

2018

African Americans Aging in Minnesota's Urban Facilities: A Phenomenological Study of their Lived Experiences

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**African Americans Aging in Minnesota's Urban Facilities:
A Phenomenological Study of their Lived Experiences**

A DISSERTATION SUBMITTED TO THE FACULTY OF THE
COLLEGE OF EDUCATION, LEADERSHIP AND COUNSELING OF THE UNIVERSITY
OF ST. THOMAS
ST. PAUL, MINNESOTA

By

Antonia Maria Apolinário-Wilcoxon

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF EDUCATION

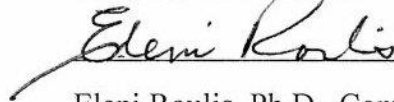
2018

UNIVERSITY OF ST. THOMAS, MINNESOTA

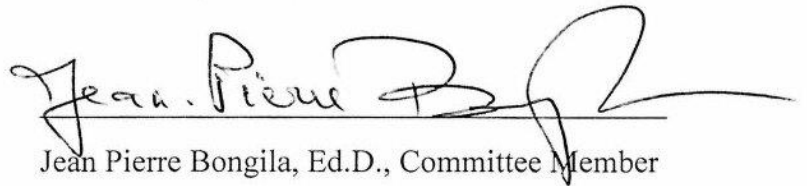
African Americans Aging in Minnesota's Urban Facilities:
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We verify that we have read this dissertation and approved it as adequate in scope and quality. We have found that it is complete and satisfactory in all respects, and that any and all revisions required by the final examining committee have been made.

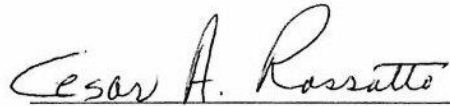
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ACKNOWLEDGMENTS

This body of work would not be possible without the contribution of many who are both still with us the living, and ones who have passed on. To my parents Evelina and Elson Apolinário, I owe you my life, my resilience, my resolve, and my love of learning. To Zai, my loving gratitude for taking care of me and my siblings, as small children, while mother worked to maintain her family together with the sudden loss of our young father. To my siblings Sebastião, Luiz Carlos, and Ermínia for cheering me on, thank you. To my sons, Elliott and Carl, for your steadfast support and presence in my life, as you watched your mother wrestle with a language which is not one of her birth, and for helping me strive to do more; your quiet love and sustenance were precious to me. To the Roth family, in Lake Crystal, MN, for welcoming me into your home and community as an American Field Service student. I did not know then how my life and the lives of my beloved family would change forever. To Scot, the father of our two sons and the love of my life. I owe you more than I can quantify.

My grateful thanks to Dr. Eleni Roulis, my supportive dissertation chair, and committee members Dr. Jean-Pierre Bongila, thank you for your support in my success and Dr. Cesar Rossatto for your gift of knowledge, experience and generous spirit.

I am grateful beyond measure to all those who encouraged me to continue writing, to pursue a long-held dream of pursuing this doctorate degree, for devoted support and belief in me: Sandra Crump, Paula Pedersen, Christine Black-Hughes, Stephen Miles, M.D., Mother Atum Azzahir, my colleagues at DHS and the citizens members of the CECLC who often asked me how my studies were going. Your friendly and supportive reminders helped me keep my “eyes on the prize” in this journey.

My sincere gratitude to the Nursing Facility resident participant African American elders I had the unique opportunity to interview and listen to their stories, for your gift of time, wisdom and love. Your generosity filled my heart each time we met as I left feeling motivated to tell your stories to others. I was indeed in the presence of living libraries.

I am grateful to the Nursing Facility staff who provided me entry and safe access to these gems of wisdom.

My humble debt to the ancestors, to the Creator and the Orishas, who watched over me, my family and my relations. May this labor of research, love of learning and discovery please you.

Abstract

Older Adults are a rapidly growing population in the United States and in the state of Minnesota (Passel & Cohn, 2008, Minnesota Department of Human Services, 2018). African Americans as well as other minority groups experience race, socioeconomic status, and health disparity issues found to be “large, pervasive, and persistent over time” (Williams, Mohammed, Leavell & Collings, 2010, p. 93). This study asks three questions to learn about the lived experiences of African American Older Adults residing in a large Minneapolis nursing facility: How they experience life in the nursing facility; what elements of racial disparities exist in the facility as they experience them, and how staff/administrator perceive such racial disparities. In-depth interviews, participant observations and research of facility were sources of data.

Answers revealed that: Seven out of the ten interviewees moved North to avoid segregation and seek a better life for themselves and their families. Each African American resident participant grew up under segregation surrounded by loving adults who buffered them from their suffering and providing solidarity in their shared experiences of dehumanization. The African American resident participants exhibited strength, resilience, pride, joy and triumph as they examined their lived experiences and took stock that they have indeed overcome obstacles.

It is recommended that staff and administrators explore training in understanding disparities, inequities, and structural racism to be better prepared to welcome diverse residents, and to better match residents' wants and preferences. Inviting resident participants' voices into the administration of the nursing facility and listening to their opinions, suggestions and ideas for improvement of the quality of their experiences in the facility, could help add to their quality of life, provide opportunities for their voices to be heard both inside and outside the facilities in the community where it is located.

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Chapter I: Introduction

A West-African saying states that “when an elder dies a library burns,” and, according to Hawaiian ethnographer and curator of humanity, Elizabeth Lindsey (December, 2010), in a powerful TED Talk that laments “throughout the world libraries are ablaze” 10:13min. This reference to the elder is in a village of old, where s/he is surrounded by relatives, linked by culture, ethnicity, blood or kinship, as the elder expires their last breath in this world to pass on to the next. In 2000 almost 10 million people needed some form of long-term care in the United States (Roger & Komisar, 2003). Of this population, 3.6 million (37 percent) were under age 65 and 6 million (63 percent) were over age 65, and almost 70 percent of people turning age 65 will need long-term care at some point in their lives (Roger & Komisar, 2003).

“On January 1, 2011, the oldest Baby Boomers will turn 65. Every day for the next 19 years, about 10,000 more will cross that threshold. By 2030, when all Baby Boomers will have turned 65, fully 18% of the nation’s population will be at least that age, according to the Pew Research Center, population projections, today, just 13% of Americans are ages 65 and older” (Cohn & Taylor, 2010, p. 1). Key projections of the Minnesota State Demographic Center for the aging populations estimates: People in the state of Minnesota “turning 65 in this decade (about 285,000) will be greater than the past four decades combined” (Minnesota Department of Administration, 2018, p. 2). And, it is expected that in 2020, “Minnesota's 65+ population will overtake ages 5-17-year-old population; and that older adults (65+) are anticipated to double in number between 2010 and 2030, when more than 10% Minnesotans will be an older adult, including all the Baby Boomers” (Minnesota Department of Administration, 2018, p. 2).”

Elderly people in need of long-term care in their community, about 30% (1.5 million persons) were found to have significant long-term care needs (requiring assistance with three or

more Activities of Daily Living [ADL]). About 25% of the 30% (1.5 million), are 85 and older and 70% consider themselves to be in fair to poor health. This study focused on Older Adults from Communities of Color who cease to be able to care for themselves, bathe, cook, drive, or actively participate in their community (requiring assistance with three or more Activities of Daily Living [ADL]). This community involvement includes attendance at faith communities, volunteer activities, participation in social events with relatives, and then retiring home to lead an 'independent' life.

The aging process includes frailty of bodies, fading memory and an inability to live 'independently' by Western standards, which result in the need for physical, psychological, social, economic, and spiritual support from relatives. These elders have relatives that lead busy lives, employed, participating actively in their many communities, faith communities, social groups, play groups, and a myriad of activities modern life engenders that maintaining distractions away from the elderly relative. Caring for an elderly relative who may depend on the family caregiver to support their activities of daily living is not possible for most relatives. Modern urban homes are not equipped to support aging adults with additional rooms, special equipment in baths, wide hallways for a wheelchair, etc., nor is there a vision of multigenerational communal families residing under one roof (Miles, 2018, personal conversation).

Aging services to persons of minority groups brings complex challenges to institutions: According to a 2010 Williams, Mohammed, Leavell, and Collins' study on race, socioeconomic status and health issues, "The research reviewed concluded that social disparities in health are large, pervasive, and persistent over time" (p. 93).

Problem Statement

In 2015, 47.5 million Americans or 15% of the population were over the age of 65 (Kaiser Family Foundation, 2017). Many older Americans have complex health needs such as heart disease, diabetes, and dementia. Nearly "one in three seniors live below 200% of the federal poverty level [FPL] (100% FPL=\$12,060/year for an individual in 2017)", according to the Kaiser Family Foundation's Infographic (2017) on the role of Medicaid for seniors (p. 1). Complex health needs cause an increasing number of elderly citizens to depend on support to attend to their activities of daily living provided in a nursing facility. Nursing homes continue to be segregated (Rahman & Foster, 2015, Chang, Siegel & Wilkerson, 2012), are segregated like the country's lingering practices of metropolitan residential segregation (Smith, Zhanlian, Fennell, Zinn, and Mor's (2007) who also found that "Blacks are more likely than Whites to live in nursing homes with high degree of deficiencies, lower staffing ratio, and greater financial instability (p. 1)." Further, these authors' state: "Since the inception of Medicaid and Medicare in 1966, the status of nursing home segregation in the south, under Jim Crow laws and in the north with residential segregation, never received the same attention as other sectors protected under Title VI of the Civil Rights Act" (Smith, Zhanlian, Fennell, Zinn & Mor (2007, p.2). "Post 1964 backlash and national diminishing support for anti-discrimination laws played an important role on this, when initial plans to certify Medicare nursing homes to desegregate" were delayed (Smith, Zhanlian, Fennell, Zinn & Mor, 2007, p. 2). A study in Minnesota, by Shippee (2014) revealed the existence of differential services at the residential and structural level for minority populations. Shippee (2014) concluded that though disparate outcomes exist, they are explained by health status, with minority residents exhibiting poorer healthy conditions due to experience

with discrimination and poverty, compared to Whites and it encourages a study on how the nursing facilities are structured. Residents of color are a growing population using nursing home care in their later years (Agency for Healthcare Research and Quality (AHRQ), 2000). Racial and ethnic diversity within Minnesota's older population will continue to increase over the next 30 years. While the overall population will grow in Minnesota, African American adults 65 and older will increase from 5,400 in 1995, to 31,200 in 2025, according to the 2005 Minnesota Department of Health's brief on Demographics of Aging Populations in Minnesota.

This study sought to learn the lived experiences of African American Older Adults in a large metropolitan nursing facility in the state of Minnesota.

Significance of the Research Topic

While studies can give an insight into preliminary causes for disparities in the quality of life for African American older adults, further research is necessary to fully understand the development, continuation along with the maintenance of disparities within nursing facilities today. Consequently, this qualitative study addresses racial differences in the quality of life for Aging African Americans in Minnesota's urban facilities, a topic of high value for public health, policy, nursing home residents and their families, and is of key importance for achieving equitable outcomes in later life.

Purpose

Little is known about reasons for racial and ethnic disparities in the quality of life for aging African Americans. This study sought to determine the mechanisms that influence African American (US born) residents' quality of life from the perspective of the African American resident participants in comparison to the perspectives of the direct care staff. This qualitative study took place at a large nursing facility in the Twin Cities of Minnesota with a high

proportion of African American residents. I conducted in-depth interviews with ten residents and three staff employed at the facility. I also conducted selected observations of resident/staff interactions while waiting to be taken to the floor where residents were, or while at the conference room where I met the resident participants. Staff also took me to residents' rooms and provided introductions.

This study sought to understand the reasons for racial and ethnic disparities in care and quality of life for African Americans in nursing facilities. It also sought to uncover potential solutions to inform the next generation of professionals in elder care within the context of equity and social justice.

Reflexive Statement

I grew up in a poor neighborhood in the coastal city, Vitoria, in southeastern Brazil. In that community elders held a special place of respect and deference. They are the individuals considered to be wise, experienced, caring, and protective. I remember observing uncles and aunts coming into the home and kneeling asking her grandfather and grandmother for blessings as a means of greeting. A custom I would learn hailed from across the Atlantic: I observed this same behavior when spending time at the home of an elder matriarch in the city of Salvador, state of Bahia. That same form of greeting manifested itself as this matriarch, a Candomble priestess, being greeted by her adult sons. Mãe Hilda of Ile-Aye was the matriarch and a reknown community leader. Well into old age, she created a school for low-income African-Brazilians that I was interested in visiting. In a Brazilian household, there are usually several generations under one roof. Young adults move out of their family homes to get married, for studies abroad, or a career opportunity in another state. I do not recollect the existence of any

nursing facility while growing up in my city. Usually frail elders are cared for by their extended families until their last breath.

I have lived in the US for over thirty years. The past two decades were spent in roles as manager of social services for low income individuals who experience dependency on publicly funded services to lead their lives. For the past thirteen and a half years, I have been employed by a state agency with a mission to “provide essential services to Minnesota's most vulnerable residents” (Minnesota Department of Human Services (DHS) Webpage, 2018).

Working with many others, including counties, tribes and nonprofits, DHS helps ensure that Minnesota seniors, people with disabilities, children and others meet their basic needs and have the opportunity to reach their full potential.” (DHS Webpage, 2018). The conditions of life of African descendants in nursing facilities in the state of Minnesota, became a subject of interest while reading *Racial Differences in Nursing Home Residents' Quality of Life and the Association with Facility Characteristics* (Shippee, Henning-Smith, Rhee, Held, & Kane, 2015).

My employment responsibilities entail collection of disparities reduction efforts achieved in the publicly funded human services state agency in the areas of access and outcomes of health and social services. I reviewed the report which explored the existence of disparities in quality of life and quality of care utilizing data provided by DHS. This state data contained evidence of disparities in quality of life and quality of care in city nursing facilities receiving public funds. The findings of this report compared White residents, against Residents of Color who were found to be younger (14 years), to depend on Medicaid, to reside in for-profit facilities, with majority female, and to reside in larger institutions. These Residents of Color also occupied fewer private rooms, and resided longer periods of time in institutions as compared to the White residents.

My work as DHS' Community Relations Director entails supporting members of cultural and ethnic communities as they engage with DHS leaders and other employees to find solutions that eliminate stubborn disparities in access and outcomes to health and human services and help ethnic community members attain successful outcomes equitably.

I facilitated meetings of community members representing those most impacted by differences in access to publicly funded services. The agency senior leadership identified five major areas serving populations that the agency needed to improve on and to develop initiatives to dedicate attention in order to "meet the agency's mission." I became the project manager for two initiatives: Integrated Services for At-Risk Adults, who had lost health coverage as the state legislators eliminated the state funding for medical assistance to older adults without children.

The second initiative was Disparities Reduction. DHS's Senior Leadership had decided to include the reduction of disparities in access and outcomes experienced by cultural and ethnic populations as a strategy in the 2007 strategic plan. A DHS-wide work group of near 30 employees responsible for processing data on services funded by the agency, was tasked with developing a list of program measures with evidence or near-evidence of suspected disparities in access or outcomes for cultural and ethnic populations to DHS-funded human services. The work group completed its task and delivered a list of 85+ measures. I presented the list to the agency's senior leadership, and they instructed me to work with the group to choose 10 to 15 measures, found in Appendix J. The choice of a few targeted measures would give agency leaders a small group of programs to focus on for gaining understanding of the nature and impact of the disparities. The disparities on certain populations would be addressed effectively and those impacted by these disparities could achieve easier access and better outcomes to services.

I worked in community-based organizations prior to employment at the Minnesota Department of Human Services. While leading these agencies I learned the importance of including those impacted by the problems challenging them in solving such problems (Schor, 1997, Konopka, 1966). The agency's Commissioner and cabinet met with a select group of leaders of nonprofit community-based agencies and other concerned leaders about disparities in human services experienced by cultural and ethnic communities. The purpose of this first meeting was to tell the community members about agency's initiative and to extend an invitation from the agency leader to engage with agency staff in discussions to find solutions to disparities with the intent to include the voices of impacted communities in resolving racial and ethnic disparities. 2009 marked the beginning of monthly meetings with ten appointed employees from various divisions within DHS who met with community members to discuss disparities, exchange knowledge and understanding on the nature of the disparities, programs funded by the agency in inclusive, collaborative and resourceful conversations. The Disparities Reduction Advisory Committee (DRAC) members guided agenda items, inquired about different programs within the agency, listened to program experts' presentations and became a sought-after group as DHS staff and leaders would attend meetings to receive feedback and community input.

DHS endorsed three of DRAC's major recommendations at the end of their 3 ½ year period:

1. Increase the diversity its staff to more appropriately respond to cultural communities' needs and preferences in its program and policies; (the Affirmative Action hiring goals were increased to higher goals for minority, women and persons with disabilities).

2. Encourage senior leadership to attend an Anti-Racism training to best understand and become attuned to the realities and lived experiences of communities most impacted by disparities; (during Summer 2012 Senior Leadership including the Commissioner took training using *The White Racial Frame*, Feagin, 2010, as the text).
3. Change the DRAC into a more influential body within the organization. The community members' request was taken to the 2013 MN Legislature which created a leadership council to advise the Commissioner of Human Services on disparities reduction directing the newly formed council to hold its first meeting November 2013.

DHS-Community Council Outcomes

Because voices of people located on the margins of society are often silenced, powerless and often not heard (Hooks, 2000), the impact that this small group of diverse individuals made on the largest state agency in the state was compelling.

The MN Legislature created the Cultural and Ethnic Communities Leadership Council (CECLC) during the 2013 session. Minnesota Law, chapter 107, article 2, section 1, required council members to be appointed by the Commissioner, no later than Sept. 15, 2013, and to convene the first meeting by Nov. 15, 2013. In February 2014, and each year, the Council "must submit a report to Chairs and Ranking Minority members of the Health and Human services Committees of the Legislature" (MN State Statute Chapter 107).

Appointments included representation from racial and ethnic minorities, representatives of the American Indian community, advocacy groups, human services program participants, and

members of the faith community. Majority chairs and ranking minority leads of the Health and Human Services Legislative Committees are also members of the council by statute. The Council sunsets June 30, 2020. Efforts are underway to position the Council in perpetuity and expand its model to other state agencies. One Minnesota health plan ratified an equity policy modeled after the policy on equity in place at DHS. The Minnesota Department of Health created its own community council, called HEAL, in 2018.

To date, this Council has achieved significant progress: Recommendations framed in the National Partnership for Action to End Health Disparities (NPA) (2006), an initiative of the Office of Minority Health/Federal Department of Health and Human Services (2006) were ratified. The recommendations aligned with the initial strategic approaches for change that the earlier Disparities Reduction Advisory Committee (DRAC) had advanced to the agency:

- Leadership needs to be more diverse,
- Awareness of the existence of disparities and the harm it causes certain populations, while leaving others unscathed,
- Research and Evaluation, when examining policies, programs, the community members encouraged DHS to review the research for evidence-based practices that had been adapted to cultural communities, and to ascertain what past success had such policy indeed benefitted certain populations, and an encouragement to
- Partner to Learn about historical trauma, the historical experience of peoples in the US who experience the worst disparities, and an understanding of what root causes there are,

- Reform policies that perpetuate disparities: an attempt to influence DHS leaders and legislators to examine policies, procedures, rules to avoid unintended consequences.

The goals of the NPA resulted from a similar long-term engagement of people nationwide discussing disparities, (National Leadership Summit to End Racial and Ethnic Disparities in Health, 2006), its impact on communities, and the urgent need to address it.

In 2018, the Cultural and Ethnic Communities Leadership Council (CECLC) reached its five-year milestone and has met every month since Nov. 15, 2013. As a result of monthly meetings and the work of five subcommittees, the council members recommended five overarching goals to DHS in order to impact disparities reduction, using the goals of the National Partnership for Action to End Health Disparities from the US Department of Health and Human Services' Office of Minority Health (2006) as a framework, and including recommendations they chose for Minnesota Human Services:

1. **Awareness Goal:** DHS increases awareness of the significance of inequities, their impact on the state's cultural populations, and then moves to action to achieve equity.
2. **Leadership Goal:** Strengthen relations among the council and state agency to promote clear and meaningful dialogue about equity in a governmental structure.
3. **Community Health and Health Systems Goal:** Families experience well-being as they enter the health systems DHS manages. They receive collaborative care giving; they trust and are comfortable with their providers. They actively engage in their health care. Providers are trained to deliver services that address complex needs, and culturally-based beliefs and practices are embedded in healing. Diagnosis need not be criteria for care.

4. **Culturally and Linguistically Competent Services Goal:** Rigorous vendor selection meets community needs. Eligibility determination is more transparent. Community-based organizations are regarded as partners and powerful allies supporting the health of their communities. Utilization of community health workers and doulas becomes the norm.
5. **Research and Evaluation Goal:** Change attitudes about data: data must explain the whole person. Develop measurement strategies to best obtain most appropriate data with community-defined cultural and ethnic groups' input. Promote evidence-based research into practice (2014).

The work of this community council has gained attention: The Minnesota Management and Budget (MMB) agency under direction of the Minnesota Governor's Office, developed language from the CECLC's recommendations for the equity note – a template instructing state agencies how to submit their policy and budget proposals in preparation for the 2017 legislative session. The Council members are active in participating on equity efforts in the community.

They joined with other advocacy groups by supporting their efforts, presented in meetings to bring their voices to the space where disparities were discussed, and they joined by signing onto a letter in 2016 written to the United Nations inviting a working group visiting the US to assess the conditions of African Americans in the Decade of Peoples of African Heritage (2015-2025). CECLC members are also sought after for consultation from various areas of the agency on issues of equity, community engagement, grant review, etc.

Recommendations initiated under this framework are now listed on the policy on equity (Appendix P) approved by DHS Commissioner, thus bringing the voices of community members

into the agency to influence a shift in organizational culture in several aspects of the organization:

1. Hiring, retention and promotion;
2. Adopting the Culturally and Linguistically Appropriate Services Standards (CLAS);
3. Establishing a system to engage minority businesses in its contracting;
4. Making legislative and budget decisions utilizing an equity analysis, a process that asks questions about the potential positive or negative impact of policy decisions on the population served.
5. Encouraging the insertion of reflective practice into what can be an automatic set of actions, until later unintended consequences are brought to the legislators' attention for redress.
6. Utilizing community engagement and inclusion practices to support the agency's efforts to invite the "Other" into conversations that are inclusive, resourceful and collaborative. This practice of engaging with populations dependent on social services helps the agency staff and leadership learn how to value their wisdom, knowledge and lived experiences, and what helps these communities to thrive.

Disparities in access and outcomes to publicly funded services when developed in the absence of community voices, the impact can be at times disastrous, though not intentional. The engagement activities showed DHS employees and leaders alternative ways to listen to the communities the agency serves. I learned to listen and learn when I am in the community, it informs my work and helps me to bring their suggestions to the agency's processes: I learned

that I am enriched about my own leadership as I perceive, interpret and arrive at conclusions they posit.

Research Questions

1. How do African American elders experience life in urban nursing facility in Minnesota?
2. What elements of disparities exist in nursing homes as experienced by African American residents?
3. How do nursing home staff/administrator perceive such disparities?

Glossary

The voices of the community inform this work. A set of definitions seeks to bring clarity to the language used in this work. Some of these definitions were from the care facilities' residents and staff and others are from more formal academic resources.

Activities of Daily Living (ADL). The need for support in completing basic daily activities including eating, bathing, dressing, personal hygiene/grooming, toileting, mobility, positioning and transfers (DHS, 2014).

Antebellum: Events belonging to the period prior to the Civil War in the United States. The antebellum South continued to use Blacks as enslaved people, though did not call them slaves, as most Whites did not have any. In 1860, families with enslaved Blacks were about twenty-five percent of the area's Whites. Only three percent Whites owned at least twenty Blacks. Profitable crop was cotton. (Kutler, 2003).

Health: In 1948, the World Health Organization (WHO) defined health with a phrase that is still used today. "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (para. 1).

Health Care: "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (World Health Organization, 2005, para 2).

Health disparity: Defined under U.S. Public Law 106-525, also known as the "Minority Health and Health Disparities Research and Education Act," provided a legal definition of health disparities in 2000 as: "A population is a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population" (Section (d) Subpart 1, 2000).

Health inequalities: Differences in health status or in the distribution of health determinants between different population groups (World Health Organization, 2008).

Inequitable health care: The Commonwealth Fund (2015) defines "health care is inequitable, when there are disparities in access and availability of care (e.g., the number of people who have insurance or who visit a dentist regularly) and health status (e.g., the number of people who are obese or smokers) between various groups based on different factors, like their income level (p. 1)."

Quality of life in nursing home residents: Defined as a set of outcomes self-selected by nursing facilities residents (Kane, 2003).

Social determinants of health: Consists of the context in which people live, the social and economic environment, the physical environment, and a person's individual characteristics and behaviors. Commonly described as the places where people live, work, play, worship and attend schools the determinants of health impact a person's health condition, longevity and quality of life (DeMILTO, and Nakashian, 2016)

Inequities: "Health inequities are a result of systemic, avoidable and unjust social and economic policies and practices that create barriers to opportunity" (World Health Organization, 2008, para. 1).

Structural racism: Structural racism is the normalization of an array of dynamics — historical, cultural, institutional and interpersonal — that routinely advantage White people while producing cumulative and chronic adverse outcomes for People of Color and American Indians. Structural racism is deeply embedded in American society and is a potent factor leading to inequities in all major indicators of success and wellness. Structural racism is perpetuated during the decision-making-process without accounting for the possible benefit for one population more than another, or when cultural knowledge, history, and locally-generated approaches are excluded. When this occurs, programs, and policies can reinforce or compound existing race-based inequities (MDH, 2014).

Disparities: Are differences in health status among distinct segments of the population including differences that occur by gender, race or ethnicity, education or income, disability, or living in various geographic localities (Whitehead, 1991 and Euro/World Health Organization, 1991).

Nursing facilities: is used in place of nursing homes, homes for cultural and ethnic communities denotes a term that is much unlike what US nursing facilities exhibit. Home means a physical, spiritual and psychological place of respite, refuge and loving care.

Quality of life: Going beyond health status alone, quality of life considers the individual's sense of competence, ability to perform activities of daily living, and satisfaction with social interactions, in addition to functioning health (Merck Institute, 2002).

Resilience: The adaptive capacity to bounce back from hardships. Communities and families strengthen resilience factors across multiple contexts. "Factors include: (1) providing supportive adult-child relationships; (2) scaffolding learning so the child builds a sense of self-efficacy and control; (3) helping strengthen adaptive skills and self-regulatory capacities; and (4) using faith and cultural traditions as a foundation for hope and stability" (Website Harvard Center for the Developing Child, 2017).

Social emotional support: Twin Cities based nonprofit Cultural Wellness Center (2015), developed a "People's Theory of Sickness, which states that individualism, loss of culture, and loss of community, makes you sick. In many cases, this is at the core of the problems faced by people in communities." The work of this Center is focused on helping communities "build a body of knowledge and web of relationships that support community engagement, intercultural communication, and personal responsibility" (para. 2). The voices of African American elders residing in nursing homes are absent from their communities where they have traditionally played a role of leadership, counsel, and wisdom. Engaging Older African Americans residing in nursing facilities will help illuminate their perspectives, ways of knowing their own reality and lived experiences.

Conclusion

This chapter sought to explain the current situation of older adult African Americans in the US as well as in the State of Minnesota who reside in nursing facilities. It describes the efforts on disparities reduction in the Minnesota Department of Human Services (DHS). DHS is responsible for regulating and funding services provided to elders residing in nursing facilities. Reducing disparities for African American elders in nursing facilities in Minnesota is of interest to this agency. A glossary was also presented. The next chapter is the review of relevant literature on the state of African American elders residing in nursing facilities.

Chapter II: Relevant Literature Review

The review of the literature sought to explore Older African Americans' experiences and disparities in health care while living in nursing facilities, their perception of these disparities and the indicators salient in their circumstances. It examined the conditions of African American participants residing in nursing facilities, the historical account of Older African Americans' admissions into nursing facilities, their day-to-day living experiences, the quality of care received, and studies that examined their condition in the context of disparities.

Historical Context: Enslavement and Wealth Accumulation

In 1920 over 50% of the US elderly population lived in mental institutions. They numbered over 7 million experiencing abject poverty compared to 200,000 residing in mental health institutions. The Social Security Act of 1935 sought to address their plight of poverty, by providing cash assistance to eligible beneficiaries as determined by states (Vladeck, 1980).

The 1935 Social Security Act was the first cash assistance grants for indigent elderly and amended in 1956 to include vendor payments (Vladeck, 1980). In 1954 an Amendment of the Hill-Burton Act allowed expansion of nursing home constructions by linking to nonprofit and public hospitals, promoting the care of older adults in the United States (Vladeck, 1980). This Act did not include the care of populations of Color nor American Indians, because during that period hospitals were segregated and under Jim Crow Laws in the South, which "separated and excluded Persons of Color from full participation in the civil society" (Smith, 2016, p. 3).

Subsequently, the 1965 Social Security Act Amendment created Medicaid and Medicare, transforming the provision of medical care for United States citizens. In the early days of the

United States, few lived to old age. Aging African Americans freed from enslavement were remanded to low income and stark indigent situations: Racist policies did not provide African American's welfare programs and without children to support them, because they had been sold away, they were deprived of resources (Haber & Gratton, 1993). Poor Houses or Almshouses became the living quarters for people of poverty or indigents without wealth or family support. Public welfare in the 18th and 19th centuries was modeled after the English (Elizabethan) Act for the Relief of the Poor of 1601, which were a local government law, not the federal government (Vladeck, 1980, p. 33). Self-help organizations built private dwellings for White immigrants who were aged, and later for elderly widows including the provision of basic needs.

Enslaved Africans in the United States during the Antebellum period, cared for their health and well-being on plantations by plantation owners who considered keeping the health of their free labor an investment on human Black bodies who were their property and used for profit. In 1860, an estimated four million enslaved persons in the United States were valued at more than two billion dollars (Smith, 2002). Post Reconstruction ended this care with the emancipation of slavery. Blacks were excluded from orphanages, private charitable hospitals, and health and social services organizations. In metropolitan cities, services to Blacks were segregated. Between 1900 and 1920, reforms in medical education restricted opportunities for Blacks to enter the medical profession (Smith, 2002).

The Civil Rights Act of 1964 and Its Impact on Access to Healthcare

The Civil Rights Act of 1964 (Pub. L. 88-352, 78 Stat. 241), enacted July 2, 1964, has been considered by many authors to be a landmark piece of Civil Rights and US Labor Law Legislation in the United States. The Act outlawed discrimination based on race, color, religion,

sex, or national origin by health care providers receiving federal dollars from programs like Medicaid and Medicare. "Since the inception of Medicaid and Medicare in 1966, the status of nursing home segregation in the south, under Jim Crow laws and in the north with residential segregation, never received the same attention as other sectors protected under Title VI of the Civil Rights Act" (Smith, Zhanlian, Fennell, Zinn, and Mor (2007, p. 1449). Attention was reduced as progress attained during the sixties because of the Civil Rights Act, generated backlash which diminished support for anti-discrimination laws, resulting in the delay of the initial plans to certify Medicare funded nursing facilities to desegregate (Smith, Zhanlian, Fennell, Zinn, and Mor, 2007).

Smith (2016) credits the passage of the Civil Rights Movement of 1964 as being the "transformational force" impacting the passage and implementation of Medicare. He states that "Civil Rights Activists in 1966 changed the nation's hospitals from segregated into most integrated institutions" (p. ix). He celebrates the contributions of many in his book *The Power to Heal* written to memorialize the Civil Rights, Medicare, and the struggle to transform America's health care system. His book *Race and Health Care in the United States*, (1999), instructs a more somber note: "Health care is an ethical and moral matter" (p.9). Further, health care serves as: "A mechanism for social control, a public economic good, and ethical and moral touchstone" (p. 9).

Key findings on a study to understand medical care costs for older Americans were as follows:

- "The government pays for 65 percent of the elderly's medical expenses.

- Medical expenses for the elderly more than double between the ages of 70 and 90. The average amount spent on medical care for an American in his or her 90s exceeds \$25,000 annually, a cost based primarily on nursing home costs.
- The poor use more medical goods and services than the rich and a larger portion of their expenses are financed by the government.
- Medical expenses before death can be high but do not appear to be a major driver of increased medical spending in the U.S. Medical spending over the last year of life averages \$59,100, of which 71 percent is covered by Medicare and 10 percent is covered by Medicaid” (National Bureau of Economic Research, 2015).

In 1985, according to the National Nursing Home Survey, at ages 65 and over, the percent of the population in nursing homes was only 5 percent, but for ages 85 and over, the figure was 22 percent in 2015 (Federal Office of Administration for Older Americans, 2016). Estimates are that with the increased population over the age of 85, their health conditions could determine the need to move from home Community-based services to nursing homes (Rivlin and Wiener, 1988).

Recent data on nursing homes demonstrates that only “8% of all the people who were members of racial and ethnic minority populations were 65+ in 2013 compared with 17.8% of non-Hispanic Whites. 9.8% of African-Americans (not Hispanic), 96% of institutionalized Medicare beneficiaries had difficulties with one or more activities of daily living (ADLs), and 83% of them had difficulty with three or more ADLs (ADLs include bathing, dressing, eating, and getting around the house). Instrumental activities of daily living (IADLs) include preparing

meals, shopping, managing money, using the telephone, doing housework, and taking medication. Limitations in activities because of chronic conditions increase with age" (Federal Office of Administration for Older Americans, 2016, p. 16).

Changing Demographics and Disparities

There is a growing population of Older Adults from Communities of Color needing nursing facilities. Recent research finds that "between 1998 and 2008, the number of elderly Hispanic people living in nursing homes increased by 54.9%, the number of elderly Asians living in nursing homes increased by 54.1%, and the number of elderly African-Americans living in nursing homes increased by 10.8%" (Center for Medicare Advocacy, 2016, p 13). During the same ten-year period, the number of White Americans living in nursing homes declined by 10.2%. Their experiences in quality of life and quality of care are not well-known from their personal viewpoint, first-person accounts.

The United Nations General Assembly proclaimed 2015-2024 (2016) as the International Decade for People of African Descent (resolution 68/237), citing the need to strengthen national, regional, and international cooperation in relation to the full enjoyment of economic, social, cultural, civil and political rights by people of African descent, and their full and equal participation in all aspects of society. The theme for the International Decade is "People of African Descent: Recognition, justice and development" as listed on the website promoting the Decade.

In its recent preliminary report to the United Nations and the public, of their visit to the US, the working group of the United Nations High Commissioner for Human Rights

(UNHCHR), the coordinator of the Decade, found that “racial discrimination continues to be systemic and rooted in an economic model that denies opportunities to development to the poorest African Americans” (UNHCHR, 2016, p. 4). Further, the report states: “The impact of social (and economic) determinants such as access to quality and health, housing conditions, lack of education and employment among other barriers serve to impede persons of African Descent the full enjoyment of right to health” (UNHCHR, 2016, p. 4).

Howard et al., (2002) studying cultural and ethnic separation in long-term care in the US, found racial disparities resulting from economic factors, exclusionary practices, or resident choice. Whites predominantly used nursing homes and other long-term care in the past; however, there has been a steady increase of African Americans in long-term care in the past 4 decades. While cultural and ethnic gaps are narrowing, the kind and quality of care received by diverse cultural groups remains ignored (Howard et al., 2002). Engle's, Fox-Hill's, and Graney's, (1998) qualitative study of indigent residents in a nursing home found Black residents reporting untreated pain at a higher proportion than their White counterparts do in the same facility.

There seems to be an urgent need to “tend to the libraries that are ablaze” (Lindsey, 2010, TED Talk) and find which gems of wisdom one can learn to inform the field on culturally appropriate and quality care. In all of publications examined in this literature review, there is an absence of African Americans description of the agency, knowledge, or opportunities to provide input in their care. This is the era of patient-centered care model, where “patients become active participants in their own care and receive services designed to focus on their individual needs and preferences, in addition to advice and counsel from health professionals” (Stanton, 2002, para. 2)

In 1946 the Hospital Survey and Construction Act was passed in Congress, known as the Hill-Burton Act. It funded a national network of hospitals shifting the perception of hospitals from places for the poor to recuperate or die to a critical element of the American Health Care System (Vladeck, 1980). Though it would not be until May 15, 1964, that "President Johnson signed the deletion of the 'separate but equal' funding clause in an extension of the Hill-Burton Act" (Smith, 2016, p. 83).

Disparities in access and outcomes to quality care are present in both at the systems (structural) level and individual level components. An examination of social determinants of health revealed that older African Americans experienced large disparities in health and wealth as compared to White older Americans in a 1964 National Urban League publication "The Older Negro in American Today."

Disparities in Care Persist

In 1985, the United States Department of Health and Human Services (DHHS) released a report, entitled the Heckler Report, named after the Secretary of DHHS, Margaret M. Heckler. The report documented the existence of health disparities among racial and ethnic minorities in the United States and called such disparities "an affront both to our ideals and to the ongoing genius of American medicine" as stated by Secretary Heckler in her letter charging a Task Force to be formed to examine the conditions of disparities she observed on the report she submitted to the US Congress in January 1984 entitled "Health, United States, 1983 to the Congress, an annual report card on the health status of the American people" (cover page). The report included encouraging health improvement indicators of Americans, except for Blacks and other minority Americans. Thus, Secretary Heckler explains, her motivation to establish the Task

Force that produced The Task Force on Black and Minority Health Report also known as the Heckler Report (after then Secretary of Health and Human Services, Margaret M. Heckler), led by Dr. Thomas E. Malone, Deputy Director of the National Institutes of Health who chaired the task force (Heckler Report, 1985). Additionally, Allen, et al, 2002, in the Institute of Medicine report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, explained the U.S healthcare system's under-treatment and poorer treatment of African Americans and found little improvement to the health conditions of Blacks and other minorities.

The annual *National Healthcare Disparities Report* (2016) mandated by Congress, reports access and quality inequities by race and ethnicity. The most recent edition (2016) shows that Blacks, Hispanics, American Indians, and Alaska Natives received worse care than Whites for about 65% of access measures. After years without improvement, access to care has improved in many important areas since 2010. The improvement was attributed to the enactment of the Affordable Care Act, which removed barriers to insurance to populations often marginalized due to income. Quality of care measures improved overall since 2010, though varied across priority areas (patient-centered care, patient safety, healthy living, effective treatment, care coordination and care affordability all improved).

Disparities persisted for all poor and underinsured in all priority areas (Blacks and Hispanics experienced smaller disparities in 20% of the measures, measures were unchanged for all other non-White populations). The report found that poor and low-income households experienced worse care as compared to high-income households and that middle-income households had worse care in 40% of the measures compared to high income households (2016). While the access to care gap for Whites did not show significant improvement, minority

populations at all ages and races benefitted as researched by Ward, Schiller, Freeman, and Clarke (2015).

Future Trends

The year two-thousand fourteen Populations Estimates and Projections (Ortman, Velkoff and Hogan) for aging adults “aged 65 and over in 2050, 77.3 percent are projected to be White alone, down from 86 percent. The percent minority is calculated by subtracting the percent non-Hispanic White alone from 100. For example, 60.9 (the percent non-Hispanic White alone) is subtracted from 100 to calculate that the projected percent minority is 39.1 in 2050. Additionally, 12.3 percent are projected to be Black alone, and 7.1 percent are projected to be Asian alone in 2050, up from 8.8 percent and 3.8 percent, respectively, in 2012. Additionally, 10.8 percent are projected to be Black alone, and 5.2 percent are projected to be Asian alone in 2050, up from 7.2 percent and 2.9 percent, respectively, in 2012,” (p. 12). By 2030, the number of Minnesotans over age 65 will almost double and older adults will compose about one-fifth of this state’s population.

The Twin Cities region has one of the lowest shares of people of color compared to other major metro areas: 22%, ranking 24th of the top 25 metropolitan areas. “Structural Racism is identified and named in the report by the Minnesota Department of Health (MDH) as the determinant impacting levels of Poverty, unemployment, home ownership, residential instability, on-time High School graduation rates, and incarceration rates as some of the disparities experienced by cultural and ethnic Communities in the state of Minnesota” (MDH, 2014, p. 6). This seminal report has supported the advancement of a more critical examination of factors that some call the Minnesota Paradox: A state that is the envy of the rest of the country on wealth,

employment, education, health insurance participation, and college graduation rates" (Website Minnesota Compass, 2015). Yet, a closer examination of the state characteristics reveals the large disparities between Whites and Populations of Color and Indigenous people are some of the worst in the nation, gaining a nickname, by a recent speaker as the "Mississippi of the North" (Jealous, B., NAACP Chair, 2015, conference presentation).

The state of Minnesota offers many encouraging aspects to support higher quality of care and quality of life for its aging population. The Minnesota Department of Human Services publishes a report card on nursing home quality, through its Minnesota Board on Aging, is active in the national stage in progressive quality improvement efforts, with incentives to facilities to help improve care, and is a leader in the Midwest on Aging Care. A concerted effort to make these benefits equitable for all elders who call Minnesota home is the challenge of the next few decades (DHS, 2017).

Disparities for African Americans in Nursing Facilities

Disparities in nursing facilities for African American residents in the US is well documented, although the causes of these disparities remain unknown these disparities may vary and range from admission procedures in nursing facilities where they are at a lower percentage of the population than Whites in day-to-day treatment and care (Shippee, 2014, Belgrave, Wykle, & Choi, 1993).

Racial Inequities Exist

Racial inequities seemingly exist in the utilization of institutional care though Smith, Zhanlian, Fennell, Zinn & Mor (2007) were unable to explain why its connection to racial disparities in quality of care. Their study (2017) found however, that nursing facilities remain

relatively segregated, similar to racial segregation found in urban areas. Smith, Zhanlian, Fennell, Zinn & Mor (2007) also found that segregation results in deficiencies in safety, lack of resources and more vulnerability to closure when inspected by regulators, as nursing facilities heavily used by African Americans and located in urban areas tend to lack the resources to pass inspection.

Some low income African Americans who do not have resources to support their aging relatives rely on the government supports (2007). Older Americans who are dependent on publicly funded assistance, residing in nursing facilities places them at high risk because the nursing facilities tend to be in low income neighborhoods without the capacity to offer the residents quality care. Historically, in the South due to Jim Crow Laws, and in the North the legal practice of redlining barring Blacks from safe and well cared for neighborhoods, have resulted in assisted-living institutions locating in suburban areas while African American who tend to need to live in nursing homes that are in urban areas and not as well-resourced. Smith, Zhanlian, Fennell, Zinn & Mor (2007), Vladeck, (1980), Smith, (2007), and Shippee, (2014) reviewed such circumstances and describe the lives of residents from a distance by examining the location of their institutions, organizational structure, and medical records. While valuable information was gained, these authors do not provide individual elders' perspective on their residential conditions. Few to no studies focused on the lives of older African Americans and their daily activities have been conducted. The voices of African American residents in nursing facilities in a first-person account, which puts meaning and description of their lived day-to-day routine do not exist.

In 2009, journalist Jeff Kelly Lowenstein documented an analysis published in 2015, of racial disparities in Chicago, Illinois and national US nursing facilities. Writing for the Center for Public Integrity, he reviewed Medicare cost reports for skilled nursing facilities and compared them to actual facilities' records. He uncovered widespread discrepancies in reported staffing levels, poorly rated Housing and Urban Development (HUD) buildings mortgaged as nursing facilities, and nursing facilities serving minorities offering less care than those housing white residents (Lowenstein, 2015). These poorly rated HUD facilities lacked the amenities available to higher wealth White elders usually residing in facilities financed differently.

Further studies uncovered disparities in many areas. Bazargan, Yazdanshenas, Han, & Orum (2016) found inappropriate medication use among underserved elderly African Americans, identified a lack of multidisciplinary team approach that could better guide appropriate use of drugs and avoidance of harmful interactions. Karter, Laiteerapong, Chin, Moffet, Parker, Sudore, and Huang (2015) found that African Americans had significantly lower prevalence of incontinence and falls, but higher prevalence of dementia in a study of ethnic differences in geriatric care of diabetic older adults.

Nieman, Marrone, Szanton, Thorpe & Lin (2016) found that racial/ethnic and socioeconomic disparities exist in hearing exams and screening and represent critical areas for research and intervention, even though both Blacks and Whites had received screening, Whites were more likely to have hearing aids. "Groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or

exclusion experience health disparities" (Office of Disease Prevention and Health Promotion, Healthy People 2020 (2018, p. 28).

Thorpe, McCleary, Smolen, Whitfield, Simonsick, and LaVeist, (2014) found presence of racial differences in social resources and environmental conditions revealed that when situated in an integrated low income urban setting, with support efforts in place, these efforts alleviated the disparities in the conditions of African Americans "by focusing on the social context in which people live" (para. 24). Integrated urban settings tend to offer a diverse menu of resources: Social connections, social supports in neighbors who may be considered kinship even if not blood relatives, and the sense of Community valued by African American elders hailing from communal cultural settings. Struly (2011) found evidence based on the 2004 U.S. National Nursing Home Survey, that individuals in nursing facilities with high percentages of Black residents have less personal immunity to flu. Black residents are less likely to have been vaccinated against the disease; they may also be more likely to be exposed to flu because more of their co-residents are also unvaccinated.

Mor, Angelelli, and Teno (2004) examined the prevalence of lower quality of care in nursing facilities where the residents depend on government funding (called Medicaid or Medical Assistance program in Minnesota, which is need-based funding by the federal government) (DHS Website, 1st para., 2018). In these facilities, there were fewer nurses on staff, lower rates of occupancy and more vulnerable to closure due to deficiencies found during inspections. Located in poorer counties, their residents are more likely to be African Americans, than in any other facilities. The authors caution that the audits using a set of standardized

metrics, may force the closure of these facilities, unless regulatory agencies take precautionary measures in mechanisms that improve quality (Mor, Angelelli & Teno, 2004).

The Role of Physicians in Disparities Reduction Efforts

There are cross cultural aspects of the primary care physicians caring for African American elderly patients: Differential access to resources exist by Black and White physicians' clinical training, which may result in differential quality of care for the residents (Bach, 2005). Bach (2005) also points to some White doctors who are board certified have easier access to make referrals to specialty care than those who are not. Similarly, Miller, Papandonatos, Fennell, and Mor (2006) found where high proportions of Black residents exhibit lower rates of quality of life, findings support the notion that differential care is provided in USA county nursing facilities caring for higher proportions of African-American residents and thereby suggest intervention at the organizational level is warranted to improve quality indicators for both racial groups. Belgrave, Wykle, & Choi (1993), examined how Older African-Americans are admitted to nursing facilities at between half and three-quarters of the rate of Older Whites. The authors were unable to explain why this situation exists.

Li, Yin, Cai, Temkin-Greener & Mukamel (2011) studied the prevalence of pressure ulcers in nursing facilities, and found that Black residents had a higher incidence than White residents. The researchers also found a correlation between the existence of disparities and location of nursing facilities with Black residents in high concentration; that pressure ulcers incidence was high for this population. Li, Yin, Cai, Temkin-Greener & Mukamel's (2011) study on quality improvement initiatives in nursing facilities aimed to improve quality in using "market-based incentives" cautioned that such incentives could instead exacerbate disparities as

an unintended consequence. These authors explained that disparities in quality of care “appear to be related to racial and socioeconomic segregation of long-term care facilities as opposed to within-provider discrimination” (p. 505). Konetzka and Werner (2009) also cautioned about the need to incorporate the intentional goal of lessening the probability of increased disparities, rather than relying solely on quality improvement initiatives that are informed by market-based incentives without attention to un-intended consequences, as the incentives may exacerbate disparities when they are focused on organizational facilities changes alone.

Bach (2005) examined several studies that established that minority patients receive poorer quality health care than non-minorities. Bach (2005) suggested that two elements for such disparities may have two causes: First, doctor’s unconscious bias, prejudice or cultural insensitivity. Furthermore, Bach (2005) explored an alternative scheme for racial and ethnic disparities in health care: “Inequities in the structure of the health care system which influences where treatment centers are located” (p. S2-32). However, he suggests that further studies should prioritize examining the contributing factors of both schemes (health care system and doctor’s interpersonal and cross-cultural skills with their nonwhite patients) to cultural and ethnic disparities, attributed to unconscious bias, prejudice, etc.

Promising Practices

King, Green, Tan-McGrory, Donahue, Kimbrough-Sugick & Betancourt (2008), wrote the proceedings of a 2006 Strategy Forum gathered at Harvard Disparities Solutions Center to identify and more efficiently solve racial and ethnic disparities in health care, recommended that health care organizations should:

1. "Collect race and ethnicity data on patients or enrollees in a routine and standardized fashion;
2. Implement tools to track and monitor for disparities in care;
3. Develop quality improvement strategies to address disparities;
4. Secure support of leadership;
5. Use incentives to address disparities; and
6. Create a message and communication strategy for these efforts."

The authors also noted the need to view the Recommendations in the "context of efforts to eliminate disparities and the barriers to progress" (p. 271). There is evidence of many studies finding differential quality of care and quality of outcomes experienced by non-Whites when compared to their White counterparts. There is also a preponderance of evidence in the number of primary care providers, as well as other caregivers helping a diverse pool of patients.

The Heckler Report (1985), the Institute of Medicine Unequal Treatment (2002), as well as Healthy People 2020 (2008), all recommend measures to improve the numbers of diverse workforce who can more culturally and linguistically address the needs of the growing populations of Immigrants, refugees and populations of color who are experiencing inequities due to a complex web of factors, one of which identified as "structural racism" (MDH, 2014).

Minnesota Aging Services History and Background

The Minnesota Department of Human Services' Aging Services division contracted with a University of Minnesota researcher Dr. Tetyana Shippee, Ph.D., to investigate the conditions of

nursing facilities to discover needed quality improvement efforts. While not conclusive to form broad generalizations, the findings pointed to some evidence of disparities in quality of life on several quality-of-life measures. I reviewed the report with the agency staff and the contracted researcher.

I was particularly interested in residents of African descent, because in Minnesota, the populations experiencing large disparities in several programs funded by the Minnesota Department of Human Services (DHS), are African Americans and American Indians. African Americans and American Indians are highly represented, though they are not a significant percent of the state's total population. The quality of care was assessed by a review of clinical indicators reported by nursing facilities staff. The quality of life was assessed by asking directly nursing facilities residents to provide their opinion on their social, psychological, environmental, and functional aspects of their lives (Shippee, Henning-Smith, Kane, & Lewis, 2015). This research correlates to the residents' functional abilities and the degree of engaging environment residents enjoy.

The review of the literature finds African Americans living in a democratic country, residing in institutions in various states, where they are dependent on services that are delivered differently because the residents are members of a different culture and ethnicity than most of the population around them. The data demonstrates a group of elderly people devoid of power, dignity and freedom. Their voices silenced from the decisions that are made about their day-to-day living in their final place of residence.

The following graph depicts the historical illustration of the experiences of African Americans in the United States. From their arrival in the United States as enslaved persons to current period. (Figure 1)

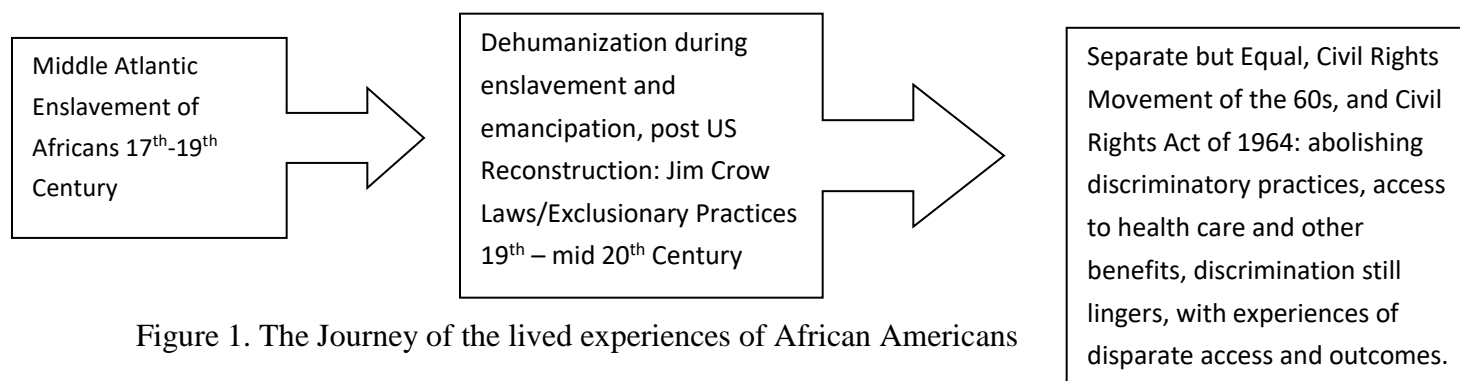


Figure 1. The Journey of the lived experiences of African Americans

Theoretical Frameworks

I examined the following theories to better understand how the lived experiences of African American elders residing in a nursing facility can illuminate issues of disparities. Disparities places these individuals in a subaltern position. What emancipatory escapes might these theories illuminate?

Critical Pedagogy

This study used Critical Pedagogy as a theoretical framework. "Critical pedagogy is concerned with human suffering as a constructed phenomenon that does not need to exist" (Kincheloe, 2008, p. 12). Paulo Freire, a Brazilian sociologist/educator, who influenced the field of study of Critical Pedagogy wrote about a "culture of silence" in his seminal work *Pedagogy of the Oppressed* (1998) as an element that needs to be dismantled to illuminate the transformative power of dialogic interaction. When marginalized persons who could not read nor write, thus

excluded from the world around them, entered his literacy programs in impoverished communities in Brazil and in other countries, they experienced conscientização: The ability to look critically at their world, examine their social reality and to powerfully deal with it.

Critical Pedagogy was not part of my educational experience in Brazil because Paulo Freire was banned by the military dictatorship into exile. When I moved to the United States and had the opportunity to pursue an advanced field of study, Critical Pedagogy attracted me to the University of St. Thomas in pursuit of a doctorate degree. My lived experience in an oppressive regime that tortured, kidnapped and killed people who were opposed to the imposing military order, is one I recollect as filled with fear and terror.

Paulo Freire was exiled because he interrogated the status quo then practiced. Brazil was governed by a military government with five-year long strategic plans, mandated by the military generals who surrounded themselves with technocrats. As a young university student in Brazil, I observed how these foreign-educated elites adopted a neoliberal agenda that promised to bring Brazil into the 21st century: they created, invented and re-invented the future of a national generation without democratic participation. I had college friends who when they expressed opposition or criticized the military government were forced into exile, or into jail with torture and disappearances. I recall students returning to class, transformed and silent.

Freire describes the situation in Brazil, as an alienated society, “incapable of autonomous projects, seeking to transplant from other cultures solutions to their problems” (Freire, 1997, p. 13). He further states that when societies find themselves in this situation of hopelessness, utilizing “borrowed solutions that are not generated by critical analysis of the context, nor are the solutions adequately adapted to the context, they prove inoperative and unfruitful” (p. 13). New

developments begin to occur that awaken societies to the “first attempts of self-awareness, where upon anew cultural climate begins to form” (p. 13). The situation shifts from one of fatalistic mandate to one of “nascent hope which coincides with an increasingly critical perception of the concrete conditions of reality” (p. 13).

It is during this phase that Freire observed the Brazilian society unfolding as a banner offering distinct aspects: “economic, social, political and cultural,” (p. 13) with citizens moving out of a “closed” (p. 13) submerged status in one reality to one in which “as the society breaks open, citizens emerge” (13) to become actors in their own destinies. Authoritarian regimes in Brazil sought to remedy to situation by ascribing paternalistic measures to offer assurances to the masses that the population was not yet ready for democracy. The word “subversive” (p. 14) became synonymous with anti-democratic and a danger to the country. The government and powerful elites made decisions for the people, powerful elites were in assistencialism mode, or massification (p. 16). Citizens next entered a period of “naïve transitivity” (p. 19), i.e., a “development of awakening to critical awareness” (p. 19) before attaining the ability to “discern, to perceive and respond to suggestions and questions in their context” (p. 19). This ability to practice “critical transitivity requires an active, dialogical, educational program concerned with social and political responsibility, prepared to avoid the danger of massification” (p. 19). When transition is successful, “critical transitivity consciousness is characteristic of a legitimately democratic mentality” (p. 20). Freire highlights the following as important elements in the individuals’ journey to humanization:

- The importance of dialogue: with and not for the individual
- The importance of individuals’ ability to locate self in the sociohistorical context

- The ability of the individual to critically examine the world
- Praxis: important to reflect and move to action to act upon the world to transform it (Freire, 1998).

It is through reflective praxis and intentional examination that the individual becomes aware of their oppression and strategizes ways to liberation and empowerment. Literacy for the Brazilian students in Freire's classrooms, engaged in a process of learning which was "inseparable from individual empowerment and social change" (Kincheloe, 2008, p. 71). In an environment of radical love, the individual can find their vocation, their humanity and thus becomes self-assured, dignified and resilient in the face of challenges. For Freire, "love is the basis of an education that seeks justice, equality, and genius" (p. 3). In *Critical Pedagogy*, theory and lived experiences cause a combined effect that makes visible both formal knowledge and movements for change (Kincheloe, 2008). Critical pedagogy's core concept of facilitating students' (or people who are oppressed) access to their own history, experiences, and culture of their own everyday environment is a path to liberation that enables them to examine their situation and make meaning of it.

When community representatives of those experiencing inequities in outcomes and inequities in access to human services, gained increased knowledge of the human services systems in the state agency, they were moved to action by creating a set of recommendations that seeks to enhance their personal lives and the lives of others in their communities. The yearlong process of developing their "critical consciousness" about root causes of disparities and inequities, motivated these individuals to enact recommendations to alleviate the suffering of

members of their communities who they knew so intimately because that suffering had visited upon their own lived experiences.

Systems Theory

In a paper published by the Kirwan Institute for Race and Poverty, authored by Menendian & Watt (2008), systems theory is explained as follows:

Systems theory is a paradigm with a different philosophical lineage and a distinct set of assumptions about knowing. The contrast is sometimes drawn between Newtonian science and Quantum physics, with the latter having parallel assumptions about the impact of the observer, the dynamic, evolving nature of reality, interconnectedness, and the appropriate unit of analysis being relationships rather than parts (p. 1).

Systems theory is used as an organizing framework in the field of social services, used by clinical social workers (Fook, Ryan, & Hawkins, 1997), as well as non-clinicians. The term systems originated by Durkheim, who was concerned with “social problems endemic to industrial societies” (Kivisto, p. 97). Systems Theory as used in social work, originated with Austrian biologist Ludwig von Bertalanffy who found “linear, cause and effect theories to explain growth and change in living organisms,” (Friedman & Allen, 2014, p. 4) to be inadequate. His approach provided a counternarrative of theories of his time: existing theories tended to break things into parts to understand the whole.

Von Bertalanffy proposed that growth and change might occur because of the interactions and relationships with other systems. Von Bertalanffy's work generated a new language used to this day, “popularizing terms such as open and closed systems, entropy, boundary, homeostasis,

inputs, outputs, and feedback” (Friedman & Allen, 2014, p. 4). “There are two conditions on which the properties of systems depend on to explain growth and change in an organism: 1. That an interaction occurs between parts; and 2. That the condition describing the relationship between the parts is linear” (p. 4). His theory has expanded to help professionals in diverse disciplines organize their information.

Durkheim believed that societal norms are maintained by agreement of individuals in the society. He believed the police to be a stabilizing form to maintain equilibrium (“organic solidarity”) in society (Kivisto, 2004, p. 96, Friedman & Allen, 2014, p. 6). Max Weber, a contemporary of Durkheim, studied social institutions and organizations. He believed that societal norms are “maintained by coercion and legitimate use of violence or force” (Friedman & Allen, 2014, p. 6). American philosopher, economist and sociologist Talcott Parsons expanded upon Durkheim and Weber’s work by proposing his “conceptual framework called Structural Functionalism. Structural functionalism, he stated that social structures involve interaction and relationships among “actors” and are characterized by a functional imperative” (p. 6). They are according to the author:

1. Adaptation (to the external environment), an active process which a system responds to the requirements and burdens of “external forces and conditions, when mutual interactions between the system and its environment occur, resulting in both system and environment being changed in the process” (p. 6)

2. Goal attainment or growth, “when a system is mobilized to obtain necessary resources directed at achieving goals,” (p. 6) it is fulfilling its function.

3. Integration (with other social systems), “integration describes the coordination and orchestration of the system’s internal components,” (p. 6) and

4. “Latency (homeostasis) or pattern maintenance- preservation of interactional patterns, norms and customs through socialization processes. Latency describes a system state in which the system is invested in maintaining and transmitting its norms and values” (p. 6). Knowledge of Systems theory helps understand how elderly African Americans experience their lives in nursing facility, how they adapted, integrated into and are maintaining their lives in the system environment, the nursing facility.

Targeted universalism theory combined with systems theory provides tools for a critical examination of who may be impacted by the policy, practice or regulation: so, for the Minnesota Department of Health seeking to alleviate the impact of diseases caused by Radon exposure on populations, by sending notices more broadly, a wider segment of potentially impacted population would become informed and ready to take precautionary measures. Leaders are encouraged to use critical thinking and equity lenses and examine: who is this policy benefitting? Who may be harmed by it? How can benefits be enhanced and harm reduced or eliminated? How can one solve this quandary without leaving others behind? (King County Equity Impact Review Tool, Seattle, 2016).

Critical Social Theory

Critical social theory emerged post World War I when social scientists were alarmed at the socio-economic upheaval post World War I in Germany, Frankfurt School, and Central Europe, and the failing of capitalism to fulfill promised expectations of wealth and well-being. These social scientists were concerned with the regulation of the social order imposed human

suffering. Theodor Adorno, Max Horkheimer, Herbert Marcuse, and Jurgen Habermas doubted the Marxist class theory of the power of the proletariat to bring about transformation, making valuable critical examination of the role of capitalism and "industrial society" (Kivisto, 2004). It is a type of theory that aims to critique society, social structures, and systems of power, and in doing so, to foster emancipatory social change. It encourages marginalized or those excluded populations from full participation in civil society to claim their freedom and access on their own right.

Jurgen Habermas, born into a middle-class family in 1929, grew up under Nazi rule and became "a member of the skeptical generation" or one of the young Germans who did not fully believe the change in the country post-the Nazi party era. Habermas criticized his fellow citizens for not more forcefully denouncing atrocities of the Holocaust Ryan, (2003, p. 43) in Kivisto, (2004, p. 83). Habermas denounced Germany's failure to a commitment to "equality, freedom, justice and democracy," though he saw "society's potential to achieve them" (Kivisto, 2004, p. 75). Habermas' writing on democracy described the practice of "communicative action," that is, consensus based and shared decision-making where community citizens practice and nurture democracy (p. 77). Communicative Action is grounded on the theory of language that can serve the purpose of building a society concerned with social equality and human freedom (Kivisto, 2004, p. 74).

Habermas (Kivisto, 2004) believed that politics and culture must be independent from the influence of economics, rejecting Marx's theory that economics should be the base of all factors in society. He wrote about his vision of how citizens make decisions outside the confines of state and market, in the public sphere: citizens participate in reasoned debates about the public good"

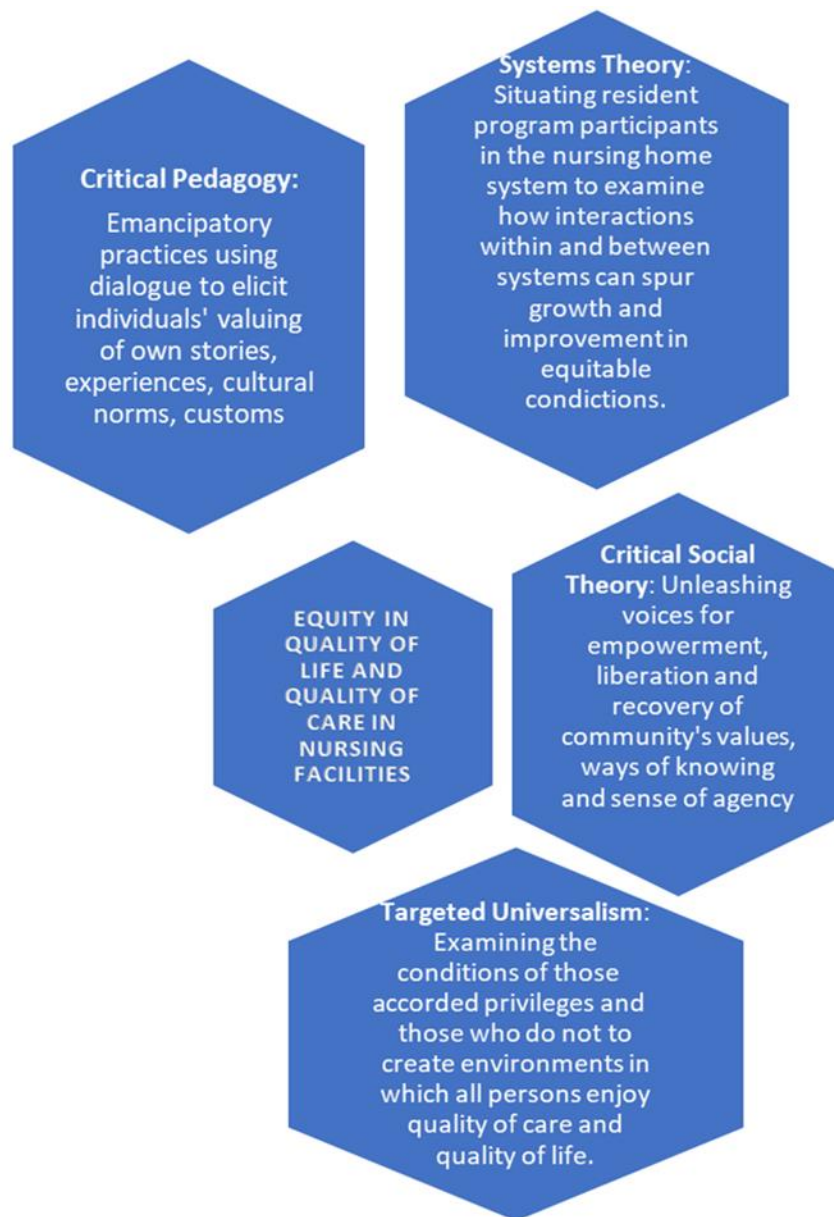
(p.77). Deeply influenced by Marx (capitalist theory) and Parsons (social democracy, race/ethnicity and citizenship) Habermas (Kivisto, 2004), a member of the second generation of social theorists continues to opine on current events, such as sovereign debt and market pressures. His writings inspire this researcher as she builds space monthly for CECLC members to impact change into a state agency, and influence policy change for the benefit of communities impacted by inequities.

The rise of fascism in Europe forced critical social theorists from the Frankfurt to leave for the US, including Walter Benjamin, Theodor Adorno, Erich Fromm, Max Horkheimer, and Herbert Marcuse. In the US, these theorists confronted the reality of the "American Dream", which did not meet their expectations. "The world was moving fast post war: Wars of liberation in Africa, Asia, and Latin America, movements of the 1960s in the US provided fertile ground for these social scientists to interrogate the status quo and develop a theory that questions issues of power and justice, ways in which economic status, race, class and gender, diverse ways of thinking, of knowing and of being in the world interacted to form a new 'social system.' Social theory is always shifting influenced by new scholarly insights and problems and social circumstances" (Kincheloe, 2008, p. 49). Critical Theory informs Critical Pedagogy in its critique of the status quo, encouraging researchers and scientists to deviate from rationality into a broad view of the individual in a democratic space where there is equity, freedom and justice.

The review of these theories helps me understand the power differential that elders in a nursing facility navigate, as they wait patiently for the signal to be answered by a nurse on the floor, they learned to keep to themselves instead of interrogating when something does not go their way in the facility. Structural racism manifests as "structural mechanisms do not require

the actions or intent of individual” (Bonilla-Silva, 1997). Inequities operate in systems where structural racism remains unabated, because it is persistent. (Jones, 2000).

Theoretical Frameworks are illustrated in Figure 2 below:



Chapter 3: Methodology

Research methodologies refer to the choice a researcher makes to test a hypothesis or assumptions about a body of study. In this case, to learn what a group of people think, how they feel and make sense of their lived circumstances, using a deductive approach, i.e., testing theories or hypotheses, would not generate the kind of data to impact change in practice. Use of an inductive approach, i.e., practices, common beliefs, and shared customs of a group of people contributes to the emergence of new theories or generalizations (Thomas, 2003).

Evidence Based Practice (EBP) is discussed and viewed widely in the field of social services, popularly known as the “cookie-cutter” approach. The resulting decades-long nationwide challenges in attaining good outcomes for diverse populations has resulted in disparities in many programs. Though programs are replicated with high levels of validity and reliability, there is a significant lack of understanding of the lived experiences of the populations who have a history of trauma, generational poverty under punitive policymaking that does not attempt to infuse a level of empathy or humanity to better support populations’ preferences and wishes (American Psychological Association, 2009, Hulme, 2010).

Qualitative Research

Qualitative methods seek to introduce a different way of studying a phenomenon with the purpose of bringing the problem into “critical considerations of democracy, race, gender, class, nation-states, globalization, freedom and community” (Denzin & Lincoln, 2013). On this journey a qualitative researcher chooses, there is a need to abandon the ‘scientific,’ linear, logical, and positivist worldview and embrace one that is rich in empirical materials, is responsive to the voice of the community being engaged with, of entering a researcher/research

participant relationship that is collaborative, inclusive and resourceful. As the researcher, I am learning with the community who welcomed the co-study, co-discovery, co-teaching and co-learning experience. The world of the African-American (US born) Older Adults residing in a nursing facility becomes visible using qualitative methods in a significantly different manner than any previously studied situation using quantitative methods have demonstrated.

Qualitative health research for awareness raising

Qualitative health research happens in the context of health care delivery environments and it is distinct from other forms of qualitative inquiry. Qualitative health research focuses on the experiences of illness, on patients' health status and behaviors, on the healthy and the sick. It includes the interactions with the sick person. It encompasses the education of health care professionals, and health care information provided to patients and their families (Morse, 2013). With foundational origins primarily in sociology, using ethnographic studies, qualitative health research found its support in studies conducted by studying socialization of medical students, *Boys in White*, (Becker, Geer, Hughes, & Strauss, 1961), mental patients and inmates, *Asylums*, (Goffman, 1961), *Awareness of Dying*, (Glaser, B., and Strauss. A., 1965), and *Aging* (Kane & West, 2005, Shippee, 2015).

The work *Patients and Healers in the Context of Culture* (Kleinman, 1980), provides instructive guidance to professionals who seek to understand how populations from cultural and ethnic communities understand and explain what ails them as they interact with Western medical professionals. The author instructs professionals to enter the world of their patients from other cultures where illness is explained from the patients' point of view. Explanatory model developed by Kleinman (1980) is a helpful tool in the field of social services in understanding

patient-physician relationship to improve culturally and linguistically appropriate care by creating a therapeutic alliance and valuing the patients' lived experiences (Kleinman, 1980). The explanatory model can be a critical adjunct tool to analyze qualitative data.

This study sought to illuminate the value of voices of individuals seldom heard and listened to as agents of their own self-determination. The use of qualitative research called attention to the importance of inclusion and social justice to achieve equity for all patients and program participants in the field of health and human services. Groups of individuals were invited to participate in focus groups and interviews.

Choice of phenomenology research for this study

Phenomenological Research is a qualitative approach that describes the meaning people assign to their lived experiences (Creswell, 2003, Smith, Flowers and Larkin, 2009, Ardington et al, 2009). Qualitative research participants in a phenomenological study share common experiences, such as they all live in the nursing facility, they share a human experience I sought to draw a composite description of what is at the core of their lived experiences. I sought to learn the perspectives of residents in nursing facilities experience and their experience of living in the facilities. There are four philosophical perspectives in phenomenology:

1. It is a search for wisdom;
2. It suspends all judgments;
3. The reality of an individual is related to one's awareness of it; and
4. The experience of an individual is the individual's reality.

These four perspectives are tools I used to support this study: From an understanding that elders in the African American community enjoy respect, deference and favor, they are wise, have more experience, and are sought after in their communities when the young need supportive advice. As a researcher, this approach instructs the suspension of judgment from the voices of African American interviewees. The interviews were transcribed from recording word for word for analysis. Elders living in nursing facilities know their experiences, their day-to-day living experiences, the routines, the predictable events, the way staff interacts with them, etc. Their voices illuminate their perceptions of their presence as people of African descent in the facilities where they are not the majority cultural group, their interactions with staff, the care they receive, etc., each resident in the nursing facility has their own lived experiences. One's lived experience is theirs alone and I learned from their description the meaning they assign to their reality.

Phenomenology data analysis builds from the responses to the research questions; a review of all the transcripts to identify significant statements that provide an understanding of the resident participants' experiences lived in these institutions. Clusters of meanings were organized from these statements to describe the residents' meaning of their lived experiences in nursing facilities: What they experience, and how they experience them. Common themes emerged from similarly described lived experiences showing an underlying common thread. The choice of staff from Populations of Color aimed at situating them in a common circumstance – of being a minority person, yet from a position of relative power in relation to the residents who depend on their care. This process enabled an examination of what life is like in a nursing facility for African American elders where they are minority in the population.

Data Collection Methods

Qualitative research uses varied “methods that are interactive and humanistic” (Creswell, 2003, p. 181). I conducted the resident participant interviews face-to-face at the site where the phenomenon occurred. Research participants were actors in the study of their experiences. I sought to “build rapport and credibility” with the individuals in the study, by spending introductory time and observing that the residents were comfortable, understood the consent forms and were ready for me to begin asking questions. Questions were prepared ahead of time: they were open-ended and allowed for the resident participants ample time to reflect and decide on their responses. Data collection consisted of text (words) data and images (or pictures) data. The recorded voices of the resident participants were used upon their informed consent. “Qualitative research provides a broad, holistic view of a social condition, rather than a limited, narrow analysis” (Creswell, 2003, p. 182).

There have been other studies of nursing facilities residents both in Minnesota and nationally pointing to potential disparities in quality of life and quality of care; I was an outsider to the lived experiences of nursing home residents and conducted the interviews by bracketing out of the individual experiences of the residents and staff. As an immigrant of African descent, I sought guidance from US born African Americans to validate perceptions as culturally congruent. Data was collected using in-depth interviews using structured and semi-structured questions. The participants were elderly, some frail, who tired easily, or who were unable to hold their energy level and attention to prolonged interaction. I interviewed ten residents.

There was a review of other items that I examined to have a better understanding of the residents: The data on the nursing facility history, reputation in the community by discussing the

facility with others in the health care community, current or former staff at nursing facilities, general inquiry in informal conversations, etc. Opinions varied: from an understanding by DHS staff who regulates such facilities, commenting that this is one of the better managed facilities. A former frontline staff had a difficult experience at this facility and was not at positive, she did not think that she was treated fairly, that she was asked to perform tasks outside her responsibilities, that management was not sensitive, etc. (personal conversation, October 2017). I sent a copy of the IRB letter to the nursing facility requesting approval to interview ten residents, two direct service staff and one administrator. A copy of the letter is found in Appendix N.

Participant observations

Participant observations are field notes that I took based on my perception of the behavior and attitudes of individuals in the nursing facility. The observations involved the nursing facility's residents, staff and facility administrator, but also included other facility staff during initial meetings with the site administrator or another staff and me. I developed topics of interest such as how I was welcomed into the facility; the way the site administrator welcomed or not the proposed study; the site administrator's openness to learning about the opinion of their residents and Staff of Color. I also observed the interaction between staff, administrator and residents. I asked if I could attend events hosted by the facility to gain additional observation opportunities. It was an opportunity to continue the observation in a manner that is not in a controlled setting, such as during the face to face interviews. These observations would include, had I had more time: Residents and staff interaction, family, or community members' and volunteers' socialization moments with residents.

I studied the chosen sites prior to the first meeting to discuss the study. The history of the facility, location, initial admissions of Residents of Color, equity practices, and quality assessments as published in Minnesota nursing home report cards. This provided context to prepare for successful rapport and engagement with the leadership of the site. The information sought was found on the facility website, from community members who had direct knowledge about the facility, general news in print and online media were also resources.

Data recording procedures were as follows: I developed a protocol to record all data, through the development of a form, where certain information is always entered prior to contact to generate consistent data for analysis. Key information such as a given name (pseudonym), age, gender, length of residency, observed health status, etc. was on the form.

Facilities

Two nursing facilities were designated to host this study, with five residents approached in each. The Minnesota Department of Human Services (DHS) provided me with a list of seven facilities in the Twin Cities area. Not one of the seven facilities would permit my entry in their institutions for this study. A professional colleague facilitated access to a large nursing facility not included in the list, because DHS had provided recommendations to a University of Minnesota researcher to conduct her federal research there. My study was negatively impacted as it could not be started until the end of the other study by the University of Minnesota in partnership with DHS and the facility for quality improvement purposes. The facilities housed African American elders who were a significant population in the building (15 to 20%).

During the study of this nursing facility, I reviewed a video tape on a website featuring a YouTube interview of one of the facility's administrators, an African American, who facilitated

my study to take place in this facility. In the video tape promoting the services offered at the nursing facility, the administrator told her employment story when starting at an entry level position, being able to have their education funded and now occupying a leadership position. A review of photographs of members in leadership in the nursing facility showed that this administrator is the only non-White leader, but not featured in the leadership roster on the organization's website.

I spent one year working with the nursing facility administrator to obtain entry. I attended staff meetings with social workers for the purpose of introduction, distribution of business cards, answered questions about the study, and established rapport before the study began. There were exchanges of several e-mail messages seeking clarification, inquiry on start date for the interviews, providing signatures of required documents both by the facility and the University of St. Thomas. The Institutional Review Board (IRB) issued a letter of approval for study to be initiated July 14, 2017, found in Appendix M.

Data Collection

The large nursing facility in the Twin Cities of Minnesota, which is the site for data collection has a rich historical existence with the Twin Cities. A Lutheran pastor founded the facility in 1896 to help young women who needed room and board in the Minneapolis area. Its first mission cottage was established November 22, 1896, in Minneapolis. As a philanthropic organization, the care facility depends on donations to support its operation. Over the past century the organization expanded its services and communities. Currently, Augustana Health Center offers housing, health care, and community-based services and is in three states, Minnesota, Colorado and Wyoming.

I started interviews of residents November 20, 2017, and one additional day was scheduled for November 22 of that week. I interviewed three residents on day one, the residents were wheeled into a conference room and spent one hour answering questions after the consent was reviewed and signed. Each resident received a copy of the consent. I ran late for the November 22 interviews due to a car service appointment, staff cancelled all interviews for that week. I spent the holiday vacation days transcribing the interviews.

The Director of Social Work who scheduled the interviews left the facility on December 1, 2017. Therefore, I contacted other administrators seeking additional dates to continue the interviews. The University of Minnesota was also conducting a study with nursing home residents from cultural and ethnic communities in partnership with the Minnesota Department of Human Services in their interest to improve quality of care. This caused my access to the facility to be further delayed until December 14 and 15, 2017 to complete the interviews.

African American elders residing in nursing home as their last residence

The selection of African American residents sought to learn from these residents their lived experiences and day-to-day routine in a nursing facility resident, where they were minority cultural group, but did have other residents with whom they shared their culture. Ten residents at a metropolitan facility were chosen by the facility administrator based on the following criteria I developed:

- Identify themselves as African Americans
- Between 75 and 85 years old
- Able to hold attention in a conversation for 30 minutes or more.

Names (pseudonyms)	Approximate Age	State of Birth	Story
1. Ms. Heart	40s	Oklahoma	Difficult childhood, included molestation, foster families, at facility due to disability – age outside criteria.
2. Ms. Smalls	80s	Oklahoma	Grew up during segregation, did not board an integrated bus until she was 21. Caring family and community, church family, bound for college, but had to take care of aging family member. Loves to read, watch certain TV shows, keeps informed.
3. Ms. Sparks	90s	Alabama	Well-informed on current events, and memory of segregation in the South, political leaders, active in her church youth, college educated, son who visits often.
4. Mr. Davids	80s	Kansas	Moved North to Chicago and later MN, first black police officer, professionally and socially active, college educated, active in faith community. Likes MN progressive history since the 60s.
5. Mr. Harold	80s	Minnesota	Grew up in both North and South of Twin Cities, summers at camp, faith as strength, family and community social supports.
6. Mrs. Howartz	80S	New York	Community life was difficult while growing up. First teacher in an all-White elementary school. Attended college. Family support was critical in times of difficulties.
7. Mrs. White	60S	TN	Bed ridden, difficult speech made it difficult to transcribe interview, hard childhood, mother who whooped her daily, talked back, has daughter but does not enjoy good relationship with her.
8. Mr. Daniels	80s	AL	Enjoys living in this nursing facility. Compares to conditions in the South and thinks he is blessed. Misses his mother, a gardener, who was always active. Had friends and siblings, community support.

9. Mrs. Tulip	80s	OK	Completed college, the first in her family, raised her children in Minnesota where she met her husband who had also migrated North.
10. Mr. Mills	30s	WI	Bed ridden due to stroke, unable to answer most questions. Outside criteria for interview.
11. Mrs. Agnes	80s	Central America	Outside criteria for interview.

Figure 3. Resident Participants Interviewed.

Two nursing facility direct service staff who self-identify as African Americans.

The following criteria was developed to recruit the two direct service staff who were African- Americans:

- The facility employed staff for at least one year. Longevity of staff in nursing facilities is an indicator of quality measure, the long-term employees provide stability to elderly residents who need consistent caregiving.
- Provided direct care to the residents: feeding, cleaning, and providing other care
- Culture and ethnicity: Both employees identified themselves as African American
- Interested in participating in the study

Nursing facility administrator criteria for interviewing

One long-term administrator familiar with the history of the facility, its organizational culture, willingness to discuss early professional life experiences, decision to work in the field of caregiving of elderly people.

Name (Pseudonym)	Years employed in nursing facility	Comments
Direct Service Staff 1& 2	Over 10 years each	Both enjoy their work. They speak of the resident participants with respect and deference. Had some suggestions for improvement: Monday night sports on TV and better ways to communicate.
Administrator	Over 30 years	Working for facility was a career choice. Worries about increased regulatory requirements, impact amenities for residents. Is concerned about care for residents' safety and well-being.

Figure 4. Employees at nursing facility who were interviewed for this study

Interviews

Some of the residents were eager to engage with me. Staff thanked me for “spending time with our elders” (personal communication with facility staff) one day as this researcher was departing. This time, the interviews occurred within the residents’ private spaces. The change in environment provided a new set of information into the lives of the residents. There were pictures on the walls, in the room, a sign requested the nursing facility staff to not launder the resident’s clothes as her daughter would pick up her laundry each week. This resident had many pictures on her bedroom walls and told me stories about her family referencing many of the pictures. The resident was well coiffed in a pretty dress and pearls. Her nails were done. In other rooms, there was contrast in the environment, from bare walls to a few pictures, some cards on their dressers, seemingly specially made blankets on their beds, or inspirational readings such as “Family is the Essence that Identifies our Very Identity” on the border of a family picture.

Interaction with each resident participants and staff began by thanking them for agreeing to spend time answering the study questions. Introductions were made and an explanation of the researcher having an accent as an immigrant from Brazil. An explanation of the topic of the study, name of the school attended, and degree that I sought, followed by words of gratitude. I shared with each nursing facility resident that the goal of the study, contents of the consent form and after asking if they understood, requested that they sign. The residents kept one copy of the consent form. Questions used during the interview are found in Appendix S.

Not every question was discussed during each meeting. Some questions were answered during conversation, when the resident provided a full explanation of their story, which included the facts they thought important and there was no interruption. In my employment as a community relations director, my community engagement experience with cultural communities has taught me not to interrupt a storyteller, especially if an elderly person, because it is considered disrespectful across many cultures. It was hoped that any remaining time would be used to review, and re-visit questions not yet asked, gain clarification, etc., however, due to the delay in the start the interviews, this was not possible. Summary of their answers are found in Figure 4.

Direct service staff interview

I followed similar protocol I used with the resident participants, by thanking employees for their gift of time and wisdom to be interviewed. I also mentioned meeting with the ten residents for interviews. After explaining the consent, form and asking if there were any questions, the interview started. Questions are found in Appendix T. The staff were thanked for

their time responding to the research questions and for their time. Summary responses in Figure 4.

Nursing facility administrator interview

I followed the same protocol used with the previous interviewees. I alluded back to the African proverb and told the administrator how the expectations of meeting resident participants who were wise and rich with experiences, were affirmed: The elders were indeed living libraries. Questions for the facility administrator are found in Appendix U. This researcher thanked the administrator for participating in this research project and ended the interview. Interview summary in Figure 4.

Methods and instruments to collect the data

In-depth interviews, are useful to capture the resident participants' first-person views, background information and an opportunity for me to learn about them (Creswell, 2003), I had to be careful to not bring my own bias and expectations into the interaction, (Creswell, 2003). Interviews sought to "capture the deep meaning of experience" in the resident participants' "own words" (Marshall, Rossman, 2011, p. 142), with each resident participant, direct staff, and facility administrator separately, the interviews were recorded and transcribed word for word. Resident participants and direct staff were asked for consent to record in the consent form to participate in the study and verbally at each meeting. The researcher conducted face-to-face interviews with the selected residents and select staff. Open ended and structured questions engaged participants to share their lived experiences and opinions about those experiences.

Data Analysis

My review of the literature had some misconceptions regarding the state of nursing facilities, residents' behavior and activities, doctors' care and the residents' overall sense of their knowledge of their lived experiences, how the residents perceived their nursing facility experience and their reactions which emerged from the interviews. These misconceptions did not come to materialize in the short time spent with residents in this one large nursing facility. The facility was clean, while there were residents on the floor with differing levels of needs, staff seemed attentive to them. My computer, used restricted access with password, contained the transcription of interviews, and related notes. This computer was not shared with anyone else and I was the sole user.

I transcribed the interviews, developed a schema that assigned a code for the residents' name, date of the interview, location and study participant's demographics. The schema also included writings from field notes, reflections, and observations following similar set of information for easy retrieval. I had planned to reserve blocks of time immediately following interviews for introspection: My own reflections on the environment (memo writing), the site, the manner and tenor of interactions, contrasting and comparing to other interviews, for similarities, differences, salient learnings. This was helpful in capturing notes while fresh in my mind. Mayetta (2006), describes this as "Sort and Sift: Think and Shift" (p. 123). The author suggests that the researcher review the data, record emerging thoughts, during revision, going back to study again elements read and utilized during data analysis. Mayeta (2006), developed a "cycle of data analysis: Diving in (read, review, recognize, record)" and "stepping back (reflection, re-strategizing)" (p. 123).

In qualitative research, data analysis, is not a linear approach, but an iterative, evolving journey of discovery (Mayetta, 2006). The researcher categorized data for analysis. Next, all the data was read, to gather a general idea of the material, to reflect and dig deeper. This allowed for meanings to emerge, taking notes on dedicated space for future reference. The researcher began this study of the data by classifying the interview statements into codes, and then grouped the statements into chunks by labeling each (Creswell, 2003). Examples of types of codes were “settings and context codes, perspectives held by study participants; participants’ ways of thinking about people and objects; process codes, activity codes, relationship and social structure codes; and pre-assigned coding schemes” (Bogdan and Biklen, 2007, p. 193).

- Childhood, and childhood experiences,
- Place of birth and elementary school attendance and experiences,
- Activities: cultural and social , family and community supports,
- Experiences with racism: in childhood, as adults, in nursing facilities.
- Experiences and interactions with Whites, experiences in the interactions.

Next step in the data analysis process included the creation of a narrative of the site, of the people, groupings, used for developing themes later. Conclusions of the analysis evolved from the themes identified in these groupings. Finally, assigning meaning making to all of the data, new discovery emerged, which included my own lived experiences as a woman of African Descent, information learned from the literature, or new questions that the discovery process identified. The results informed the researcher’s journey, which sought to understand how disparities occur in nursing facilities, how African American residents experience the disparities,

and what characteristics in these facilities may inform policy making for change and elimination of such disparities. The following results are details of the data collection, analysis and conclusions.

Chapter 4: Results

This study sought to learn from African American elders about their lives in nursing facilities, what elements of disparities they experienced and how staff and administrator perceived such disparities.

Environmental characteristics

African American elders are distinctly aware of their culture, lived experiences of racism and segregation, and proud of their own accomplishments as Black people and the accomplishments of their children. I did not notice any ill smell, nor disrepair or lack of organization. While visiting the resident participants in their room, the flyers announcing the study and the researcher's visit were on hand. Each floor had a central nurse station and staff were busy attending to the needs of the residents. Groupings of residents might be sitting around a table, others in a living-room style space watching a television show, or others in their room usually with the television on. Communal areas were sparsely decorated with pictures on the walls, carpeting and walls painted in neutral colors. These residents were not tied to life-support machines, nor any other equipment with the typical hospital beep-beep. All the residents observed required the assistance of wheel chairs. Two of the resident participants were in bed for the interviews.

Absent were any works of art, photograph, or artifacts to reflect the diversity of the residents in the common areas. Private rooms were decorated and reflected the resident participants' experiences: family photographs, their own photos on special occasions, cards, inspirational sayings, and other rooms did not feature any pictures on the walls. Interviews with

the resident participants were initiated by the questions prepared for the interview. The course of the conversation was often managed by African American resident participants who were self-assured, with clear memories of their lived experiences.

There was a preponderance of recollections that placed them in their family and communities of their youth, their caregivers, their protectors and the ones who loved them. Another common element for most: Seven out of the ten interviewed moved North to avoid segregation and seek a better life for themselves and their families. Each African American resident participant referred to their strong faith, and families seeking religious affiliation and active engagement in the church as sources of strength to cope with the negative experiences of segregation. The African American resident participants exhibited a sense of pride, joy and triumph as they examined their lived experiences and took stock that they have indeed overcome obstacles. Over 50% expressed being satisfied with their experience in the facility. While some made comments about delays in response to their call light, they seemed to understand that the facility caregivers had a heavy caseload.

For example, one compared the experiences of living in a nursing home in the state of Alabama compared to living in Minnesota:

“Well, for me it is I never thought I would end up here. I thought would just get old and pass on. I am still here and specially in a nursing home. In Alabama, they gotta [have a] place called nursing home, but you wouldn't believe how different they are. You don't have the same freedom you have here. It is as if you were still in slavery. Even now. They do not have nursing homes for many African Americans, they still stay at home, because there is no place to go.”

Another resident participant about her experience residing in this nursing facility and how elders are perceived:

“In Minnesota, elders are perceived as sort of the same way I was saying before. It is a little different attitude: African Americans tend to stay away from you, not as warm as they were when we arrived here. Of course, after I have been here a while, they got to know me, and it changed. They know I have lived here for a while.”

A reserved and calm demeanor, Mr. Daniels was reflective before answering questions. One of the questions about obstacles faced, this resident participant's face grew somber and this researcher paused and waited. Mr. Daniels grew up under segregation in the South and recollected some painful situations experienced and others that this African American nursing facility resident witnessed:

We had a lot of things. You know culturally. Some of the things you know how things were. Segregation. Sad things such as I had this friend, we used to walk home together, we were classmates. We came home from school. Some people decided they would follow us, my friend was kind of smart, and would talk back. This friend was badly hurt, beaten up and taken to the hospital. They also hurt me but not as bad. I had to leave and went my way back to my house. My friend had to go that longer way, those were White men who attacked us. I experienced too many things.”

“Being this individual is very hard, really. Because you actually feel so tight. You know they are White and there are a lot of days, I don't think I could put up with the harassment.”

Mrs. Smalls:

“I am not very talkative. Well let's see. I think I worked in a nursing home, getting ready for Christmas. A nursing home is where people who are not well, they need to be in a nursing home. Some people come to visit family and they are the ones who catch whatever is going on. They (nursing facility staff) don't like when we tell when they have to do, and they call you, we bring in somebody who is helpful. That works, it takes time, one of those things.”

Results of this study considered ethical considerations as follows: I used a given name for each resident participant as promised, and did not disclose their names, responses in any clear way that might identify them. My promise to them as illustrated in the consent to participate in the study was kept. They each signed or marked, when unable to sign the consent form and were given a copy. One resident participant will receive a copy of the transcript of the interview as requested.

Potential Researcher Bias

As an immigrant from country in South America, and while sharing African heritage, it is possible that my interpretation and understanding are influenced by my personal expectations of how elderly people should be treated and cared for. While nursing facilities are institutions that have been present in the United States for several decades, this is not my reality. I do not intend to live in a nursing facility as the one I studied. For example, in the interactions with staff and the

resident participants the colloquial addressing by their first name and not Mr. or Mrs. felt uncomfortable to me. The age disparity between the nursing facility employee and the elder was too wide for such familiarity.

I identify this feeling of discomfort also as my bias. While raising my children in the United States, my White neighbor encouraged my son to call her by her first name. I was quick to correct her that I would prefer he address her as Mrs., if she did not mind and explained her why, as my upbringing in Brazil instructed me that as a young child, that familiarity was inappropriate. I am fortunate that she understood, and she acquiesced. I recognize that my culture accompanied me in the encounters at the nursing facility.

African American colleagues reviewed my writing and did not offer any edits. They thanked me for my interest in this population.

African American family and community support

The lived experiences of each resident participants interviewed included stories of their childhood. Most of these individuals did not grow up in isolation or abject poverty. They had loved ones who took on the role of parents when their blood parents were not available. Grandmothers, parents, church pastors, church deacons and other adults played important roles in their lives. A few faced hardships growing up. The experiences of the resident participants with the trauma of segregation while hovering over their communities, were buffered by resilient adults in their communities.

Of the ten resident participants interviewed seven are members of America's great migration north as portrayed in Wilkerson's (2011) book *The Warmth of Other Suns*. Most enjoyed their childhood under the protective care of their African American communities. They attended segregated schools in the South, rode segregated buses and went to the movies together sitting at the back upstairs of movie theaters, where as any children they were mischievous, had fun playing together and were educated by caring African American classroom teachers. Their teachers knew their families and were respected in their African American communities. On one account, even the African American janitor kept an eye to make sure Black students exhibited good behavior always. This is how one resident participant, Mrs. Smalls (not her real name) described their childhood:

“As a matter of a fact, I never rode an integrated bus until I was 21. I never boarded an integrated bus until I was 21. We had these negro communities, and everybody clung to everybody else I also went to segregated elementary school and in 1948 I graduated from HS. The teachers were all friends with our families. They would call our parents if we got out of line. Even the janitor, you would not want to cross him, I still remember Mr. Bell. Lord help you if you did something wrong. They would even come to our houses.”

This African American resident participant was composed, calm and answered the questions carefully. They seemed to have clear recollection as the questions were answered. This individual is active in the nursing facility, reads a lot, participates in field trips, loves music, used to sing in a choir, loved to play Lucky 6 during earlier years, correct answers was received with a quarter and this resident participant was very good at it. This resident participant reported not

liking much television, though there was a reported favorite show: "Name that Tune." This resident participant did not complete college because of family obligation to care for their grandmother after High School, she described being a quick study in school and thought that acceptance into college was a possibility. This resident participant is grateful for the cultural upbringing and stated: "Culture, faith, respectful values - I would not be here today if it weren't for those teachings."

Participant residents scheduled to be interviewed each day were expecting me and were attentive making sure that their stories tied together, and would often ask this researcher, "did I tell you about...?" One resident participant went to segregated schools in Oklahoma and compares the experiences of relatives who attended integrated schools after moving North: "It is not true that there was no segregation in the North!" They recalled riding separate buses for Whites and non-Whites going the same direction in the Twin Cities.

Mr. Daniels misses their mother, a gardener, and their school friend. They used to walk home from school. This resident participant remembered a school classmate and how much they enjoyed school.

"Well, going to school with my classmates and I miss them a lot, and my friends. Mostly I miss my mother, a gardener, who would get up in the morning, go out, take some greens, and would just keep going around. Yes, always active. Sometimes I would tell my mother, let me do that, you just go sit down. but mother just liked to do that. We wanted to make sure our mother did not have to go out there. I had four brothers and one sister, I was the youngest child."

Segregation and Painful Recollections

The African American nursing facility residents interviewed experienced segregation, in the US South or in the North. They lived in an environment of oppression and were taught early to work hard, keep their head up high and to seek an education. I interviewed residents who recounted their lived experiences in their field of work were the first African Americans in their workplace: classroom teacher, home economics graduate, physical education, and police officer working among white counterparts who did not often welcome them. As they witnessed disrespectful behavior leveled at their parents, or grandparents, they also experienced such treatment.

Mr. Daniels also expressed satisfaction at no longer being in the home state of Alabama. When asked how this nursing facility in Minnesota, compared to similar facilities in Alabama, he laughed and said, "Well you get more freedom than in Alabama. If I were there in Alabama they do not have [nursing] homes. Some of the things here too there is (racism). It is not just in Alabama. You should just keep to yourself." "Well, for me it is I never thought I would end up here. I thought would just get old and pass on. I am still here and specially in a nursing home. In Alabama, they gotta [have a] place called nursing home, but you wouldn't believe how different they are. You don't have the same freedom you have here. It is as if you were still in slavery. Even now. They do not have nursing homes for many African Americans, they still stay at home, because there is no place to go."

Mrs. Sparks recalled how her father always wanted to make sure that they were home before dark: "My daddy always wanted to make sure we were home before the sun went down. Much later I understood why: he did not want us to be raped by White men." Mr. Daniels also

recalled: "My mother just had to say No Sir, Mr. So and So, and she knew what to do to stay out of trouble. Mother said that we should just, I know it is hard, but we have to accept something they do. We were kept safe." Mr. Stevens: "Yeah, racism, and negative attitudes, and usually here as in every place else. How overcome? I learned that if I would speak louder, I could get into trouble. I was determined to teach others. I was a radio operator in the army. My father said to always hold your head high."

Resilience, Strength and Pride

Several African American nursing facilities residents shared in their stories of painful experience living under Jim Crow Segregationist Laws or experienced the Northern US discriminatory practices in housing segregation, or other public accesses. This researcher never noticed an expression of self-pity not feeling sorry for themselves. The residents shared stories of triumph over hardships with resolve and pride. They shared how they were first on many career choices, they are proud their children attended schools and graduated from universities, they stared down oppression with an indomitable attitude of courage and faith that better days would come.

For example, Mrs. Smalls summed up the experience of overcoming difficulties as follows: "It was hard to find a job, a decent job, because it was segregated. We could not even apply for them. most of us worked as domestic help. My mom taught us to do domestic work. That was hard, some of them were so exacting, it was hard to get along with them. So, I guess it could be worse. How did I overcome? Like I said, my grandfather, my mother, my grandmother during her life were good mentors. They would tell me don't let anything get you down, don't stoop as low as other people, don't react to everything that hits you. The church was very central

to us in that Community the African Pentecostal, in our communities. I was the only African American teacher in an all-white school. My family had to work at it to help keep me going [and staying employed].”

Mrs. Sparks: “I grew up in Alabama. It is on the news. I am happy with progress. I know there is a great difference in Alabama. Rosa Parks instigated one of the greatest one, and then Martin Luther King who was the pastor at Dexter Avenue Baptist Church and took care of most of the college kids. My son graduated here from the University of Minnesota ... They respected my son, who joined them to play golf. I think my son could act to be among them. I taught him how to act. Oh, I really did!” Mrs. Tulip: “I was a quick study perhaps, and my father was an aerial photographer. Father got a degree one day and then was gone, soon after that we lost our mother. My father was very smart, polite, we are the last siblings, we are two years apart. I had one sister and two brothers. they all are gone. I am the only one left. I went to Tuskegee University; my sister got a PhD in Home Economics. I studied Physical Education, I played basketball. I knew Tuskegee since I was about so high. I had somebody to lift me up to shake [Dr.] Booker T Washington's hands, I knew the children, Mattie, and.-- I did know them all.”

Changing Demographics in Nursing Facilities

Two of the ten resident participants pointed out how they notice the increased diversity in their midst. Their comments reflect how they experience it and what they would like to learn more. It is not something that the direct service staff nor the nursing facility administrator mentioned during the interviews in addressing as it might provide opportunities to creating a more relational community among all residents. This researcher noticed the presence of

interpreters as she signed in each day she was there for the interviews. They too were being escorted to the residents who needed interpreting services.

Mr. Daniels shared the following: "A lot of us people of color live here and I like to not be the only one. If you understand their language, but it is hard to understand others who do not speak English that I cannot understand. They need interpreters. We do have conversations using interpreters it is a way to know others. If they don't speak English, and I don't know what they are saying, then I would like to talk to them. This could be just like discrimination, but I just don't speak the language. There are opportunities for us to speak about our cultures. One week, I was surprised when one of them was telling me about, it was amazing the things about their country they experienced back in their country, so I told her 'join the crowd.'"

Mrs. Smalls: "The African American Culture: some of the aides do not understand the African American culture, even though they are from Africa. They don't seem to understand that this is a different culture. It is hard for some of them to understand what I need because of the language barrier. My cultural upbringing shaped me, I would not be here today if it weren't for those teachings. Culture, faith, respectful, values, so far it has been like that in here, from the beginning. I worked for the department of education for over 30 years."

Some resident participants have positive experiences when they compare to their life in the South under segregation, which they left behind. Mr. Daniels has a positive outlook living in a nursing facility in the North: "Well, for me I never thought I would end up here. I thought I would just get old and pass on. I am still here and specially in a nursing home. They have places they call nursing homes in Alabama. But you wouldn't believe how different they are. You don't have the same freedom you have here. It is as if you were still in slavery, even now,

they don't have nursing homes like they have here. Of course, there is racism here too, as there is there. You just should keep it to yourself.”

Other resident participants interviewed made comments about the diversity in staff and the cross-cultural mis-match that sometimes occurs: sometimes difficulties in understanding because of thick accents, the fact that while culturally the staff are Africans, the fact that these staff come from different African countries impacts how they communicate with each other.

Two direct-service staff agreed to an interview, they were recruited by one of the administrators. Both were African American and are long-term employees of the facility. The administrator recommended their names to me. I contacted them by phone as there was urgency due to the short time left for collecting data and transcribing. Both employees have worked at this facility for over a decade each. Both became interested in working for a nursing facility influenced by a relative who used to work with older adults. The relatives shared their experiences while at home with family members and would tell them stories about their work, how much they enjoyed it, causing these two employees to become interested. The two staff participants seemed to genuinely enjoy their work and the resident participants they care for. There was a sense that this is a vocation for them.

Both enjoy working at this facility because, there is a family atmosphere and they have opportunities for growth: The organization pays for their education if they wish to grow in their profession. When asked about challenges of working with residents who are African American, one employee stated that s/he does not see color, likes working there, the other employee said that sometimes relatives have an opinion about the care of a resident's hair. The employee

stated: "I am accommodating, as I understand that Black hair has a different texture and requires special products."

Benefits of working at this facility, was mentioned as s/he likes people in general and the opportunities afforded to staff who can move inside the large facility and work for a higher salary level. When asked about the staff preparation for work, the staff participants indicated a morning circadian rhythm which followed a daily routine of: Brushing teeth, drinking a cup of coffee, ensuring that childcare is arranged because they need to make sure children are in good care and can go to work without worrying about their well-being.

Both manage stress: One avoids contact with negative people, the other rests, sleeps well, eats appropriately, so is ready to work, is not stressed out, nor overwhelmed. When working with residents experiencing difficulties: Exerts patience, one staff participant made the comment that are more patient with residents than with own children, is working on it. The other staff participant allows more time, even though, there is not much time, allots as much time as possible with the resident experiencing difficulties.

The question that focused on change within the facility specifically in their line of work: More sports channels as some residents would like to watch Monday night football and golf tournaments. The other employee stated that improvement in communication is needed as the flow of communication within the facility is not always optimal. S/he stated: "Without communication, you have nothing. From leadership down to us. At every level: social services, dietary aides, therapy, etc., communication should be better." One of the administrators I had been in contact to arrange the final round of resident participants' interviews, volunteered to be interviewed. I asked this administrator participant similar questions as those posed to the staff

participants with the addition of questions regarding the administrator participant leadership approach, roles and responsibilities. The administrator participant was engaged during the interview and answered the questions giving explanations. The administrator participant explained nursing facility terms and spoke about professional responsibility for a large staff body, even though, few staff under this administrator's direct supervision.

The roles of this administrator participant are broad ranging. The administrator participant did not use quality of care jargon but used mostly safety and well-being of the residents. I was impressed by the following statement that employee engagement with residents is vital because this is the "residents' home." This administrator participant has been at this facility for over three decades and made a career change from school teacher. This career decision move was motivated by the fact that this facility had a good reputation and wanted to work for a large facility. "It is very diverse; the residents have a variety of needs. All levels of care, abilities, goals, that kind of thing. There is always something new." When asked about any challenges in working with residents of color:

"I think that there are some, it is better now than 25 years ago. We have become more and more integrated. Now we have an ethnic base with enough residents. Our staff have always been very diverse, but our residents have not. We now have a more communal feeling, it is more diverse, a little more equitable now, in the more recent few years, we are getting more and more people that are not only African Americans but have lived in poverty. We know that it is poor people that are coming into nursing homes. Because older adults with more money go to assisted living, and I think that economic disparities are sometimes harder to adjust to."

This administrator participant mentioned the presence of compliance issues: When required to follow the regulations, questions emerge from staff such as 'why we have to do that every 30 days?', the administrator participant reflected: "you know, I think that these are sometimes a barrier more than any other things. " When asked, Barriers for Staff? Residents?

"Sometimes for both. Some residents have been homeless, they are used to working with the systems (Social Services), but the health care system is much more complex, which makes it harder for staff as well. For staff it is more work. The African American residents may not have a guardian, they don't have health insurance. It is just difficult to make sure we are providing the best care possible, we are meeting their needs, keeping people safe. These residents may not have good medical history, we don't know their past conditions, sometimes we don't even know what medications they have been on. Or the medications they need to be on. sometimes they have not been to a doctor for 10 years."

How does this administrator participant prepare for work each day? You know my job is more about process, regulation, I feel I am always the "double-check" on everything. To make sure that we are following regulations, compliance, do my rounds with staff and ask them if they have any questions, I view myself as some sort of resource, for both staff and residents."

How does the administrator participant support the staff manage their stress? "I have one staff person who is under me. I do have a lot of contact with staff. I do quality rounds, I do a lot of education, so even though they are not my employees/my staff, I do have a lot of contact with them and hopefully help them stay in compliance with the job, answer questions, that sort of thing." What makes a good leader in this field? "I think you have to be flexible, in a facility as large as this, it is important to have good systems in place. You know, if you keep making

exception for many things you end up having mismatch, then it can become unclear, sometimes unfair, on the flip side of that is to always put the residents first and remember that this is still their home.”

What changes in administration and leadership have you made? “We have become so over-regulated and underfunded with that regulation. We have had to pull back on some things that were amenities. We used to have free coffee in the shop every day. We used to have a computer lab, but a lot of those things had to go away to put resources into more staff, equipment, technology, taking away some of the other things.” Are there differences in the way different cultural groups age? “I think that a lot of time, palliative/end of life care, with East Africans, they do not want to discuss it. They don't feel they have any right to opine on that. A huge mistrust of health care in that population. We must look at more risk/benefits, but we have a lot of people who choose to not take care, for example, someone may be an alcoholic, but they don't seem to care (for treatment to address that), so now we need to have to manage risk/benefits. We see younger people coming in, but their biological age is different than their chronological age.”

What are traits that each African American elder brings when they enter the facility? “I don't know. Either people come in feeling defeated, or have some other attitude, such as I am going to get out of here. Not many people come in planning to spend the rest of their lives in a health care center. But they find themselves in those circumstances and have differing attitude.” In your experience as an administrator, what works best for Residents of Color? “I don't know if I see a huge amount [of difference]. Within the last couple of years, a lot of African Americans, specially men, tend to bond closer than other groups. A group of African American

men they have coffee together every day, they seem to search that differently than other groups and make the decision to be together and enjoy each other's company.”

What would you like to discuss about this profession? “The challenge has been around language barriers, is a new challenge for us in the last couple of years.” I thanked the administrator participant for answering the interview questions, time and access to resident participants. The data collected through interviews, observations, are found in Appendix F along with interview protocols. I sought to examine the lived experiences of African American elders residing in facilities as their last home. The data examined consisted of interview responses from the resident participants, direct service staff participants and administrator participant. I also searched information about the institution: its history, background, locations and types of services offered in addition to nursing facility services.

Augustana is a large presence in a downtown Minneapolis corner next to a major highway. The building I visited faces a public recreational park. It is surrounded by apartment buildings and the highway on the South side. It is religious-based organization and professes in one of its organizational values to: “We act with honesty, integrity and fairness in all aspects of our service” (organization website, para. 5, 2018). Its leadership, board of directors are Caucasian. Its line staff is predominantly employees of color. Line staff are also the lowest paid staff in a nursing facility, certified nursing assistants earn an average \$33,000 in the state of Minnesota, according to a salary survey published online (Salary.com, 2018).

The Minnesota Department of Health and the Minnesota Department of Human Services in partnership with the University of Minnesota, publish a Nursing Home Report Card on their website which rates facilities on star system to compare facilities on eight quality measures:

Resident quality of life, Family satisfaction, Clinical quality indicators, State inspection results, Hours of direct care, Staff retention, Use of temporary nursing staff , and Proportion of beds in single bedrooms. Augustana scores three and four stars (DHS website, 2018). The theories chosen for this study are analyzed based upon the study findings, as follows:

Theoretical Analysis

Critical Pedagogy

Kincheloe (2008) defines Critical Pedagogy as the discipline that interrogates human suffering, when said human suffering that does not need to exist. I learned about life in nursing facility through the eyes of its resident participants. I conducted in-depth interviews, observations during various visits to the facility before starting the interviews, of staff interactions with visitors and residents, and spending time with each resident face-to-face interviewing after they agreed to be interviewed and recorded.

The lived experience of African American resident participants in a large nursing facility in the city of Minneapolis finds them enjoying planned routines for activities, field trips, visits by wound care nurses, meals served at their rooms and activities in which they are invited to participate. Staff working at the nursing stations, are diverse, I saw them walking the floors and interacting with residents, they seemed to be professional, competent and upbeat. When I returned one day to continue the interview, the new nurse at the station did not know me. The nurse was adamant that proof of permission to interview the resident participants was available to review. I felt reassured that proper safety procedures protecting vulnerable adults was being adhered to.

The resident participants welcomed me into their lives by sharing of their childhood, early adulthood and life in general. They shared photographs of their families on display and introduced family. The resident participants joked at times, laughed at themselves and other times their faces turned somber. Each one of the residents, regardless of their health condition, were gracious, polite and generous of their time and wisdom. Questions elicited visits to resident participants' earlier experiences. Most grew up under segregation. All experienced discrimination. Their recollection was a mix of fond moments as children who enjoyed their childhood as children do. They loved their school friends, they played together, adults took them to the movies, outings, to school and to church.

Most of these African American resident participants had loving adults in their communities who worked hard to buffer them from Jim Crow discriminatory laws. Their stories provided them an opportunity for them to become the actors in their own realities. They told me of the caring adults in their communities who warned them to be home before dark, to not talk back even if offensive remarks were hurled at them, to hold their heads high, to be proud in the face of difficult circumstances. They did not share any anger, rage nor bitterness as they invited me, a stranger who they had never met, into their rich and bittersweet reality of life in the South, living separate from the White community, who enjoyed the privileges of better schooling, new books, access to higher education, and other resources denied them. Some experienced tragedy nearby, such as one recollected the bombing of a church in which four little girls were killed, or others witnessed their elders being mistreated and dis-respected.

Each time I left their presence, the awareness of their experiences was alive in the researcher's memory for several days. As an immigrant who never experienced the Civil Rights

movement of Black liberation in the United States, they engaged in a patient teaching and co-creating of ideas of their reality with me. The lessons I learned were of resilience, grace and resolve in the face of segregation. Their resilience was built supported by adults teaching the value of loving care in supportive communities, a belief in the success of another and faith beyond visible possibility is practiced.

Staff and administrator are unaware of bias or racism, they cannot perceive or alleviate their circumstances. As one direct service staff participant commented, "I don't see color," and the administrator participant when asked about disparities, believes that it is much more about economics. The administrator observed the lower income level of arrivals of African American elders in the nursing facility of late. Administration of nursing facilities includes increased pressure of as pointed out by the administrator during the interview that "regulation and compliance" in the facility are critical to maintaining operations.

Systems Theory and Targeted Universalism

Systems Theory provides a framework for examining the interaction of African American elders residing in nursing facility to uncover opportunities for growth and development that are more equitable. Parsons' functional structuralism could be applied to provide a frame for examining how resident participants experience and adapt to their place of residence, There was a lack of culturally inspired art work, signs, or a sign of recognition that other beyond Whites lived in the space. How do resident participants set goals for their new lives? How to they interact productively and contribute to their new community?

The administrator described an example of adaptation of one African American group of male elders. They seemed to have self-organized into a coffee club, could other cultural groups be encouraged similarly? Collective wisdom of persons of African descent have historically been shared and have served as the foundation for overcoming discriminatory practices and some of the damages of disparities can impose on minority communities. African Americans before 1964, year of the US Civil Rights Act, did not have access to the same quality health facilities, nursing facilities, schools and institutions in civil society available to Whites. The institutions available to African Americans did not receive the same level of support were separate between Whites and Blacks (*Plessy v. Ferguson* was an 1896 U.S. Supreme Court).

Because of the nature of these punitive approaches, African Americans and the Civil Rights Movement demanded equal rights. The Civil Rights Act of 1964 abolished discriminatory practices based on race, color, religion, sex, or national origin. Targeted Universalism if applied at a nursing facility would more carefully examine the services provided to each resident and address disparities found with the understanding that when all residents receive equitable care there is improvement in the quality of care of the residents, resulting in improving their quality of life. While not highly vocal, some residents had concerns about delay in call light responses, food taste.

Some African American elders made comments that they understood there were many residents needing care, or that food preparation for many residents makes it difficult to address the need to make food taste better. Socioemotional support for these elders is critical to their continued enjoyment of health and well-being. As community members providing recommendations to DHS, have shown, these residents could become valuable allies in the

nursing facilities' efforts at quality improvement if approached and adequately informed. The benefit could be universal: not just for a few residents. One of the examples that Dr. Powell often points to illustrate Targeted Universalism is how the passage of the American with Disabilities Act, street curbs had to be modified to allow access for persons with disabilities using a wheelchair to cross a street. While targeted to the populations with disabilities, a mother pushing a stroller, a youngster rollerblading, or someone pushing a grocery cart the indentation on the curb is valuable. The benefit is universal.

African American participants residing in nursing facilities seemed to tolerate their conditions. They were not overly critical of their conditions; they were not enthusiastically praising the conditions either. These resident participants spoke more freely when interviewed in their rooms compared to the residents interviewed in a conference room which had two doors into two offices which were occupied. Staff moved in and out of their office, which impacted privacy. There was no mention by the employees interviewed whether African American individuals residing in the facility are ever invited to provide suggestion the way they wish or prefer to be cared for.

Critical Social Theory

African American participants residing in the nursing facilities were alert, sharp and keenly aware of their circumstances. They are not devoid of agency, wisdom nor knowledge. They are observers of their surroundings, know when to speak up as they choose regarding which field trips to join, activities to participate in, or which television channel they wish to watch. Their lived experiences of surviving very difficult circumstances in the segregated South,

the children they raised and educated, and their acuity in engaging in conversations was foremost to them and seems to continue to fortify them.

These resident participants notice that direct service staff are not attuned to their wants and needs, the difficulty in understanding certain accents, and the limitations that living in an institution brings. It seemed that these African American resident participants can become vocal actors on their own right in Habermas' public square where caring for older African Americans are topics of interest and provide important contribution, in a system that is projected to grow in demand for Populations of Color. I did not see any evidence of active participation or involvement in the operations of the facilities by the resident participants interviewed.

African American nursing facilities residents notice the changing demographics in their surrounding and had ideas and opinions about how this affects them. As the literature review noted projections of increased nursing facilities residents from cultural communities (Howard et al, 2002) are on the rise, this fact did not go unnoticed by these African American resident participants. Some welcome this change and would like to have connections with other People of Color, a few do not.

Resilience

Resilience has been studied when vulnerable families in need of public assistance experience differing outcomes. The science has advanced the knowledge on resilience as it becomes an important discipline to support children and adults in their journey to overcoming difficulties. Studies show that some children in families experiencing difficulties seem to bounce back while others in the same family do not (Sandstrom & Huerta, 2013, Child Welfare

Information Gateway, 2014, Harvard, 2017). In 2000 Philips and Shonkoff edited and published *From Neurons to Neighborhoods*, the work of a committee informing the field of family and child development as a call to action how adverse experiences have significant impact later in the lives of children. Phillips and Shonkoff (200) also provided policymakers urgent recommendations that sought to bring clarity to children and families' environment and their influence on well-being with later consequence into their adulthood.

Harvard Center for the Developing Child (2017) carries on this work by informing the field on developments in brain science, adversity faced in childhood, and the importance of early interactions for child's brain development. The interview responses with each resident participant revealed early experiences of racism, poverty and oppression, and how their families helped and supported their success, by providing what is known by experts as vital to the healthy growth and development: Social supports, family cohesion, participation in cultural traditions, practices and ways of knowing: protective factors (Center for the Study of Social Policy, 2006).

Nursing Facility Reponses Analysis

Nursing facility employees interviewed were not aware of the topic of disparities: when asked, one said s/he does not see color, another did not answer the question, and one alluded it to economic disparities alone. While economic disparities are one the factors in health disparities, they are not the only factor (MDH, 2014).

The lived experiences of African American resident participants in nursing facilities is vulnerable to disparities occurring because of the high number of residents, staff that has limited time to give attention to everyone, and a seemingly absence of any critical thinking or understanding of power dynamics between caregivers and cared, for example the comment, "I

don't see color," is not adequate response, as it elicited this researcher to further inquire. The comment by the administrator that disparities are economic, were also of concern. As Freire (1998) teaches, the oppressor (in powerful position) must attain liberation by learning the world around themselves, and gaining awareness, as without this knowledge, there is danger of continuing oppression, in this case disparities. An illustration follows, to summarize the experiences of African American elders residing in nursing facility in Minnesota, in Figure 5.



Lived Experiences of African American Elders in Nursing Facilities, figure 5.

Chapter 5: Observations, Interpretations and Recommendations

Observations

I entered this journey with a few ideas or information on the discovery this research might uncover. The literature was not positive as it depicted the lives of African American nursing facility residents experiencing disparities, in both quality of care, facilities physical conditions and access to resources. Nursing facilities are not considered places where one would choose to spend their final days. Each African American participant residing in the nursing facility who was interviewed welcomed the participation in this study. Each had received a flyer inviting their participation and had said yes, a few said no.

Resident participants were engaged, listened attentively to the questions and told their stories. There were times in which I was transported into their world. None of the residents who were interviewed had serious complaints about their condition. Some were grateful for having a place to call home as compared to experiences they may be exposed elsewhere. Others built a community around them. They had friends in the nursing facility, which they were engaged, read books or shared current events with.

Interpretations

Resident participants are aware of their presence in a large facility where they are not in the majority, as African Americans in proportion to White residents, but mentioned occasionally, the fact that they are not the only ones, which I came to understand, they are not the only Black individuals in the facility. Some found comfort in not being the only Black individuals in the facility.

Resident participants know of their conditions. They experience racism in the nursing facilities. As one commented, "Of course, there is racism here too, as there is there. You just should keep it to yourself." Or another resident: "Yeah, racism, and negative attitudes, and usually here as in every place else." They do not have any recommendations how to change their situation. Their comments lead me to believe that keeping to themselves, or not complaining will assure peace while living in this nursing facility. For example, further comments about life in the nursing facility:

African American elder resident participants perceive differential treatment in their day to day experiences. These elders choose to "keep to themselves." They are aware of their vulnerable situation and learned to resign themselves to live with it: "They take a while answering the light [call signal]." "I understand that I have to wait because they only send the workers who are familiar with us." "I like it here OK. It is a place to live in. You get all kinds of things that you must deal with. I stay in my own room. I am with people that I know. I don't mix with others." Residents expressed a sense of resignation.

Staff participants employed by this facility who were interviewed, each had worked for the facility for over a decade. They seemed to care for their charges. They spoke about the working conditions as one with routines that must be maintained due to regulatory tasks, but even then, they found time to spend a bit more time with a resident who may be having difficulties on a given day. Employees interviewed seemed to enjoy their work, appreciate the incentive this employer provided for the career ladder and both referred to the residents in fond ways that gave the impression of respect and deference.

The administrator participant, responsible for quality assurance has been at the facility for over three decades. The administrator participant was able to provide an interesting picture of the organization's culture. The administrator reported that the facility was segregated at one point in time: All the residents were White. Many direct care staff were diverse. The administrator participant observed the change in the past decade or so: There are more Residents of Color, including immigrants are now using nursing facilities services. When asked about disparities, the administrator deflected to socioeconomic as the sole factor. The administrator expressed the common reaction which is poverty that causes African Americans to be in publicly funded nursing homes, or in poor health. In 2007, Minnesota along with other nursing homes in US Midwest were found to be the most segregated regionally in the US and with highest level of disparities (Smith, Feng, Fennell, Zinn, Mor. (2007).

Recommendations

With rising cost for nursing facilities care around the US, there is pressure from the federal government that funds nursing facilities costs for low wealth elderly persons to encourage home-based rather than institutional living which is more expensive. The focus of this study was not to assess whether residents preferred to live in the nursing facilities or at home. Their health conditions, advanced age, and frailty led me to better understand that they were in settings where their needs could be best met. I promised the resident participants and staff/leadership participants to return to inform them of the results of this study. The residents and staff seemed to welcome my promise to return with the study's conclusions.

As I review the results of this study, there is the potential for possible future studies to address the shortcomings faced due to limitations in access for more interviews with residents. I

had only one hour with each resident. My main concern was to not rush the residents, to not interrupt them and to allow their storytelling to unfold. This produced very rich data set. I was not able to return for more interviews, nor did I have the opportunity to confirm with residents their responses, or when the taped stories were inaudible I could not re-visit them, which presented a limitation.

The African American resident participants were able to converse in one-hour long conversations and it was expected they might welcome more such experiences. The interaction with each one seemed to be a welcome event in their day and something that they seemed to enjoy. The resident participants exhibited knowledge, wisdom and actively engaged in their world: They talked about the national news, their knowledge of historical and current events, along with connecting to their perception of lives within the facility. Families and their communities continue to be a source of support and pride to them. Segregation and painful recollections were brought into the interviews by 70% of the African American resident participants. They were also people of pride, resilience and strength: They overcame difficult circumstances and their families succeeded. They notice the change in their nursing facility community. Some were eager to know the newcomers and others were reluctant.

Nursing facility staff did not seem to notice the change from the same standpoint, their perspective did not seem to register in the same manner. As the administrator participant pointed out, the staff complement has been diverse for many years, and that it has been only in the past decade that the nursing facility resident population has increased in its diversity. I intend to complete her academic requirements for a doctoral degree in education and return to the nursing facility to report back, to the nursing facility staff, the nursing facility resident participants and

the administrator participant. This study may be of interest to them to inform the work of the organization to become more culturally relevant and responsive.

The findings of this study demonstrated:

- African American resident participants living in nursing facilities come from strong families and communities
- Resident participants overcame experiences of segregation, Jim Crow Laws and segregation in the Northern US
- These experiences are important to acknowledge so that Trauma Informed Care, racism is considered to be a traumatic event, is provided and does not further exacerbates their well-being (Harvard Center for the Developing Child, 2017)
- Resident participants have some ideas about how to open their nursing facilities communities to the incoming cultural groups
- Nursing facility resident participants are resilient, strong and proud
- Nursing facility staff participant are not as attuned to the shift in demographics in the nursing facility population as the residents are
- Nursing facility industry should invest in training and development that interrogates disparities experienced by its residents of color,
- Nursing facility industry should engage in long-term sustainable efforts that transform its environment and surroundings to be more culturally attuned to the diversity of its people – both as residents and staff.
- Nursing facility industry ought to be equipped to serve the changing demographics of its nursing facility residents as the Population of Color increases

A study by an intern to DHS/Community Relations Division a few years ago, identified emerging trends in the nursing facility residents. The conclusions and recommendations are inserted here as the problems are compelling to provide an alternative to the examination of this aging Population of Color residing in nursing facilities.

The stated problem: The Older Adults demographic is growing tremendously and along with increasing diversity, the demand for culturally appropriate services will increase. Recommendations for DHS related to Older Adults, in its legislative report to the Health and Human Services committees in the House and Senate, rings true for this nursing facility in order to support efforts of the nursing facility staff and administrator. The recommendations listed and summarized later, insert the findings from this study to the work at the DHS on Aging Adults.

- The nursing facility administration should engage the community to determine needs and gaps in services, in partnership with their resident participant African American elders.
- Communities know where to go where their needs will be met: the resident participants, along with their families, or in their absence, concerned citizens, are able to understand and access all available services; emphasis needs to be prioritized on choice and right to live in dignity in environment of their choice.
- Community: ownership, engagement, supports for individuals; engage the political process to support individuals. Resident participants, their relatives, community concerned about their well-being, can join in supporting the organization become more culturally responsive.

- Health services: DHS and legislators should create policies that meet the needs of the community; create policies that integrate foreign trained health professionals, helping them adapt to African American culture which is distinct from their country of origin;
- Utilize the assets of the community to meet needs and preferences of the community members; provide funding available for grants focused on this population.

Cultural and ethnic communities urge DHS to be prepared so that all levels of care can meet the diverse needs of older adults in the community. To narrow the gaps and achieve equity in access and quality to improve outcomes for all older adults it is essential to engage cultural and ethnic communities, as well as other communities to best determine what their needs and preferences are. The proportion of minority older adults is growing, with a greater proportion living in poverty than their white counterparts. Their remaining years in a caring and supportive nursing facility is in the best interest of policymakers and the industry in general to reduce costs.

References

Agency for Health Care Research and Quality [AHRQ] (2016).

Retrieved 15 April 2018 from

<http://www.ahrq.gov/research/findings/nhqdr/nhqdr16/summary.html>

Agency for Health Care Research and Quality [AHRQ] (2015).

<http://www.ahrq.gov/research/findings/nhqdr/nhqdr15/access.html> Retrieved August 30, 2016

The Six Domains of Health Care Quality. Content last reviewed March 2016. Agency for Healthcare Research and Quality [AHRQ], Rockville, MD.

<http://www.ahrq.gov/professionals/quality-patient-safety/talkingquality/create/sixdomains.html> Retrieved 10 March 2018

American Psychological Association (2009). Office of Ethnic Minority Affairs. Communiqué Special Issue: *Psychological and Behavioral Perspectives on Health Disparities*.

<http://www.apa.org/pi/oema/resources/communique/2009/03/march.pdf> Retrieved 11 March 2018

Ardington, C., Case, A., Islam, M., Lam, D., Leibbrandt, M., Menendez, A., Olgiati, A. (2008) Conference: The Impact of AIDS on Older Persons in Africa and Asia (November 2008).

The impact of AIDS on intergenerational support in South Africa: Evidence from the Cape Area Panel Study. South African National Institute on Aging and the National Institute of Child Health and Development Conference. University of Michigan

https://www.princeton.edu/~accase/downloads/AIDS_and_intergenerational_support_in_Cape_Town.pdf Retrieved 11 March 2018

Bach, P. B. (2005). Racial disparities and site of care. *Ethnicity and Disease*, 15(2Suppl 2), S31-33.

Bazargan, M., Yazdanshenas, H., Han, S., & Orum, G. (2016). Inappropriate medication use among underserved elderly African Americans. *Journal of Aging and Health*, 28(1), 118-138.

Belgrave, L. L., Wykle, M. L., & Choi, J. M. (1993). Health, double jeopardy, and culture: The use of institutionalization by African Americans. *Gerontologist*, 33(3), 379-85.

Bonilla-Silva E. Rethinking Racism: Toward a Structural Interpretation. *American Sociological Review*. 1997;62(3):465-480.

Center for the Study of Social Policy. (2006) The Protective Factors Framework.

<https://www.cssp.org/> Retrieved 11 March 2018

Chang YJ, Siegel B, Wilkerson G. Measuring healthcare disparities and racial segregation in Missouri nursing homes. *Journal of Health Care Quality*. 2012 Jan-Feb;34(1):16-25. Retrieved 8 April 2018 from

<https://www.ncbi.nlm.nih.gov/pubmed/22059384>

doi: 10.1111/j.1945-1474.2011.00135.x. E pub 2011 Mar 1. PubMed PMID: 22059384.

Child Welfare Information Gateway. (2014). Parenting a child who has experienced trauma.

Washington, DC: U.S. Department of Health and Human Services, Children's Bureau.

<https://www.childwelfare.gov/pubPDFs/child-trauma.pdf> Retrieved 11 March 2018

Cohn, D. and Taylor, P. (2010). Baby Boomers Approach 65 – Glumly: Survey Findings about America's Largest Generation. Retrieved 8 April 2018 from www.pewsocialtrends.org

Commonwealth Fund (2015). Policy Brief: Scorecard on State Health System Performance.

http://www.coMMonwealthfund.org/~media/files/publications/fund-report/2015/dec/2015scorecard_equity.pdf?la=en retrieved January 31, 2018

Creswell, J.W. (2003). *Research Design: Qualitative, Quantitative and Mixed Method Approaches*. Sage Publications: Thousand Oaks, CA

Cultural and Ethnic Communities Leadership Council (2013). The Cultural and Ethnic Communities Leadership Council (CECLC) was established by the Minnesota Legislature under Laws of Minnesota 2013, chapter 107, article 2, section 1, and became effective August 1, 2013. <https://edocs.dhs.state.mn.us/lfservlet/Public/DHS-6891A-ENG> Retrieved 31 January 2018

Cultural Wellness Center. (2015). Organization website

<http://www.culturalwellnesscenter.org/about-us/> retrieved January 30, 2018

DeMillo L., and Nakashian M. Editor McKaughan M. (2016). *Using Social Determinants of Health Data to Improve Health Care and Health: A Learning Report*. Robert Wood Johnson Foundation. Princeton, NJ

DeNardi, M., French, E., Jones, J.B., McCauley, J. (2015). *Medical Spending of the US Elderly*. National Bureau of Economic Research. <http://www.nber.org/papers/w21270> Retrieved 12 March 2018 (DOI): 10.3386/w21270

- Engle, V. F., Fox-Hill, E., & Graney, M. J. (1998). The experience of living-dying in a nursing home: Self-reports of black and white older adults. *Journal of the American Geriatrics Society*. 1091-1096-46(9).
- Feagin, J.R. (2010). *The White Racial Frame: Centuries of Racial Framing and Counter-Framing*. Routledge: New York, NY
- Freire, P. (1998). *Pedagogy of the oppressed*. The Continuum Publishing Company: New York, NY.
- Freire, P. (1997). *Education for Critical Consciousness*. The Continuum Publishing Company: New York, NY.
- Friedman, Bruce & Allen, Karen. (2014). *Essentials of Clinical Social Work, Systems Theory*, pp. 3-20. Edition: 1, Chapter: 1, Publisher: Sage, Editors: Jerrold R. Brandell. 10.13140/2.1.1132.9281.
- Haber, C. and Gratton, B. (1993). *Old Age and the Search for Security: An American Social History*. Indiana University Press.
- Hansan, J.E. (2011). Jim Crow laws and racial segregation. *Social Welfare History Project*. Retrieved 15 January 2018 from <http://socialwelfare.library.vcu.edu/eras/civil-war-reconstruction/jim-crow-laws-andracial-segregation/>
- Harvard Center for the Developing Child (2017). *Issue Brief on Resilience* www.developingchild.harvard.edu Retrieved 28 February 2018
- Executive Function and Self-Regulation Issue Brief*. <https://developingchild.harvard.edu/science/key-concepts/executive-function/> Retrieved 11 March 2018
- The Henry J. Kaiser Foundation. *Long-term Care: Medicaid's role and challenges*. (1999) Policy Brief Publication #2172. Washington, DC.
- <https://www.kff.org/medicaid/issue-brief/long-term-care-medicaids-role-and-challenges/> Retrieved 7 February 2018
- Hooks, B. (2000). *Feminist Theory: From Margins to Center*. South End Press, Cambridge, MA
- Howard, D. L., Sloane, P. D., Zimmerman, S., Eckert, J. K., Walsh, J. F., Buie, V. C., Koch, G. G. (2002). *Distribution of African Americans in Residential Care/Assisted Living and*

Nursing Facilities: More Evidence of Racial Disparity? *American Journal of Public Health*, 92(8), 1272–1277.

Hulme, P.A. (2010). *Journal of Transcultural Nursing. Cultural Considerations in Evidence-Based Practice*. Volume: 21 issues: 3, page(s): 271-280

<https://doi.org/10.1177/1043659609358782>

Johnson, K. (2017). Case Workers: Changes to Child Protection System are Leaving Kids Less Safe. Eyewitness News TV, KSTP TV, LLC. Hubbard Broadcasting Company. St. Paul, MN

Jones CP. Levels of Racism: A Theoretic Framework and a Gardener's Tale. *American Journal of Public Health*. 2000;90(8):1212–1215. [[PMC free article](#)][[PubMed](#)]

Karter, A. J., Laiteerapong, N., Chin, M. H., Moffet, H. H., Parker, M. M., Sudore, R., Huang, E. S. (2015). Ethnic differences in geriatric conditions and diabetes complications among older, insured adults with diabetes and aging study. *Journal of Aging and Health*, 27(5), 894-918. King, R. K., Green, A. R., Tan-McGrory, A., Donahue, E. J., Kimbrough-Sugick, J., & Betancourt, J. R. (2008). A plan for action: Key perspectives from the racial/ethnic disparities strategy forum. *The Millbank Quarterly*, 86(2), 241-72.

Kane, R.L., West, J.C. (2005). *It Shouldn't Be This Way: The Failure of Long-Term Care*. Vanderbilt University Press: Nashville, TN

Kane, R.A. (2003). *Quality of Life Scales for Nursing Facility Residents*. Centers for Medicaid and Medicare (CMS) Project: Measures, Indicators and Improvement of Quality of Life in Nursing Homes. Study conducted under contract #500-96-0008 between CMS and the University of Minnesota. Minneapolis, MN

King County. Equity Impact Review Tool (2016).

https://www.kingcounty.gov/~media/elected/executive/equity-social-justice/2016/The_Equity_Impact_Review_checklist_Mar2016.ashx?la=en

Retrieved 8 February 2018

Kleinman, A. (1980). *Patients and Healers in the Context of Culture*. Berkeley, CA: University of California Press.

Konetzka, R.T., Werner, R. M. (2009). Disparities in Long-Term Care: Building Equity into Market-Based Reforms. *Medical Care Research and Review*. Vol. 66 no. 5 491-521

- Kutler, S.I. (2003). *Dictionary of American History*. New York: Charles Scribners' Sons. 3rd Ed.
- Li, Y., Yin, J. S., Cai, X., Temkin-Greener, H., Mukamel, D.B. (2011). *Association of Race and Sites of Care with Pressure Ulcers in High-Risk Nursing Home Residents*. *Journal of the American Medical Association (JAMA)*.
- Lindsey, E. (2016). TEDWomen 2010. Curating Humanity's Heritage.
https://www.ted.com/talks/elizabeth_lindsey_curating_humanity_s_heritage, retrieved August 29, 2016.
- Lowenstein, J. K. (2015). How data-driven journalism revealed racial disparities in U.S. nursing facilities. *The Center for Public Integrity*.
- Malone, T.E. (1985), Chair. The Heckler Report. The Report of the Secretary's Task Force on Black and Minority Health. Washington, D.C.: U.S. Department of Health and Human Services.
- Mapping Prejudice Project (2017).
<https://www.mappingprejudice.org/>
Retrieved 8 February 2018
- Marshall, C. and Rossman, G.B. (2011). *Designing qualitative research* (5th ed.). Thousand Oaks, CA: SAGE Publications, Inc.
- Menendian, S. & Watt, C. (2008). *Systems Primer*. Kirwan Institute for the Study of Race and Ethnicity. The Ohio State University.
- Merck Institute of Aging and Health. (2002). *The state of aging and health in America*. Washington, DC: Merck Institute.
- Miller S.C., Papandonatos G., Fennell M., Mor V. (2006). Facility and county effects on racial differences in nursing home quality indicators. *Social Science and Medicine*, 63(12), 3046-59.
- Minnesota Compass. Minnesota's older adults' demographics.
<http://www.mncompass.org/demographics/overview> retrieved 3 October 2015
- Mattessich, P. (2015). The Minnesota Paradox.
<http://www.mncompass.org/trends/insights/2015-03-01-minnesota-paradox>
Retrieved 7 February 2018

Minnesota Department of Health (2005). Demographics of an Aging Population. Workgroup on Healthy Aging.

<http://www.health.state.mn.us/divs/orhpc/pubs/healthyaging/demage.pdf> retrieved 10 March 2018

Minnesota Department of Human Services (DHS).

Activities of Daily Living (ADL) (2014), MN Choices Assessment Domains.

http://www.dhs.state.mn.us/main/groups/county_access/documents/pub/dhs16_180273.pdf Retrieved 11 March 2018

Nursing Report Card gets top Grade (2017)

Minnesota Achieves Another High Ranking from AARP on Long-Term Services and Supports

<https://mn.gov/dhs/people-we-serve/seniors/whats-new/Supports> Retrieved 7 February 2018

Children's Services Report to the 2002 Minnesota Legislature (April 2002)

<https://www.leg.state.mn.us/docs/pre2003/mandated/020299.pdf>

Retrieved 8 February 2018

Minnesota Department of Human Services (2018). Mission Statement. Retrieved from

<https://mn.gov/dhs/general-public/about-dhs/what-we-do/> 19 February 2018

Minnesota Health Care Programs. (Medicaid). <https://mn.gov/dhs/people-we-serve/adults/health-care/health-care-programs/programs-and-services/medical-assistance.jsp>

Retrieved 10 March 2018

Minnesota Nursing Home Report Card. Retrieved 20 April 2018 from

<http://nhreportcard.dhs.mn.gov/nhreportcardfactsheet.pdf>

Minority Health and Health Disparities Research and Education Act of 2000 (2000). Subpart 6, National Center on Minority Health and Health Disparity. Center for Minority Health Disparities Research, Section (d), Subpart 1. https://www.nimhd.nih.gov/docs/advisory-council/public_law106-525.pdf Retrieved 10 March 2018

Mor, V., Angelelli, J., & Teno, J. M. (2004). Driven to tiers: Socioeconomic and racial disparities in the quality of nursing home care. *The Milbank Quarterly*, 82(2), 227-256. doi:10.1111/j.0887-378X.2004.00309.x

- Nelson, R.N., Committee Chair (2002). *Unequal Treatment: Understanding Racial and Ethnic Disparities in Health Care*. National Academies Press: Washington, DC.
<http://www.nap.edu/catalog/10260.html>
- Nieman, C. L., Marrone, N., Szanton, S. L., Thorpe Jr., R. J., & Lin, F. R. (2016). Racial/Ethnic and socioeconomic disparities in hearing health care among older Americans. *Journal of Aging and Health*, 28(1), 68-94.
- Office of Disease Prevention and Health Promotion. The Secretary's Advisory Committee on Health Promotion and Disease Prevention Objections for 2020. Phase I Report: Recommendations for the Framework and Format of Healthy People 2020 (2008)
<https://www.healthypeople.gov/> Retrieved 10 March 2018
- Ortman, J. M., Velkoff, V.A., Hogan, H. (2014). *An Aging Nation: The Older Population in the United States Population Estimates and Projections Current Population Reports*. U.S. Department of Commerce Economics and Statistics Administration: Washington, D.C.
<https://www.census.gov/prod/2014pubs/p25-1140.pdf> Retrieved 10 March 2018
- Passel, J.S. and Cohn, D. (2008). Pew Research Center,
<http://www.pewhispanic.org/2008/02/11/us-population-projections-2005-2050/> retrieved 7 February, 2018.
- Plessy v Ferguson (1892) US Supreme Court Decision uphold "Separate but Equal" doctrine of separation based on race. <http://www.history.com/topics/black-history/plessy-v-ferguson>
Retrieved 27 February 2018
- Rahman, M., & Foster, A. D. (2015). Racial Segregation and Quality of Care Disparity in US Nursing Homes. *Journal of Health Economics*, 39, 1–16. Retrieved 8 April 2018 from
<http://doi.org/10.1016/j.jhealeco.2014.09.003>
- Rivlin, A. M., Wiener J.M., Hanley, R. & Spence, D.A. *Caring for the Disabled Elderly: Who Will Pay?* The Brookings Institution, Washington DC. 1988, 318 pp.
- Roger, S. & Komisar, H. (2003). *Who needs long-term care? Fact Sheet*, Long-Term Care Financing Project. Washington, DC: Georgetown University Press.
- Salary.com. Salary for Certified Nursing Assistants in the State of Minnesota, retrieved 21 April 2018 from <https://www1.salary.com/MN/Certified-Nursing-Assistant-salary.html>
- Sandstrom, H., Huerta, S. (2013). *The Negative Effects of Instability on Child Development: A Research Synthesis, Low-Income Working Families Discussion Paper 3*. The Urban

Institute. <https://www.urban.org/sites/default/files/publication/32706/412899-The-Negative-Effects-of-Instability-on-Child-Development-A-Research-Synthesis.PDF>
Retrieved 11 March 2018

Shippee, T.P., Henning-Smith, C., Kane, R.L., Lewis, T. (2013). Resident- and Facility-Level Predictors of Quality of Life in Long-Term Care. *The Gerontologist* doi: 10.1093/geront/gnt148

Shippee, T. P., Henning-Smith, C., Rhee, T. G., Held, R. N., & Kane, R. L. (2016). Racial Differences in Minnesota Nursing Home Residents' Quality of Life. *Journal of Aging and Health*, 28(2), 199-224. [10.1177/0898264315589576](https://doi.org/10.1177/0898264315589576)

Shippee, T.P., Henning-Smith, C., Gaugler, J.E., Held, R., Kane, R.L., (2015). Satisfaction with Nursing Home Care: *The Role of Facility Characteristics and Resident Quality-of-Life Scores*. <https://doi.org/10.1177/0164027515615182> retrieved 19 February 2018

Smedley, B.D., Stith, A.Y. and Nelson, A.R. (2003). Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Editors. Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. Washington (DC): National Academies Press (US).

Smith D.B. (1999). *Health Care Divided: Race and Healing a Nation*. The University of Michigan Press. Ann Arbor, MI.

Smith D. B. Feng Z, Fennell ML, Zinn JS, Mor V. (2007). *Separate and unequal: Racial segregation and disparities in quality across U.S. nursing facilities*. *Health Affairs*, 26(5), 1448-1458. doi:10.1377/hlthaff.26.5.1448

Smith, D.B. (2002). *Health Care Divided Race and Healing a Nation*. Ann Arbor, MI: The University of Michigan Press.

Smith, D.B., 2016. *The Power to Health Civil Rights, Medicare, and the Struggle to Transform America's Health Care System*. Nashville: Vanderbilt University Press.

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretive Phenomenological Analysis: Theory, Method and Research*. London: SAGE

Stanton, M. (2002). *Expanding Patient-Centered Care to Empower Patients and Assist Providers*. Research in Action. Agency for Health Care Research and Quality (AHRQ). Issue #5

- Struly, K. W. (2011). Health care segregation and race disparities in infectious disease the case of nursing facilities and seasonal influenza vaccinations. *Journal of Health and Social Behavior*, 52(4), 510-526.
- Thomas, D. R. (2003). A general inductive approach for qualitative data analysis. School of Population Health: University of Auckland, NZ
- Thorpe, R.J., Jr., McCleary, R., Smolen, J.R., Whitfield, K.E., Simonsick, E.M., LaVeist, T. (2014) *Racial Disparities in Disability Among Older Adults: Finding From the Exploring Health Disparities in Integrated Communities Study*. *Journal of Aging and Health* (pp. 1261-1279). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4350679/#R62> Retrieved 10 March 2018
- U.S. Department of Health and Human Services (2015). A Profile of Older Americans: 2015. Administration on Aging, Administration for Community Living
- Vladeck, B. C. (1980). *Unloving care: The nursing home tragedy*. New York: Basic Books.
- Ward B.W., Schiller J.S., Freeman G., and Clarke T.C. (2015). Early release of selected estimates based on data from the January-June 2015 National Health Interview Survey. Hyattsville, MD: National Center for Health Statistics;
<http://www.cdc.gov/nchs/data/nhis/earlyrelease/earlyrelease201511.pdf>
Retrieved 7 February 2018
- Whitehead, M., Dahlgren, G. (2007). Concepts and Principles for Tackling Social Inequities in Health: Levelling up Part 1. EURO/World Health Organization, Collaborating Centre for Policy Research on Social Determinants of Health. University of Liverpool: Great Britain
- Wilcoxon, A.A. (2008) Critical Pedagogy Paper, CIED 940 Course, University of St. Thomas: Minneapolis, MN. (unpublished paper).
- Wilkerson, I. (2010). *The Warmth of Other Suns*. Random House: NY
- David RCollins
- Williams, D.R., Mohammed, S.A., Leavell, J., and Collins, C. (2010). *Race, socioeconomic status, and health: Complexities, ongoing challenges, and research opportunities*. *Annals of the New York Academy of Sciences*. Issue: The Biology of Disadvantage. New York, NY.

World Health Organization (2008). Definition of health inequities

http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/

Retrieved 19 February 2018

Principles of the Constitution of the World Health Organization (1946). The Constitution was adopted by the International Health Conference held in New York from 19 June to 22 July 1946, signed on 22 July 1946 by the representatives of 61 States and entered into force on 7 April 1948. Later amendments are incorporated into this text.

<http://www.who.int/about/mission/en/> retrieved 10 March 2018

Yosso, T. J. (2005). Whose culture has capital? A critical race theory discussion of community cultural wealth. *Race ethnicity and education*, 8(1), 69-91. Retrieved from

<http://search.proquest.com/docview/62140898?accountid=14756>. *Race, Ethnicity and*

Education, 8(1), 69-91.

Appendices

Appendix A - **Initial focus group questions with community members concerned for African Americans residing in nursing facilities.** [This group was not formed due to time restriction]

Presentation of a summary of the literature: the existence of disparities, types, situations

State of Minnesota population, history of nursing facilities, current information

Nursing facilities where African Americans live

Study findings (Dr. Shippee) of minority residents in MN nursing facilities and quality of life

Reflection time: after the short presentation, a guided conversation will engage those present:

What information presented was new to you?

What information presented made you curious to learn more?

What other information would you like to learn about?

What information made you interested in participating in this proposal?

Can you help me review these questions that I would like to ask the nursing facilities' residents I am going to meet with?

Appendix B - Proposed One-on-One Interview Questions for First Interview (with residents)

I am interested in learning about stories, experiences and opinions of the residents who are African Americans and are the minority in the facility.

What is the day to day living experiences of these residents, how do they enjoy life, activities, and socialize in their living situations?

What are certain aspects of their lived experiences that may inform facilities administrators, funders and policy makers?

What matters most for the individuals in the larger metropolitan area who care, are concerned about and wish to see their end of life be filled with enriching experiences?

How does the cultural background of a resident influence the quality of their lives in a facility where they are the minority?

What are your day-to-day experiences in this facility as an African American person and member of a minority group?

What affects your experiences as an African American and one of a few African Americans in the facility?

What factors being an African American and living here influences your experiences?

What about the facilities do you like most? Why?

What about the facilities do you like least? Why?

What activities do you participate in? Why?

What activities do you enjoy most? Why?

How does your life here compare to your former home life?

What do you miss most?

Appendix C – Resident Consent Forms**CONSENT FORM (1)****UNIVERSITY OF ST. THOMAS****African Americans Aging in Minnesota's Urban Facilities: A Phenomenological Study of their Lived Experiences**

I am a doctorate student at the University of Minnesota seeking to obtain a doctorate degree in Critical Pedagogy. Critical studies seek to understand and uncover suffering that does not need to exist. I am conducting a research study about *quality of life of African American (US Born) elders living in Minnesota nursing facilities Twin Cities area*. I invite you to participate in this research. You were selected as a possible participant because *your name was indicated to me by (facility staff, the administration of the facility, the Minnesota Department of Human Services)*. *You are known for being an active member of your community and your colleagues respect your opinion. You are also a leader in your African American community. I am interested in learning your perspectives, opinions and ideas from your position as an African American residing in a nursing facility.*

Please read this form carefully and ask any questions you may have before agreeing to be in the research study.

This research study is being conducted by: Antonia Apolinário-Wilcoxon, Dr. Eleni Roulis is my professor and dissertation chair, University of St. Thomas School of Education.

Background Information:

The purpose of this research study is: to learn about the quality of life of certain populations residing in nursing facilities. I am interested in learning about stories, experiences and opinions of the residents who are African Americans and are the minority in the facility. What is the day to day living experiences of these residents, how do they enjoy life, activities, and socialize in their living situations? What are certain aspects of their lived experiences that may inform facilities administrators, funders and policy makers? What matters most for the individuals in the larger metropolitan area who care, are concerned about and wish to see their end of life be filled with enriching experiences? How does the cultural background of a resident influence the quality of their lives in a facility where they are the minority?

Procedures. If you agree to be in this research study, I will ask you to do the following things:

- To meet with me for about 60 minutes to interviews over a period of three months.

- Two interviews per month.
- As I will be interviewing other people, I need your permission to take notes and record the conversation. This will help me later to compile everyone's responses.
- My questions will be about your early life experiences, your recollections of your childhood, your family, important events in your life, as an African American person.
- I also have questions about your life in the nursing facility, your day to day experiences, your likes and dislikes, as an African American person.
- I hope we can conclude the interview by meeting six times
- I would like to check back with you to make sure I have captured your comments correctly
- I will also share with you the combined findings I collect. Your name will be kept in strict confidentiality.

Risks and Benefits of Being in the Research Study:

There are minor risks and inconveniences to participating in this study. First, you will need to take about six hours of your time to participate in the study over three months. Second, you may feel uncomfortable with someone taking notes/ or recording as they speak to you. However, there are no significant risks to participation. And you are not required to answer any questions with which you are uncomfortable.

The benefit to participation is that your opinion, along with the others in this study, might provide new information that improves the quality of life in the nursing facilities and provides a unique inside view of the facility from someone such as you. You hold important perspective, wisdom and knowledge. I would like to learn from you.

Confidentiality:

The records of this research study will be kept confidential. In any sort of writing I publish, I will not include information that will make it possible to identify you in any way. As I am a student during this period, some of your comments and the comments of others I interview will be shared with my professor and others who are members of my dissertation committees. The types of records I will create include: *recordings, transcripts, master list, computer records, which I will maintain in my home computer. These items will be stored in my home, or in a password protected file at the University of St. Thomas. The only people who will have access to*

the information are me and my professor. My professor is bound by a confidentiality agreement, and I will not use your name or any identifying information that can be tracked to your identification. I will use pseudonyms (a nickname). All tapes and identifying information will be destroyed upon completion of my study.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the nursing facility where you live, the Minnesota Department of Human Services, or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until _____. Should you decide to withdraw data collected about you that has already been added to the study will be used. You are also free to skip any questions you do not wish to answer.

Contacts and Questions

My name is *Antonia Apolinário-Wilcoxon*. You may ask any questions you have now. If you have questions later, you may contact me at my cell number 952-200-5334. You may contact my instructor, Dr. Eleni Roulis, at _____. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the research study. By signing below, I also consent to the use of audio tape or video recording during the interviews.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Signature of Instructor

Date

Informed Consent Form (2) adapted from Dedeaux, A.J., 2010 dissertation (A Phenomenological study of African American Women and Care Receipt, Tulane University)

University of St. Thomas

Instructions for Completing the University of St. Thomas Consent Form Template

Principal Investigator: Antonia Apolinario-Wilcoxon

Study Title: African Americans Aging in Minnesota's Urban Facilities: A Phenomelological Study of their Lived Experiences

Introduction

You are invited to participate in a research study to learn what it is like to live in a nursing facility as an African American. We are interested in learning your opinion about what you like or dislike living in the nursing home as a person of African descent. Your health care providers and/or others who provide care for you in the nursing home would like to learn how to make your quality of life according to your wishes and preferences. What you like/dislike in the manner of your routine daily care such as dressing, bathing, eating taking our medications, or doing other activities that help you remain healthy and strong. You are being asked to participate because you are part of a large segment of our population for whom we have very little information about your desires for nursing facility daily assistance you receive.

Why is this study being done?

The purpose of this research study is to find out, from you, what you would want others to know about how you like to be cared for in this facility. This study is being conducted to learn from you how you want others to care for you while you are in the facility. What do you want family members, the health care, your community or others to know about your desires for helping services?

What are the study procedures? What will I be asked to do?

If you agree to take part in this study, you will then be asked to answer interview questions. You will be asked to describe the kind of care you would want others to provide for you.

The study will be conducted in the nursing facility where you live, in a place that is most

comfortable to you. The interview can take one hour or less, depending on our ability to talk about the kind of care you want/like.

The interview will be audio taped. It will be necessary to have you agree or disagree to have the interview audio taped. This agreement/disagreement will be made part of this consent form. At the end of the interview, I will transcribe the conversation, label the audio tape with identifying number and a fictitious name and I will store the audio tape in a locked file where I am the only one with access. Once the study is complete the tapes will be erased. The study should be complete by _____.

What are the risks or inconveniences of the study?

We believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the interview. I will schedule time and place most accommodating to your needs. If you agree I will arrive and depart at your expressed time.

Breach of confidentiality may exist. I will minimize this risk by transcribing each interview before I begin another interview. Your personal information will be placed in locked file where I am the only one with access. Your interview will be marked with identifiers specific to your interview only. Your participation will not be discussed with anyone except those necessary the University of St. Thomas officials.

What are the benefits of the study?

You may not directly benefit from this research; however, we hope that your participation in the study may provide a knowledge base on which health providers and anyone providing caring services to African Americans similarly situated can benefit.

Will I receive payment for participation?

You will not be paid to be in this study.

Are there costs to participate?

There are no costs to you to participate in this study.

How will my personal information be protected?

You will be asked your name, your age, and no other personal information will be necessary for this study. Once your interview is complete it will be transcribed and assigned a number and a fictitious name. A master list with your name will be kept in a locked file where I am the only one to have access.

Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

You do not have to answer any question that you do not want to answer.

Who do I contact if I have questions about the study?

Take as much time as you like before you make a decision to participate in this study. We will be happy to answer any question you have about this study. If you have further questions about this study, want to voice concerns or complaints about the research or if you have a research-related problem, you may contact the principal investigator, Antonia Apolinario-Wilcoxon at (952) 200-5334, or my dissertation chair, Dr. Eleni Roulis at _____

If you would like to discuss your rights as a research participant, discuss problems, concerns, and questions; obtain information; or offer input with an informed individual who is unaffiliated with the specific research, you may contact the University of St. Thomas Human Research Protection Office at _____ or email at _____

Documentation of Consent:

I have read this form and decided that I will participate in the research project described above. Its general purposes, the particulars of involvement, possible risks, inconveniences and the use of audio taping have been explained to my satisfaction. I have been advised that I can withdraw from this study at any time. My signature also

indicates that I have received a copy of this consent form.

I agree/ disagree to audio taping.

Signature _____ Date: _____

Code for participant _____

Person Obtaining Consent _____

Date _____

Nursing Facility Name _____ Code: __

Address: _____

Appendix D - Invitation to African American Resident Participants Residing in Nursing Facility

Dear (African American community member):

You have been recommended as someone who might have members of your congregation that might be interested in taking part in my research study. My study title is:

African Americans Aging in Minnesota's Urban Facilities: A Phenomenological Study of their Lived Experiences (in nursing facilities)

The objective of the study is to find out how African American elders experience life in nursing homes in Minnesota cities where they are a minority population. What is their opinion, perspectives and ideas of their day to day living in these facilities, what they like/dislike, would like to see different? I will interview ten elderly residents (five in each facility).

I am requesting entry into your facility to obtain answers from some of your residents. This is a confidential study in which their names will not be disclosed. The name of your facility is only known by the Minnesota Department of Human Services which provided me with the name of your facility.

I will hold six interviews with each individual resident, plus three staff providing direct care to the residents: two are African American, one is from another culture. I am interested in learning how the nursing facility direct staff perceive their work with African American elders, what they like/dislike, how they talk about the elders in their charge, and their ideas for change/modification.

I am interested in learning from the African American elders their opinion about their living day to day routine in the nursing facilities, their experiences as African American people, what they like most, what they dislike, and what they miss.

I am requesting use of your facility and assistance in identifying five African American older adults to participate in the study, ages 75 to 85 years of age, male or female. There will be six meetings lasting no longer than 60 minutes, twice each month for three months. I am requesting use of your facility in a space in which there would not be any disruption to other residents and when it does not interfere with planned activities of these residents.

I would like to interview two residents separately each time I come to your building with a one-hour interval in between interviews.

I will also identify three persons on your staff I would like to interview outside of their working hours. I will appreciate it if you can advise me which employees providing direct services to the residents of your facility I may contact. I am interested in learning about their profession, their choice to work with elders and their perspectives on elders from African American culture as well as a culture different than their own. I would like to interview two African American employees and one employee who is not African American. My request is to meet them outside working hours.

Should this be of interest to anyone in your staff, kindly contact me with their names and contact information. I would like to follow up with a visit once we can establish the schedule. I can also meet all of them as a group to introduce myself and talk about the study to answer any questions they may have.

Thank you for your time and I look forward to working with you.

Sincerely,

Antonia Apolinario-Wilcoxon

1310 Preston Lane

Hopkins MN 55343

952-200-5334 (cell)

Appendix E - Letter requesting assistance in the formation of an African American advisory group to a study

Dear (pastor of an African American church):

You have been recommended as someone who might have members of you congregation that might be interested in taking part in my research study. My study title is:

African Americans Aging in Minnesota's Urban Facilities: A Phenomological Study of their Lived Experiences

The objective of the study is to find out how African American elders experience life in nursing homes in Minnesota cities where they are a minority population. What is their opinion, perspectives and ideas of their day to day living in these facilities, what they like/dislike, would like to see different? I will interview ten elderly residents (five in each facility).

I am seeking to form an advisory group to guide me in this study. I am an immigrant to the US, originally from Brazil and living and working in Minnesota for over 30 years, I am concerned that the study is ethical, transparent, and culturally appropriate and accurately depicts the voices of the residents. This group would counsel me as I proceed with my studies.

I will hold six interviews with each individual resident, plus three staff providing direct care to the residents: two are African American, one is from another culture. I am interested in learning how the nursing facility direct staff perceive their work with African American elders, what they like/dislike, how they talk about the elders in their charge, and their ideas for change/modification.

I am interested in learning from the African American elders their opinion about their living day to day routine in the nursing facilities, their experiences as African American people, what they like most, what they dislike, and what they miss.

I am requesting use of your facilities and assistance in identifying African American older adults to participate in the study as my senior advisors (over the age of 65). There will be three meetings lasting no longer than 90 minutes:

An introductory meeting to talk about my study, what I have learned from the available literature: there is disparities in quality of life and quality of care experienced by African American elders in nursing homes. We do not know the cause, circumstances, or a description of the disparities as voiced by the residents.

A second meeting to share with the advisory group the preliminary results: the answers collected from my six interviews from the residents, and the three interviews from the direct staff. Summary of findings, and potential conclusions. To share with them my initial results and ask if what I found is in line with what they know about African American elders residing in a nursing facility.

The third and last meeting will happen when I am at the final stages of the study and preparing for dissertation defense.

Should this be of interest to anyone in your congregation, kindly contact me with their names and contact information. I would like to form a group of eight individuals. I would like to start the interviews in _____ months. I plan to spend three months interviewing, spending two months organizing the data collected and analyzing them to prepare for the second meeting.

Thank you for your time and I look forward to working with you.

Sincerely,

Antonia Apolinario-Wilcoxon

1310 Preston Lane

Hopkins MN 55343

952-200-5334 (cell)

Appendix F - Interview Protocol – Nursing Facility Resident*

Individual Interview Session Agenda

This protocol describes the key aspects and timing interview sessions. Session(s) with participants will have three¹ distinct parts:

Introduction

Interview questions administration

Informal Discussion and closure

Part 1: Session Introduction (5 minutes)

- a. Introduce myself
- b. Review the purpose of my visit; thank the resident for the gift of her/his time/wisdom/knowledge
- c. Review the informed consent, answer any questions, ask resident to sign two copies, keep one and give one to resident

Part 2: Interview Questions & Answers Session (50 minutes)

- a. Ask resident if he/she is ready to start. Verbally, go over procedures:

To meet with me for about 60 minutes to interviews over a period of three months.

Two interviews per month.

As I will be interviewing other people, I need your permission to take notes and record the conversation. This will help me later to compile everyone's responses.

My questions will be about your early life experiences, your recollections of your childhood, your family, important events in your life, as an African American person.

I also have questions about your life in the nursing facility, your day to day experiences, your likes and dislikes, as an African American person.

I hope we can conclude the interview by meeting six times

I would like to check back with you to make sure I have captured your comments correctly

¹ One-on-one sessions will **not** have the meet & greet/discussion after the survey session.

- b. Ask if OK to record and start the recording
- c. Ask first question and proceed to the next questions.
- d. Stop to give further clarification, explanation, without changing the meaning if different wording is necessary, etc.
- e. Note clarification requests for later analysis

Part 3: Informal Discussion and Closure (5 minutes)

Repeat thanking resident for the time, comment on her contribution and bid good bye.

Scheduling Sessions

Researcher will work with DHS, nursing facility administrator to schedule interviews.

Researcher calls the nursing facility the previous day to confirm appointment. Researcher arrives at least 15 minutes early. If possible, ask to schedule two persons per visit. Allow time for notetaking, perspective, and reflection, etc. between interviews. Ask nursing facilities if OK to bring water/juice, for resident.

Researcher will contact staff directly and schedule interview time, location as convenient to the interviewee. Researcher arrives on time. If meeting at a café or restaurant, researcher will cover staff's costs.

In preparation for interviews, researcher develops form that will be completed. Participant ID codes will be developed and assigned before the date of interviews.

Assigning Participant ID Codes

For assigning Participant ID Codes, researcher will use the following protocol to assign a code for each participant:

[2-letter initials of residents] [2-digit day of interview] [2-digit month] [Number of the order in which resident was interviewed]

Example 1: For resident named Amy Smith interview, interviewed on 10 August, and the first resident to be interviewed. Participant ID Code: AS10Aug01

Assign fictitious names for inclusion in dissertation.

Interview sessions should always start on time to be respectful of the study participant's gift of time and talent.

These are general guidelines to help establish a climate of trust and openness to facilitate the interview session as well as ensure the accuracy of the data.

The researcher's primary role is to communicate the questions and provide clarification if needed.

Engage the respondent/respondents. Establish rapport with all. Be courteous, thanking each participant taking time for the session and encouraging them to be comfortable and emphasize how valuable their input would be towards understanding residents' experiences as African American persons. The validity of the project is critical in establishing rapport and making connections to the relevance of the interview process. Explain the reasons for the study and how their responses will be used, using the script above and the informed consent policy.

Be enthusiastic. It is usually contagious and will help you establish rapport.

Convince each respondent that his/her answers are important. The best incentive to the respondent is often just being heard.

Create a sense of privacy for the respondent. Not sure how this should be rephrased. Consider the nature of the questions. Be sensitive to potential sources of embarrassment for the respondent. Privacy enhances the climate of confidentiality during a session.

Keep the session on track. Maintain control of the session but be diplomatic and respectful. Respecting and recognizing the agendas that respondents may bring to the session is important, but this does not have to mean surrendering to them. Only questions that are meant to clarify or

aid in understanding a survey question should be answered during the session. All other questions should be saved for the end of the session.

PARTICIPANT OBSERVATION

The nursing facility occupies a large urban area the Twin Cities. Its buildings are an imposing presence in the neighborhood, and I have the impression that it may be viewed as an employer for several residents. The lower level staff, aides, receptionists on each floor of the building I visited were minority individuals.

INSTRUCTIONS & FIELD REPORT FORM

Name of participant observer: Antonia Apolinario-Wilcoxon

Meeting title / purpose: First session of data collection. Four residents were identified by the director of social services for me to interview.

The purpose of the interviews was to gauge the residents' experiences of life in a nursing facility.

Date & time (start time & end time) of observation: November 20, 2017 9:00 – 3:00

Location of observation: Downtown Minneapolis

Information about all interview participants: Four residents of the nursing facility.

Meeting focus: Residents received flyer the previous week, asking if they would like to participate in interview for my study. (Appendix P).

First contact with residents: Introduction, review of consent language, item by item, check for comprehension and if any questions, conduct interview with prepared questions. Signatures and handing out copy of consent form for their files or to share with relatives/others.

 x Nursing Facility

Other meeting focus (specify here): N/A

This document's name: _____

MEETING SUMMARY (including purpose, goals & outcomes):

The meeting ran smoothly: each resident was wheeled in a wheelchair. They were allotted 1 hour with me, which was sufficient to include introduction, explanation of language in consent form, questions, and beginning recording.

PARTICIPANT OBSERVER'S INITIAL COMMENTS & OBSERVATIONS: Day, date, time
("Systematic noting of activities, events, behaviors and objects... visually as well as through other senses (Marshall and Robinson, 2011, p. 139):" noisy environment? Tone of interactions? Demeanor of people present?

A nursing home is an institution. As such, it has all the signs of a closed system in which freedom of movement on who comes in and who gets out is closely monitored. I do not want to grow old there. When I first arrive, I have to sign in, my name, whom I am visiting, the time in which I arrive, and I wear have to wear a visitor's badge, for security reasons, I assume. When I asked about parking, I was told that there was no parking available. I was to use the two-hour parking, move the car between breaks. The receptionist offered "we all have to do the same."

It is not a welcoming space. I visited the institution on several occasions in order to meet leadership, explain my study, share the paperwork, submit a copy of the IRB letter of approval, obtain their permission to enter the facility, and finally to interview the African American residents. On the days in which I was scheduled to interview, I obtained vacation time off work and let the staff know of the time availability. On the first day, I was able to interview four individuals. They were all brought to me by this staff, in their wheelchairs. I was given a conference room. The room is connected to two offices being used by staff. There was no privacy as I had requested. Residents seemed to notice and hesitated in their answers each time someone left or entered the office from the conference room. The space was quiet otherwise.

I also had a service appointment for my car earlier one morning. It ended up with an unexpected delay and I let the staff know. She cancelled all the visits for the remaining couple of days. I was dumbfounded. I did not return to the office, but spent the extra days writing and working from home.

I noticed that thus far I have only met one person in management level position who is a person of color. The other individuals I met are all European Americans. I have the impression I am not welcome there. I had asked to have one hour in between interviews, so I could organize my notes, journal and prepare for the next resident. No such luck. When all were cancelled, I became highly concerned about the delay in my scheduled tasks per my dissertation chair. Was I going to have to forfeit my dream of a degree and thousands in student debt? At my age? There is no way I can re-start another doctorate degree program.

As a person on color in this space, it feels uncomfortable, un-welcome, I feel like I am an intruder.

Describe who said what? When? How was it responded?

PRIMARY OBSERVATION DATA:

Theme: The second round of interviews, visits to nursing facility

[1-3 sentence description of the interaction, if not obvious from the theme name above or "Speakers & their Comments."]

Description/Context of Interaction:

Returning to the nursing facility to complete the interview sessions before writing can begin. Time is running short. The days need to be used efficiently.

Speakers & Their Comments:²

This time around this researcher goes to the rooms where residents live. The floor is linoleum throughout. There is no rug by the bedside, or any floor covers. The space is sparse. Rooms have single bed, most are made as the residents are sitting on their wheelchairs. They greet me with anticipation. They sign the consent after I read the items and stop to ask if they have any questions. Signing presents a challenge for some. Their hands may no longer be strong or nimble to hold a pen, I jot an X after asking for their permission to do so. They wait patiently for my questions. Each resident is poised, attentive and start their responses as their faces open in broad smile to some happy memories or become somber to some difficult times. They are very alert to what they experienced. With exception due to their illness, their recollection is clear, crisp, and they are able storytellers. Some gesture to give emphasis to their accounts; others sit against the back of their chairs for comfort. Sometimes, one will ask me, did I tell you about that? Oh, let me tell you. There is laughter as they recollect their youthful adventures. There is sadness, or quiet anger at living under Jim Crow laws, comments that tell me that pain is still present, though it happened in distant past.

COMMENTS/ANALYSIS:

² Add as many (or as few) comments as necessary to describe the interaction related to each theme.

As I leave each room, I am in awe of what I just heard, I have so much to transcribe, how will I make sense of all these rich stories and experiences? Does anyone know what gems are kept in these buildings? I am also feeling bittersweet: they are hidden here, no one knows of their existence, except for close relatives, for those lucky enough to have them. How can what I learned inform others?

* Protocols adapted with permission from Jackie Copeland-Carson's, Nexus Community Partnership Evaluation, 2013, St. Paul, MN, this researcher worked on this evaluation project as a consultant.

Appendix G - Institutional Review Board (IRB) Approved Participant Consent Form**Participant Consent Form****[1009585-1] African Americans Aging in Minnesota's Urban Facilities: A Study of their Lived Experiences**

You are invited to participate in a research study about elder African Americans residing in a nursing home in the state of Minnesota. I invite you to participate in this research. You were selected as a possible participant because your name was given to me as a someone who meets the characteristics I seek in persons to interview. You are eligible to participate in this study because you are an African American, an elder and you reside in a nursing facility. You are also considered to be an active member of the nursing facility community and one whose opinions people listen to and respect. The following information is provided help you make an informed decision whether or not you would like to participate. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Antonia Maria Apolinário-Wilcoxon, a doctorate candidate at the University of St. Thomas, School of Education Program in Critical Pedagogy. Research advisor is Dr. Eleni Roulis, Ph.D. This study was approved by the Institutional Review Board at the University of St. Thomas (pending approval).

Background Information

The purpose of this research study is: to learn about the quality of life of certain populations residing in nursing facilities. I am interested in learning about stories, experiences and opinions of the residents who are African Americans and are the minority in the facility. I would like to learn about your day to day living experiences as a nursing home resident, how do you enjoy life, activities, and socialize in your living situations? what are certain aspects of your lived experiences that may inform facilities administrators, funders and policy makers? What matters most for African Americans in the larger metropolitan area who care, are concerned about and wish to see their end of life be filled with enriching experiences? How does the cultural background of a resident influence the quality of their lives in a facility where they are the minority?

Procedures

If you agree to be in this research study, I will ask you to do the following things:

- To meet with me for about 60 minutes to interviews over a period of two months.
- One interview per month. Total 2 interviews.
- The interviews will take place at your nursing facility.
- As I will be interviewing other people, I need your permission to take notes and record the conversation. This will help me later to compile everyone's responses.
- My questions will be about your early life experiences, recollections of your childhood, your family, important events in your life, as an African American person.
- I also have questions about your life in the nursing facility, your day to day experiences, your likes and dislikes, as an African American person.
- I hope we can conclude the interview by meeting two times
- I would like to check back with you to make sure I have captured your comments correctly
- I will also share with you the combined findings I collect. Your name will be kept in strict confidentiality.

Risks and Benefits of Being in the Study

This research study has some risks. You may feel that recalling painful memories is difficult. You will do not need to answer a question that makes you uncomfortable. Please let me know and I will move to the next (different) question. You may tire from the number of questions. Please let me know and we will stop and continue our interview later.

There are no direct benefits for participating in this research study.

Compensation

There is no compensation for participating in this research study.

Privacy

Your privacy will be protected while you participate in this research study. The records of this research study will be kept confidential. In any sort of writing I publish, I will not include information that will make it possible to identify you in any way. As I am a student during this

period, some of your comments and the comments of others I interview will be shared with my professor and others who are members of my dissertation committee. The types of records I will create include: recordings, transcripts, master list, computer records, which I will maintain in my home computer. These items will be stored in my home, or in a password protected file at the University of St. Thomas. The only people who will have access to the information are me and my professor. My professor is bound by a confidentiality agreement, and I will not use your name or any identifying information that can be tracked to your identification. I will use pseudonyms (a nickname). All tapes and identifying information will be destroyed upon completion of my study.

All signed consent forms will be kept for a minimum of three years upon completion of the study. Institutional Review Board officials at the University of St. Thomas reserve the right to inspect all research records to ensure compliance.

Voluntary Nature of the Study

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the nursing facility where you live, the Minnesota Department of Human Services, or the University of St. Thomas. There are no penalties or consequences if you choose not to participate. If you decide to participate, you are free to withdraw at any time without penalty or loss of any benefits to which you are otherwise entitled. All data collected from you will be destroyed if you choose to withdraw. You can withdraw by contacting Antonia Wilcoxon at 952-200-5334. You are also free to skip any questions I may ask if they make you uncomfortable, though they will not provide the complete information needed for this research study. There will be no pressure for you to answer the questions.

Contacts and Questions

My name is Antonia Wilcoxon. You may ask any questions you have now and any time during or after the research procedures. If you have questions later, you may contact me at 952-200-5337, or my dissertation advisor, Dr. Eleni Roulis, Ph.D., at the University of St. Thomas, telephone number 651-962- 4837. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6035 or muen0526@stthomas.edu with any questions or concerns.

Statement of Consent

I have had a conversation with the researcher about this study and have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I give permission to be audio recorded during this study.

You will be given a copy of this form to keep for your records.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix H - Institutional Review Board (IRB) Approved Direct Service Staff Consent Form



Direct Service Staff Consent Form

[1009585-1] African Americans Aging in Minnesota's Urban Facilities: A Study of their Lived Experiences

You are invited to participate in a research study about elder African Americans residing in a nursing home in the state of Minnesota. I invite you to participate in this research study. You are eligible to participate in this study because you are a worker providing direct care in a nursing facility where African American elders reside. The following information is provided in order to help you make an informed decision whether or not you would like to participate. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Antonia Maria Apolinário-Wilcoxon, a doctoral candidate at the University of St. Thomas, School of Education Program in Critical Pedagogy. Research advisor is Dr. Eleni Roulis, Ph.D. This study was approved by the Institutional Review Board at the University of St. Thomas (pending approval).

Background Information

The purpose of this research study is: to learn about the quality of life of certain populations residing in nursing facilities. I am interested in learning about stories, experiences and opinions of the residents who are African Americans and are the minority in the facility. I would like to learn about the day to day living experiences as a nursing home resident, how they enjoy life, activities, and socialize in living situations? what are certain aspects of their lived experiences that may inform facilities administrators, funders and policy makers? What matters most for African Americans in the larger metropolitan area who care, are concerned about and wish to see their end of life be filled with enriching experiences? How does the cultural background of a resident influence the quality of their lives in a facility where they are the minority?

Procedures

If you agree to be in this research study, I will ask you to do the following things:

- To meet with me for about 60 minutes to interviews over a period of two months.
- Up to three interviews per month. Total 2 interviews.
- The interviews will take place at a place of your choosing.
- As I will be interviewing other people, I need your permission to take notes and record the conversation. This will help me later to compile everyone's responses.
- My questions will be about your early professional life experiences, your decision to work in the field of caregiving of elderly people.
- I also have questions about your perspectives of life in the nursing facility, the residents' day to day experiences, their likes and dislikes, as an African American person.
- I hope we can conclude the interview by meeting three times
- I would like to check back with you to make sure I have captured your comments correctly
- I will also share with you the combined findings I collect. Your name will be kept in strict confidentiality.

Risks and Benefits of Being in the Study

This research study has no known risks.

There are no direct benefits for participating in this research study.

Compensation

There is no compensation for participating in this research study.

Privacy

Your privacy will be protected while you participate in this research study. The records of this research study will be kept confidential. In any sort of writing I publish, I will not include information that will make it possible to identify you in any way. As I am a student during this period, some of your comments and the comments of others I interview will be shared with my professor and others who are members of my dissertation committees. The types of records I will create include: recordings, transcripts, master list, computer records, which I will maintain in my home computer. These items will be stored in my home, or in a password protected file at the University of St. Thomas. The only people who will have access to the information are me and my professor. My professor is bound by a confidentiality agreement, and I will not use your

name or any identifying information that can be tracked to your identification. I will use pseudonyms (a nickname). All tapes and identifying information will be destroyed upon completion of my study.

All signed consent forms will be kept for a minimum of three years upon completion of the study. Institutional Review Board officials at the University of St. Thomas reserve the right to inspect all research records to ensure compliance.

Voluntary Nature of the Study

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the nursing facility where you work, the Minnesota Department of Human Services, or the University of St. Thomas. There are no penalties or consequences if you choose not to participate. If you decide to participate, you are free to withdraw at any time without penalty or loss of any benefits to which you are otherwise entitled. All data collected from you will be destroyed if you choose to withdraw. You can withdraw by contacting Antonia Wilcoxon at 952-200-5334. You are also free to skip any questions I may ask if they make you uncomfortable, though they will not provide the complete information needed for this research study. There will be no pressure for you to answer the questions.

Contacts and Questions

My name is Antonia Wilcoxon. You may ask any questions you have now and any time during or after the research procedures. If you have questions later, you may contact me at 952-200-5337, or my dissertation advisor, Dr. Eleni Roulis, Ph.D., at the University of St. Thomas, telephone number 651-962- 4837. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6035 or muen0526@stthomas.edu with any questions or concerns.

Statement of Consent

I had a conversation with the researcher about this study and have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I give permission to be audio recorded during this study.

You will be given a copy of this form to keep for your records.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix I - Institutional Review Board (IRB) Approved Nursing Facility Administrator Consent Form



Nursing Facility Administrator Consent Form

[1009585-1] African Americans Aging in Minnesota's Urban Facilities: A Study of their Lived Experiences

You are invited to participate in a research study about elder African Americans residing in a nursing home in the state of Minnesota. I invite you to participate in this research study. You are eligible to participate in this study because you are an administrator in a nursing facility where African American elders reside. The following information is provided in order to help you make an informed decision whether or not you would like to participate. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Antonia Maria Apolinário-Wilcoxon, a doctoral candidate at the University of St. Thomas, School of Education Program in Critical Pedagogy. Research advisor is Dr. Eleni Roulis, Ph.D. This study was approved by the Institutional Review Board at the University of St. Thomas (pending approval).

Background Information

The purpose of this research study is: to learn about the quality of life of certain populations residing in nursing facilities. I am interested in learning about stories, experiences and opinions of the residents who are African Americans and are the minority in the facility. I would like to learn about the day to day living experiences as a nursing home resident, how they enjoy life, activities, and socialize in living situations? What are certain aspects of their lived experiences that may inform facilities administrators, funders and policy makers? What matters most for African Americans in the larger metropolitan area who care, are concerned about and wish to see their end of life be filled with enriching experiences? How does the cultural background of a resident influence the quality of their lives in a facility where they are the minority?

Procedures

If you agree to be in this research study, I will ask you to do the following things:

- To meet with me for about 60 minutes to interviews over a period of two months.
- Up to two interviews per month. Total 2 interviews.
- The interviews will take place at your office or a place you find more convenient.
- As I will be interviewing other people, I need your permission to take notes and record the conversation. This will help me later to compile everyone's responses.
- My questions will be about your early professional life experiences, your decision to work in the field of caregiving of elderly people.
- I also have questions about your perspectives of life in the nursing facility, the residents' day to day experiences, their likes and dislikes, as an African American person.
- I hope we can conclude the interview by meeting two times
- I would like to check back with you to make sure I have captured your comments correctly
- I will also share with you the combined findings I collect. Your name will be kept in strict confidentiality.

Risks and Benefits of Being in the Study

This research study has no known risks.

There are no direct benefits for participating in this research study.

Compensation

There is no compensation for participating in this research study.

Privacy

Your privacy will be protected while you participate in this research study. The records of this research study will be kept confidential. In any sort of writing I publish, I will not include information that will make it possible to identify you in any way. As I am a student during this period, some of your comments and the comments of others I interview will be shared with my professor and others who are members of my dissertation committee. The types of records I will create include: recordings, transcripts, master list, computer records, which I will maintain in my home computer. These items will be stored in my home, or in a password protected file at the University of St. Thomas. The only people who will have access to the information are me and my professor. My professor is bound by a confidentiality agreement, and I will not use your

name or any identifying information that can be tracked to your identification. I will use pseudonyms (a nickname). All tapes and identifying information will be destroyed upon completion of my study.

All signed consent forms will be kept for a minimum of three years upon completion of the study. Institutional Review Board officials at the University of St. Thomas reserve the right to inspect all research records to ensure compliance.

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Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the nursing facility where you work, the Minnesota Department of Human Services, or the University of St. Thomas. There are no penalties or consequences if you choose not to participate. If you decide to participate, you are free to withdraw at any time without penalty or loss of any benefits to which you are otherwise entitled. All data collected from you will be destroyed if you choose to withdraw. You can withdraw by contacting Antonia Wilcoxon at 952-200-5334. You are also free to skip any questions I may ask if they make you uncomfortable, though they will not provide the complete information needed for this research study. There will be no pressure for you to answer the questions.

Contacts and Questions

My name is Antonia Wilcoxon. You may ask any questions you have now and any time during or after the research procedures. If you have questions later, you may contact me at 952-200-5337, or my dissertation advisor, Dr. Eleni Roulis, Ph.D., at the University of St. Thomas, telephone number 651-962- 4837. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6035 or muen0526@stthomas.edu with any questions or concerns.

Statement of Consent

I had a conversation with the researcher about this study and have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I give permission to be audio recorded during this study.

You will be given a copy of this form to keep for your records.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

APPENDIX J - Early Process of Community Engagement at DHS for Disparities Reduction**Minnesota Department of Human Services**

Priority to Reduce Disparities: Performance Measures

The Minnesota Department of Human Services has established a priority to reduce disparities in service access and outcomes for racial and ethnic populations. The following performance measures, established in January 2010, will be used to assess progress in achieving this priority.

1. Percentage of children who do not experience repeated abuse or neglect within 12 months of a prior accepted report (outcome).
2. Number of children who spent some time in out-of-home care compared to their representation in the Minnesota child population (representation).
3. Children adopted in fewer than 24 months from the time of the latest removal from their home (outcome).
4. Percentage of Diversionary Work Program or Minnesota Family Investment Program participants in a baseline quarter who are working at least 30 hours per week or off cash assistance in the same quarter of the year three years later. This is known as the MFIP/DWP Self-Support Index (outcome).
5. Percentage of clients who successfully complete a chemical dependency program (outcome).
6. Reduction in recidivism following chemical dependency treatment, as measured by treatment readmission or detox admission in the year following discharge from treatment (outcome).
7. Changes in a child's functioning, mental health, and developmental assets across settings and over time, as measured by the Child and Adolescent Service Intensity Instrument and Strengths and Difficulties Questionnaire (outcome).
8. Changes in an adult's functioning, mental health, and stability in community living over defined time intervals as measured by the Program Outcomes Status Report (outcome).

9. Percentage of clients successfully remaining in the community 180 days following discharge from an inpatient psychiatric setting (outcome).
10. Percentage of lower-income Minnesotans who lack health care insurance as measured by the Minnesota Department of Health survey, conducted every three years (access).
11. Minnesota Health Care Program women enrollees ages 40 to 69 who received a mammogram (access).
12. Children up to 15 months old enrolled in Minnesota Health Care Programs who receive six well child check-ups (access).
13. Percentage of people with disabilities receiving publicly funded long-term care who live in community versus institutional settings (outcome).
14. Percentage of elders receiving publicly funded long-term care who live in the community versus institutional settings (access).
15. Percentage of elders participating in home and community-based services who have high needs (access and outcomes).

APPENDIX K - Leadership in Community Engagement (DHS)

DATE: XXXXX, 2009
TO: Commissioner Cal Ludeman
FROM: Katie Bauer, information officer
SUBJECT: Remarks at CLUES (Comunidades Latinas Unidas en Servicio)

Wednesday, Nov. 4, 2009

Mexico Conference Room

CLUES

720 East Lake St.

Minneapolis, MN 55047

Logistics

- A map of the CLUES location in Minneapolis is attached. A parking spot will be reserved for you in the building parking lot, which is located behind CLUES.
- The meeting begins at 11:30 a.m. and you are scheduled to speak at 11:45 a.m. for about 10 minutes.
- It is expected that about 35 representatives from nonprofit organizations that receive funding from DHS will be present for the meeting.
- Anne Barry and Antonia Wilcoxon will be at the meeting.

Your remarks

Antonia Wilcoxon will introduce you to the group. You will speak for about 10 minutes, then open the floor for questions for about five minutes. You are only scheduled to be at the meeting for 15 minutes, optimally, you would stay for the duration of the meeting. The main point you are making is that DHS is strongly committed to the reducing disparities priority.

Please let me know if there is anything else I can do to help you prepare for this meeting.

Disparities meeting – external stakeholders

Talking points/Opening remarks • Nov. 4, 2009

- Thank you for the invitation to attend this important meeting and to spend some time with all of you today.
- Thank **you** for being here, making an investment of your time and contributing your ideas and expertise as a partner in our project to reduce disparities in service access and outcomes for racial and ethnic populations.
- I'm here today to underscore the importance of this initiative, not only to my department and to your organizations, which carry out much of our work, but also to the people we serve. They are depending on us to do our very best with all the programs we oversee, providing an equal opportunity for recipients from all racial and ethnic groups to achieve successful outcomes.
- Although we want everyone in our programs to achieve successful outcome, the reality behind this project and the reason we're here today is that not all Minnesotans participating in human services programs experience the same results. Unacceptable disparities exist in many of our programs. We need to learn more about these disparities so we can work toward eliminating them.
- Recently our Senior Management Team reaffirmed our department's commitment to tracking, monitoring and learning more about disparities in human services programs so we can identify the magnitude and causes of disparities in service access and outcomes. In fact, this project is one of our department's seven top priorities. Priorities are like a roadmap for our department – to help guide us to where we need to go. We are committed to this priority and are putting much energy and resources behind our commitment. I am here today to tell you that we intend to see this project through.
- While some business areas in our department have been tracking outcomes by racial and ethnic populations over the years, many areas haven't done so because they haven't collected the data that way. One aspect of this project is to look at how we can change how we collect information. Because of the multiple computer systems behind our human services programs and the logistics, this is a great challenge. But we remain committed to this project and the many steps involved in making the data we collect more meaningful.
- In December, our Senior Management Team will be presented with a final list of access and outcome measures to track and to hold our agency accountable for. Your recommendations and feedback are important as this list is shaped.

- Understanding where these disparities exist in our department's programs and how they change over time is fundamental to our being able to develop interventions and strategies to address them and to set ongoing goals and to share our progress.
- Identifying and tracking this data over time will help the department to track the effect of any interventions we initiate. We plan to respond to and learn from the data gathered in this effort.
- You are here today for an important duty: To provide input on the set of recommended measures that we will use in this project. We welcome your ideas and input.
- We want this project to be successful. More importantly, we want the people who participate in human services programs to be successful and to move forward. And to do that, we need to hold ourselves accountable for making these programs work for all of their participants.
- In the few minutes I have left before I turn the floor over to our Chief Compliance Officer and Disparities Project Sponsor Anne Barry, I welcome any questions you have.

APPENDIX L - Comments and Discussion by Community Members in Attendance.**UNKNOWN: WHAT CAN WE DO, SO THIS TIME IT WILL WORK?**

- We have been doing this for at least 15 years.
- I have a concern that we don't seem to have made any progress
- How can we set [durable] outcomes, so we are not facing the same issues in 15 years?
- What happens after your tenure [as commissioner] is over?
- How can you ensure that this effort is sustained?
- Will future governors address this issue?
- We have had several initiatives on this issue, but we have seen poor outcomes across the spectrum
- Why are we still faced with this issue?
- We have been tracking over the years, and it seems that we will track more
- What comes next?
- Is there funding going to be invested in this?

FRAMEWORK HOPED FOR: WHAT IS DHS' INVESTMENT IN A GOOD STRUCTURE FOR SUSTAINABILITY OVER A LONG-TERM EFFORT?

- We need real leadership.
- I am pleased to learn that you are naming this a priority
- I am concerned about focusing on measures/metrics alone, we are talking about human beings, not just numbers
- There is a need to better communicate, look at cultural competency and address some missing pieces such as the intangibles, immeasurable
- Please do not include the word advisory – I have participated in many such advisories in which you invite community, I give my suggestions, you go away and decide differently

- I want to know if my input will be taken into account in your decisions
- There is a need to see representatives of cultural communities in the leadership of this effort
- I am not talking about using a token representative
- What is the membership of the council going to look like?
- To address issues of privacy/confidentiality consider inviting former recipients of services
- There is a need for more representatives of the American Indian Community

Potential partners in collaborative effort: WHAT OTHER INSTITUTIONS TOUCH THE LIVES OF MINNESOTANS WHO USE SOCIAL SERVICES? WHO ARE DHS PARTNERS IN SERVICE DELIVERY?

- The Minnesota Department of Health has set some tangible goals [for their Eliminating Health Disparities Initiative]
- Has DHS worked to align this work with the Social Determinants of Health—CDC's? It is at least 15 years old and is a grass roots approach to addressing this issue
- Wisconsin's approach will be studied as it involves counties in this effort to address health disparities, we have SHIP grants here in MN*
- What is being done around statues in place on the state service delivery model of county administered, state supervised?
- Outcome measures have a connection to the internal operational structure of the current human services delivery model via counties*
- There was an effort by the Governor this past legislative session to consolidate county social services delivery from an array of 87 counties to 15. It did not pass. We will try again. *
- 45 counties in MN are facing severe declining population*
- We will work with DEED and MDH regarding building capacity*

- Our work with counties entails understanding the impact of the measures: what do they mean? Is it positive? Negative? We need to use measures as a means to arrive at outcomes*
- Policy makers need to be infused with the social determinants of health philosophy
- We do not know whom we are not serving, and there is a need to address this

WORKFORCE: LOOKING TO THE FUTURE OF OUR COMMUNITIES

- There was a recent meeting with current and past legislators discussing serious concerns about trends being faced by the State of Minnesota
- Disparities becomes an economic issue because of work force issues, productivity is at risk of decreasing in the next 20 years
- The impact of health and well-being outcomes has direct impact on the ability of the work force to contribute to the economy
- We have to address productivity in the state by basing the work on the values of freedom, safety, and fairness

HISTORY OF BIAS//RELATIONSHIPS: LEARNING ABOUT HISTORICAL IMPACT TO MOVE FORWARD

- There is a need to understand whether the majority community perceive the circumstances of others (not in the majority community)
- We are learning that we don't always measure the right things*
- We need to improve, gain buy in and build on the hope of what we want to do better
- We need to understand why is help not available when it is asked for?
- Is the service delivery system barrier free?
- There is a need to find other and better ways to do this

DHS INTERNAL OPERATIONS – LEARNING ABOUT THE IMPACT/IS THERE WILL TO CHANGE?

- Operational structures, policies and procedures need to develop within this framework
- To what extent do these over representation issues are created at the ground level?
- How can we measure the degree to which we implement measures upholding the principles of reducing disparities?
- Is there an examination on how program recipients are affected by policy change?
- How is the delivery of resources managed when there is a crisis? Is there care to not undercut communities of color?
- There needs to be a different set of attitudes, values that allows those who have been left behind to be empowered
- How do Whites see the relevance of our community (of color)?
- A paradigm shift needs to happen
- It seems that as we measure these there are populations represented in multiple measures

Systemic change that adheres to principles of reducing disparities

Social Determinants of Health

Workforce projections

Measures: quantitative and qualitative

Representative and inclusive leadership

Operational structure to sustain effort: policies and procedures, staff, resources

Decision points adhere to principles of disparities reduction

Policy needs to take into account social determinants of health.

APPENDIX M - Institutional Review Board Letter



Date: July 14, 2017

To: Antonia Apolinario-Wilcoxon

From: Sarah Muenster-Blakley, Institutional Review Board

Project Title: [1009585-1] African Americans Aging in Minnesota's Urban Facilities: A Phenomenological Study of their Lived Experiences

Reference: New Project

Action: Project Approved

Approval Date: July 14, 2017

Expiration: July 13, 2018

Dear Antonia:

I have read your protocol and approved your project as reflected in the modifications that you submitted. Please note that all research conducted in connection with this project title must be done in accordance with this approved submission.

Please remember that informed consent is a process beginning with a description of the project and assurance that the project is understood by the participants and their signing of the approved consent form. The informed consent process must continue throughout the project via a dialogue between you and your research participants. Federal law requires that each person participating in this study receive a copy of the consent form. All research records relating to participant consent must be retained for a minimum of three years after completion of the project.

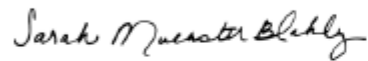
Amendments or changes to targeted participants, risk level, recruitment, research procedures, or the consent process as approved by the IRB must be reviewed and approved by the IRB prior to your making changes to your research study. No changes may be made without IRB approval except to eliminate apparent immediate hazards to the participant.

Any problems involving project participants or others must be reported to the IRB within one (1) business day of the principal investigator's knowledge of the problem. Any non-compliance or complaints relating to the project must be reported immediately.

Approval to work with human subjects in connection with this project will expire on **July 13, 2018**. This project requires continuing review on an annual basis. Documentation for continuing review must be received at least two weeks prior to the expiration date of **July 13, 2018**.

Please direct questions at any time to Sarah Muenster-Blakley at (651) 962-6035 or muen0526@stthomas.edu. I wish you success with your project!

Sincerely,



Sarah Muenster-Blakley, M.A.
Chair, Institutional Review Board

APPENDIX N Nursing Facility Letter

**Augustana Health Care Center of Minneapolis***An Affiliate of Augustana Care Corporation*

The mission of Augustana Care Corporation is to serve God by fostering fullness of life for the elderly and other people in need through the provision of healthcare, housing and other services in a Christian environment.

03/24/2017

To: Whom it may concern

RE: Ms. Antonia Apolinário-Wilcoxon, MIM, Ed.D., ABD Critical Pedagogy

This letter is a consent of agreement with Antonia Aolinario-Wilcoxon to proceed with her request to conduct informational qualitative research studies at Augustana Minneapolis, a skilled nursing facility serving elderly and medically vulnerable patients. This agreement is limited to the necessary actions needed to complete the doctoral research project regarding “**African Americans Aging in Minnesota’s Urban Facilities: A Phenomenological Study of their Lived Experiences**”. Antonia will be required to gain individual consent from residents prior to enrollment in the qualitative research project. If you have any questions regarding this consent to initiate research at Augustana Health Care, Minneapolis Campus; Please contact, Kaleeca Bible, Director of Nursing @ 612-238-5337

Kaleeca Bible B.S.N., P.H.N., (D.O.N)

Director of Nursing

APPENDIX O - Interviews

Ms. Agnes is an immigrant to Minnesota. *"She used to be married to a man who left her and most of her money. She is from Central America and comes from a family of wealth. She had difficulty talking articulating her sentences but tried so she would be understood. She answered questions speaking about her loving family, how they moved her and her siblings to another school in another island to go to better school and to learn English. They owned one of the biggest houses in the island of her birth. She was reared by her grandmother while going to private school.*

Favorite memories were going to the movies, enjoying Mickey Mouse and American Westerns movies. She is the oldest of three children, and they all went together. She had a sheltered childhood buffered by wealth and protective parents. She did not experience racism as a child. The elderly person was respected in her community of origin. She notices that it is different here in the US. She is a former classroom teacher and recalls she was one of the top teachers, often referenced as a model for student-teachers to come and observe her classes. She recalls how students brought their parents and introduced them to her. She notices that students here talk back to their teachers. She tried to maintain discipline and never raised her voice."

When asked, she said that she would describe a nursing home *"as place where you care for elderly - giving them meds; if they are unable to walk, toileting, my aides are sweet. They take good care of me, they help me shower, with Marci leaving puts stress on m I would describe a nursing home as a place where you care for elderly - giving them meds; if they are unable to walk, toileting, my aides are sweet. They take good care of me, they help me shower, with Marci leaving puts stress on me, as I like her very much. We share the same middle name. This is home away from home, it is about caring and sharing."*

Ms. YG. She depicted a hard life of experiences that started quite early. She was sexually molested, and a neighbor contacted social services. This started a life of moving from one foster care from home to another. An upbeat and joyous person, I was not able to record her meeting, however, she left an indelible mark in the journey this researcher started. She is young and was there because of a physical disability that made her dependent upon assistance for activities of daily living.

Ms. CR moved North from Oklahoma, where she was born. She grew up during segregation. *I had good grades in High School, and I planned to go on to college. But my grandmother became ill at the time. My grandfather worked nights in the railroad, shoveling coals in the car, and because I am the oldest child in the family, I was designated to take care of her, and I did*

not mind. I took care of her until I was 21. As I said we were very close, so I did not mind. As a matter of fact, my grandfather died at the age of 102 years old. He was kind of lonely without my grandmother, and he did not have the same kind of care that we have up here. I think she suffered from diabetes that was untreated and eventually she had a stroke, and eventually she went into a comma and then she died. I lived there in Muscogee, from when I was 21 until I was 25. My childhood sweetheart went into the air force and, he came home, and we were married, and I moved to California. I was out of town, in Monterey, CA, he was stationed between Monterey and San Francisco. And eventually we busted out, of course, we could not get along fine. My mother had divorced my father, she married someone she had known years before. She moved up here and she was working at the packing house, in Minnesota, St. Paul. So, my youngest sister went to the university, and my other sister, they all came up to be with mother and they wanted me to come and bring the children and in 1962, that how I came to St. Paul. I have been here ever since. I had three children.

Favorite memories: as I said, my grandfather, who every Christmas, he always had gifts for the children, and I don't care how poor we were. And the deacons always had gifts for the children. I remember those very well. I also remember being on plays at school, and things like that.

Learning the parts, and the dramas at school. as a matter of fact, one of my classmates, we were on the play Jane Eyre together, our 3rd grade play, I remember we were in that together along with other people. She is now the head of TV network called TVI. Every time I think about that and the trick they pulled on the teacher that was over us. She had a twin sister Zenovia and Zenonia, we had one play the part of another and the teacher never found out.

Obstacles/Challenges: It was hard to find a job, a decent job, because it was segregated. We could not even apply for them. most of us worked as domestic help. My mom taught us to do domestic work. That was hard, some of them were so exacting, it was hard to get along with them. So, I guess it could be worse. How did I overcome? like I said, my grandfather, my mother, my grandmother during her life were good mentors. They would tell me don't let anything get you down, don't stoop as low as other people, don't react to everything that hits you. The church was very central to us in that community the African Pentecostal, in our communities."

How do you think people perceive the elderly? "I think that their opinion about us getting old, is that society tends to set older people aside, we cannot think as well as they can. Younger people, tend to think that way. I think they are missing out on a lot of talent that could be available to them. Like I said, people used to listen to the older ones. They figure the older ones must know something. In Minnesota, elders are perceived as sort of the same way I was saying before. It is a little different a different attitude: African Americans tend to stay away from you, not as warm

as they were when we arrived here. Of course, after I have been here a while, they got to know me, and it changed. They know I have lived here for a while."

How would you describe a nursing home to someone who did not know? *"How would I describe a nursing home? I had some experience seeing relatives and friends living in other facilities, life here is nice, for me, number one, I can move around some, I am articulate, I can talk, I can read, I can look at other things. I don't know for other people they might not feel as good. How different? Purpose there is no other place I can be taken care of, this is the kind of place you find. First and only facility I fell in my apartment, they detected that I had an intestinal obstruction, major surgery, my granddaughter used to work here, and she helped me move here, I was on first floor before, in re-habilitation and now I am here. "*

Day to day activities? *"Not too much on activities, not because I can't or get discouraged. I watch the news, read a whole lot, I like to read everything, history, biography, I like the once a month trips."*

Mr. Mills is on the bed and welcomed me with a smile. His voice is faint, and he had difficulty remembering details, and he was unable to answer most of the questions. He looks younger than all the three previous residents. He comes from Milwaukee where he spent most of his life.

When asked about his favorite memories: I don't know. I am 35 years old. I moved here in 1967. Hunting, fishing, I had many friends, big family. I am the oldest. Six more children. One of them passed on. There are 3 in Milwaukee, three brothers here in the Twin Cities.

Obstacles/difficulties he faced: *I have had a wonderful life. I had a stroke and three months ago. That is what brings me here. I worked as --- I cannot remember.... I came here 18 years ago. I got my old lady, we had a home together. I --unable to understand. With the stroke everything got messed up. Everything got messed up. I used to be active. I liked to play basketball, baseball. I will take physical therapy in the future. I may leave in one month. No, I don't participate in activities. I go get coffee downstairs. I live here. I watch TV. I would like to go home.*

Ms. Sparks was happy to see me, as she smiled as the researcher entered her room. She had been unable to meet the previous time as she was in pain and a nurse was working with her. She seems to feel much better now.

As she was asked to sign the consent form: *"I don't have the ability of writing anymore. I am 94 years old, so I have been around quite long, and I cannot use my hands. I grew up in Alabama. It is on the news. It stays on the news. They are making some progress. It is losing lives too. It is the price we must pay. I am happy with progress. I know there is a great difference in Alabama.*

Rosa Parks instigated one of the greatest one, and then Martin Luther King who was the pastor at Dexter Avenue Baptist Church and took care of most of the college kids."

Favorite memories: "Some of my favorite memories: School, learning to read and everything. I was a quick study perhaps, and my father was an aerial photographer. He got this degree. He got a degree one day and then he was gone, so after that we lost our mother. He was very smart, polite, we are the last siblings, we are two years apart. I had one sister and two brothers. they all are gone. I am the only one left. I went to Tuskegee University; my sister got a PhD in Home Economics. I studied Physical Education, I played basketball. I knew Tuskegee since I was about so high. I had somebody to lift me up to shake [Dr.] Booker T Washington's hands, I knew his children, Mattie, and.-- I did not know them all."

Obstacles/Difficulties? "No, just a lot of nasty stuff we had. So, I was so young when this stuff was going on. My dad often told us to be back in the house before the sun went down. I found out later why it was important for us to be home early. To keep us from being raped by white man."

Overcome them? "Well, my parents faced obstacles, but the real difficulty, was the remarks. When we went to the store, they wanted your money. But when we went to the movies we had to sit upstairs, if they only knew what we were doing up there, looking innocent, playing with gum, we lost some great people. But we overcame. I will say that. Georgia and Alabama played a big part in it. In Birmingham the girls in church, they looked so good and so clean, dressed up, and they had a ribbon on their hair. You could see the fear as they marched. When you had to have a regiment, so Ruby Bridges who had to have the US Marshalls walk her into the school. They were cleaner than other white kids. Then, George Wallace, said, Segregation then, segregation now, segregation forever. Until someone popped him, and he was paralyzed and guess who was helping him wheel around a black man. He was quite a terrible person. And we and my uncle and my dad told us that we should not get too close to them. If they are in a store don't go in there. We wanted to see what was inside. The adults wanted us to make something for ourselves. To stay safe, not to learn how to do the devious things that they did. I don't know many of them, but it was hard to fend off. Until that book on Nat Turner in Mississippi, Florida, I started reading to learn more and I read some books, very true, unbelievable. Some of the things got left out. You never find who put them that one drop of African blood, and then – (unable to understand). It was rare for someone to go and end up unharmed. Bullets, barrels, ----- go without risking getting injured. He used to fix gun and he had a way of doing things. My daddy, I knew my daddy. Un huhn"

How were elderly people treated when you were growing up? *“Caucasians had no respect towards elderly negroes. Black people nearest grade school and middle school and High School were to get their own ice cream in a separate store. It was fun to get ice cream, peanuts. Compared to when I was coming up, you would know not to use certain words. There was a manner in which children knew how to respect older people. Much has changed. Filling station and asked for a gallon of gas, he was about the same age as my brother. My brother went in the [military] service, they did not.”*

Difference/similarities between Alabama and Minnesota on how elderly is treated? *“AL and MN? It is about the same. I think it is less here. My son graduated here from the U of MN. He is there (pointing to a picture). Randy is one of my boys. I had three boys and one girl. My first two children were born in a hospital in Tuskegee. I was going to school there. I went back home to have my first two children. It turned out that they had everything done for them and for me. He was a track star. She (the nurse) gave my baby to bring her up to breastfeed. You had your baby so fast. One o'clock in the morning, they said put that baby back, or when you get home, you are going to have a hard time. They would come and get her, I could hear her coming down the hall to my room, to her it was a precious baby. They had fun with my baby. When we got home they wanted so much attention. The other two babies were born in Minneapolis. Child rearing: not too different from the South: there were quite a variety of culture within the race in Alabama. Sometimes, it made me kind of mad, because I had all kinds of color. Not in my immediate family, but on my mother's side, on my father's side he was very dark.*

A nursing home is just like where people can't take care of themselves. Like I had a fall and it took about a year for my hair to grow back. So, I cannot do many things I used to be able to do. My son found me a baseball hat when my hair was missing. He put the hat in my head and said, oh that will work. When I fell, I hurt my head, I told my son, pick your momma a hat, so while I was in the hospital they could not mess with my neck. In Kentucky, white people were separate. Nobody had the money to stay in a home. I had no problem. They had some of the biggest cemetery, so well-kept, some healthcare, you would not see many people. One cathedral they all attended, but my son liked it there. They respected him, he played golf with them. I think he could act to be among them. He knew how to act. Oh, he really did!

Not too many, bookstore, students, brought one of the books. I had to write a check for those. I tell them the books are OK. One of them Texan boy, football player, would call me Dixie --- would come.... So many kids. I went back there about a year ago. It has grown, so many things changed, there was another bridge across the way, glass window all across the building. I have not been able to participate in the things. Some of things I cannot do. I cannot write. I can

make the G and the L, but I still cannot do it. I am working on trying to get well. I can color books, I like that sometimes, when I get a good book, I do. I went out yesterday, that was OK, but I have a hard time adjusting to, it is just the people of different nationalities. I don't trust them. Like I say, I am my own grandpa, I am my own grandpa. I suppose my people, negroids, are survivors. We had to be. I have some very dark kinfolks and some of them, they are the sweetest folks, always looking for something to learn, to do. Like my brother told my sister he wanted her to go to Tuskegee. And she said no. I am not going to spend my life..... I could not wait to get over to... We had a gate with a great big house, great big lawn. She gave me to mama, for house because she was alone, and then in Junior College, there was --- now she stayed. Adieyla that was her name. My mama she had two long black shiny braids. That picture there --they used to ask, is this hair real? Mama said, you know my hair is real. One of them had black hair, prettiest and shiny, she did not need to put no grease on her hair.

I found out that the kids went to college. She got a scholarship. She did quite well. And they got to be roommates with someone from Chicago. Going to Minneapolis, me and Randy. Do people live there? It is a strain, but they live there. Fanny Lou Hammer had a house in Minneapolis. I flew to see Randy. Ohio River and Kentucky, it is one big river.... Underground Railroad. I have friends in the African American community whom I know. No, I do not live together.”

Mr. Davids was born in Kansas, Missouri. *“This interview was not well recorded because his television set was quite loud. As a young adult Chicago, IL. I liked to live in Chicago because I could visit my mother on the cemetery. I lived in Riverview, West Side of Chicago. I liked Chicago, IL. Mostly in High School, I had lots of friends. I was very active in activities with friends. I was successful. I went to college, toured, with friends, I had three children. Some here some in Chicago. I really enjoyed going to shows, to the movie theater, catholic church, the streets of Chicago.”*

Difficulties *“I had was I remember I was 20 and I got married and again at 49. At the time, I went to church all the time, I studied. Spiritual life, sometimes difficulties makes you a better person. In MO, segregation, a lot of times, you could not go, I used to stand back. Police matters which makes it ridiculous. I was the first black policeman and the only one. I was sent to work in the projects, which was kind of rough. I used to work for the time being... arrested citizens, district brothers, I was determined to stay on the payroll and do the job. It is one of the things about the state of Minnesota. It is better here. It has a history since 60's. Living here, it is not too bad. My lights off, I hurt my hip when I fell. This hand, I told them to put some heating pad, so”*

Mr. Harold lived in Minneapolis, *"I lived in the South side of Minneapolis until I was 9 years old. As an adult I lived in both North and South Minneapolis."*

Favorite memories, *"activities at school, with friends, sports, photography in North Minneapolis. Yes, going up to the cabin, playing outdoors, we went to 3-4 different camps."*

Obstacles/Difficulties? *"Yeah, racism, and negative attitudes, and usually here as in every place else. How overcome? I learned that if I would speak louder, I would get into trouble. I was determined to teach others. I was a radio operator in the army. My father said to always hold your head high."*

Ms. White grew up in both Memphis, TN and in Gary, IN. Favorite memories: *"going out to dance in Gary, IN, when she was a little girl."*

Obstacles/Difficulties she faced: *"Oh, my mother used to whoop me every day, because of my mouth. I used to talk back. I don't let people talk to me in that way. I don't allow people to cuss at me. I would tell her what I wanted to do. She did not like that. I cannot remember what."*

How did you overcome? What helped? *"She died. I don't know how old I was. My dad died. I am not gone deal with that. I live by myself. Live me alone. She can keep her beautiful house all she wants. I don't need it, I don't want any part in it. I had six children and I have granddaughter, but I say leave me alone. They come to see me, I talk with them. But they don't have my temper. They come sometimes."*

What is it like to be an African American woman? *"Hard. You got whooped every day. I got up every day. I went to school. It was fun. I liked school. I moved here this past Christmas. I had to come here because my husband got sick something to do with work. He lost the house, and I was out, and things got bad for me. She had never been married, so she wanted to get my husband. She did not get anything. My husband died, she died. I am still living, and she is not."*

I like it here OK. It is a place to live in. You get all kinds of things that you have to deal with. I stay in my own room. I am with people that I know. I don't mix with others. I like to play card games. Does not play bingo. I like some games, other than that, no. I have a daughter. She comes and visit. She has a nasty attitude. She wants my money."

Mr. Daniels was born in Alabama. *"I went to school in Alabama. Spent his young adult life in Alabama. Favorite Memories: Well, going to school with my classmate and I miss him a lot, and my friends. Mostly I miss my mother. She was a gardener, would get up in the morning, go out, take some greens, she would just keep going around. Yes, always active. Sometimes I would tell*

her, let me do that, you just go sit down. But she just liked to do that. We wanted to make sure she did not have to go out there. I had four brothers and one sister. I was the youngest."

Difficulties/Obstacles: "We had a lot of things. You know culturally. Some of the things you know how things were. Segregation. Sad things such as I had this friend, we used to walk home together, he was my classmate. We came home from school. Some people decided they would get him, he was kind of smart, would talk back. They hurt him, and put him in the hospital, they beat him up. They hurt me but not as bad. I had to leave and went my way back to my house. He had to go that way, they went after him, and those were white men. I experienced too many things. My mother just had to say No Sir, Mr. So and So, and she knew what to do to stay out of trouble. She said that we should just, I know it is hard, but we have to accept something they do. We were kept safe.

Being a man is hard, really. Because you actually feel so tight. You know they are white and there are lot of days, I don't think I could put up with the harassment. [Being reminded to eat this breakfast] No, I am fine, I don't need to finish my breakfast. I don't eat too much anyway. That is what my daughter tells me."

What helps? "Oh, my Lord, well, I actually don't know sometimes, I have to say, that I went through a lot of things. Getting old the way I feel right now. I know that I have been blessed. Because He brought me through so many things. Without Him I would not been here. my mother was a woman of faith. "

Difficulties/Obstacles? "Well; night and day. Well you get more freedom than in Alabama. If I were there in Alabama they do not have [nursing] homes. Some of the things here too there is (racism). It is not just in Alabama. You should just keep to yourself."

How would you describe a nursing home? "Well, for me it is I never thought I would end up here. I thought would just get old and pass on. I am still here and specially in a nursing home. In Alabama, they gotta [have a] place called nursing home, but you wouldn't believe how different they are. You don't have the same freedom you have here. It is as if you were still in slavery. Even now. They do not have nursing homes for many African Americans, they still stay at home, because there is no place to go.

Words used to describe a nursing facility: I would try to explain to him that you don't have to wait to die. There are these places you can go, people to take care of you. You get to know a lot of people, some are better than others, you know. Some you avoid. I get good care, and way better care than if I were back in Alabama."

Activities? *"They take you out to a lot of places. I like to go out. I can go out when I get ready, thank God, I can go out when I get ready. I like to play bingo, and then different things you can do. Classes you can participate in if you want to. I do not like too many things, but most I can do if I want to. If I don't want to, I don't have to. Day to day: some of my relatives are here in Minnesota, but not all of them. On a picture frame: "Family is the essence that helps define our very identity." Nurse walks in: Hello Mr. W. "I am the wound care nurse. Should I come back after lunch? "I really enjoy it here, it is nice. I can go on things when I want to, when I don't like something they listen to me."*

What matters most to African Americans? *"I am happy with the care I receive here. We really talk about a lot of times ask what happened in life, if some news that some of us don't know. Some things here, some things in the news. A lot of us people of color live here and I like to not be the only one. If you understand their language, but it is hard to understand others who do not speak English that I cannot understand. They need interpreters. We do have conversations using interpreters it is a way to know others. If they don't speak English, and I don't know what they are saying, then I would like to talk to them. This could be just like discrimination, but I just don't speak the language. There are opportunities for us to speak about our cultures. One week, I was surprised when one of them was telling me about, it was amazing the things about their country they experienced back in their country, so I told her join the crowd."*

"They had no respect for elderly negroes."

"When George Wallace got shot, even though he said, 'Segregation today, segregation tomorrow, segregation forever,' guess who pushed him on his wheel chair? A negro man!"

"The four little girls who were bombed and killed in that church basement (Birmingham, AL) were all dressed up, ribbons in their hair, and cleaner than the other white girls."

"While in college, when my mother would write she always included a bible passage in "My daddy always wanted to make sure we were home before the sun went down. Much later I understood why: he did not want us to be raped by white men"

"My mother would whoop me as a child about every day because of my mouth. I used to talk back."

"I had this friend and we used to walk home from school. One day these white men decided to follow us. I stayed quiet and hurried home. My friend kept talking back. They beat both of us, but they put my friend in a hospital. He had a longer way to go than me."

When asked about challenges faced:

The African American elders interviewed experienced segregation, in the US South or in the North. They lived in an environment of oppression and were taught early to work hard, keep their head up high and to seek an education. This researcher interviewed residents who recounted their lived experiences in their field of work were the first African Americans in their workplace: classroom teacher, home economics graduate, physical education, and police officer working among white counterparts who did not often welcome them. As they witnessed disrespectful behavior leveled at their parents, or grandparents, they also experienced such treatment.

"I was the only African American teacher in an all-white school. My family had to work at it to help keep me going."

They learned to overcome their difficulties from their experiences growing up and learning from their family. They all understood expectations of blacks from whites under the Jim Crow laws in the US South, which were to enforce "racial segregation in the South between the end of Reconstruction in 1877 and the beginning of the civil rights movement in the 1950 mandated the segregation of public schools, public places, and public transportation, and the segregation of restrooms, restaurants, and drinking fountains for whites and blacks (Hansan, J.E., 2011)."

"I experienced so many things. My mother just had to say Yes, Sir, No, Sir; Mr. So, and So, and she knew what to do to stay out of trouble. She told us, 'I know it is hard, but we have to accept these things they do. We were kept safe.'"

What is it like to be an African American wo/man?

"Being a man is actually hard. Because at times you felt so tight. You know they are white and there are a lot of days, I didn't think I could put up with the harassment."

"It was hard. We all had to work so hard, it just was that way. We did everything together as a family. Our church was our community. We lived across the street and spent a lot of time in church activities. Some people used to tease us, but we had to do it that way."

How would you describe a nursing home to someone who knew nothing about a nursing home?

"Nursing home is where people go when they can no longer take care of themselves. Like, I had a fall and hurt my head, they had to shave my hair. My son found me a baseball cap and brought it for me to wear. So, I cannot do the things I used to be able to do."

"Well, for me I never thought I would end up here. I thought I would just get old and pass on. I am still here and specially in a nursing home. They have places they call nursing homes in Alabama. But you wouldn't believe how different they are. You don't have the same freedom you

have here. It is as if you were still in slavery, even now, they don't have nursing homes like they have here. Of course, there is racism here too, as there is there. You just should keep it to yourself."

"I like it here. You can play bingo, they take you to a lot of places. Thank God, I can go out if I want to. There are different things you can do here. Classes you can participate in, if I want to. I really enjoy it here, it is nice. I can go on things if I want to. When I don't like something, they listen to me."

"I had some experience seeing relatives and friends living in other facilities. Life here is nice, for me, number 1, I can move around some, I am articulate, I can talk, I can read, I can look at other things. I don't know for other people they might not feel as good. The purpose is there is no other place I can be."

"I like it here OK. It is a place to live in. You get all kinds of things that you have to deal with. I stay in my own room. I am with people that I know. I don't mix with others."

"I am not very talkative. Well let's see. I think I worked in a nursing home, getting ready for Christmas. A nursing home is where people who are not well, they need to be in a nursing home. Some people come to visit family and they are the ones who catch whatever is going on. They don't like when we tell when they have to do, and they call you, we bring in somebody who is helpful. That works, it takes time, one of those things. "

Activities they do here. They were not too concerned about activities. There seemed to be agreement that there is good programming and that they are free to participate if they wish to.

"I like to read the bible, watch TV, "Name that Tune," I love music, I used to be in choir, Lucky 6, correct answers would get a quarter, I like to watch the weather, play bingo."

"Day to day: not too much on activities, not because I can't or get discouraged. I watch the news, read a whole lot, I like to read everything, history, biography, I like once a month trips. We talk about what is on the news, our families, our children, grandchildren, it is great."

"No, I don't participate in activities. I go get coffee downstairs. I live here. I watch TV. I would like to go home."

"Not too many, bookstore, students, brought one of the books. I had to write a check for those. I tell them the books are OK."

What matters most for African Americans in a nursing home?

“The African American Culture: some of the aides do not understand the African American culture, even though they are from Africa. They don't seem to understand that this is a different culture. It is hard for some of them to understand what I need because of their language barrier. I would like for them to answer the light as quick as they can. What is culturally appropriate care? I don't know. I interact with recreation, as that person brings me books, favorite places: all of them it sounds silly, all the needs I have are being met. The doctors are interested in me, any doctor's culture is fine, most of my doctors have been Caucasian so I got used to it. My expectation: listen to my concerns, tell me what needs to be done, if they can do it. I have grandchildren, I was raised Pentecostal, but they do not practice it. I used to watch on television when there is preaching that I am used to. My cultural upbringing shaped me, I would not be here today if it weren't for those teachings. Culture, faith, respectful, values, so far it has been like that in here, from the beginning. I worked for the department of education for over 30 years.”

I am happy with the care I receive here. We really talk about a lot of times ask what happened in life, if some news that some of us don't know. Some things happening here, some things in the news. A lot of us people of color live here and I like to not be the only one. You understand their language, but it is hard to understand others who do not speak English that I cannot understand. They need interpreters. We do have conversations using interpreters it is a way to know others. If they don't speak English, and I don't know what they are saying, then I would like to talk to them. This could be just like discrimination, but I just don't speak the language. There are opportunities for us to speak about our cultures. One week, I was surprised when one of them was telling me about, it was amazing the things about their country they experienced back in their country, so I told her ‘join the crowd!’ “

The residents interviewed left segregation in the US South seeking better lives in the North. Some followed relatives, loved ones, or friends who told them of their new lives in the North. Not all settled in Minnesota. Some went to other Midwest states where they lived and then moved to the Twin Cities.

Difficulties/Challenges faced ranged from the experiences of seeing their elders mistreated in the South, poverty growing up and humiliation, pain and embarrassment of racism in the South and in the North. They seemed overall content in living at this facility.

They perceive differential treatment in their day to day experiences. These elders choose to “keep to themselves,”

They are aware of their vulnerable situation, and learned to resign themselves to live with it:

"They take a while answering the light [call signal]"

"I understand that I have to wait because they only send the workers who are familiar with us"

"I like it here OK. It is a place to live in. You get all kinds of things that you must deal with. I stay in my own room. I am with people that I know. I don't mix with others."

When asked what is it like to be an African American person?

"Oh! you are causing trouble! It is very competitive. Not only among African Americans, but Whites, and when you have that competition it is hard to get along"

Please see Appendix P Flyer Inviting Participation in the Study

*African American Aging in Minnesota's Urban Facilities:
A Phenomenological Study of their Lived Experiences*



Thank you for agreeing to participate in an
interview with

Antonia Wilcoxon for her research study!

Antonia will be in the building on December 14th
from 10:00 a.m. – Noon

And December 15th from 10:00 a.m. – 3:00 p.m.
She will come to your room for the interview.

APPENDIX Q Quality of Life Indicators in Assessing Nursing Facilities' Resident Participants

Domains and Their Definitions

Physical comfort. Residents are free from pain, uncomfortable symptoms, and other physical discomforts. They perceive that their pain and discomfort are noticed and addressed by staff.

Functional competence. Within the limits of their physical and cognitive abilities, residents are as independent as they wish to be.

Privacy. Residents have bodily privacy, can keep personal information confidential, can be alone as desired, and can be with others in private.

Autonomy. Residents take initiative and make choices for their lives and care.

Dignity. Residents perceive their dignity is intact and respected. They do not feel belittled, devalued, or humiliated.

Meaningful activity. Residents engage in discretionary behavior that results in self-affirming competence or active pleasure in the doing of or watching of an activity.

Food enjoyment. Residents enjoy meals and food.

Individuality. Residents express their preferences, pursue their past and current interests, maintain a sense of their own identity, and perceive they are known as individuals.

Relationships. Residents engage in meaningful person-to-person social interchange with other residents, with staff, and/or with family and friends who live outside the nursing home.

Safety, security & order. Residents feel secure and confident about their personal safety, are able to move about freely, believe that their possessions are secure, and believe that the staff has good intentions. They know and understand the rules, expectations, and routines of the facility.

Spiritual well-being. Residents' needs and concerns for religion, prayer, meditation, spirituality, and moral values are met.

APPENDIX R DHS Equity Policy

The Minnesota Department of Human Services (DHS) will provide resources to make equity an integral part of all programs, policies and procedures it implements. This policy requires that considerations of equity, that is, fairness and justice, are embedded in decisions at all levels of DHS, including leadership, operations, programming, investments, and policy development.

The goal of this policy is to institutionalize an approach to decision-making, program and policy development, implementation, and evaluation, which improves outcomes and reduces health and human services disparities and inequities for the people we serve.

The agency shall:

A. Engage and empower all agency employees to advance equity through their daily work;

B. Identify standards, processes, metrics and systems of accountability to advance equity goals, including:

- Link agency service delivery of human services programs to the determinants of health;
 - Institutionalize an equity focus in decision-making;
 - Promote fairness and opportunity in agency practices;
 - Collaborate across program areas; and
 - Build community trust and capacity.
- Invest in human, capital and infrastructures to meet the needs of communities experiencing inequities

Description: DHS is committed to advancing equity, reducing disparities in DHS program outcomes, and improving access to human services for communities experiencing inequities.

For the purpose of this policy, communities experiencing inequities refers to communities of color, American Indians, veterans, LGBT, and persons with disabilities. DHS acknowledges and embraces the role we can play in developing policies and procedures to advance equity.

DHS will utilize a health in all policies (HiAP) approach. This “is a collaborative approach to improving the health of all people by incorporating health considerations into decision-making across sectors and policy area. ... Ultimately the Health in All Policies approach seeks to institutionalize considerations of health, equity, and sustainability as a standard part of decision-making processes across a broad array of sectors. 30” In this context, health does not refer merely to the absence of disease, but to a complete state of physical, mental, and social wellbeing. Recognizing that Minnesota’s structural inequities cut across sectors, DHS’s HiAP approach will require solutions that both focus within DHS and also cut across agency and public-private sector boundaries and address the broad factors that make up the determinants of health 31.

This policy requires that communities experiencing inequities be consulted when programs are designed, implemented, and evaluated. This policy aims to incorporate equity department-wide, ensuring that we will consider equity in all aspects of our business.

30 Healthy Decisions Healthy Places; www.healthy-decisions.org/health-in-all-policies/

31 Healthy People 2020; www.healthypeople.gov 83

Reason for Policy: In order to reduce inequities, it is necessary to address broad social, economic, and political factors that result in systemic disadvantages as well as the needs, assets, and challenges of communities experiencing inequities. The Department acknowledges and embraces the role it can play in developing policies, investments, and procedures that advance equity.

Standards: The following are standards to advance equity and disparity reduction work at DHS:

- I. DHS will regularly engage persons from communities experiencing inequities during the agency's planning, program development, program evaluation, and decision-making process.
- II. DHS human resources department, managers, and supervisors will recruit, hire, welcome, develop, promote and support a workforce, which is diverse and inclusive of people from communities that experience inequities. This includes leadership development and promotion of people from communities that experience inequities into positions of formal leadership at all levels within the agency.
- III. When contracting for services DHS managers, supervisors, and staff will conduct outreach, welcome, develop, promote and nurture a diverse group of vendors capable of meeting the needs of DHS clients and in accordance with Executive Order 15-2 and recommendations of the Governor's Diversity and Inclusion Council.
- IV. DHS will incorporate equity analysis into the development of policies, rules, procedures, budget, and legislative proposals, as well as program design and implementation.
- V. DHS will continue to provide staff support to the Cultural and Ethnic Communities Leadership Council (CECLC) in advising the agency on equity and disparity reduction efforts.
- VI. DHS recognizes the variety of ways that human services programs impact the social determinants of health and the role that addressing them will have in improving equity.

Procedures

1. Equity Committee

- The person overseeing each administration will work on establishing an equity committee. This equity committee will be charged with advising the responsible leadership of that administration on advancing equitable outcomes for all people we serve and DHS employees.

2. Equity Analysis

- DHS managers and supervisors should consult their equity committee when reviewing administrative policies for renewal.
- Employees who are involved in developing legislative proposals will engage in an equity analysis and consult with equity liaisons when evaluating potential equity impact.
- Agency staff shall analyze equity impact when preparing legislative proposals, using the following questions contained in the Governor's 2018-2019 Change Item Template.

Specific questions analyzed may be modified based on direction from the Governor's office and DHS's understanding of analyzing equity impact:

- o What groups are impacted by the proposed change item? (Racial and Ethnic groups, Lesbian, Gay, Bisexual and Transgender groups, Persons with Disabilities and Veterans) 84 What is the nature of the impact? Have representatives from these groups been consulted and collaborated with in order to determine how to address these impacts?
- o Is the proposed change item submitted to reduce or eliminate any disparities for Racial and Ethnic groups, Lesbian, Gay, Bisexual and Transgender groups, Persons with Disabilities and Veterans? Please explain how implementation of the proposed item will reduce or eliminate these disparities;
- o Are there potential positive or negative impacts on the identified groups? Explain those impacts. If negative, please adjust the proposal to achieve a more equitable outcome. o Can the change item be sustainably successful? Discuss the on-going funding, implementation strategies/opportunities, and performance measures/accountability mechanisms.

III. Workforce and Leadership Development

- Affirmative Action Officer will provide hiring supervisors and senior management with data and advice to help them increase number of underrepresented group members in all levels of workforce.
- Human Resources Office will utilize data to inform hiring managers to increase members of underrepresented groups employed by DHS in all levels of workforce.
- Hiring Manager shall make every reasonable effort to include at least 1 underrepresented group member on interview panels.

- Human Resources and the Affirmative Action Officer will track and monitor data on employee separations and develop and implement interventions if there are statistically significant disparities in separation numbers between majority member employees and employees from communities experiencing inequities in all levels of workforce.
- Enterprise Learning and Development, in collaboration with Human Resources and others, will track and monitor participation of employees from communities experiencing inequities in agency and state-sponsored leadership development opportunities.

IV. Contracting and Procurement

• The Director of Contracts, Procurement, and Legal Compliance will develop and apply equity criteria throughout the contracting, grants, and procurement process, while maintaining compliance with local, state and federal contracting regulations, in order to increase vendor diversity. "Equity select" procurement, authorized by 2016 MN Statute 16C.08 and 16C.16, shall be utilized in order to directly select vendors owned by targeted groups for procurement up to a value of \$25,000.

- DHS employees who engage in contracts and procurement should
 - (a). be trained in applying an equity analysis or
 - (b.) consult with an individual or equity committee that have been trained in applying equity analysis

V. Community Engagement and Inclusion 85

- When developing strategic initiatives and work plans, DHS managers and supervisors will ensure that communities experiencing inequities are engaged through the planning, program development, budgeting, program evaluation and decision-making process.
- Managers and supervisors who oversee staff who plan community engagement activities should consult with the Director of Community Relations for support and resources, when appropriate.

VII. Enhanced Cultural and Linguistic Appropriate Services (CLAS) Standards:

- The enhanced National CLAS standards are intended to advance health equity, improve quality, and help eliminate disparities in health care. DHS will endeavor to pilot and implement CLAS standards in the delivery of human services.

Failure to Comply: The Department shall develop measures, monitor implementation, and enforce the policy on equity across the agency. The Department expects all department employees to comply with relevant provisions, but the policy is not intended to be punitive. The Department views this policy as a mechanism for all DHS employees to better understand and incorporate equity into their work.

Related Policies and Reference(s):

- Affirmative Action Plan: <https://edocs.dhs.state.mn.us/lfsrserver/Public/DHS-4355-ENG>

- Affirmative Action Policy:

http://dhsinfo.dhsintra.net/InfoLink/Policies_Procedures/Equalopportunity/Affirmativeaction/index.htm?ssSourceNodeId=159&ssSourceSiteId=InfoLink • Prohibition of

Discrimination Policy:

http://dhsinfo.dhsintra.net/InfoLink/Policies_Procedures/Equalopportunity/Discrimination/index.htm

Prohibition of Sexual Harassment Policy:

http://dhsinfo.dhsintra.net/InfoLink/Policies_Procedures/Equalopportunity/id_042754?ssSourceNodeId=159&ssSourceSiteId=InfoLink

- Accessible Formats Policy:

http://dhsinfo.dhsintra.net/InfoLink/Policies_Procedures/Equalopportunity/Alternativeformats/index.htm?ssSourceNodeId=196&ssSourceSiteId=InfoLink

- Employee Request for Reasonable Accommodations Policy:

http://dhsinfo.dhsintra.net/InfoLink/Policies_Procedures/Equalopportunity/Reasonableaccommodation/index.htm?ssSourceNodeId=196&ssSourceSiteId=InfoLink • Web

Accessibility Policy:

http://dhsinfo.dhsintra.net/InfoLink/Policies_Procedures/Equalopportunity/Affirmativeaction/id_061692?ssSourceNodeId=159&ssSourceSiteId=InfoLink

- Civil Rights Policy and Complaint Procedure: <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-4027-ENG>

- Civil Rights Plan: <https://edocs.dhs.state.mn.us/lfserver/Legacy/DHS-5362-ENG>

- Limited English Proficiency Plan: <https://edocs.dhs.state.mn.us/lfserver/Legacy/DHS4210-ENG>

- Enhanced Culturally and Linguistically Appropriate Services Standards:

<https://www.thinkculturalhealth.hhs.gov/pdfs/enhancednationalclasstandards.pdf> 86
<http://dhhs.ne.gov/publichealth/Documents/EnhancementsToCLASStandards.pdf>

Healthy People 2020 <https://www.healthypeople.gov> (retrieved 10 March 2018)

- 16C.08 Professional or Technical Services <https://www.revisor.mn.gov/statutes/?id=16C.08> Training: DHS is developing required training. Legal Authority: CECLC Legislation The legislature charged the Cultural and Ethnic Communities Leadership Council with advising the commissioner of human services on reducing disparities that affect racial and ethnic groups.

Laws of Minnesota 2015, Chapter 78, Article 4, Section 50 [256.041] Executive Order 13-10 Affirming the Government-to-Government Relationship between the State of Minnesota and the Minnesota Tribal Nations: Providing for Consultation, Coordination and Cooperation Executive Order 15-2 Signed in January 2015, this order affirms Minnesota's commitment to diversity and inclusion and establishes the Diversity and Inclusion Council Title VII of the Civil Rights Act of 1964 Statutory Citation: 42 USC 2000e et seq Regulatory Citation: 29 CFR 1601 Americans with Disabilities Act of 1990, Title I Statutory Citation: 42 USC 12111 Regulatory Citation: 29 CFR Part 1630 Title VI of the Civil Rights Act of 1964 Statutory Citation: 42 USC 2000d et seq.

Regulatory Citation: 45 CFR Part 80 Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons Federal Register Citation: 68 Fed. Reg. 47311 (2003) 87 Section 504 of the Rehabilitation Act of 1973 Statutory Citation: 29 USC 794 Regulatory Citation: 45 CFR Part 84 Section 508 of the Rehabilitation Act of 1973 Statutory Citation: 29 USC 794 Americans with Disabilities Act of 1990, Title II Statutory Citation: 42 USC 12131 Regulatory Citation: 28 CFR Part 35 Minnesota Human Rights Act Statutory Citation: Minn. Stat. Chapter 363A Chapter 43A, State Personnel Management Statewide Affirmative Action Program, Rules Statutory Citation: Minn. Stat. Chapter 43A.04, Subd. 3 Affirmative Action Statutory Citation: Minn. Stat. Chapter 43A.19 Affirmative Action Programs Statutory Citation: Minn. Stat. Chapter 43A. 191 Community Engagement: process of co-creating solutions in partnership with people, who through their own experiences, know the barriers to opportunity best. It is grounded in building relationships based on mutual respect and that acknowledge each person's added value to the developing solutions (Voices for Racial Justice).

Communities Experiencing Inequities: consist of the communities made of up the following populations:

People of Color: individuals of non-Caucasian heritage who identify as non-white. Houghton Mifflin Company (2005).

The American Heritage Guide to Contemporary Usage and Style. Houghton Mifflin Harcourt. p. 356.

American Indians: Descendants of the native peoples of North America who identify as American Indian

Persons with Disabilities: Any person who has a physical or mental impairment that substantially limits one or more major life activities; has a record of such impairment; or is regarded as having such an impairment. 88

Determinants of Health: structural determinants and conditions in which people are born, grow, live, work and age.”⁶ They include factors like socioeconomic status, education, the physical environment, employment, and social support networks, as well as access to health care. <http://kff.org/disparities-policy/issuebrief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>

Disparity: difference in health that is closely linked with social, economic, or environmental disadvantage. Health disparities impact groups that systematically experience greater obstacles including communities of color, American Indians, and persons with disabilities.

Engagement: process of collaboration and inclusion in which entities build ongoing relationships for the purpose of applying a collective vision to solve complex problems.

Enhanced National Culturally and Linguistically Appropriate Standards (CLAS: A series of standards that are intended to advance health equity, improve quality, and help eliminate health care disparities. Beyond healthcare delivery, CLAS standards should be understood as applicable to public institutions addressing individual, family, or community health, health care or well-being (National Standards for CLAS in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice, HHS 2014).

Equity: achieved when every person in a community has the opportunity to reach their full health potential and no one is "disadvantaged from achieving this potential because of social position or other socially determined circumstances."

Equity Analysis: An analysis of the impact of proposals, policies, and programs on various populations, with a particular focus on impact on communities experiencing inequities. The analysis shall address the following questions, contained in the Governor's 2018-2019 Change Item Template.

Specific questions analyzed may be modified based on direction from the Governor's office and DHS's understanding of analyzing equity impact

- What groups are impacted by the proposed policy or budget item? (Racial and Ethnic groups, Lesbian, Gay, Bisexual and Transgender groups, Persons with Disabilities and Veterans) What is the nature of the impact? Have representatives from these groups been consulted and collaborated with in order to determine how to address these impacts;

- Is the proposed item submitted to reduce or eliminate any disparities for Racial and Ethnic groups, Lesbian, Gay, Bisexual and Transgender groups, Persons with Disabilities and Veterans? Please explain how implementation of the proposed item(s) will reduce or eliminate these disparities;

- Are there potential positive or negative impacts on the identified groups? Explain those impacts. If negative, please adjust the proposal to achieve a more equitable outcome.

- Can the policy or budget idea be sustainably successful? Discuss the on-going funding, implementation strategies/opportunities, and performance measures/accountability mechanisms.

Health: Health encompasses many aspects, including physical, mental, social, and spiritual well-being (HHS IHS, n.d.; HHS OSG et al., 2012; WHO, 1946). Health is "not merely the absence of disease or infirmity" (WHO, 1946). How individuals experience health and define their well-being is greatly informed by their cultural identity.

Health in All Policies: "Health in All Policies is a collaborative approach to improving the health of all people by incorporating health considerations into decision-making across sectors and policy areas...Ultimately the Health in All Policies approach seeks to institutionalize considerations of health, equity, and sustainability as a standard part of decision-making processes across a broad array of sectors."
https://www.apha.org/~media/files/pdf/factsheets/health_inall_policies_guide_169pages.ashx 89

Inequities: Differences in outcomes that are systematic, avoidable and unjust.

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 Issue Date: MM/dd/yy Effective Date: MM/dd/yy

Appendix S Interview Questions for Resident Participants

1. I am interested in learning about your stories, experiences and opinions of residents who are African Americans and are the minority in the facility.
2. Let's start with learning more about you. Please tell me where you grew up.
3. Tell me where you spent your childhood?
4. Where did you live as an adult?
5. What are some of your favorite memories?
6. What were some obstacles you faced during your adult life?
7. How did you overcome them?
8. What is it like to be an African American?
9. What is your opinion about how aging is viewed in the larger society?
10. How are elderly people viewed in the African American community here in Minnesota?
11. (If not from Minnesota,) how are elderly people viewed in the community you lived?
12. What is different?
13. What is similar?
14. How would you describe a nursing home to some people who do not know about it?
15. What words come to mind when you think of the words nursing home?
16. When did you move here?
17. I would like to learn about your day to day activities as a nursing home resident, how do you enjoy life, activities, and socialize in your living situations?
18. What are certain aspects of your activities here that you like and would tell the facilities administrators, funders and policy makers? Which ones don't you like?
19. What matters most for African Americans in the larger metropolitan area who care, are concerned about and wish to see their end of life be filled with enriching experiences?
20. How many other African Americans do you socialize with? What do you do? What do you like about getting together with them?

21. What does it mean to you to be an African American elder?
22. How does the cultural background of a resident influence the quality of their lives in a facility where they are the minority?
23. When you hear, the words aging, elderly what comes to mind?
24. When you hear the words "culturally appropriate care," what comes to mind?
25. Briefly describe your experiences living here.
26. Describe the care you have received your doctors, nurses and workers here. Were your needs met?
27. Think about conversations you've had with others about life in a nursing facility. What are some of the subjects discussed?
28. How does your doctor treat you when you discuss this with him or her?
29. Do you prefer to see an African-American doctor rather than a white doctor? Why? or Why not?
30. How do you *expect* your doctor to care for you when you need his/her care? How do you expect the staff to care for you?
31. How does the care you receive *meet* or *not meet* your expectations of good care?
32. Describe the importance of faith and culture in your life. How does this impact the care you expect and receive?
33. Imagine receiving medical care that is respectful of your faith, values, and culture. Describe what it looks like.
34. Are there any issues that are important to you that we haven't addressed?

Appendix T Interview Questions for Nursing Facility Staff

1. How long have you worked at this facility?
2. Did you work at another facility before this one?
3. How did you choose to work with people in this age?
4. What are the benefits of working here?
5. What are the challenges working with residents of color?
6. What are the benefits?
7. How do you prepare for work each day?
8. How do you manage stress?
9. How do you work with elders experiencing difficulties?
10. What would you change in the facility if you were asked? What would you maintain?
11. How do you make each resident feel special?
12. Are there differences in the way different cultural groups age?
13. What are the differences?
14. How do you determine the course of care for each resident?
15. What are traits that each elder brings when they enter the facility?
16. What do you do to help them adjust to a new environment?
17. What works best for residents of color?
18. What can be challenging?
19. What would you like to discuss about this profession?
20. What question did I not ask of you?

Appendix U Interview Questions for the Facility Administrator

1. How long have you worked at this facility?
2. Did you work at another facility before this one?
3. How did you choose to work with people in this age?
4. What are the benefits of working here?
5. What are the challenges working with elderly residents of color?
6. What are the benefits?
7. How do you prepare for work each day?
8. How do you support staff manage their stress?
9. What makes a good leader in this field?
10. What changes in administration and leadership have you made?
11. How do you help staff make each resident feel special?
12. Are there differences in the way different cultural groups age?
13. What are the differences?
14. How do you determine the course of care for each resident?
15. What are traits that each elder brings when they enter the facility?
16. How do you support staff work with elders having difficulties adjusting to a new environment?
17. In your experience as an administrator, what works best for residents of color?
18. What is a challenging day? What is a typical day?
19. What would you like to discuss about this profession? What suggestions might you give others contemplating entering this field?
20. What question did I not ask of you? What would you like others to know about this facility?