness of breath, nausea, vomiting and back or jaw pain."

Deborah also identified racism as an issue in clinical care and health research. Deborah's response prompted me to examine her interview more closely and critically. After review, a comment she made when asked to define health inequities stood out, given just prior to her response about women and heart attacks:

"Well, I mean, I know, and then of course, it's been in the news so, so much, and stuff that …being black, you tend to have certain diseases and other things that maybe have not been caught even being a woman…"

The common ground between Carolyn and Deborah's knowledge is that both of them learned about the disparity in women's cardiac health through an educational channel – Deborah through the news and Carolyn through the nature of her work in data collection. It is important to note as well that neither woman reported that they learned of gender-bias in clinical and health research through their healthcare providers or their educational institutions. They learned through the use of news to share health data and reporting (press, public relations, and journalism, often used in health promotion) and through on-the-job learning. This speaks to Rowlands et al.'s (2018)

Health Literacy Policy Model (as referenced in Dadaczynski et al., 2022) of ecosocial societal levels and vectors of health literacy.

Geopolitical Cultural Norming

Perhaps most difficult to examine is the internalizing influence of the geopolitical environment on these women and their perceptions of what impacted their health and the health inequities they face. This could be seen in the women's responses to the interview questions in various forms: fatalism; pragmatism; stigmatizing of health anxieties or health seeking behavior; silences; misunderstandings or common political rhetoric about healthcare policies such as the ACA, and more.

Barbara, who endured extreme adverse childhood events, including incarceration, and who understood that these events impacted her health, nevertheless, shared her (stigmatizing) thoughts regarding the health behavior she saw from people who had Type II diabetes:

"I worked as a part-time person just for a little while after I retired at a drugstore and…I would see people come in, and…like diabetics and everything, and they'd be getting all this insulin and all this medicine…through this. It's free, I'm assuming it was TennCare or something, and then...their baskets would be overloaded with Cokes and cookies and ice cream and all that stuff, and I'm thinking, "Did you not even have access to education on health care or do you not understand what drives your health?", and so...that's always bothered me a lot."

Barbara's use of the phrase "what drives your health" illustrates her understanding that certain things impact our health, but the remainder of her comment illustrates, as has been common throughout this study, that Barbara perceives health behavior as the primary factor responsible for ill health and disease., Barbara's comment illustrates how the lack of knowledge (health literacy) around health behavior's interrelationship with other social determinants of health can not only be an example of one's own lack of health literacy, but how perceptions can be driven by geopolitical, social, and cultural norms (e.g., health behavior change norms around Type II diabetes and diet alone, absent contextual structural and systemic drivers of diabetes).

The effects of geopolitical cultural norming were also shown in the experiences Anita reported about the segregated clinical care she received as a result of the geopolitical climate of the Jim Crow South. This played out in the women's familial attitudes and beliefs about health, illness, and death, and healthcare itself, including such things as parental withholding of care, familial silence rules around health, and familial misunderstandings of causes of death and illness. Some of the women's responses showed that they had adopted these norms, while others showed that they were aware of their familial norms, and either had changed them in their own lives and their children's (generationally) or were working to break them.

Most of the women were, as is discussed in the next section on policies and interventions, aware of the impact of Tennessee's geopolitical norming environment on certain policies that affect them (such as Medicaid expansion) and on the policymakers and decisionmakers in Tennessee making those decisions.

Policies and Interventions

A major aim of the study was to add to existing literature via a qualitative, critical health geographies lens by examining whether similarities or differences exist in current federal, state, and local policies and interventions affecting health equity compared to the perceptions and experiences of older women in East Tennessee. When asked if they knew specific federal, state, or local policies or interventions enacted for and impacting older women, their answers regularly showed that they were unaware of these.

Deborah said: “I don’t know if I know a whole bunch of laws…” while Carolyn said: "Well, this may take a minute for me to think about because I'm just going over 65 by a year, and I…haven't [sighs], I can't think of any,” and Margaret, when asked if she knew any policies or interventions affecting older women asked me what those were (not in jest) to which I replied “I can’t tell you. I want you to tell me.”

When participants did identify policies, the Affordable Care Act (ACA), sometimes referred to colloquially as “Obamacare”, Medicare, and Medicaid were the most identified. All participants but one felt the ACA was beneficial at the federal level, but that state level policies worked to restrict additional benefits offered by the federal government. Of particular concern were those affecting Medicaid expansion, Medicare additional coverage benefits, income and the working and retired poor, and the need for policies relating to better clinician education on older women.

This is important because most of the women usually mentioned only one state policy or intervention - the lack of Medicaid expansion - and no local policies or interventions. Some of the women needed a number of services – support and respite for being a caregiver of a spouse and the subsequent loss of employment income (and social security income), support for finding retirement-based employment, assistance with Medicare-gap medical bills and other care bills in light of recent hospital and rehabilitation facility stays, and more. Yet, none of them mentioned that they knew of services available through the East Tennessee Human Resource Agency (ETHRA) or any other state or local agencies. In fact, when asked what they felt caused their health outcomes or the health and mortality outcomes of their family members, the most common causes they cited were health behavior, lifestyle choice, and individual responsibility, irrespective of the fact that they had spoken in other parts of their interview about the discrimination, lack of accessible and affordable healthcare, and their state and county geopolitical environment.

There may be additional reasons the women may not have mentioned these policies and interventions, if they were aware of them. This is of additional concern because internalization of geopolitical or cultural norms may lead to unintended propagation of the very policies and interventions which are ineffective in reducing the health inequities they endure (Akguloglu & Con Wright, 2021; Cardona, 2021). While this cannot be definitely said about the cohort of the women in the study, it must be considered.

The study has confirmed previous research that states and other geopolitical areas, like Tennessee, that implement neoliberal, highly conservative, and / or faith-based legislation, hinder federally enacted policies intended to support older women (Baru & Mohan, 2018; Sager & Bentele, 2016; Townsend et al., 2020). These findings show large differences between what older women want and need, and the policies and interventions enacted at state and local level. The women in this study cited concerns about the differences in what policies and interventions are there to support them, specifically at federal level, and what their realities of this support is in East Tennessee.

The women's responses show that place has deeply impacted the experiences and perceptions of the participants. If these women lived in states, including other southern central Appalachian states, that did not have highly misogynistic, patriarchal, neoliberal (and historically Jim Crow-based) cultures that impact legislative decision-making, or if Tennessee had accepted federal funding options (such as Medicaid expansion), and had enacted policies and interventions that specifically prioritized older women's health, their experiences and perceptions of health inequities may be very different (Montez, 2020).

Tennessee's state and East Tennessee's local-level policies and interventions particularly fall short for those older women in the funding gaps that aren't provided for by legislation such as the Older Americans Act, and while there may be some regional affinity in these findings, a look at the literature shows that this may be the case for other states (and countries) with highly neoliberal, patriarchal, evangelically conservative and libertarian led legislatures (Baru & Mohan, 2018; Sager & Bentele, 2016; Townsend et al., 2020). Where federal services and funding are available in local counties and municipalities, Tennessee's constitutional mandate to annually balance the budget constrains the consistency of comprehensive service availability. In other words, services may be available and may be geared to reach those most in need, but not all of those in need. This disproportionately impacts older women, especially the oldest of old, and those who fall in the funding gaps (such as the Medicare coverage gap) providing them less access and affordability (Cortis, 2012). Women like Kathryn, who had to give up her job to care for her husband, know this well.

For those policies and acts that allow for states to decide how to spend allocated funds and in which services will be invested, older women are forced into an unwelcome game of ‘place roulette’. This means that they must make decisions about which state in which to live based upon the services they may receive. Of course, many older women, like the women in this study, have financial, familial, or other concerns which prohibit them from relocating to states that invest more heavily in services for older people. This means that they may have left a state which had accepted relevant federal expansion funds or offered them more older-age state resources and support than they currently receive in East Tennessee. Many of the women in the study indicated that, at the time of their decision to relocate, the impact of the differences in services and resources available to them was not part of their decision-making. Their needs for relocating to (or back to) Tennessee ranged from childhood moves due to parental job transfers, to taking up job offers of their own, to being with Tennessee-based spouses, aging parents or other family in need. Knowing what a state provided for them as they age was not a consideration.

> Some felt that even without knowing specific policies or interventions, the current policies and interventions were unacceptable and did not meet their needs. Deborah said, “I just know that…whatever’s provided through Medicare, I’m sure it could be better,” and Peggy simply said, “They suck,” while Margaret echoed that sentiment, “They’re rotten.”

It is of note that although they did not discuss which policies or interventions to which they were referring, other than Medicare, they felt they could be improved, or simply felt they were very poor. While the women do offer recommendations on how policies and interventions can be improved, it is important to recognize that it may be difficult to improve specific policies and interventions without the women's knowledge of them. What the women seem to be saying is that whether or not they know of specific policies and interventions they feel that that many policy and intervention outcomes are not helpful to them.

Some felt that policymakers were the problem, rather than just the policies themselves. The section below breaks down a large response from Ruth regarding this perception.

> Ruth said: "Well, it…mainly worries me that…politicians who know nothing about medicine are making these laws, and when they did Obamacare, they didn't consult with the insurance industry or the medical industry. They just decided they were going to do that…"

Ruth's comment that the ACA was enacted by politicians without any input from the insurance or medical industries, which is untrue, but shows Ruth's perceptions of how that health policy and legislation was formed by policymakers without regard to their constituents and reflects a common misconception among many people in the U.S. (G. M. Li et al., 2022).

> She continued, "I'm doing [sic] [applying for] Obamacare for [her child]…and it's expensive. It's not affordable, and…they use it…as an excuse not to cover certain things. I mean, it's better than nothing."

Ruth has also been undergoing the process of applying for insurance through the ACA for her child and has found it unlikeable and expensive because her child falls into the category that does not qualify for ACA subsidies. Ruth finds herself in the difficult position of not having insurance provision available for her child because she chose not to have health insurance prior to retirement and, therefore, did not have coverage for her child, but also because her own coverage now comes through Medicare, of which her child cannot qualify. Had she purchased insurance, even though she herself transitioned to Medicare, she could have potentially continued insurance payments for her child until her child reached a certain age. Still, this coverage gap is the most common complaint by those opposed to the ACA, and reflects particular beliefs about policymakers' decision-making in relation to healthcare provision in the United States (Kirzinger et al., 2022). Ruth continued, "I think what's going to happen...is that it's going to be like Britain, where you limit care for the elderly, and I don't like that trend...going that way, I guess, because I'm getting older, but [laughs] I didn't like that trend previously before...I reached this age, so I'm not happy with it."

Ruth shares her beliefs and attitude about the UK's version of universal healthcare, specifically regarding limiting care for older people, a fear that is factually based as it is for all countries (E. Klein, 2020), and confirms the research on many Americans' distrust in government (and policymakers) oversight of health, even though care rationing exists in the U.S. healthcare system itself (Hook & Markus, 2020; Yoder, 2002). She said, "Then my brother read through the Obamacare [sic], and only half of it has to do with medicine, the rest of it is pork-barreling as usual." Interestingly, Ruth did not mention that she read the ACA documentation, only that her brother did.

She continues,

> "I just don't think they're on the right track at all, you know. People think that they're helping out, that the politicians are helping them, and they're not, they're

> hurting them. You've got to have a multi-approach [sic] from many different angles. You can't just do it from one end which the politicians are trying to do, and they're only trying to do it to get votes. Put them on our health care system, and then they'll make changes that are beneficial. I mean, they don't have to put up with what we're putting up with, and, I don't know, it's just, I don't see it getting any better because I don't see the politicians really working for us."

Ruth's comment shows how conflicting the internal and external dichotomy of perceptions of health inequities can be and the role of policymakers and decisionmakers in shaping policies and interventions which impact health inequities. For Ruth, this dichotomy encompassed working in healthcare for most of her life; running her own healthcare services business for many years; refusing to purchase insurance for herself, saying she refused to pay insurance companies, which affected her access to healthcare; and then sitting on the board of a healthcare organization, which she says has opened up her understanding of healthcare provision from service providers' points of view rather than just viewing health provision and health inequities from her own perspective. Ruth's responses illustrate just how conflicted but interrelated the issue of health inequities is for older women (and others) in East Tennessee. Finally, what is important is that Ruth, like all of the women in this study, is afraid of what will happen to her as she ages, and these fears may be shaping her (and their) perceptions of policies, interventions and policymakers. Moreover, Ruth's statement that health policies and interventions require a multi-pronged approach – what might be called an intersectional approach – is exactly what those researching and working in health inequities call for, including what this study calls for.

In opposition to Ruth, Sylvia spoke about the positive impact the ACA has had on her and on women in general with the removal of pre-existing conditions clauses, the removal of gender-based insurance premiums, benefits, and services. She also spoke about her awareness of two state policies that she felt were currently or could impact both younger and older women at the time of the interview, one regarding the potential overturn of Roe v Wade and the subsequent enaction of Tennessee's Roe v Wade highly restrictive abortion legislation[14] and Tennessee's refusal to expand Medicaid. She said, "where [a] state really hurts… women right now is the lack of expansion of Medicaid because there's a lot of uninsured people, and a lot of people who really need to be on TennCare who don't have health insurance."

Sylvia's comments reflect many of the women's comments regarding their perceptions of and knowledge about local, state, and federal policies and interventions. While they were in direct opposition to Ruth's perceptions about the ACA, she, like Ruth and most of the women, expressed concerned about the two policies areas they were most aware of – the possibility of restrictive abortion legislation and the current lack of Medicaid expansion in Tennessee. Sylvia's concerns about Tennessee's abortion legislation illustrate that some older women may recognize that gender inequity starts early in life for women and that tackling their own health inequities must include tackling the health inequities younger women face as well.

Conclusion

The findings show that the participants grew up in an environment of silences around health, healthcare, and mortality (or death). These silences were familially,

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[14] At the time of Sylvia's interview, Roe v Wade had not yet been overturned by the Supreme Court.

socially, and culturally constructed, most often resulting in the reinforcement of young people not learning or thinking about health or death. The absence of open discussion or challenges to normed health messages may have helped to ‘open the door’ for inculcation of the perception that individual responsibility and lifestyle behavior were the primary causal factors of their and their familial health and mortality outcomes. Their perceptions of their own childhood illnesses and the family illnesses and deaths they witnessed as children support this argument. Some internalized the norms in which they were steeped, some understood the genealogical (and genetic) factors involved, and some were prompted to change their attitudes and beliefs toward health. But all were focused on what their or other individual responsibility factors were involved in their perceptions and on what changes they could make themselves, as ‘responsible individuals’, to mitigate health and mortality outcomes.

As the study pushed beyond the immediate relationships that influenced their perceptions, the findings were mixed. The women varied in their understandings of the chosen health definitions listed above, with some remaining fixed in health behavior and individualist understandings, while others perceived some wider social determinants, norms, and systemic factors (such as societal influence, system discrimination and gender-based inequitable treatment, lack of access, and lack of gender-based health research) involved in the way they viewed health inequities, good and poor health, healthy life expectancy and well-being. Half of the women were unsure or unaware of any policies or interventions, health or otherwise, related to women aged 65 years and over. Several were more aware of certain policies related to younger women, particularly around pregnancy and reproductive rights. This made sense given that the concerns many of the women had regarding the potential reversal of Roe v Wade at the time of the interviews. Some were aware of Medicare policies, particularly the Tennessee state legislature’s refusal to accept Medicare expansion.

Their healthcare provision and insurance services experiences were also mixed. A common theme regarding these experiences is related to the way clinicians and providers treated them, and how they took control of those experiences at the individual engagement level (micro level). If they had received what they perceived to be poor care, they refused to return to that provider, chose to confront the provider, or chose to participate in a knowledge exchange session with a provider prior to making treatment choices. It must be noted that their perceptions about their healthcare and insurance experiences may have been influenced by their conscious or subconscious normed attitudes and beliefs about any of the other drivers in this study. Likewise, participants equated the healthcare experiences they had in a given location (state, city, town) as representative of those locations having ‘bad’ or ‘good’ healthcare.

For self and familial health outcomes and inequities, some felt place mattered and some did not. As stated earlier in this chapter, this is concerning as they may attribute their experiences to solely micro-level interactions, and this may help or hinder their continued engagement in healthcare and / or insurance services and certainly in the policymaking and election processes. Participant perceptions build their responses, beliefs, and attitudes about health and health inequities, and, likewise, their beliefs, attitudes, and responses are built by their experiences of social and familial norms. In some cases, this led to participant perpetuation of health-related stigmatized norms (e.g., calling others hypochondriacs).

Finally, although the participants may have not been aware of specific policies or interventions impacting their health or are unable to define or unsure about specific health-related terms, they nonetheless identified those policies and interventions as inadequate to meet their health needs and wants. This research has found that when the participants were unable to define health terms or identify policies, most attempted to create definitions from component parts which may make up a definition or be part of a policy. Often, they did not differentiate between policymakers and clinicians in regard to speaking of how they were treated or wished to be treated. This is important to note because both policymakers and clinicians are figures of authority, and while both have power over the lives of older women, these participants saw clinicians in a more deeply personal light, holding them responsible to a degree for the decisions made by legislators.

CHAPTER NINE

DISCUSSION AND CONCLUSION

In this study of older women in East Tennessee, I explored how perceptions of and lived experiences with gendered health inequities, and the social determinants (SDOH) thereof, are situated in older women's genealogical (familial) and geographical health and mortality outcomes histories and how their perceptions and experiences of health inequities and their familial mortality outcomes histories are characterized by the geopolitical and social norms in which they live.

I examined a number of areas in support of these research questions including the women's perceived impact of: (U.S.) federal, (Tennessee) state, and (East Tennessee county) local policies and interventions on the participants; the role of social norming and health narratives, particularly stigmatization and discrimination around ageism, sexism, and health marginalization of older women, and the resultant older women's internalization of health norms; the familial role in health inequities; the usage of family health histories and older women's genealogies of health and mortality outcomes; and the role of place and place-effects. In this study, I aimed to examine patterns in the women's responses across these areas.

I also aimed to examine the place-based and temporal geopolitical, social, and cultural norming and social conditioning of older women in relation to their perceptions, attitudes, and beliefs. I sought to determine if these norms impact the participants' awareness or lack of awareness of their family health histories. This was in order to examine the health inequities burden on older women, as carried generationally, potentially passing from their ancestors to them to their descendants.

This study showed that internalization of these norms, and the replicating of beliefs, attitudes, and perceptions that older women have around health inequities and familial mortality outcomes may be reproduced in their own families. This may deprive them of awareness of the structural drivers of health inequities which they face. Instead, these norms have the effect of locking them into the narratives of individual responsibility and “lifestyle choice” for their own health inequities. This systemic conditioning reiterates the influence of conservative, neoliberal norms about older women and their health, perhaps keeping them from being aware of policies that affect them and from accessing protections and services which may be available to them. However, even if older women do have awareness of the protections and services available to them, systemic structures including discrimination, inequitable treatment, social norms, and gender-bias in health research, clinical care, and policies and interventions, exacerbate the health inequities and health and mortality outcomes they and generations of their family members face.

This chapter provides insights into the recommendations to policy and decision-makers the women gave during their interviews, and well as recommendations.

Impacts

This study has demonstrated that research that looks at policy and intervention decisions impacting older women, must consider the gendered, aged-based, and place-dependent nature of relevant health policies and interventions (Bambra, 2016; H. Hahn et al., 2017). The implications of political decision-making regarding older women, like all other groups, may be detrimental to their health outcomes and equity (Montez, 2020). Additionally, if services that older women are eligible for go unused, this may feed into state and local governments’ counts of caseloads and enrollments (Knox CAC, 2020). As noted earlier in this dissertation, this can allow the state or local government to reduce the funding available for those services over time, and thereby feed the cycle of health inequities older women face.

A major aim of the study was to add to existing literature via a qualitative, critical health geographies lens by examining whether similarities or differences exist in current federal, state, and local policies and interventions affecting health equity compared to the perceptions and experiences of older women in East Tennessee. As stated earlier, this study has confirmed that Tennessee, which implements neoliberal, highly conservative, and / or faith-based legislation, hinders federally enacted policies intended to support older women (Baru & Mohan, 2018; Sager & Bentele, 2016; Townsend et al., 2020), with large differences between what older women want and need, and the policies and inventions enacted at state and local level. The women in this study cited concerns about the differences in what policies and interventions are there to support them, specifically at federal level, and what their reality of this support is in East Tennessee.

This study has also found that place has deeply impacted the experiences and perceptions of the participants, though perhaps in levels and ways not fully expected. It means that if they were unaware of these policies and interventions, any services available to them are going unused, and therefore exacerbating health inequities for them personally and as a demographic cohort. Here, it may be said, is where the impact of Tennessee’s policy implementation can be seen most acutely, particularly upon personal internalization, a form of psychosocial harm, in which older women internalize the policy narrative. Where many major policies and interventions are available that would reduce the inequities older women face, the State had long chosen not to take them, despite retaining a large federally funded monetary reserve (Friedman, 2022). For women in rural parts of East Tennessee, health inequities are exacerbated by spatial inequalities – such as lack of hospital and clinical care services (including lack of available internet access which affects telehealth options) in addition to policies perpetuating inequities around transportation, employment, and more (Evan, 2018; Letheren, 2021; Pedigo & Odoi, 2010; Tarazi et al., 2017). Place, when it comes to health, can literally be a matter of life, death, disability, or unhealthy life expectancy, when policymakers are invested in anything (party, donor funding, religious beliefs) over lifesaving, inequity-reducing policymaking. Because most of the women in this study had lived in East Tennessee for decades and had relocated to be with or to take care of family members, leaving was not necessarily an option for them.

There may be additional reasons the women may not have mentioned these policies and interventions, if they were aware of them. This is of additional concern because internalization of geopolitical or cultural norms may lead to unintended propagation of the very policies and interventions which are ineffective in reducing the health inequities they endure (Akguloglu & Con Wright, 2021; Cardona, 2021). While this cannot be definitely said about the cohort of the women in the study, it must be considered.

If these women lived in states, including other southern central Appalachian states, that did not have highly misogynistic, patriarchal, neoliberal (and historically Jim Crow-based) cultures that impact legislative decision-making, or if Tennessee had accepted federal funding options (such as Medicaid expansion), and had enacted policies and interventions that specifically prioritized older women's health, their experiences and perceptions of health inequities could likely be very different. Tennessee's state and East Tennessee's local-level policies and interventions particularly fall short for those older women in the funding gaps that aren't provided for by legislation such as the Older Americans Act, and while there may be some regional affinity in these findings, a look at the literature shows that this may be the case for other states (and countries) with highly neoliberal, patriarchal, evangelically conservative and libertarian led legislatures (Baru & Mohan, 2018; Sager & Bentele, 2016; Townsend et al., 2020).

Where federal services and funding are available in local counties and municipalities, Tennessee's constitutional mandate to annually balance the budget constrains the consistency of comprehensive service availability. In other words, services may be available and may be geared to reach those most in need, but not all of those in need. This disproportionately impacts older women, especially those in their 80s older, and those who fall in the funding gaps (such as the Medicare coverage gap) providing them less access and affordability (Cortis, 2012). Women like Kathryn, who had to give up her job to care for her husband, know this well.

Those policies and acts that allow for states to decide how to spend allocated funds and in which services will be invested, older women are forced into an unwelcome game of ‘place roulette’. This means that they must make decisions about in which state to live based upon the services they may receive. Of course, many older women, like the women in this study, have no such liberty, being financially unable to relocate to states that invest more heavily in services for older people.

The issue of silences was addressed in this study by examining the role of social norming and health narratives, particularly stigmatization and discrimination around ageism, sexism, and health marginalization of older women, and resultant older women’s internalization of health norms. There were a lot of silences in the women’s responses to the interview questions in this study. By looking at the women’s familial and peer attitudes and beliefs around health and mortality, patterns began to emerge of temporal and cultural health norms that the women may have internalized. Some were aware of this internalization at various topic points in their interviews, though most were not aware for most of the topic points. Their answers and silences confirmed internalized norms consistent with this study’s arguments on the intensely conservative, neoliberal geopolitical environment in East Tennessee, as well as familial and cultural norms. These patterns could not have been determined, it may be said, without the in-depth examination of familial health and mortality attitudes and belief histories. Family health risk histories are simply not enough to get at the heart of why older women are experiencing the health inequities they face. The normed environment they have grown up in and live in currently must be examined, given the continued (and, in Tennessee, worsening) stigma women and older women face in the United States.

The silences undertaken by the women in this study demonstrate the underpinnings of the silences framework (Janes et al., 2019; Serrant-Green, 2011). This study has confirmed that the women not only internalized norms which exacerbate the health inequities they face but these women have been and are the subject themselves of stigmatizing social norms. A major aim of this study is to share the perceptions of this marginalized and silenced group (older women) and how their perceptions and experiences of health inequities are characterized by the norms in which they live. Therefore, examining the silences of the women in this study is as equally imperative as examining their vocalized responses.

Participant Recommendations to Policy and Decision Makers

Another major aim of this study is to examine the women's recommendations as answered to the question about what they would like policy and decision-makers to know about their health needs and wants. The overwhelming themes were for decision-makers at all levels to approach older women with respect and dignity, particularly in relation to discriminatory and dismissive attitudes (sexism, ageism, ableism); and a willingness to truly listen to more fully and frequently engage with them, and to create trust-building partnerships. Table 6 in Appendix 1 provides an in-depth breakdown of the women's specific recommendations.

The women also identified recommendations for a wide range of specific policy areas mainly based on their own personal experiences and needs. These included:

Equitable Treatment in Policymaking, Clinical Care, and Insurance Systems

Systemic and individual discrimination in the forms of paternalism, sexism, racism, ageism, classism, and ableism against women, especially poor and / or BIPOC women was the most stated concern by the women in this study. For many of the participants, this was perceived as profiling / othering by clinical / medical staff or by legislators regarding their knowledge, capability and understanding of their own health and of health inequities. The women's recommendations for equitable treatment mirror their responses to the findings in Chapter Seven on inequitable treatment, discrimination, and bias. It also confirms the recommendations found throughout health inequities research to mitigate the unjust effects of this determinant of health inequities (see pages 120-21, 142-45, and 167).

Universal Health Care

All of the women in this study, with the exception of Ruth, expressed their desire to have universal healthcare and / or expansion of Medicare. This included the need for federal intervention to ensure the establishment of universal healthcare across the states (an idea which would require constitutional change regarding state's rights). Given that the one of the major findings in this study was the lack of healthcare access, their recommendations to establish a universal healthcare system in the United States was not surprising. Ruth, as noted, felt very differently about this, due to her concerns about the costs involved to healthcare providers. Clearly, Ruth is not alone in this concern or perception as the U.S. remains divided on this issue. But for this study, all of the other women desired it and, therefore, provided their thoughts and recommendations as to why it is needed for older women.

Compassionate Clinical Care

Irrespective of the form of healthcare system in place or the healthcare access available to older women, compassionate care in healthcare provision is needed. Compassionate care is more than equitable treatment, and should extend to all people, irrespective of age. However, Deborah felt that the care shown to older women, especially BIPOC older women, requires special attention to older age-specific (and cultural) competency. The women's commentaries on the need for compassionate care, and care that takes into account their age and the stigma, inequitable treatment, and discrimination older women face is in keeping with the literature calling for compassionate and age-specific competency care (Babaei & Taleghani, 2019; Hilli & Sandvik, 2020; Jaramillo et al., 2021; Tehranineshat et al., 2019; UF Health Jacksonville, n.d.).

An End to Care Rationing

As shown earlier in this dissertation, all healthcare and insurance systems, and many clinical providers have established care rationing systems based on age (see pages 22-26). When looking at their perceptions, concerns, and recommendations coupled with their body language, it may be said that care rationing is an unspoken fear that ran through the silences of these women's interviews. Social norms which emphasize individual responsibility seem to offer a false solution to care rationing in the belief that one can do all that they can to ensure that their health prevents them from facing care rationing. But this has sometimes not been the case for older women, regardless of how healthy they are (Jecker, 1991).

It may be said that care rationing of people, including those over 65 years, without explicit involvement of patient's desires and wishes, is not just a health inequity, it is, as many argue, a grievous violation of the Hippocratic Oath and of a person's basic human and civil rights (Axelsson et al., 2020; Eijkholt et al., 2021; The Arc, 2021). It is fraught with the issues of who gets to decide what age and under what circumstances care rationing of older people should begin, what a 'natural end of life' comprises, who is more deserving of care, what entails determining where resources ‘will do the most good’, and, as noted in the introduction of this dissertation, since age is a social construct, what age is ‘age enough’. Moreover, it may be argued that if care rationing is a necessary solution, many governments who do not currently allow medically overseen human euthanasia, should allow terminally ill people, including older people, to decide when to end their own lives. If a government or a healthcare or insurance system or a clinician can decide to ration care and end an older person’s life based on a set of financially-rooted clinical guidelines, then certainly, in the U.S. especially where distrust of the government is so high, a person should get to make this same life-ending decision for themselves. Certainly, Mary’s uncle who committed suicide in late age due to his health made this decision rather than go into institutional care or to be cared for by family members. Care rationing is at odds with efforts to mitigate health inequities in this sense and may exacerbate older women’s health inequities. Therefore, the women’s recommendations to end care rationing confirm the calls for an end to this decision and policy-making effort (Farrell, Ferrante, et al., 2020; Farrell, Francis, et al., 2020; Fink, 2020; Kertesz, 2020).

Resources for Healthcare Services and Insurance Provision

The women provided several recommendations for additional or extended healthcare services and insurance provision, including carer pay and pay for older women’s work; home health services provision; preventative care screenings for women over 65 years; mental health, dental, eye, hearing, and prescription drug coverage; and indigent care.

Carer Pay and Pay for Older Women's Work

As noted in Chapter Four, older women often give up work early or give up later life work opportunities in order to become the primary caregiver to a number of relatives in various circumstances. This has been the case for some of the women in this study. This impacts their income not only from work earnings but higher social security earnings they would have accrued had they been able to stay in the work force.

The women's responses confirm the literature which argues that informal, familial, and unpaid caregiving is a social determinant of health and that, without carer's pay or pay for 'older women's work', older women face worsening socio-economic status, an increase in social isolation, and the concomitant issues that come with those circumstances (such as mental ill health). This means that older women who are unpaid carers or are unpaid for work they do, face worsening health inequities (Bindley et al., 2021; Strazdins et al., 2016).

Home Health Services Provision

Adequate, affordable, and accessible home health provision was recommended by several of the women. This is related to their recommendations for better access to care and for paying older women for carer's work because of people's desire to stay in their homes at the end of their lives but is specifically focused on the need for providing financial resources to ensure adequate and affordable home health services provision is available for this purpose. Sylvia and Kathryn, who has had significant advocacy duties for family members in her lifetime, spoke about the need for aging-in-place policies.

This recommendation is a reflection on the women's lived experiences not only during the time of their interviews but of their familial health histories. Some have been caregivers or care advocates for a very long time in their families. Some have been caregivers or care advocates for multiple family members. Some have genealogical / family health histories that show patterns of unpaid caring throughout their generations, so these concerns and needs are long-standing in their lives. This recommendation also confirms the body of research on the need for more state-level or more state allowance of federal funds for resources and supports for provisions like adequate, affordable, and accessible home health (including those noted as being provided under Tennessee’s CHOICES Act as discussed in Chapter Four) to allow aging in place. After the time of these interviews, the federal government has made some additional funding available for Medicaid (as opposed to Medicare-only) recipients for help with these issues, through the “Build Back Better” plan (Holly, 2021; The White House, n.d.). However, Tennessee, like many other states, chose to use most of their Build Back Better funding for improving the healthcare workforce and to reduce waiting lists for care, rather than making funding resources or more appropriate eligibility changes for in-home supports directly available to older people on Medicare and Medicaid. Still, as noted by many, the Build Back Better plan initiatives are a very good start towards meeting this recommendation by the women in this study. (Breysse et al., 2022; CMCS, 2021; Garfield et al., 2021; Holly, 2021; Mattson & Bergfeld, 2017; Pellegrin, 2018b, 2021; Simmons-Duffin, 2021; Szanton et al., 2016; The White House, n.d.; TN Comptroller, 2022; TN TennCare, n.d.).

Preventative Care Screenings for Women Over 65 Years of Age

In the United States, screening for certain diseases in older age is recommended to stop at certain ages (Cedars Sinai, n.d.; Cimons, 2020; U.S. PSTF, n.d.). As noted by the women in this study, this is a serious concern for older people because disease is not age-specific, even if older people may be considered at less risk for a given disease. In fact, several of the women have family health histories of older relatives who had diseases of which preventative screening had stopped prior to the age of which they were diagnosed. As noted earlier in this dissertation, the women have concerns about developing the diseases their family members developed or died from, so they have asked for preventative screenings for those diseases, only to be denied by their healthcare or insurance provider.

Current preventative care screenings recommendations are at odds with the desires of the women in this study for continued screening into old age, even as they reach the oldest of old ages. While there are risk reasons that healthcare providers and health bodies have for the stoppage of certain screenings, perhaps the best solution would be to allow older women in partnership with their providers to make well-informed decisions regarding their own preventative screenings.

Coverage for Mental Health, Dental, Eye, and Hearing Care, and Prescription Drugs

None of the women in this study qualify for TennCare, placing several of them in the “Medicare gap”. Only some of them can afford supplemental health insurance, leaving those who can’t without the ability to afford healthcare services they need, such as mental health care, dental care, eye care, hearing care, or access to affordable prescription drugs. This would also include more providers, facilities, and health programs that accept supplemental insurance and / or Medicare.

For these women, concerns around Tennessee’s funding of services (or lack of it) and refusal to expand federal services such as Medicaid contributed to their responses of lack of access as their major concern of the health inequities they face. Their concerns about access for themselves most often referred to these areas that may not be covered by the type of Medicare for which they are eligible (CDC, 2021; Gunja & Williams II, 2022; Kirzinger et al., 2019; Olson et al., 2022; Queen, n.d.; Tarazi et al., 2017), and that they could not afford the costs associated their supplemental insurance (if they had supplemental insurance). This recommendation confirms the literature regarding access and older women (mentioned throughout this dissertation) but also the literature that discusses the lack of access to the healthcare areas noted in this recommendation, and the need for older women to have coverage for these areas (Bunis, 2022; Gunja & Williams II, 2022; Mahmoudi et al., 2018; Northridge et al., 2020).

Indigent Care

Ruth, who was, once again, an outlier when it came to approval for universal care, spoke about the pitfalls, as she saw them, of universal health care provision on healthcare providers and systems. As discussed elsewhere in this chapter, she felt that clinicians and hospitals could not afford to provide care due to the low payments they receive from Medicare. Additionally, she feels this has a disproportionate impact on indigent care since so many private emergency clinics will not care for the indigent, leaving the indigent with access to only certain healthcare facilities, and leaving those healthcare facilities overburdened.

Ruth’s concerns could be seen as a justification for universal healthcare because if all of her recommendations were enacted, that would constitute universal healthcare. However, she accurately discussed the financial burden of indigent care on hospitals (Community Catalyst, 2022), her concerns confirm common arguments that are often used by policy and decision-makers, particularly conservative policy and decision-makers, when it comes to funding and resourcing decisions for healthcare provision in the U.S. for the most vulnerable people in society, especially the elderly and particularly older indigent women (Kirkland, 2015). Ruth's concerns also show the internal conflict, mentioned earlier in this dissertation, of which solutions are the best solutions to tackle health inequities.

More Health Research on Older Women

This recommendation is in tandem with the findings in Chapter Seven regarding gender bias in clinical care and health research and calls for an increase in health research on older women. Sylvia, who has worked in the healthcare field for her entire life, perceives that there is now a trend toward less medical health research on older women (and others) rather than more. Carolyn expressed this concern too, particularly for more health research focused on pre-menopause and post-menopause women, women's heart health research, and also, interestingly, hormone research on men as they age in comparison to women. The recommendation for more health research on older women confirms the literature on this issue which goes as far back as the WHO's call in 2007 (as covered in the literature review) (Bird, 2022; Davidson et al., 2022; Rochon et al., 2020; WHO, 2007).

Researcher's Recommendations

As noted throughout this dissertation, place matters in health, mortality, and health inequities (Arora et al., 2016; Bambra, 2016; Finkelstein et al., 2021; Kuuire & Dassah, 2020; Macintyre et al., 2002; Marmot et al., 2012; Marmot & Wilkinson, 2005; Wilkinson & Marmot, 2003), but this study has shown it matters for these older women in ways that requires a multi-level focus, rather than solely at local or national level. These women spoke of place at state level most of all, followed by places of individual clinical experiences they had. Researchers, clinicians, and policymakers must establish working partnerships with older women in order to translate or implement our research findings into adequate, representative, coordinated and comprehensive policies and services that mitigate their health inequities and genealogical health trajectories. In other words, the democratic processes currently in place in the U.S. at federal, state, and local levels for policy and decision-making for older women's health must be changed. It is not enough to speak with older women and leave them behind at the study door, moving forward on our own research agendas or with policy and decision makers to shape policies and interventions which affect them. Nor is it enough to primarily seek answers in impersonal surveys.

As one solution, representative working groups should be established, particularly at the community and local levels, that consist of older women, all levels of policy and decision makers, clinicians, health researchers, national women's and older people's groups, economics and finance personnel, patient navigators (Natale-Pereira et al., 2011), and other relevant partners, to design, develop, and ensure on-going effective solutions to older women's health inequities. These partnerships should exist in perpetuity, meeting on a regular basis, rather than one-off or short-term convenings. Local groups can then meet and collaborate with state and regional level policy and decision-makers to create more appropriate state-level policies and interventions to address older women's health inequities. These groups could also consult with and include older women in developing and enacting campaigns, events, and other educational opportunities to challenge the stigma around older women’s health and familial and cultural norms about health and mortality. While much more still needs to be done, these suggestions provide helpful ideas for engaging spatially in mitigating and dismantling older women’s health inequities, the role of inequities in their genealogical health outcomes, and the destructive norms and stigma they face.

Finally, where policies and interventions exist for removing discriminatory policies and interventions for older women, such as the Health Stigma and Discrimination Framework (Stangl et al., 2019), multi-level stigma interventions (Rao et al., 2019), and U.S. acts such as Title VII of the Civil Rights Act of 1964, the Equal Pay Act of 1963, the Age Discrimination in Employment Act of 1967, Title IX of the Education Amendments of 1972, the Rehabilitation Act of 1973 (covering employees and job applicants with disabilities), and the Civil Rights Act of 1991, the Equal Credit Opportunity Act, the Family and Medical Leave Act, the Violence Against Women Act, and the Fair Housing Act (FindLaw, 2017; FTC, n.d.; The White House, 2022), policies and interventions should be meaningfully implemented for initial and continuing training and assessment for policymakers, other decision-makers, clinicians and others specifically involved in policymaking and health intervention decision-making for older women. This should include health inequities training and assessment for elected officials over and above standard ethics training or health inequities overview training (Lane et al., 2016; O’Mara et al., 2015). However, it is noted that these recommendations require a geopolitical environment and policymakers which are open to and willing to act upon a health inequities mitigation and health and mortality outcome partnership arrangements with the older women of Tennessee.

Contribution

This dissertation contributes to the health inequities body of knowledge and practice by demonstrating the importance of creating health inequities policies and interventions for older women that incorporate intersectionality at all spatial levels (Homan et al., 2021). This study has included examinations of this intersectionality and multi-spatiality from the geopolitical context in which the women live; the lived experiences they have had which have influenced their perceptions about health, healthcare, policies, and interventions; and their genealogical familial health impacts.

By examining a cohort of older women who were born, lived, and worked across various states within the U.S., but who have spent significant portions of time in their later lives in East Tennessee, this research has examined their perceptions and experiences of the healthcare provision, policies, and interventions available to and affecting them at federal, state, and local levels. It has shown that this cohort of older women were aware of components of policies and interventions at federal level, particularly Medicare, Medicaid, and the ACA, but were not aware of or did not mention state or local government level policies and interventions or resources at all, neither for East Tennessee or any other state they had lived in prior to relocating to East Tennessee. This research, therefore, confirms and adds to the literature regarding the call for more focused multi-spatial intersectional research, policy and decision-making regarding women’s health and healthcare (Homan et al., 2021).

This study has examined the women’s perceptions of their childhood recollections of what their family members’ attitudes and beliefs seemed to be about health, death, and the causes of illness and death of their family members and peers. It has also examined the women’s perceptions, as children, of their own health in childhood and their attitudes and beliefs of health and death and the causes of illness and death of their family members. As a result, this research shows that investing in qualitative genealogical familial health beliefs, experiences, and attitudes history, as opposed to just family disease and illness risk history, helps researchers to understand whether genealogical replication of normed health narratives have situated their experiences.

By examining the women’s understandings of health literacy, through their answers in defining selected health terms, this study also contributes to the understanding of how their familial, geopolitical, and social cultures impact or influence women’s perceptions of tenants of health inequities and the social determinants of health.

This study also adds to the literature regarding older women’s perceptions regarding the impact of place on their health, as shown throughout the dissertation – from their answers on how they feel place has affected their health, healthcare, and insurance experiences to how where they were born or grew up, lived, and worked contributed to their perceptions across all of the findings in this study.

This study shows how older women may perceive and act upon the systemic drivers and social determinants of the health inequities they face, such as reverting to the neoliberal norm of individual responsibility for health, or to naming and taking up activism to mitigate against the systemic nature of racism, ageism, and gender-bias. The study has contributed to research on older women’s health inequities by adding to the limited body of literature through a nuanced examination of this marginalized group of people, of whom this study has confirmed much more research is needed. This study aids in assisting researchers to determine what older women see as impacting them the most and what they want and need in tackling their health inequities and / or negative health and mortality.

For health geography, this study adds to calls such as Kristen Beyer’s (2016) for moving community-based health and small-area / local-level health inequities geography research from identification of spatial and relational inequalities in health towards a translational health geography. It has shown that comparing the gaps between perceptions, needs and wants of older women to what policies and interventions are in place, researchers and policymakers can more readily identify where the policy and intervention foci should be, and co-produce translational strategies that allow policymakers and older women to work together for more effective, appropriate, efficient ‘health-in-all’ policies and interventions (Epp, 1986; Fleming et al., 2008; Lane et al., 2016; O’Mara et al., 2015; WHO, 2017b).

This paper differs from earlier or other research by filling the current gap on health equity research focused solely on older women, a highly stigmatized demographic, particularly their lived experience and perceptions of national, state, and local policies and interventions that shape health and health inequities. It provides a capture of a cohort of women who live in an Appalachian region of the US, a deeply divided, equally stigmatized area of the country, but who’s ages and spatial inequalities, often preclude them from health inequities and policy studies (Rochon et al., 2020).

All of these women come from different walks of lives and different geographic spaces and yet have managed to end up with very similar perceptions, with limited exception, regarding health inequities. By examining the women's perceptions through the lens of ecosocial theory, this study provides a unique insight into embodiment of older women in and through the systems and norms in which they have grown up, and how they have navigated, temporally and spatially, those norms and social determinants, to arrive at how they approach the health inequities they face. Using semi-structured interviews, it has allowed the women to tell their stories, thoughts, attitudes, and beliefs, and to explore social determinants of health in ways some had never done, and in ways that allow researchers to understand the impacts of health inequities on these women through a genealogical lens. Incorporating a number of family systems theories has also contributed to the understanding and confirmation of the necessity of genealogically-focused familial histories when looking at health inequities from a life course perspective. Additionally, in reference to silences framework theory, this study has focused on the silences these women used, consciously or sub-consciously in answers to the interview questions. By observing these silences and looking at where they happened and when, and by observing their body language and voice tone, this study has been able to provide some interpretations on what has gone unsaid by these women about health inequities. Using these methods and theories has helped to reduce bias and misinterpretation wherever possible, including my own bias and misinterpretation.

This study has shown women aged 65 years and over face a unique set of circumstances compared to older men, younger women, and others given the geopolitical context in which they were raised, particularly in relation to patriarchy, gender-bias, stigma, and limited women's rights at the time of their birth and growing up. It has shown that place matters deeply for older women regarding healthcare access, attitudes and beliefs towards health, healthcare, and death, familial health history, and the decisions they make in order to challenge (or not) the health inequities they face.

Implications for Future Research

Implications for this research include continued theoretical exploration of older women's perceptions, awareness of and beliefs about the health inequities they face, particularly as woven through genealogical health histories and health norms frameworks. Because health inequities is an intersectional issue, more interdisciplinary, translational, implementation-oriented qualitative research on these issues is needed (Boulware et al., 2022; Breen et al., 2019; Homan et al., 2021; Jeffries et al., 2019; Kivits et al., 2019; Lapalme et al., 2020), especially for older women (McLemore & Choo, 2019; Rochon et al., 2020), and particularly in health geographies (Enßle-Reinhardt & Helbrecht, 2022; Milton et al., 2015). While each research tool has its purpose and contributes to the literature and the body of practice, it is imperative, and this study has confirmed other recent studies, that researchers and clinicians spend the time needed to establish working relationships with older women in order to better understand the nuanced perceptions of women relating to systemic determinants of health, policy, and interventions affecting women aged 65 years and over (Bartz et al., 2020).

This study is centered on older women born with the sex of female in three counties in East Tennessee. This study originally began as a comparison / contrast study between East Tennessee and Inverclyde, Scotland. It is highly recommended that future research should examine other geographical study areas. All other marginalized sub-groups of women, and their perceptions and experiences should also be examined, such as older Trans women's, other women-identifying as older women, and institutionalized older women, as well as racial and ethnic specific populations. As mentioned earlier in this paper, qualitative research, such as this study has addressed, could benefit significantly from investment in longitudinal studies on the issues encompassed in this study, particularly to capture the experiences and perceptions of the "oldest old" women.

A major finding in this research was the silences in these women's lives surrounding health and death – social, geopolitical, cultural, and familial. Future research would greatly benefit from focusing specifically on those silences in relation to older women's health inequities. This study could also benefit from examination using other theoretical models and usage of other constructs / variables.

Consideration must be given to how to integrate the women's recommendations with current policy frameworks given that it may be likely that policy and decision-makers will respond with reasons why changes to government, financial / funding, and healthcare systems cannot be made. A long-standing issue for researchers, policy and decision-makers and citizens is how to fund systems that cover everyone equitably. In the U.S., at the time of writing this dissertation, this brings the added question of how to bring the deeply partisan political bodies together to create bipartisan solutions that include older women as co-creators of policies and interventions which support all of them. Consideration must be given to whether or not such solutions are attainable, and who is for and against those solutions. Consideration must also be given to how to develop translational or implementation scientific methods that incorporate and co-produce the women’s recommendations, building on any current researching findings that may have recommendations on this area. Researchers also face how to incorporate person-centered, intersectional, community-based and culturally competent ways of problem solving into recommendations for tackling older women’s health inequities. This is a tall order. The study of older women and health inequities is a large area of study and comes with many questions – more than can be answered by the scope of this study.

This study was originally intended to incorporate creative methodologies as part of the research methodology and output functions, but this aspect of the study did not move forward for several reasons. Given that study interviews can form the basis of storytelling, creative methodologies are a vital and original way of sharing individual’s perceptions and experiences and should be considered in future research such as this.

Final Note and Epilogue

At the start of this dissertation, Anita, Mary, Sharon, Margaret, Ruth, Deborah, Sylvia, Peggy, Barbara, Kathryn, Carolyn, and Cynthia, who’s experiences and perceptions have made up this study, were introduced. Several areas within the social determinants of health which impact health inequities, health and mortality outcomes for them, and other older women were explored. Like many older women across the United States, they have endured and survived extraordinary things – abuse, neglect, disease and illness, incarceration, homelessness, divorce, single parenthood, poverty, geopolitical environments which further exacerbate their health and mortality outcomes, and social and cultural norms that lay the blame and responsibility for the health inequities they face solely on them. Having grown up in restrictive social and cultural norms (for women and for health), as well as in the post-WW2, Korean and Vietnam wars, and Jim Crow segregation eras, they have faced unique challenges. These challenges have all contributed to the genealogical health and mortality repercussions on these women's lives. They were willing to talk about the most difficult and intimate life circumstances they have endured, how they have navigated them, and what they recommend to policy and decision-makers, clinicians, and researchers. Yet, the conflict remained that I held a power position and was a stranger, and that their silences were also around these most difficult and intimate circumstances. It is difficult to know what they were withholding which means that the findings and recommendations were made with this in mind. Still, with solutions such as longitudinal studies, allowing the women to read the findings and follow-up with any additional comments or clarifications – something doable with extensions to this study – the silences and limitations of this study are far outweighed by the knowledge and experiences these women bring to the research on older women and health inequities.

This study has shown that one of the most important things in tackling older women's health inequities is listening – listening to older women, listening to their silences, listening to their recommendations. By regularly and deeply listening to older women, researchers, clinicians, and policy and other decision-makers can create spatially representative, intersectional, sustainable, and critically engaged policy and intervention design partnerships that provide for their and their family's health needs and wants. As stated in Chapter Seven, their responses help shape an understanding of the time and places which developed their health story, the knowing of which centers them in the solution to the health inequities that affect them. Nothing for them, without them.

After reading my dissertation and hearing my dissertation defense presentation, my committee members asked me to add an epilogue discussing the heavy emotional labor that went into this dissertation both on my part and the part of the women in this study. They asked me to write it in the format of a spoken word poem since I am a professional spoken word performer, with the great luck to also have published and won an award or two. I am honored to do so.

Genealogy Tells

In the two years of writing of this dissertation,
I lost fourteen loved ones.
The last two were three weeks before
my dissertation defense.
There came a point when I stopped
telling people, and
wrapped myself in the silences
the women I studied also embraced
with fierce self-protection.
Everyday my losses sang to me,
wrapped in the stories of these women.
Tales that were telling my story,
their story,
our story.

But will it ever be enough,
to research,
write,
ask,
examine,
advocate,
explain,
beg,
plead,
and steal
for people at the margins,
people closed-up in institutions,

people hidden in plain sight,
people mocked,
ridiculed,
stigmatized,
antagonized,
inculcated,
invaded?

Genealogy tells.
It tells stories you want to hear.
Glorious, vain, proud moments of
anchoring us in history,
It tells stories you don’t want to hear.
It challenges tales told by the victors,
tales of people bought and sold by
people who let their consciouses go,
people in our family histories devoid of
all rational reason,
people harming, hurting, and being harmed.

In the body, genealogy tells of
the emotional labor of a woman’s labor,
and the death and health and sickness
embodied in our families.

I heard their stories and their losses
while I lay across
the hospital bed of my father
while I raged at preventable death,
systematic death,
avoidable death.

The women raged too and cried,
stunned and exhausted from
the illnesses and deaths of
mothers,
fathers,
sisters,
brothers,
uncles,
aunts,
husbands,
wives,
partners,
children.

Decades and centuries of
preventable,
avoidable
unknowning.

Unknowing in cultures telling them
it was our fault for illness,
hidden in the women’s desire to be seen alive
before they go missing in the margins,
knowing something’s...not…right!

It’s not right that we live and die
like we do in such wealthy places,
that we scrape and bow just to
buy our right to age.
That some think health and aging
are not a right.

Instead, they train little girls,
telling them,
“Don’t say a word,
you see what they did to
the mockingbird…”

“Daddy, get up from that bed
and walk out of here!” I cried.
“Momma, don’t let go when
you’ve got this far!” these women cried.
It’s too soon,
too late,
too far from what should have been.

Life, we want life,
We want it to never end.
But what I really want,
is for… you… to never end.

I wrote and wrote, and
got lost in the writing.
I gave up a million times, swearing,
“I can’t do this work
one more second of this day.”
Still, I did because I was held
up by my ancestors and buoyed
by those who wouldn’t let go
of my dream.

No, it will never be enough.

But we and genealogies tell these tales.
We trace our histories to go
down in the earth and
let it claim us as home.

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APPENDIX

Table 1. Geographical and health profile tables of participant counties: Females aged 65 years and over by age bracket in Knox, Blount, and Sevier Counties as of July 2019

County	**Total Pop**	**65-69 yrs**	**70-74 yrs**	**75-79 yrs**	**80-84 yrs**	**85+ yrs**	**Total F65 yrs+**	**% F65yrs+**
Knox	470,313	13,442	10,932	7,773	5,150	5,653	42,950	9.13%
Blount	133,088	4,599	4,011	2,811	1,807	1,857	15,085	11.33%
Sevier	98,250	3,576	2,930	2,112	1,190	1,056	10,864	11.06%

(U.S. Census Bureau, 2021a)

Table 2. Geographical and health profile tables of participant counties: Aged 65 years (all genders) and over population projections by 2040 in Knox, Blount, and Sevier Counties as of July 2019

County	**Total Pop**	**65-69 yrs**	**70-74 yrs**	**75-79 yrs**	**80-84 yrs**	**85+ yrs**	**Total 65%**	**% 65+**
Knox	549,800	24,280	19,200	13,195	8,451	8,535	73,661	13.40%
Blount	151,526	8,470	7,118	5,049	3,060	2,878	26,575	17.54%
Sevier	123,451	6,542	5,402	3,663	2,058	1,676	19,341	15.67%

(UT Boyd Center, 2021)

The Tennessee Advisory Commission on Intergovernmental Relations (TACIR) provides county indicator profiles which detail several relevant health-impact statistics across the state. Additionally, the Tennessee Commission on Aging and Disability (TCAD) provides an annual state of aging report. Together, they provide a county-level geographical contextual snapshot for the experience and perception responses of the women involved and which help to paint a picture of some geosocial determinants in which this study's participants, as older women, live (TACIR, 2021; TCAD, 2019).

Table 3. Geographical and health profile tables of participant counties: County-Level Snapshot - Selected County Indicators

TACIR AND TACD APPLICABLE COUNTY INDICATORS (for 2019)	**Blount**	**Knox**	**Sevier**	**State**
Poverty Rates (all ages)	8%	9.5%	10.7%	11.1%
Mortality Rates (per 1k pop)	11.6	10.1	11.6	10.5
Access - Medical doctors (per 1k pop)	2.1	4.8	0.9	123
Access - hospital beds (per 1k pop)	3.4	5.1	0.8	3.7
Access – nursing home beds, 65+ (per 1k pop)	25.7	26.1	14.4	33.8
Charity Care – Percent All Hospital Care (2015)	8.2%	4.7%	6.3%	10.4%
Pop less than 100% below Fed Poverty Level	8%	8%	8%	
65+ who receive property tax relief	1.2%	0.8%	1.3%	
65+ civic participation	>60%	>60%	>60%	
65+ who have difficulty walking	24%	22%	22%	
65+ who are raising grandchildren	1.1%	0.8%	1.4%	
Medicare Enrollees[15]	17,689 (13.3%)	70,343 (15%)	18,534 (18.9%)	
Four or more chronic conditions	39%	37%	36%	
Food Environment Index	7.5	7.2	7.9	
65+ who live alone	27%	29%	22%	
65+ who are housing insecure	20%	20%	17%	

(TACIR, 2021; TCAD, 2019)

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[15] Medicare enrollees' percentages calculated (in blue) by taking the US Census 2019 county populations and diving them INTO the TACD numbers then multiplying by 100 to get the percentages.

Table 4. Participant City / Town Residences (Disclosed) (minus East Tennessee cities / towns)

City / Town	**Number of Participants Residencies**	**City / Town**	**Number of Participants Residencies**
Alexandria, VA	1	Rochester, NY	1
Ann Arbor, MI	2	Santa Cruz, CA	1
Arlington, TX	1	Somers, CT	1
Boston, MA	1	Walkerville, IN	1
Charlottesville, VA	1	Wallingford, CT	1
Chicago, IL	2	Washington, IL	1
Columbus, OH	1	Westchester Co, NY	2
Davis, CA	1	Wichita Falls, TX	1
Findlay, OH	1	Winona Lake, IN	1
Greenberg, NY	1	Unspecified, CO	1
Hartford, CT	1	Unspecified, NC	1
International	2	Unspecified, north DE	1
Livingston, NJ	1	Unspecified, Pacific Northwest	1
Mount Vernon, NY	1	Unspecified, Southern CA	1
Muncie, IN	1	Unspecified, Southern IL	1
Nashville, TN	2		
New York, NY	2		
Los Angeles, CA	1		
Peoria, IL	1		

Table 5. Participant's perceptions of whether place mattered in their healthcare experiences

Participant	**Place Matters in healthcare experiences**	**Perceptions of whether place mattered in their healthcare experience**
Mary	Yes	However, when thinking of her birthplace, she wondered if she perceived healthcare there as not as good because of her parents' attitudes toward health and healthcare.
Peggy	Yes	Peggy viewed healthcare in one state she lived as worse than every other place she lived. However, she based this on one physician's patronizing treatment and poor care regarding her first heart attack.
Deborah	Not stated	
Barbara	Yes	Yes. She noticed a significant different in cultural attitudes towards health, healthy living, wellness, well-being and nutrition in one area of the country in which she lived compared to all other areas of the country.
Cynthia	No	Cynthia did not think place really made a difference. Instead, she felt ethnicity did, again focusing on weight as the indicator of health.
Anita	Yes	Anita lived abroad in a Global South country for several years and had need of dental care while she was abroad. As a result, she felt that place matters in that every place has a different cultural approach to medical care.

Table 5 continued

Participant	**Place Matters in healthcare experiences**	**Perceptions of whether place mattered in their healthcare experience**
Sharon	No	Sharon gave no explanations as to why she felt that place didn't matter.
Margaret	Yes	Born and raised abroad prior to relocating to East Tennessee. As a result, she felt there were also cultural differences in how places approach healthcare provision.
Ruth	Yes	Felt place mattered in relation to the efficacy of healthcare services available in each area that she lived.
Sylvia	Not stated	
Carolyn	Yes	Felt place mattered in relation to cultural attitudes toward health, but that age, and the people who are in your life make a difference in how she perceived place to play a role in health.
Kathryn	Yes perhaps	Felt that one state in particular had a noticeable difference in cultural attitudes towards health. However, she felt that age and the silence norm played a role in whether or not her observations of place mattering were accurate.

Table 6. Participants' Recommendations to Policy and Decision Makers

Participant	**Recommendations to Policy and Decision Makers**
Mary	More provision for aging counseling. Creation of programs in senior centers for older women's movement and exercise (similar to programs offered by the supplemental insurance) that accept supplemental insurance payments). Less policymaker patronizing. Equal treatment by clinicians. Carer pay (of spouses, children, grandchildren) that older people do. No care rationing based on age.
Peggy	Listen to older women. Pay more attention to older women's cardiac health. Medicare for All. Access to high quality medicine. Equal treatment – respectful treatment.
Deborah	Better preventative care for women over 65, including preventative care of diseases that are often associated with older age (Alzheimer's, osteoporosis) - but starting well below the age of 65.
Barbara	Healthcare access Good clinical care Provider compassion
Cynthia	Preventative care continuation, regardless of age (mammograms, pap smears, etc.)
Anita	More federal government involvement in health and healthcare. Good care for older people, without worry of affordability or lack of care.
Sharon	Universal healthcare

Table 6 continued

Participant	**Recommendations to Policy and Decision Makers**
Margaret	Less policymaker patronizing, more policymaker empathy, and more policymaker direct engagement with older women constituents
Ruth	Healthcare access for all Spread the healthcare load across care facilities for indigent care Population education on where to get help if someone is unable to afford care Investment in rural care, access, hospitals and clinical care / facilities
Sylvia	Universal free mammograms Coverage of dental, eye, and hearing costs for older people through Medicare and supplemental health insurance Alternatively, affordable dental insurance Affordable drug prices More older women age group health research
Carolyn	More health research focused on women and focused on pre-menopause and post-menopause; particularly more heart health research focused on women; but also research on men in relation to their drop in hormones
Kathryn	Medicare expansion Affordable healthcare for everyone Access for everyone Affordable in-home care- more financial support for home carers and for in-home care

VITA

Heather A. Davis (née Turner) was born in Knoxville, Tennessee on September 20, 1970. She attended elementary and middle schools in the Knox County and Blount County School Districts and graduated from William Blount High School with honors in May 1988. The following August she entered the University of Tennessee, Knoxville, switching to part-time attendance in 1989. She received a Bachelor of Arts in Political Science and a minor in Economics in May 1996. She entered the University of Notre Dame of Maryland (formerly College of Notre Dame of Maryland) in May 2002 graduating with a Master of Arts in Contemporary Communication in December 2004.