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Karah Alexander

# Examining Health Literacy and Medical Discrimination in Black Caregivers of Persons Living with Dementia: An Explanatory Sequential Mixed Methods Study

By

Karah Alexander

Doctor of Philosophy

Nursing

Fayron Epps
PhD Co-Advisor

Ken Hepburn
PhD Co-Advisor

Leila Aflatoony
PhD Committee Member

Stephanie Bennett
PhD Committee Member

Iris Feinberg
PhD Committee Member

Accepted:

Kimberly Jacob Arriola, PhD, MPH
Dean of the James T. Laney School of Graduate Studies

Date

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Advisor: Fayron Epps, PhD, RN, FGSA, FAAN

Advisor: Ken Hepburn, PhD

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# Abstract

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By Karah Alexander

**Background:** Disparities in the Black dementia family caregiving experience are well-documented, specifically in healthcare management. Black caregivers experience challenges with healthcare system navigation, communication with healthcare providers, and have limited knowledge of and access to dementia-related information and resources. These tasks require adequate health literacy. Individual health literacy may contribute to disparities in healthcare management among Black caregivers of persons living with dementia (PLWD). Despite the existing exploration of health literacy and previous study findings highlighting its importance in family caregiving, these studies included few to no Black caregivers. Rates of limited health literacy are higher among Black Americans. Medical discrimination may also contribute to challenges with healthcare management among Black caregivers, as well as present a barrier to achieving/maintaining optimal health literacy.

**Purpose:** The purpose of this study was to examine health literacy and medical discrimination in Black caregivers of PLWD.

**Methods:** An explanatory sequential mixed methods study was conducted in a sample of Black caregivers of PLWD. A cross-sectional quantitative design was first carried out, and a survey was distributed to 99 Black caregivers across the U.S. Follow-up qualitative procedures consisted of 4 focus groups with a purposeful sub-sample of 10 caregivers guided by the *Discover* and *Define* phases of the Design Thinking Process. Data integration took place at the planning stage for qualitative procedures (methods) and analytic and interpretation stages. Meta-inferences were drawn from integrated data.

**Findings:** Caregivers scored highest on the health literacy scale '*Understanding health information well enough to know what to do'* and lowest on the scale '*Feeling understood and supported by healthcare providers.'* Bivariate analyses of health literacy scales and medical discrimination scores were all significant; as caregivers' experiences of medical discrimination while seeking care for PLWD increased, health literacy scale scores decreased. Qualitative data gave a deeper understanding of Black caregivers' most salient health literacy problems. *Receiving health information in medical jargon*; *insurance coverage dictates navigation*; and *healthcare professionals' lack of cultural competency* were some of the key problems discussed. Integrated findings revealed the importance of health literacy as a shared responsibility and caregivers' challenges further amplified by healthcare providers and organizations.

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# Introduction

## Background of the Problem

### *Disparities in the Black Dementia Caregiving Experience*

Disparities in the caregiving experience of Black family members or friends who assist, typically unpaid, someone living with limitations in their physical, mental, or cognitive functioning are well-documented (Alzheimer’s Association, 2023). Black Americans have been found to spend more time in the family caregiving role compared to non-Hispanic white adults, providing 40 hours of care per week or more (54.3% vs. 38.6% reported among white caregivers) (National Alliance for Caregiving, & AARP Public Policy Institute, 2020; Fabius et al., 2020). Black caregivers have reported poorer physical health and heavier caregiving demands and assist older adults with greater functional impairment compared to caregivers of other racial and ethnic groups (Fabius et al., 2020). Non-Hispanic white family caregivers are more likely to institutionalize care recipients or utilize formal services, such as home health assistance, compared to Black Americans. This is partly due to a higher prevalence of Black caregivers having fewer economic resources, thus not being financially able to utilize professional care (Badana, Marino, & Haley, 2019). It is also due to cultural values of Black Americans being more likely to care for their person(s) living with dementia (PLWD) in the home setting (Badana, Marino, & Haley, 2019; Alzheimer's Association, 2023).

Disparities in family caregiving also extend to healthcare management tasks and utilization. As a caregiver, the responsibilities of engaging with health-related material, identifying and navigating healthcare services and supports, and conversing with clinicians and other healthcare professionals and administrators on behalf of PLWD are common occurrences (Fields et al., 2018). These responsibilities are especially crucial for dementia caregivers since care recipients, typically those in the middle-late stage of the disease process, are not always cognitively able to manage their healthcare (Mullins et al., 2016). Such responsibilities pose greater challenges for Black caregivers of PLWD. (Mullins et al., 2016; Alzheimer's Association, 2023).

Studies have shown that Black caregivers experience difficulties with healthcare system navigation, have limited knowledge about dementia and related resources, and have limited opportunities for communication with healthcare providers on behalf of their care recipient (Fields et al., 2018; Abramsohn et al., 2019). Difficulties engaging with and navigating the healthcare system have been linked to Black caregivers' having limited financial resources with which to provide care (Abramsohn et al., 2019). Additionally, prior work has found that Black caregivers feel the United States (U.S.) healthcare system they experience is "broken" and they can often face communication challenges with healthcare professionals and misunderstand insurance policies and details on coverage, which all contribute to complexities with healthcare management in the caregiving experience (Alexander et al., 2022). Black adults living with dementia have higher rates of hospitalization, and although Black Americans make up 13.6% of the U.S. population, they shoulder a third of non-governmentally covered dementia-related costs, including 1.7 times more in Medicare costs (Unpublished Tabulations based on data from the National 5% Sample Medicare Fee-or-Service Beneficiaries, 2014; Alzheimer's Association, 2021; Centers for Disease Control [CDC], 2023). These costs are related to more frequent hospitalizations, greater severity of illness, longer lengths of stay, and higher readmission rates in Black PLWD (Alzheimer's Association, 2023). Black caregivers and their PLWD who experience disparities in care are typically under-treated and have lower rates of formal service use (Dilworth-Anderson, Pierre, & Hillard, 2012).

### ***Health Literacy and its Implications for Caregivers' Health Management***

Low health literacy is a major problem in the U.S., and it is estimated that approximately 80 million people in the country have limited health literacy (Garcia et al., 2013). Economists estimate that the consequences of low health literacy add $106 billion to $238 billion annually to U.S. healthcare costs (Garcia et al., 2013). The consequences of inadequate health literacy include poorer health status, lack of knowledge about medical care and medical conditions, decreased comprehension of medical information, limited understanding and use of preventive services, poorer self-reported health and compliance rates, increased hospitalizations, and increased healthcare spending (Garcia et al., 2013). Adequate health literacy skills are needed by family caregivers for optimal healthcare management and disease-specific knowledge (Abed et al., 2020). Caregivers receive information from healthcare professionals, provide patient information to clinicians, aid in treating and caring for the patient, and weigh in on treatment decisions; each of these dimensions can be impeded by limited caregiver health literacy (Abed et al., 2020). Family caregivers provide more hands-on, day-to-day care than any other individuals and need not only access to information but also the ability to process and act upon that information to provide the best quality care (Ward-Griffin & McKeever, 2000).

A few studies have demonstrated the associations between the health literacy of family caregivers and health outcomes in those receiving care. One study examined associations between caregiver health literacy and their matched care recipient's scores on three self-care heart failure management scales: maintenance, management, and confidence (Levin et al., 2014). Caregivers with low health literacy were more likely to have care recipients who reported poorer self-care maintenance or behaviors to maintain clinical stability (Levin et al., 2014). Another study found significant associations between caregivers' low health literacy and the frequency of their elderly care recipient's hospital admission, the duration of their hospital stay, and the care recipient's health-related quality of life (Rahman, 2014). Researchers of another study discussed how caregiver health literacy is an imperative element of cancer care since it can influence caregiving and health outcomes among cancer patients (Bevan & Pecchioni, 2008). They also reported that limited health literacy among caregivers of cancer patients could negatively affect communication about patient medical history, shared decision-making, and constancy with clinicians (Bevan & Pecchioni, 2008). A more recent study examined the relationship between health literacy, social support, and the care ability of dementia caregivers (Li et al., 2020). Researchers concluded that improving the health literacy of caregivers aided in improving dementia care abilities (Li et al., 2020).

Health literacy may serve as a factor contributing to disparities in healthcare management among Black caregivers of PLWD. Despite the existing exploration of health literacy and previous study findings highlighting its importance in the family caregiving experience and impact on care recipient health outcomes, these studies included few to no Black caregivers. Rates of limited health literacy are higher among Black Americans, with 58% having basic or below basic health literacy compared with 28% of non-Hispanic white Americans (Muvuka et al., 2020). Additionally, Black Americans (and Hispanics) are among the lowest-scoring racial and ethnic demographics in all three categories of literacy assessed by the U.S. Department of Education, which is significant because health literacy is correlated with general literacy (Nutbeam, 2000; U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003).

Limited individual health literacy is directly associated with frequent use of emergency room and hospital services, prevents optimal health system navigation, and limits healthcare access, all of which are commonly reported among Black caregivers of PLWD (Cho, 2008; Garcia et al., 2013; Abramsohn et al., 2019). According to empirical evidence, limited health literacy negatively affects an individual's motivation and capacity to seek, comprehend, and act on health information (Fields et al., 2018). Determinants such as aging, suffering from chronic disease, low-income status, and poor education are all regarded as risk factors for limited health literacy (Muvuka et al., 2020). Black caregivers of PLWD are more likely to have chronic morbidities, lower levels of educational attainment, and fewer financial resources; thus, it is imperative to assess health literacy in this population (Alzheimer's Association, 2023). Black caregivers of PLWD are also more likely to experience discrimination and racial bias in the healthcare setting, which can further challenge individual health literacy (Muvuka et al., 2020; Alzheimer's Association, 2023).

The National Institute on Aging (NIA) Health Disparities Research Framework includes health literacy under its environmental level analysis as a health-related factor that further contributes to health disparities of ethnic and racially marginalized populations (Hill et al., 2015). Individual health literacy can typically be understood as “the combination of personal competencies and situational resources needed for people to access, understand, appraise, and use information and services to make decisions about health” (Levin-Zamir et al., 2019). Individuals can have health literacy strengths and weaknesses that influence how effectively they engage with health-related information and services (Beauchamp et al., 2015). The Institute of Medicine conceptualizes health literacy as a “constellation of skills” needed to function effectively in the healthcare setting and act on healthcare information (Kindig, Panzer, & Nielsen-Bohlman, 2004). Such skills can be developed, matured, enhanced, and even lost throughout one's lifetime (Squiers et al., 2012). The Health Literacy Skills Framework (Squiers et al., 2012) builds on this conceptualization, illustrating how health literacy functions at the individual level (while simultaneously considering external factors to the individual such as family, setting, community, culture, and media) and hypothesizes the relationship between health literacy and health-related outcomes. The framework is characterized by four parts: (1) individual factors that influence the development and use of health literacy skills (e.g., sociodemographic characteristics); (2) health-related stimuli (e.g., a prescription label, brochure); (3) health literacy skills needed to understand the stimulus and perform the task. These skills include: a) *print literacy* (reading, writing, numeracy), which encompasses one's ability to process written materials, read and understand text, and locate and use information in documents; b) *communication* - as health information is often provided verbally, especially during medical visits, communication skills are essential in obtaining and sharing health information and include the ability to listen, speak, and negotiate; and c) *navigation/information seeking*, which encompasses one's ability to locate health information and understand the different levels of care (e.g., self-care, primary care, urgent care, emergency care, etc.) and the different ways to access the needed services and supports. (4) The last part of the framework encompasses mediators between health literacy and health outcomes such as self-efficacy (one's confidence to execute the task) (Squiers et al., 2012).

### ***Medical Discrimination in Dementia Care***

Discrimination experienced in the healthcare setting may also contribute to challenges with healthcare management among Black caregivers of PLWD, as well as present a barrier to achieving optimal health literacy. Under its sociocultural level of analysis, The NIA's Health Disparities Research Framework highlights and prioritizes institutional racism as a social factor that may shape important individual-level decisions that affect health status and life expectancy (Hill et al., 2015). A report that examined perspectives and experiences of different ethnic and racial populations regarding Alzheimer's disease and dementia care found that 41% of caregiver respondents who provide informal care to a Black

PLWD felt that race made it more difficult for them to receive excellent healthcare (Alzheimer's Association, 2021). In the same report, 66% of Black American respondents believed their race made it more difficult for them to receive excellent care for Alzheimer’s disease or other dementias (Alzheimer's Association, 2021). Extending beyond Alzheimer’s disease and dementia care, nearly half of Black respondents reported that they have experienced discrimination while seeking healthcare (Alzheimer's Association, 2021). Less than 17% of non-Hispanic white caregivers reported having such experiences. In a qualitative study that examined Black caregivers’ challenges in engaging with the U.S. healthcare system, such challenges were found to be amplified by systemic discrimination in the U.S. healthcare system concerning race, social class, sex, and payor source (Alexander et al., 2022). Ultimately, being “a person of color” or living at an intersection of marginalized identities can lead to added difficulties for Black caregivers managing the healthcare of their PLWD (Bailey, Feldman, & Bassett, 2021; Alexander et al., 2022).

Experiences of discrimination in the healthcare setting can breed mistrust, which can, in turn, impede health literacy development as it influences interactions with the healthcare system, access to health-related resources, and health-related decision-making (Politi et al., 2014). Therefore, it is crucial to examine both health literacy capacity and experiences of medical discrimination among Black caregivers to assess how these factors relate and further explore how they affect the healthcare management of PLWD. The examination of health literacy and medical discrimination among Black caregivers of PLWD is an understudied topic, and there is a need to prepare Black health-literate caregivers to better navigate a healthcare system plagued by racism and other forms of discrimination. It is warranted to assess health literacy capacity and explore its relationship with medical discrimination among Black caregivers and adopt an equitable approach to hear directly from Black caregivers about key problems and potential solutions related to the healthcare management of PLWD.

### ***Design Thinking: A Human-Centered Approach to Address Health-Related Complexities***

Understanding the perspectives of the population that one aims to serve is crucial in creating solutions that solve the correct problem and meet the needs of the population affected (Hartung &

Rottenberg, 2019). Design Thinking (DT) is an evidence-based method of understanding health-related problems faced by different populations. DT is a “human-centric approach” that embraces collaboration with the intended audience to develop a clear and salient problem definition, engage in creative ideation, and form an optimal solution (Plattner, 2013; Ku & Lupton, 2020). The DT process navigates the beginning phases of innovation through sincere empathy for the target audience and a clear understanding of the complexities they face (Plattner, 2013).

Researchers have incorporated the DT technique to recognize and better understand the dementia caregiving challenges they are studying and seek to address (Aflatoony et al., 2022). The Design Thinking Process has proven effective in supporting researchers in developing clear viewpoints of the caregiving problem space and speculating caregiving-specific interventions that can, specifically, enhance caregiving mastery (Aflatoony et al., 2022). The DT process has also been used to understand and identify prioritized solutions to general caregiving mastery challenges among Black caregivers of PLWD as part of a three-part design studio workshop through the Emory Roybal Center for Dementia Caregiving Mastery (Aflatoony et al., 2022). The workshops followed the Double-Diamond Design Process Model, which is divided into four phases: *Discover, Define, Develop*, and *Deliver*, and emphasizes divergent and convergent modes of thinking (British Design Council, 2005). The *Develop* phase of the process led to 17 intervention ideas developed by Black caregiver participants and ideas for researchers on how to support Black caregivers with appropriate resources and information. Some ideas included a media application to connect with and support other caregivers, customer service type support, a reminder tool for check-ins and reminders at different stages of dementia care, and culturally appropriate programs to prevent dementia-related injuries. Compared to traditional approaches to problem-solving in public health and other health-related fields, DT leads to more successful and sustainable interventions for diverse patient populations (Abookire et al., 2020).

## Purpose of Study and Summary of Papers

This study employed an explanatory sequential mixed methods design to explore the relationship between health literacy and medical discrimination in Black caregivers of persons living with dementia

(PLWD) and understand the fundamental problems Black caregivers face in the healthcare management of those they provide care for. A mixed methods approach calls for collecting and analyzing quantitative and qualitative data, which is beneficial to exploring research topics more thoroughly, particularly those understudied (Creswell & Clark, 2017). A mixed methods approach is needed to examine health literacy and medical discrimination among Black caregivers of PLWD, as studies that have highlighted the importance of caregiver health literacy and its impact on care recipient health outcomes have included few to no Black caregivers. Disparities in health literacy capacity are well-documented among Black Americans, as well as racism and other forms of discrimination experienced in the healthcare setting, which can hinder optimal health literacy capacity (Muvuka et al., 2020).

The explanatory sequential design encompasses two phases of data procedures- the first of which is quantitative data collection and analysis, followed by qualitative data collection and analysis, and lastly, overall data interpretation (Creswell & Clark, 2017). Each procedure was highlighted in the following three papers:

Paper 1 examined health literacy and medical discrimination in 99 Black caregivers of PLWD across the U.S. The purpose was to quantitatively assess the association between two factors that may further contribute to disparities in healthcare management among Black caregivers. For this study, health literacy was conceptualized as a skillset (print literacy, communication, system navigation) aligned with the skills emphasized in the Health Literacy Skills Framework (Squiers et al., 2012). Health literacy was measured with a multidimensional evaluation of individual health literacy (Osborne et al., 2013), and medical discrimination was evaluated according to caregivers' self-reported experiences of discrimination while seeking healthcare for their PLWD (Peek et al., 2011).

Paper 2 highlighted the qualitative procedures to explain quantitative results further and gain a deeper understanding of Black caregivers' most salient problems in healthcare management. A subsample of caregivers (N = 10) who participated in the quantitative phase underwent the problem definition stage (*Discover* and *Define* phases) of the Design Thinking (DT) Process (British Design Council, 2005) initiated by focus group discussions. The goal of undergoing these initial DT phases was for caregivers to formulate a clear and salient problem statement encompassing a collective understanding of the pertinent challenges faced when using their health literacy capacity to engage in the healthcare setting and make decisions about their care recipient's health. This was valuable data that would not otherwise be known in a sole quantitative assessment.

The purpose of paper 3 was to illustrate data integration at multiple levels of the research study including the methods (focus group formation and developing focus group questions) and the analytic and interpretation stages. Data integration is a crucial component of mixed methods research to draw meta-inferences and strengthen a study's conclusions (Guetterman, Fetters, & Creswell, 2015; Creswell & Clark, 2017). Meta-inferences were drawn from integrated data to obtain a comprehensive understanding of health literacy among Black caregivers of PLWD and an understanding of their most salient problem in healthcare management. Ultimately, findings from this explanatory sequential mixed methods study will lay the groundwork for a future culturally appropriate intervention to help prepare Black health literate caregivers so that they can more effectively navigate a multifaceted healthcare environment characterized by discrimination. As a result of the intervention, there is hope that the following will occur: (a) Black caregivers will have increased knowledge of dementia-related resources, improved overall healthcare management, and decreased out-of-pocket healthcare costs; (b) Black persons living with dementia will have improved health-related outcomes and decreased emergency department visits/readmissions; and (c) within the healthcare system there will be decreased healthcare costs and improved patient and caregiver satisfaction.

# Chapter 1: The Association of Health Literacy and Medical Discrimination among Black Caregivers of Persons Living with Dementia: A Cross-Sectional Study

## Abstract

Black caregivers have reported hardships with healthcare management of persons living with dementia (PLWD) including challenges navigating the healthcare system, communicating with healthcare professionals, and limited access to dementia-related material and resources. Health literacy is a malleable risk factor for health disparities and a multidimensional concept represented by a “skillset” needed to function effectively in the healthcare setting and act on health-related information. Medical discrimination is a barrier to acquiring health literacy skills and has also been reported by Black caregivers. The purpose of this cross-sectional study was to quantitatively examine health literacy and its association with medical discrimination among Black caregivers using survey data. Ninety-nine Black caregivers from across the U.S. participated in the survey. The survey was comprised of self-reported sociodemographic information, 6 scales from the Health Literacy Questionnaire (HLQ), and the Discrimination in Medical Settings Scale (DMS). Descriptive and inferential statistics with an alpha set at $p<0.05$, were performed. Pearson bivariate analyses analyzed the strength and direction of the DMS and HLQ scale mean scores, and linear regression analysis examined relationships between predictor socio-demographic variables of interest and the dependent variables. Caregivers scored the highest on the HLQ scale ‘*Understanding health information well enough to know what to do.’ ‘Navigating the healthcare system’* had the lowest score. Bivariate analyses of HLQ scales and DMS scores were all significant; as caregivers’ experiences of medical discrimination while seeking care for PLWD increased, HLQ scale scores decreased. This study was the first step in better understanding the health literacy of Black caregivers of PLWD.

# Introduction

Black adults living with dementia have higher rates of hospitalization, and, although Black Americans make up 13.6% of the United States (U.S.) population, they shoulder a third of non-governmentally covered dementia-related costs (Unpublished Tabulations based on data from the National 5% Sample Medicare Fee-or-Service Beneficiaries, 2014; Alzheimer's Association, 2023; Centers for Disease Control [CDC], 2023). These costs are related to more frequent hospitalizations, greater severity of illness, longer lengths of stay, and higher readmission rates in Black PLWD (Alzheimer's Association, 2023). Black caregivers and their PLWD who experience disparities in care are typically under-treated and have lower rates of formal service use (e.g., paid home health aides or care provided in the formal setting such as nursing homes or assisted living) (Dilworth-Anderson, Pierre, & Hillard, 2012; Gaugler et al., 2023).

Disparities and inequities in the dementia family caregiving experience among Black Americans are well-documented (Oliver et al., 2022; Bond Johnson et al., 2022). Such disparities and inequities are particularly evident in the healthcare management of Black persons living with dementia (PLWD). Black caregivers have reported hardships with navigating the healthcare system, faced challenges and limitations in communicating with doctors and other healthcare professionals, and experienced limited access to and engagement with dementia-related material and resources (Abramsohn, 2019; Alexander et al., 2022). These responsibilities are especially crucial for dementia caregivers as PLWD, commonly those in the middle-late stage of the disease process, are not always cognitively able to manage and make decisions on their healthcare, which makes the disparities in healthcare management among Black caregivers even more alarming (Mullins et al., 2016). Engaging with health-related material, identifying and navigating healthcare services and supports, and conversing with healthcare professionals are common occurrences in the family caregiving experience (Fields et al., 2018).

Health literacy is a malleable risk factor for health disparities (Yuen et al., 2018). Research has found that the health literacy of family caregivers of PLWD and other chronic diseases is directly related to care ability and can negatively affect competent care provision, and, consequently, the health outcomes of those receiving care (Yuen et al., 2018; Li et al., 2020). Individual health literacy is generally understood as “the combination of personal competencies and situational resources needed for people to access, understand, appraise, and use information and services to make decisions about healthcare” (Levin-Zamir et al., 2019). Health literacy is a multidimensional concept represented by a “skillset” needed to function effectively in the healthcare setting and act on health-related information (Kindig, Panzer, & Nielsen-Bohlman, 2004). The few U.S.-based studies that have examined caregiver health literacy and some aspect of the dementia caregiving experience (e.g., incontinence, physician communication) have included few to no Black caregivers (Bliss et al., 2013; Mullins et al., 2016; Fields et al., 2018) which is significant as research has found a higher prevalence of limited health literacy among non-white Americans, and specifically Black Americans (Baker et al., 2007; Muvuka et al., 2020).

Medical discrimination and culturally insensitive healthcare are commonly reported among Black caregivers and further amplify challenges in healthcare management (Kennedy, Mathis, Woods, 2007; Alexander et al., 2022). Black caregivers have reported that discriminatory attitudes perpetuated by healthcare professionals based on differences in their race, sex, class, and identities makes it more difficult for them to receive optimal care for their PLWD (Alexander et al., 2022). A report that examined perspectives and experiences of different ethnic and racial groups regarding dementia care found that 41% of caregiver respondents who provide informal care to a Black PLWD felt that race made it more difficult for them to receive excellent healthcare (Alzheimer's Association, 2021). In the same report, 66% of Black American respondents believed their race made it more difficult for them to receive excellent care for Alzheimer’s disease or other dementias (Alzheimer's Association, 2021). Thus, when assessing health literacy in Black American caregivers or the general Black community, it is also important to consider discrimination, such as racism in the medical setting. Limited financial resources, accessibility, and inequities commonly experienced by Black caregivers, are all barriers to achieving optimal health literacy and acquiring or maintaining the needed skills to effectively engage with health-related material and the overall health system (Abramsohn et al., 2019; Alexander et al., 2022). The purpose of this cross-sectional study was to quantitatively examine health literacy and its association with medical discrimination among Black caregivers of PLWD using survey data.

### *The Health Literacy Skills (HLS) Framework*

For this study, health literacy was conceptualized following the HLS Framework. The HLS Framework builds on existing theoretical frameworks of health literacy and conceptualizes health literacy as a set of skills (Squiers et al., 2012). The framework illustrates how health literacy functions at the individual level and hypothesizes the relationship between health literacy and health-related outcomes and behaviors (Squiers et al., 2012). The framework is characterized by four parts: (1) factors, such as demographic characteristics and prior knowledge, that affect the degree to which a person has and/or can gain health literacy skills; (2) health-related stimuli (e.g., a prescription label, brochure); (3) health literacy skills needed to understand the stimulus and perform the task. These skills include: a) *print literacy* (reading/comprehension, writing, numeracy) - one's ability to process written materials, read and understand text, and locate and use information in documents; b) *communication* - as health information is often provided verbally, especially during medical visits, communication skills are important in obtaining and sharing health information and include the ability to listen, speak, and negotiate; and c) *navigation/information seeking* - one's ability to locate health information and understand the different levels of care (e.g., self-care, primary care, urgent care, emergency care, etc.) and the different ways to access needed services. (4) The last part of the framework includes mediators, such as one's confidence to execute the task (e.g., self-efficacy), between health literacy and health-related outcomes (Squiers et al., 2012).

### *The National Institute on Aging (NIA) Health Disparities Research Framework*

The NIA's Health Disparities Research Framework classifies factors examined in health disparities research at multiple levels of analysis including environmental, socio-cultural, behavioral, and biological (Hill et al., 2015). Under its socio-cultural level of analysis, the framework theorizes institutional racism as a social factor that can shape important individual health-related decisions (Hill et al., 2015). Institutional racism encompasses racist policies and practices perpetuated within an organization or a whole society that support the unfair or harmful treatment and disadvantage of others based on race or ethnicity (Needham et al., 2023). In healthcare institutions, institutional racism is expressed through disparities in access to quality care, differential treatment based on race or ethnicity, and the perpetuation of biases in medical decision-making (Needham et al., 2023). According to the framework, socio-cultural norms and values affect individual-level self-concepts, cognition, and perceptions of bias that shape individual behavior and can influence interpersonal relationships and interactions with healthcare institutions (Hill et al., 2015). Individuals may find negative interactions with clinicians to be culturally insensitive, perceive restricted access to quality health care as institutional racism, and view this hardship as discrimination (Hill et al., 2015). Discriminatory practices have systematically restricted Black Americans' access to resources and skills needed to obtain, understand, and apply health information, resulting in disparities in health literacy skills among Black Americans (Muvuka et al., 2020). Thus, experiences of discrimination in the medical setting were also examined with the health literacy of Black caregivers in this study.

## Methods

### *Ethics Approval*

This study was approved by the institutional review board of Emory University (STUDY0000557).

### *Recruitment & Eligibility*

To be eligible for participation, caregivers self-identified as Black or African American, were 18 years of age or older, had internet access, were currently providing care for someone living with dementia, memory loss, or cognitive impairment, and were involved in their healthcare decisions. Caregivers did not have to reside with their care recipient to participate. Caregivers who were not able to clearly understand English, were former caregivers, were not yet 18 years of age, or were cognitively impaired were not eligible to participate. The lead researcher used convenience sampling to build a network of Black caregivers and encourage study participation. The researcher sought out her research lab's established community partners with predominantly Black faith-based organizations, as well as grassroots, non-profit, and civic organizations that serve caregivers and older adults and churches. She contacted caregiver support groups, adult day care centers, and Black health organizations. Among these different organizations, the lead researcher gave informational talks on health literacy, provided rationale and importance of participating in the study, and spoke on requested topics such as the role of diet in brain health. Recognizing the importance of community for Black families, the lead researcher also attended professional seminars to meet others in dementia care and aging. Study information was distributed through several U.S. universities' Alzheimer's Disease Research Centers and the Emory Roybal Center for Dementia Caregiving Mastery. Informal channels of recruitment were also used to build a network of Black caregivers (Epps, Skemp, & Specht, 2015). The lead researcher sought out family members of close friends, community health events in predominantly Black communities, and social gatherings such as professional networking events and social club meetings hosted at local Historically Black Colleges and Universities. The lead researcher also used snowball sampling as many caregivers were referred by other caregivers who had participated in the study.

### *Survey Measures*

The online cross-sectional survey included the following measures:

*Socio-demographic information.* Self-reported information on age, yearly household income, gender identity, level of educational attainment, health insurance status (caregiver and care recipient), and information on caregiving history was collected.

*Medical discrimination.* Self-reported experiences of discrimination were assessed with the 9-item Discrimination in Medical Settings Scale (DMS) (Peek et al., 2011) which is adapted from the existing Everyday Discrimination Scale (EDS) (Williams, Jackson, & Anderson, 1997). The Cronbach's alpha for the DMS was found to be 0.893 and the instrument has been found to demonstrate moderate test-retest reliability (0.58), convergent validity, and discriminant validity (Peek et al., 2011). The DMS has also been tested extensively on a variety of Black patient populations (Peek et al., 2011). The DMS proxy was used to assess the frequency of caregivers' experiences of mistreatment while seeking healthcare for their PLWD. The DMS asks respondents whether they have experienced specific scenarios, such as *'A doctor or nurse acts as if he or she is afraid of you and your person'* and how often they have experienced it.

Responses are based on a 5-point Likert scale {1-never, 2-rarely, 3-sometimes, 4-most of the time, 5-always}. Total DMS scores range from 7 to 35.

*Health literacy.* Various dimensions of health literacy were assessed with the Health Literacy Questionnaire (HLQ). The HLQ is a multidimensional health literacy assessment developed using a "grounded, validity-driven approach" and has been tested on ethnically diverse populations of adults (ages 18-65 years+), caregivers of older adults, and caregivers of patients with chronic disease (Osborne et al., 2013; Burton et al., 2021). Cronbach's alpha for the HLQ was found to be 0.80 and the instrument has been found to demonstrate content, concurrent, and criterion validity (Burton et al., 2021). The HLQ has nine scales that do not "simply measure whether an individual can read or write, but rather identify profiles of health literacy strengths and needs of individuals related to healthcare provider interaction, accessing, and understanding health information, and other distinct areas of health literacy (Osborne et al., 2013)." The individual nine scales have been found to demonstrate high reliability (composite reliability: 0.8-0.9 for each scale) (Osborne et al., 2013). There is no overall score of the HLQ, and each scale must be assessed individually. All scales contain 4- to 6 items scored on a Likert-type scale.

Scales with 4 response options {1-strongly disagree, 2-disagree, 3-agree, 4-strongly agree}:

- (HPS): '*Feeling understood and supported by healthcare providers'*
- (CA): '*Appraisal of health information'*

Scales with 5 response options: {1-cannot do/always difficult, 2- usually difficult, 3-sometimes difficult, 4-usually easy, 5-always easy}:

- (AE): '*Ability to actively engage with healthcare providers'*
- (NHS): '*Navigating the healthcare system'*
- (FHI): '*Ability to find good health information'*
- (UHI): '*Understand health information well enough to know what to do'*

These six scales were used as they closely captured the health literacy skills that are the focus of this study. Table 1 lists truncated HLQ items and interpretations of scale scores.

*Procedures*

Prospective participants were screened for eligibility. If deemed able to participate, participants were given an online informed consent form for them to sign that provided details on the study and participation expectations. Caregivers had the option of completing the survey on their own or during a scheduled data-gathering interview led by the lead researcher through Zoom or by phone if unable to access the videoconference. Surveys were completed and managed online using REDCap, a secure HIPAA-compliant database (Harris et al., 2009 & Harris et al., 2019). To maintain confidentiality, participant identification numbers were assigned to ensure all data were de-identified. Caregivers were given an electronic $25 honorarium after completing the survey. Data collection occurred from February to September of 2023.

### *Data Analysis*

Data were exported into SPSS software v. 29 (IBM Corp. 2022) and cleaned. The DMS and the six HLQ scales were scored and analyzed for missing data. For the HLQ - if there were missing data in 3 or more items on a scale of 4 to 5 items, or missing data in 4 or more items on a scale of 6 items, these scales were excluded for the caregiver participant (Osborne et al., 2013). Descriptive statistics were conducted to summarize socio-demographic characteristics and medical discrimination and health literacy profiles. Inferential statistics were performed with an alpha set at $p<0.05$. A Pearson bivariate analysis was performed to analyze the strength and direction of the DMS and HLQ scale mean scores. Multiple linear regression analysis was employed to examine relationships between predictor socio-demographic variables (age, level of educational attainment, yearly household income, health insurance status of caregiver, and health insurance status of care recipient) and the dependent variables of interest (HLQ scale averages and average DMS score). Dummy variables were created to represent the categorical variables. Before conducting regression analyses, the lead researcher confirmed that the data met the 8 assumptions of multiple regression in SPSS (Laerd Statistics, 2018).

## **Results**

Ninety-nine Black caregivers of PLWD from across the U.S. including California, Michigan, Ohio, Arizona, Wisconsin, Minnesota, Illinois, Georgia, and Pennsylvania, participated in the survey.

Most caregivers identified as female (n = 69, 69.7%) and cared for a parent (n = 56, 56.6%). Majority of caregivers and their care recipients were insured, with Medicare most cited for the care recipient (n = 44, 44.4%) and private (employer-sponsored, self-pay, etc.) among caregivers (n = 36, 36.4%). Those who chose ‘other’ cited dual coverage (either United Health Care Dual Complete [Medicaid and Medicare] or Medicare and private). Ninety-four percent of caregivers reported their PLWD had been formally diagnosed, and the average time diagnosed was 4.52 years. See Table 1.1 for the full socio-demographic profile of the caregivers.

For the two HLQ scales answered using response options ranging from strongly disagree to strongly agree (range: 1 to 4), the highest mean score was ‘*Appraisal of health information’* (CA) (2.96, SD = 0.48). For the last 4 scales answered using response options from cannot do or always difficult to very easy (range: 1-5), the highest mean score was for ‘*Understanding health information well enough to know what to do’* (UHI) (3.79, SD = 0.51). The mean scores for each HLQ scale are shown in Table 3. The average score on the DMS was 18.35(SD = 6.01) and 32 was the highest overall score. The DMS item with the highest mean value was ‘*You feel like a doctor or nurse is not listening to what you and your person are saying’* (2.85, SD = 0.99). ‘Race’ was the most cited reason for experiences of medical discrimination (N = 38, 38.4%). The mean scores for all DMS items are shown in Table 1.2.

Based on results of the Pearson bivariate analyses, the overall DMS mean score had significant, moderate negative associations with the following HLQ scales: ‘*Feeling understood and supported by healthcare providers’* (HPS) (r = -0.46, p<.001); ‘*Ability to actively engage with healthcare providers’ (*AE) (r = -0.51, p<.001); and ‘*Ability to find good health information’* (FHI*)* (r = -0.45, p<.001). The DMS mean score had significant, weak associations with the following HLQ scales: ‘*Appraisal of health information’* (CA) (r = -0.24, p = .018); ‘*Navigating the healthcare system’* (NHS) (r = -0.35, p<.001); and ‘*Understanding health information well enough to know what to do’* (UHI) (r = -0.25, p = .017). The results of the bivariate analyses all signified a linear negative association indicating that as experiences of medical discrimination while seeking care for PLWD increased, health literacy constructs decreased.

Regression analyses yielded one significant HLQ model for ‘*Understanding health information well enough to know what to do’* (UHI): F(2,93) = 2.26, p = 0.022, $R^2$ = 0.21. The level of educational attainment (*B* = 0.548, p = 0.026) and yearly household income (*B* = -0.603, p = 0.025) were statistically significant predictors of the dependent variable – ‘*Understanding health information well enough to know what to do’* (UHI). The model explained 21% of the variance in the dependent variable based on the level of educational attainment and yearly household income. This indicated that while the model captured some of the patterns in the data, there was a significant amount of variability in ‘*Understanding health information well enough to know what to do’* (UHI) that the model did not account for. Regression analyses also yielded one significant overall model for the average DMS score: F(1,95) = 3.29, p =.001, $R^2$ = 0.28, with age as the only significant predictor (*B* = -.024, p = 0.002). The model explained 28% of the variance in the average DMS score based on the age of the caregiver indicating that the model captured some of the patterns in the data but there was a significant amount of variability in the average DMS score.

## Discussion

The purpose of this cross-sectional study was to quantitatively examine health literacy and its association with medical discrimination among Black caregivers of PLWD. The results provided a comprehensive profile of health literacy skills among a national sample of Black caregivers of PLWD. There continues to be a lack of consensus on what health literacy represents, which has made it more difficult to develop a reliable and valid measure of the concept (Liu et al., 2020). Measures to assess health literacy have long focused primarily on reading ability, comprehension, and numeracy, which is an incomplete capture of the concept as there is more to the healthcare experience that requires additional skills (Beauchamp et al., 2015). Acknowledging health literacy as a single construct falsifies its complexity and restricts clinicians, researchers, public health practitioners, and other relevant professionals from being able to target specific health literacy needs to improve health-related outcomes (Beauchamp et al., 2015). More tools, such as the HLQ, that assess health literacy as a multidimensional concept are being developed, which is vital, especially when seeking to examine health literacy among

Black Americans who are more likely to have limited health literacy than non-Hispanic white Americans (Muvuka et al., 2020).

Using a multidimensional health literacy tool in this study allowed for more than an assessment of whether caregivers could read or write - it also assessed psychosocial and cognitive strengths and weaknesses in healthcare provider interaction, accessing, understanding, and appraising health information, and navigating the healthcare system, which aligns with the comprehensive nature of health literacy and its conceptualization in the HLS Framework. Black caregivers in this study exhibited higher scores in '*Appraisal of health information'* and '*Understanding health information well enough to know what to do.'* Lower scores were on '*Navigating the healthcare system'* and '*Ability to actively engage with healthcare providers.'* Prior research has found that navigating the healthcare system, particularly for someone living with dementia, presents stressors and challenges for Black caregivers who have reported that the healthcare system in America is "broken" with "numerous cracks" (Alexander et al., 2022). System navigation and communication with healthcare providers are key components of managing healthcare for PLWD that have previously been identified as weaknesses in Black caregivers yet have been frequently excluded from existing health literacy measures (Jordan, Osborne, & Buchbinder, 2011).

Within this study population, as scores for medical discrimination, while seeking care for PLWD increased, each health literacy construct score slightly or moderately decreased. Research has found medical discrimination to be a health literacy barrier for Black Americans, who experience disparities in health literacy (Politi et al., 2014). Black caregivers have reported that the top problem faced in the healthcare setting is that providers and staff do not listen to them because of their race, ethnicity, or color and have cited discrimination as a top hurdle in receiving dementia care for their PLWD (Alzheimer's Association, 2021). By historically failing to accommodate marginalized ethnic and racial populations' needs and preferences in the delivery of services and health information, healthcare providers, clinics, and systems have contributed to disparities in health literacy (Muvuka et al., 2020). Further, healthcare providers may not recognize the extent of health literacy gaps as a study found that doctors overestimated the health literacy scores of 54% of Black patients, compared with 11% of non-Hispanic white and 36% of patients of another race/ethnicity (Kelly & Haidet, 2007).

The HLS Framework highlights influential factors, such as socio-economic status and level of educational attainment, in the development of health literacy (Squiers et al., 2012). Studies have found that individual characteristics such as older age, lower educational attainment, and lower income are associated with lower levels of health literacy (Martin et al., 2009). Our study assessed whether certain socio-demographic characteristics were predictors of the individual HLQ scales. Yearly household income and level of educational attainment were found to be significant predictors for '*Understanding health information well enough to know what to do*.' The foundation of health literacy is literacy (reading, writing, speech, comprehension, and basic math skills) (Kindig et al., 2004), and literacy is often represented by one's level of educational attainment in health literacy research. Some healthcare providers use the level of educational attainment as a proxy measure for health literacy given the link between health literacy and general literacy (Van Vliet et al., 2021; Martin et al., 2009). This practice, however, can lead to under- or over-estimation of the roles of each in health-related outcomes and behaviors (Martin et al., 2009). This practice and the significance of these factors must be used with caution as the exposure to new or unfamiliar health concepts (often while under a fair amount of stress) and the complexity of the healthcare system, both of which are common to dementia caregivers, can impede one's health literacy skillset (Castro et al., 2007; Martin et al., 2009).

### *Limitations*

This study presented some limitations. The sample comprised highly educated caregivers, over half of whom graduated college or had a graduate/professional degree. Efforts to recruit Black caregivers with diverse educational backgrounds would be beneficial for future research. Mediators that influence the relationship between health literacy and health-related outcomes were not assessed. Although research has shown a direct relationship between health literacy skills and health-related outcomes and behaviors, factors such as self-efficacy, individual health status, and motivation may also mediate the association and should thereby be considered when assessing individual health literacy (Berkman et al., 2010).

Additionally, cognitive abilities typically measured with working memory and comprehension, and verbal fluency were not considered though commonly evaluated in health literacy studies. Health literacy research has shown that scores on health literacy assessments are related to various abilities including verbal influence, memory, and general intellectual functioning, and should be included when measuring individual health literacy (Yost et al., 2013). Items on the HLQ are in the context of general health information. While this study aimed to measure the health literacy of Black caregivers with no specific context, perhaps survey responses would have varied if in the context of dementia-related information or more insightful findings would have emerged with the inclusion of a disease-specific knowledge assessment.

### *Conclusion and Future Research*

This study is the first of its kind to describe health literacy skills of a national sample of Black caregivers of PLWD using a multidimensional health literacy instrument. This study also evaluated the association between different health literacy constructs and medical discrimination. Findings pinpointed specific areas of health literacy that need to be addressed among the population of interest, to improve healthcare management in the dementia caregiving experience and potentially improve health-related outcomes in Black PLWD. Although there have been numerous validation studies of the HLQ, none have been conducted in this specific population to ensure understanding of the items. Future research seeking to use the HLQ with Black American caregivers may consider first conducting a cognitive interview among the population. This study was the first step in better understanding the health literacy of Black caregivers of PLWD. Future research may consider re-assessing health literacy in a larger sample size of Black caregivers and include the absent measures of this study (mediators, cognitive abilities, and verbal fluency), while also including measures of dementia-specific knowledge for a more generalizable and thorough health literacy profile of this population.

**Table 1**

*Health Literacy Questionnaire (HLQ) items and interpretation of scale scores*

**1. Feeling understood and supported by healthcare providers (HPS)**

1a. I have at least one healthcare provider who…
2b. I have at least one healthcare provider I can…
3c. I have the healthcare providers I need…
4d. I can rely on at least one healthcare provider

*High scores: Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.*

*Low scores: Unable to engage with doctors and other healthcare providers. Individuals don't have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice.*

**2. Appraisal of health information (CA)**

2a. I compare health information from different…
2c. When I see new information about health, I…
2d. I know how to find out if the health…
2e. I ask healthcare providers about the quality…

*High: Able to identify good information and reliable sources of information. Individuals can resolve conflicting information by themselves or with help from others.*

*Low: No matter how hard they try, individuals cannot understand most health information and get confused when there is conflicting information.*

**3. Ability to actively engage with healthcare providers (AE)**

3a. Make sure that healthcare providers understand…
3b. Feel able to discuss your health concerns with a…
3c. Have good discussions about your health with doctors
3d. Discuss things with healthcare providers…
3e. Ask healthcare providers questions to get…

*High: Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional health care providers when necessary. Individuals keep going until they get what they want. Empowered.*

*Low: Is passive in their approach to health care, inactive, i.e., they do not proactively seek or clarify information and advice and/or service options. Individuals accept information without question. Unable to ask questions to get information or to clarify what they don't understand. Individuals accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns.*

**4. Navigating the healthcare system (NHS)**

4a. Find the right health care
4b. Get to see the healthcare providers you need to
4c. Decide which healthcare provider you need to see
4d. Find out what healthcare services…
4e. Make sure you find the right place…
4f. Work out what is the best care for you

*High: Individuals able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.*

*Low: Individuals unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.*

**5. Ability to find good health information (FHI)**

5a. Find information about health problems
5b. Find health information from several…
5c. Get information about health so you are
5d. Get health information in words you…
5e. Get health information by yourself

*High: Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date*
*Low: Cannot access health information when required. Is dependent on others to offer information.*

**6. Understand health information well enough to know what to do (UHI)**

6a. Confidently fill medical forms in the correct way
6b. Accurately follow the instructions from…
6c. Read and understand written health information
6d. Read and understand all the information on…
6e. Understand what healthcare providers are…
*High: Individuals able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required.*
*Low: Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.*

*Note.* Items are truncated. The HLQ is protected by copyright and cannot be used without authors’ permission. Full copy of the items can be requested at ghe-licences@swin.edu.au

**Table 1.1**

| Characteristic | M [Range] / N (%) | Missing Data (n) |
|---|---|---|
| Age (years) | 41.96 [23-70] | 2 |
| Gender identity | | 2 |
| (Female) | 69 (69.7%) | |
| (Male) | 28 (28.3%) | |
| Educational Attainment | | 3 |
| (College graduate or Graduate/Professional Degree) | 61 (61.62%) | |
| (Some College) | 22 (22.2%) | |
| (Highschool/GED) | 11 (11.1%) | |
| (Less than high school) | 1 (1%) | |
| Neighborhood Environment | | 5 |
| (Urban) | 47 (47.5%) | |
| (Suburban) | 38 (38.4%) | |
| (Rural) | 8 (8.1%) | |
| Yearly Household Income | | 16 |
| ($0-$10,000) | 2 (2%) | |
| ($10,000-$25,000) | 6 (6%) | |
| ($25,001-$50,000) | 23 (23.2%) | |
| ($50,001-$100,000) | 46 (46.5%) | |
| ($100,001 or more) | 6 (6.1%) | |
| Person Caring For | | 2 |
| (Parent) | 56 (56.6%) | |
| (Spouse) | 7 (7.1%) | |
| (Sibling) | 9 (9.1%) | |
| (Other relative) | 23 (23.2%) | |
| (Friend) | 2 (2%) | |
| Care Recipient Stage of Diagnosis | | 2 |
| (Early stage) | 28 (28.3%) | |
| (Middle stage) | 53 (53.5%) | |
| (Late stage) | 15 (15.2%) | |
| Average Time Spent Caring (years) | 3.66 [1 month-11years] | 8 |
| Health Insurance Status – Care Recipient | | 3 |
| (Private) | 16 (16.2%) | |
| (Medicare) | 44 (44.4%) | |
| (Medicaid) | 22 (22.2%) | |
| (Other) | 3 (3%) | |
| (None) | 12 (12.1%) | |
| Health Insurance Status – Caregiver | | 6 |
| (Private) | 36 (36.4%) | |
| (Medicare) | 20 (20.2%) | |
| (Medicaid) | 21 (21.2%) | |
| (Other) | 2 (2%) | |
| (None) | 15 (15.2%) | |

*Socio-Demographic Profile of Caregivers*

**Table 1.2**

| | **Mean (SD) [95% CI] / N (%)** | **Missing Data (N)** |
|---|---|---|
| **HLQ Scale** | | |
| | Range 1 (lowest) – 4 (highest) | |
| 1. *Feeling understood and supported by healthcare providers* | 2.81 (0.41) [2.70, 3.0] | 4 |
| 2. *Appraisal of health information* | 2.96 (0.48) [2.86, 3.13] | 4 |
| | Range 1 (lowest) – 5 (highest) | |
| 3. *Ability to actively engage with healthcare providers* | 3.46 (0.49) [3.33, 3.67] | 4 |
| 4. *Navigating the healthcare system* | 3.42 (0.57) [3.29, 3.61] | 4 |
| 5. *Ability to find good health information* | 3.46 (0.56) [3.32, 3.67] | 4 |
| 6. *Understand health information well enough to know what to do* | 3.79 (0.51) [3.66, 4.0] | 4 |
| **DMS Items** | | |
| 1. *Your person is treated with less courtesy than other people* | 2.70 (1.00) [2.50, 2.91] | 5 |
| 2. *Your person is treated with less respect than other people* | 2.64 (1.11) [2.41, 2.87] | 5 |
| 3. *Your person receives poorer service than other* | 2.51(1.06) [2.29, 2.73] | 5 |
| 4. *A doctor or nurse acts as if he or she thinks you and your person are not smart* | 2.66 (2.26) [2.46, 2.87] | 4 |
| 5. *A doctor or nurse acts as if he or she is afraid of you and your person* | 2.26 (1.11) [2.03, 2.48] | 5 |
| 6. *A doctor or nurse acts as if he or she is better than you and your person* | 2.82 (1.14) [2.59, 3.05] | 4 |
| 7. *You feel like a doctor or nurse is not listening to what you and your person are saying* | 2.85 (0.99) [2.65, 3.05] | 5 |
| 8. *What do you think the MAIN reason is for these experiences?* | | 18 |
| Race | 38 (38.4%) | |
| Ethnicity | 14 (14.1%) | |
| Gender | 3 (3.0%) | |
| Age | 18 (18.2%) | |
| Income Level | 2 (2.0%) | |
| Language | 1 (1.0%) | |
| Physical Appearance | 1 (1.0%) | |
| Other | 4 (4.0%) | |

*Health Literacy Questionnaire (HLQ) and Discrimination in the Medical Setting (DMS) scores*

*Note.* Abbreviations: SD – standard deviation

# Chapter 2: "The Problem with Healthcare": Understanding Black Caregivers' Fundamental Problem in Healthcare Management Using the Design Thinking Process

## Abstract

Design Thinking (DT) has been successful in understanding and identifying prioritized solutions to general caregiving challenges among Black caregivers of persons living with dementia (PLWD). There are currently no interventions to address the health literacy of Black caregivers. The purpose of this paper was to engage Black caregivers of PLWD in the problem-definition stage of the DT process (*Discover* and *Define* phases) to develop an improved understanding of challenges related to healthcare management and medical discrimination and lay the groundwork for future intervention ideation and development. Ten Black caregivers (2 groups of 5) from various parts of the United States participated in the DT process initiated by focus groups. During the *Define* phase, caregivers used divergent thinking to discuss challenges aligned with predetermined categories that were examined in a larger parent study: *print literacy; communication; navigation/information seeking;* and *medical discrimination.* Some challenges included - *receiving health information in medical jargon*; *insurance coverage dictates navigation*, and *healthcare professionals' lack of cultural competency*. During the *Define* phase, both groups of caregivers used convergent thinking to construct two problem statements that encompassed their most salient problem in healthcare management. The groups did not arrive at the exact same problem statement, however, both statements pointed to the complexities of verbal health information given by healthcare providers concerning PLWD. Next steps include further validating the qualitative data and continuing the iterative process of DT so that a single problem statement will be constructed, making for the development of a more specified culturally relevant intervention.

## Introduction

Design Thinking (DT) is an evidence-based, systematic process of innovation and a method of understanding health-related problems faced by various populations (Roberts et al., 2016). It is a "human-centered approach" in which the population of interest collaborates to establish a problem definition and brainstorm new ideas and optimal solutions (Plattner, 2013; Ku & Lupton, 2020). The DT process is comprised of stages that employ empathy, idea development, "iterative prototyping", continuous testing, and implementation of an effective strategy or intervention to address the complex challenge(s) of interest (Roberts et al., 2016). Empathy is an important attribute of DT, thus the intended population's desires, needs, and challenges must be centered to better understand a problem in hopes of developing an adequate, sustainable solution (Roberts et al., 2016). Understanding the perspectives of the population that one aims to serve is crucial in creating solutions that solve the correct problem and meet relevant needs (Hartung & Rottenberg, 2019). Innovation is brought forth after undergoing the various iterative and nonlinear stages that use divergent and convergent ways of thinking (Aflatoony et al., 2022). Divergent thinking is used to come up with original ideas, solutions, and choices for a problem by exploring possible directions (Aflatoony et al., 2022). In contrast, convergent thinking aims to make choices or define one well-established solution (Ferreira et al., 2015). DT has been successfully applied in dementia caregiving, from training researchers to recognize the dementia caregiving challenge and solution in greater depth through a caregiver approach, to understanding and identifying prioritized solutions to general caregiving challenges among Black caregivers of persons living with dementia (PLWD) (Aflatoony et al., 2022; Aflatoony et al., 2022).

Interventions to meet the needs of Black caregivers, who face a dementia-caregiving experience influenced by cultural factors and often plagued with disparities and inequities are needed (Fabius et al., 2020; Alzheimer's Association, 2021). There has yet to be a plan of action to address the health literacy of Black caregivers. In general, individual health literacy is "the combination of personal competencies and situational resources needed for people to access, understand, appraise, and use information and services to make decisions about health" (Levin-Zamir et al., 2019). Adequate health literacy skills are needed by family caregivers for optimal healthcare management (Abed et al., 2020). Black caregivers have reported challenges with accessing dementia-specific information and resources, navigating the healthcare system, and limitations in communication and engagement with healthcare professionals - experiences that call for adequate health literacy skills (Abramsohn et al., 2019; Alexander et al., 2022). Limited health literacy among Black Americans has been documented across multiple studies (Dolan et al., 2004; White et al, 2008; Muvuka et al, 2020), as well as experiences of discrimination in the healthcare setting (Alzheimer's Association, 2021; Alzheimer's Association, 2023) which can impede individual health literacy skills (Muvuka et al, 2020). Thus, it is imperative to develop a culturally appropriate intervention to prepare health-literate Black caregivers so that they may efficiently manage the healthcare of their care recipient, as health and service utilization disparities are also well-documented among Black PLWD.

The purpose of this study was to engage Black caregivers in the problem-definition stage of the DT process (*Discover* and *Define* phases) to develop an improved understanding of challenges related to healthcare management and medical discrimination and lay the groundwork for future intervention ideation and development. Specifically, Black caregivers had the opportunity to openly discuss and expand on each other's ideas to arrive at a collective view of the pertinent challenges faced when using their health literacy skills to engage in the healthcare setting and make decisions about their PLWD health as well as their experiences of medical discrimination while seeking care.

## Methodology

This study was part of a larger explanatory sequential mixed methods study that examined health literacy and medical discrimination among Black dementia caregivers. The overall study was approved by the institutional review board of Emory University (STUDY0000557).

To be eligible for participation in the parent study, caregivers self-identified as Black or African American, were 18 years of age or older, and were actively caring for someone living with dementia, memory loss, or cognitive impairment and involved in their healthcare decisions. Caregivers did not have to reside with their care recipient to participate. Caregivers who could not provide consent, were not able to clearly understand English, were former caregivers, or were cognitively impaired were not eligible to participate. The last question of the quantitative survey of the parent study asked caregivers whether they consented to participate in a series of 2 focus groups; all who consented were eligible to participate in the present qualitative study. During the preliminary analysis of survey data, purposive sampling was used to select focus group participants for the current study. Information about the DT approach, caregiver participants, qualitative data collection, and the focus group discussions (FGDs) guide is provided in the following sections.

### ***Design Thinking Approach***

Focus groups were guided by the DT process based on the Double-Diamond Design Process Model illustrated in Figure 1 (British Design Council, 2005). The model is comprised of 4 phases, and for this study, caregivers only underwent the *Discover* and *Define* phases (problem-definition stage). The *Discover* phase emphasizes divergent thinking in exploring a problem through empathizing and listening to the intended audience (British Design Council, 2005; Aflatoony et al., 2022). During the *Discover* Phase, the moderator works to understand the experiences of the intended audience through observation and listening to their lived experiences (Ferreira et al., 2015). Divergence is a process that encourages participants to freely explore and create a wide range of ideas that align with the problem of interest without judgment or criticism (Ferreira et al., 2015). Using divergent thinking, participants collectively brainstorm and consider various perspectives, insights, and angles of the problem before refining and narrowing down to the best idea in the following phase (Ferreira et al., 2015). The *Define* phase emphasizes convergent thinking to develop the right solution by bringing focus and direction (British Design Council, 2005; Aflatoony et al., 2022). The moderator presents the ideas and context from the previous brainstorming session and facilitates the discussion while refraining from contributing personal ideations during convergence (Ferreira et al., 2015). Convergence is a process of selecting, assessing, and refining the ideas generated during the divergence process (Ferreira et al., 2015). Using convergent thinking, participants collectively evaluate their ideas based on viability, feasibility, and desirability using evaluation tools such as decision matrices (Ferreira et al., 2015). The goal of using convergent thinking during the *Define* phase is to clearly define the problem to prepare for effective solution ideation. The purpose of only undergoing the initial phases of the DT Process was to explore and delineate how Black caregivers' health literacy and experiences of medical discrimination affect healthcare management, with the end goal of developing a clear problem statement that encompasses the fundamental problem of managing healthcare for PLWD.

### *Caregiver Participants*

Ten Black caregivers participated in the *Discover* and *Define* phases of the DT process. To accommodate the caregivers' conflicting schedules and time preferences, 2 groups, each comprised of 5 caregivers, were held per phase. All FGDs were held in September of 2023 and lasted 55-90 minutes each. Caregivers resided in various parts of the United States (U.S.) including Georgia, South Carolina, Texas, Ohio, California, and Wisconsin. The average age of caregivers was 48.9 years and the majority identified as female (n = 8, 80%). All but one caregiver reported that their PLWD received a formal diagnosis of dementia, and all caregivers reported that their care recipient was experiencing either middle or late-stage symptoms (n = 5, 50% for each stage). Table 2 illustrates the demographics of the caregivers for each group.

### *Data Collection*

Focus groups were moderated by the lead researcher who had prior experience leading FGDs with Black caregivers, including a workshop series that underwent all 4 phases of the DT process. Before each FGD, the lead researcher took reflexive notes on expectations and any personal biases that needed to be addressed before the start of the session. Notes were also taken after each FGD to document what went well, and what needed to be improved before the next discussion. The researcher also took detailed field notes during each FGD. Before each FGD, the respective DT phase was explained to the caregivers and what was hoped to be accomplished by the end.

The FGD guide was developed based on the assessment of the following variables in the parent study: medical discrimination (Peek et al., 2011) and individual health literacy skills: *print literacy* (reading/comprehension, writing, numeracy); *communication* (listening, speaking, negotiating with healthcare providers and professionals); and *navigation/information seeking* (locate and apply health information and locate and understand the different levels of care), which are outlined in the Health Literacy Skills Framework (Squiers et al., 2012) and assessed with the Health Literacy Questionnaire (Osborne et al., 2013). During the *Discover* phase, the lead researcher asked the following open-ended questions, starting with the exploratory question, *what does it mean to be health literate?*

Print Literacy:

- *What are your experiences with filling out medical forms and reading medication labels?*

Communication:

- *What are your primary challenges when engaging with healthcare providers?*
- *What difficulties do you have when communicating with healthcare providers so that you get the information you need for your person?*

System Navigation/ Information Seeking:

- *What sources do you rely on to get health information and what makes finding information about health problems challenging?*
- *What makes navigating the healthcare system for your person difficult?*

Medical Discrimination:

- *What discriminatory experiences have you faced while seeking healthcare for your person? How have these experiences impacted healthcare management?*

To ensure the FGDs aligned with the objectives of the respective DT phases, questions and session agendas were confirmed with another member of the research team with extensive experience in DT methods. All caregivers had previously participated in the quantitative phase of the lead researcher's parent study, and thus had familiarity with and trust in her as well as a clear understanding of the purpose of her dissertation research which prompted them to be open and very communicative during the FGDs.

All FGDs were held virtually over Zoom and verbal permission to record the sessions was given. Caregivers were given an electronic $25 honorarium after participation in each FGD ($50 total).

### ***Data Analysis***

Qualitative data analysis was performed simultaneously with data collection so that earlier findings (*Discover* phase) informed the later focus groups (*Define* phase), allowing the researcher to seek emerging observations and patterns in the data. Groups 1 and 2 FGDs were transcribed and caregivers' names were de-identified. All transcripts were stored in a secure cloud network. Individually, the lead researcher used the RADar technique, in combination with field notes, to analyze transcripts through a series of phases (Watkins, 2017). During phase 1, data transcripts were similarly formatted, and the lead researcher read through each transcript. During phase 2, the sections of the FGD guide: print literacy; communication; system navigation/information seeking; and medical discrimination were used as pre-determined categories for initial coding and data reduction. All-inclusive data tables were created in two Excel spreadsheets for the *Discover* and *Define* phase with detailed column headers. The transcripts were re-read, and all data were copied and pasted under the respective headers. During phase 3, each predetermined category was further explored inductively allowing the specific challenges or subcategories to emerge from the data. Data in the all-inclusive data table were reduced to produce a new data table, related to the predetermined categories. After developing the new data table, the researcher conferred with the DT methods-experienced researcher and discussed the challenges that were discussed, and a plan for carrying out the *Define* phase.

Challenges for each group of caregivers were documented, color-coded based upon the respective predetermined category it aligned with, and compiled in a slide show to help facilitate discussion and allow caregivers to better visualize the challenges they prioritized. During the *Define* phase FGDs, caregivers were provided with the following list of criteria to be considered when collaboratively excluding challenges to come up with a narrowed problem statement: a) a solution exists for this problem; b) the problem is NOT as critical; c) The problem is NOT caregiving-related; d) The problem is NOT worth tackling; e) the solution is outside our expertise (public health/nursing research). After transcription and de-identification of the *Define* phase data, analysis using the RADar technique continued. Additional data tables encompassing *Define* phase data were developed and reduction techniques were used to assess patterns in all FGDs among the two groups and DT phases that aligned with the predetermined themes.

## Results

### *Discover* Phase: Listen and Empathize with Black Caregivers

The goal of the first FGD was to understand the influence of Black caregivers' health literacy skills and experiences of medical discrimination on healthcare management for their PLWD. Caregivers were asked to think broadly about their caregiving experience and challenges in healthcare management tasks for their PLWD. Divergent thinking was used as a means of empathizing with caregivers - including uninterrupted brainstorming, storytelling, and providing an open forum for caregivers to reflect on their lived experiences. The *Discover* Phase lasted 90 minutes for each group and led to the discussion of 12 challenges in Group 1 (GR1) and 7 challenges in Group 2 (GR2) that aligned with the four pre-determined categories. Table 2.1 illustrates the pre-determined themes and all corresponding challenges (or lack thereof) of GR1 and GR2 with examples.

#### *Print Literacy*

Caregivers were asked about their experiences with reading/understanding and filling out medical forms. Caregivers from GR1 stated, *"no challenges (R1)"* and "*for me that has become a habit, that's become such a routine and habit that I'm accustomed to filling out forms (R3)."* Another caregiver stated, *"…I don't have to ever fill out any forms, per se (R2)."* A caregiver in GR2 answered with

> *"ah, for me the challenge is just feeling like doing it, cause it's like everywhere you go you gotta fill out this paper… it's overwhelming to have to take care of another whole adult and you know that adult is dying, so now you gotta sit here and fill out this paperwork (R6)."*

Another caregiver from GR2 said, *"Sometimes I feel rushed... oftentimes I do feel anxiety when I'm having to be rushed to get those forms in (R9)."*

Caregivers were also asked about their experiences reading/understanding medication labels, which prompted a caregiver from GR1 to say, "*I'm already familiar with medication labels (R3)."* A caregiver from GR2 stated, "*I have not had much problems understanding prescription labels. It might be because I'm a breast cancer survivor, so five years ago I got into reading labels, and looking at everything twice… I've just kind of developed that skill so that's really not a problem (R7).*"

Another caregiver in GR1 responded, *"When they're changing medication dosages of the same medication, changing to a different medication, sometimes that's hard for me to keep up with (R2)."* A caregiver from GR2 stated:

> *"It's not always clear when a new medicine is prescribed; how does that impact the other medicines that they're taking, should they stop taking something? That's where you have to rely on what the doctor's saying you know, we don't know. Do we really need to keep taking four and five pills, if nothing's gonna change? Like, we know there's no cure is this any benefit (R8)?"*

A few others from GR2 experienced no problems with medication labels because both the caregivers and their PLWD were *"not on any medications (R6, R10)."*

### *Communication*

GR1 discussed the challenges of receiving verbal information in the healthcare setting:

> *"The challenge that I face is getting the information in real-time… I'll have an appointment, or we might have a visit to the emergency room, and everything is moving pretty quickly. But when I go back and look at the notes on* [the patient portal] *…when I need to decipher and go back and ask questions, 'Why didn't you tell me my mother was in a-fib?' or, whatever I find that they did not tell me. That's my challenge is to get real-time information from different providers (R2)."*

Another caregiver in GR1 discussed her experiences when receiving verbal information: *"Sometimes I feel I've had to do a lot of research because when you go to the hospital, you're bombarded with so much information and you can't digest everything. So afterwards I'll go back and try and Google and find more information online (R5)."*

Caregivers in GR1 also discussed receiving verbal information in medical jargon: *"If there's too much of the medical jargon, that's when I know I start getting overwhelmed like, 'well what are they really talking about?' You know (R2)?" "I feel like with the doctors, they sort of talk as if they're talking* *to a fellow colleague like someone who understands what they're saying (R4)." "...to me, it's sometimes explaining the information to my relatives. There are times when the information is in more of a medical jargon…or medical terminology, and usually, I'm able to explain it to them, but there are times when it's difficult to get them to understand (R3)."*

A caregiver from GR2 also spoke about receiving information on his mother in medical jargon:

> *"...you're not in the medical field and you really don't understand the language as much as you would if you were in the field…when you try to approach them* [doctors] *or try to tell them the problem… they would always expect you to talk to them not in layman language (R10)."*

A caregiver from GR1 spoke on having to ask for more time with her relatives' doctors: *"I've had some situations where the doctors were very busy and did not have time to speak with me at length, so what I've done to try to curtail that is to schedule some time with them. I would say I want 10 minutes or five minutes… I have to initiate it (R3)."* Another caregiver from GR1 spoke about her *"concerns not being taken seriously"* or seeming as if she was "*overreacting…when in fact you're just trying to articulate yourself (R5)."* GR2's communication challenges also extended to the "*medical assistant or the nurse (R9)."*

GR1 discussed the challenges of communicating with multiple providers on their PLWD's care team and some caregivers in GR2 commented on similar experiences:

> *"You know, as a caregiver? Come on, now. I'm here taking care of my mother 24/7, and I don't mind interacting with the doctors if I don't understand something, but when I have to connect them through the computer systems to talk to each other, that is so frustrating. I should never have to do that…that's something they need to fix (R2)."*

The topic of communication generated discussion about healthcare providers' limited knowledge of dementia and dementia-related diseases in GR2: *"I would say more so the lack of knowledge about dementia, rather than the poor communication... I would lean towards the lack of knowledge about the disease, the different diseases or the stages, probably, especially at a PCP* [primary care provider] *level (R7)."*

> *"When you're looking at communication, part of the problem for me that stem from poor communication was a lack of knowledge 'cause they weren't communicating anything...we didn't have poor communication, it was really no communication 'cause no one was understanding what was going on (R6)."*

*System Navigation/Information Seeking*

GR2 caregivers spoke on the challenge of *"knowing where to start (R6, R8)",* when navigating the healthcare system and finding information, as well as the problems with using internet sources:

> *"I think one of the barriers or why people have trouble getting information is Google… and the internet. There's a lot of misinformation out there that people sometimes take as the gospel, so I think when you're trying to get information, finding information, you have to know where to start. Like you* [R6] *said you don't really know where to start (R7)."*

*"Healthcare financing, specifically insurance dictating care and accessibility (R5)",* was an issue when navigating the healthcare system discussed in GR1 and touched upon among caregivers in GR2. One caregiver discussed that when it comes to navigating her mother's healthcare, *"sometimes it boils down to insurance coverage…what I may find helpful versus what the insurance covers (R2)."* A caregiver in GR2 stated, *"If you can have the kind of insurance that is kind of all-inclusive...then everything is connected. All the records are there instantly (R7)."*

The topic of system navigation/information seeking also brought forth a discussion on the usage of the patient portal in GR1:

> *"A lot of my questions go through the* [patient portal] *so the challenge for me is them responding in a reasonable timeframe…that's a bit annoying… it seems like they put it off like you have to call up there…If we're not gonna utilize the tool then we shouldn't have it. You know what I mean? (R1)."*

A caregiver from GR2 also shared her experiences with using the patient portal and "*where I've put an email in there and it has not been responded to, timely (R7)."*

*Medical Discrimination*

Caregivers from both groups spoke on experiences of discrimination while seeking healthcare for their PLWD:

> "*I think he* [the doctor] *just looks at me a little bit beneath my mother…I'm still doing a lot. So, that's my thing. It's just more so like the respect level, with the ages. He's been working with my mom longer so I feel he's like, 'Oh, you're just a kid,' kind of thing (R1)."*

Another caregiver from GR1 shared:

> "*I do feel that other people, in other groups, don't experience these types of things. The cardiologist, versus the ER versus the respiratory docs, they don't care explanations aren't coming to me…. I just don't get it, but I feel it is a racial thing you know? I hate to even say that but sometimes they bring me to that level (R2)."*

A caregiver from GR2 also shared his experiences:

> "*My wife's age…She was 48 when this started. I realize that our primary care physician and even the psychiatrist that we were seeing, no one really picked up on the fact that she may be in the beginning stages of dementia because of our ages and at the end of the day, what I have come to realize is that nobody really gives a damn (R6)."*

A caregiver from GR1 shared that while in the healthcare setting "*only the male family members are addressed (R4)."* Another caregiver from GR1 shared:

> "*I've had a couple of situations where the doctors would discuss the health condition with me, and my relatives would be there sitting next to me and the doctors would really not make eye contact with my relatives and I didn't feel that it was because of race. I thought it was because of their diagnosis…Alzheimer's and dementia. As though, you know, if he were to talk about it, then they wouldn't be able to comprehend it, or he wouldn't be able to explain it to them (R3)."*

A caregiver in GR2 discussed his experience with microaggressions:

> *"Microaggressions… some of the people that come to our home and it's, I guess we shouldn't be living here…or they're surprised that, you know, the house looks nice; the grass is cut. Ah, you can just kind of hear it in their compliment and when they're sitting down, they're looking*

*around… or me being called… me being told that I'm very articulate, you know, while in a support group (R6).*"

Caregivers from both groups stated that they *"come prepared (R2, R3, R7, R8)", "come knowledgeable (R2, R3, R7, R8)"*, are "*dressed appropriately (R2, R3, R7, R8)"*, and/or have a *"well-established relationship with the provider (R3, R5, R8, R9, R10)."* to *"avoid facing 'such' experiences (R2, R3, R5, R8, R9, R10)."*

## ***Define* Phase: Develop Insights**

After the *Discover* Phase, the lead researcher analyzed the transcripts to pinpoint shared contextual challenges that aligned with the pre-determined themes. The challenges, along with examples of each discussed among caregivers, were compiled into a single slide show (one slide for GR1, another for GR2, and only shown to the respective group). The purpose of the slide show was to help facilitate discussion during the *Define* phase and help caregivers better visualize the challenges they came up with to define the right problem. The same groups of caregivers participated in the *Define* phase FGDs. At the start of the discussion, caregivers were shown the list of challenges and corresponding examples they came up with to confirm the data. Once caregivers confirmed the list, convergent thinking and prioritization techniques were used to review the challenges and think through the most salient problems related to the healthcare management experience as a Black caregiver based upon the criteria provided and discussed in the above *Data Analysis* section. The lead researcher acted as a facilitator while caregivers discussed each challenge and decided which were the most critical to them and could be addressed in a future intervention. After caregivers collectively agreed a challenge was not as critical or they could not see it being addressed, the lead researcher crossed it off the list and moved on to the next. Caregivers were allowed to return to challenges at the end of the discussion if they determined it potentially could be a fundamental problem or if they could not come to a consensus. The *Define* phase for GR1 lasted 55 minutes and 65 minutes for GR2. Caregivers agreed on a shorter, prioritized list of challenges to be addressed through a future intervention, which led to identifying a problem statement for each group:

**GR1 Problem Statement**: *Receiving real-time health information in medical jargon is an added burden… Dementia caregiving is challenging enough without receiving an abundance of pertinent health-related information on [our] loved one in complex terms.*

**GR2 Problem Statement:** *Primary care providers' lack of knowledge in how to recognize dementia/dementia-related disease(s) is a problem.*

## Discussion

This study engaged Black caregivers in the problem definition stage (*Discover* and *Define* phases) of the Design Thinking (DT) process. Using convergent and divergent methods of thinking, the process elucidated challenges that aligned with different individual health literacy skills (print literacy, communication, and system navigation/information seeking) and medical discrimination, factors that can directly affect caregivers' healthcare management of PLWD (Abed et al., 2020; Alzheimer's Association 2021). The process also detailed external barriers and complexities Black caregivers face at the healthcare provider and system level that further affect their health literacy. DT methods' emphasis on collaboration and co-creation in the innovation process is a valuable approach to empowering underserved communities, allowing their voices and lived experiences to lead which sets the foundation for an equitable solution to the given problem(s) (Wilkerson & Trellevik, 2021). A competent and comprehensive problem definition is a key first step in any type of innovation process and paves the way for a sustainable result (Harrington, Erete, & Piper, 2019). The *Discover* and *Define* phases of this study promoted realism, collaboration, and the points of caregivers to be elicited to provide valuable insights into what Black caregivers of PLWD do, value, and desire in managing healthcare.

The first question posed during the *Discover* phase was exploratory and asked caregivers *"What does it mean to be health literate?*" Of the seven caregiver responses to the question, five felt being health literate encompassed *"the ability to be able to understand what the doctor is saying (R5, R8)"*; *"understand what the doctors think (R1)"*; or have some *"overall understanding of the medical terminology healthcare professionals use (R2, R6)."* Over 250 different definitions of health literacy exist in the academic literature (Pleasant & Mckinney, 2011). Although there is a general objective understanding of health literacy and its importance to human health, unclear and inconsistent details on what the concept represents are well-documented (Malloy-Weir et al., 2016). Numerous studies have objectively examined health literacy in various populations, but the subjective interpretation of the concept, outside the academic literature, has been somewhat understudied, particularly among Black Americans who have been found to have limited health literacy (Muvuka et al., 2020). In using the DT process to generate collaborative discussion around the meaning and understanding of this concept among the population of interest, we were able to understand what Black caregivers deem important in acquiring and/or maintaining health literacy skills which will aid in the development of the future health literacy-focused intervention for Black caregivers. The U.S. healthcare system has been known to rely upon the assumption that patients can understand complex written and spoken information (Gotlieb et al., 2022). Most caregivers aligning health literacy with being able to understand complex verbal information coincided with challenges discussed in both groups and the problem statement generated by GR1 - the added burden of receiving health information in medical jargon.

Traditionally a single, detailed problem statement is constructed after a group of individuals, representing the population of interest, undergoes the DT process, however, this study was carried out differently. Two groups of Black caregivers underwent the problem-definition phase separately and arrived at two problem statements. Although caregivers underwent the same process separately, challenges in healthcare management and shared experiences of discrimination overlapped in all FGDs revealing the extent to which the qualitative data represents the reality of Black caregivers. The groups did not arrive at the exact same problem statement, however, both statements pointed to the complexities and limitations of verbal health information given by healthcare providers concerning PLWD. The shared theme between both problem statements illustrates the benefits and ability of the DT process to arrive at a fundamental problem experienced by Black caregivers when managing healthcare for their PLWD so that an effective intervention can be developed. Similarities between problem statements also validated the effectiveness of the DT process in collecting reliable data.

Divergently exploring Black caregivers' experiences with different aspects of healthcare management and empathizing with them, brought forth needs, capabilities, emotions, and frustrations that may not otherwise be stated directly. For example, caregivers from both groups were not incapable of filling out and reading/understanding medical forms and medication labels due to some already being familiar with and used to the process and others not having to engage with medication because they and their PLWD were not taking any. If anything, caregivers, specifically in GR2, saw filling out medical forms as an added burden due to knowing the fate of their PLWD or getting anxious when forced to complete the forms before the start of the visit. Additionally, we came to realize that it was medication management versus reading/understanding the labels that were frustrating. From the difficulty of keeping up with newly prescribed medications to questioning the benefit of having to manage new medications knowing there is no cure for dementia or dementia-related diseases.

Divergent thinking also revealed that the bulk of caregivers' challenges, frustrations, and experiences revolved around communication with healthcare providers. GR1 discussed experiences with gathering real-time information, receiving health information in excessive medical jargon, and challenges communicating on behalf of multiple providers on their PLWD's care team, who often did not communicate with each other. GR2 cited similar challenges and included that the lack of knowledge about dementia from the primary care provider (PCP) makes communication more challenging. Additionally, both groups discussed their frustrations with limited time spent with doctors and instances of disrespect experienced during visits.

During the *Define* phase, convergent thinking was used, and caregivers focused on adjusting and validating their proposed challenges and rejecting those they did not see as crucial to their caregiving situation or able to be addressed during a future intervention (Aflatoony et al., 2022). Using convergent thinking caused both groups to focus on their challenges aligned with communication. At the end of the *Define* phase, caregivers in GR1 crossed off all other challenges on the list except 'gathering real-time health information' and 'receiving health information in medical jargon', as they believed both challenges went together. After collaborative discussion, caregivers combined both challenges and agreed that the fundamental problem they face is getting information that is not wrapped in medical jargon. This was a burden for them because caregiving is challenging enough without receiving an abundance of pertinent health-related information in complex terms. Caregivers in GR2 were quick to cross off all other challenges on their list and collectively agreed that their fundamental problem is the PCP's lack of knowledge in how to recognize dementia and dementia-related disease(s), and what ultimately makes communication challenging.

Both groups had in-depth discussions on medical discrimination. Some shared personal experiences and discussed their adopted behaviors to avoid such discriminatory ordeals. In using convergent thinking, caregivers from both groups agreed that while this problem is very crucial, they could not see it being solved through a future intervention. Medical discrimination is a factor that still must be considered during the ideation and development phases of the future, culturally relevant health literacy intervention. Discrimination is a barrier to dementia care and can impede individual health literacy skills, further influencing the healthcare management of Black PLWD (Muvuka et al., 2020; Alzheimer's Association, 2023).

### *Study Limitations*

There were a few limitations in this study. Convenience sampling techniques were used and many caregivers were recruited through established caregiving networks in the parent study, which may have resulted in selection bias. Fourteen caregivers were invited to participate in the focus groups for the current study, however, only 10 were able to commit. Additional caregiver participants may have added more diverse perspectives, particularly male caregivers as there were only two. The sample comprised highly educated caregivers, all of whom had some college education. Efforts to recruit Black caregivers with various educational backgrounds are warranted for future research.

### *Study Implications & Next Steps*

The Double Diamond Design Thinking Model outlines four phases that target audiences are expected to undergo to develop a solution/intervention to solve a problem of interest. This study only called for caregivers to undergo the first two phases – *Discover* and *Define*. Although developing a clear problem definition is a crucial first step in solving the right problem, one may see solely undergoing part of the Design Thinking (DT) process as a limitation to the study. No matter the model or framework that is adopted to guide the DT process, it is important to understand the method is flexible and not a concrete approach. Although DT may be taught linearly, when practicing sometimes the phases will not always be sequential. Designers and researchers are not required to abide by a specific order and some projects and topics of interest call for phases to occur in parallel and repeated several times (Lewrich, Link, & Leifer, 2020). Other projects may call for phases to be switched or move back and forth between them (Lewrich, Link, & Leifer, 2020). What remains concrete are the main objectives of the respective phase and what should be achieved by the conclusion. Solely undergoing the problem-definition stage of the process was useful in focusing on two key, overlapping problems that Black caregivers face when carrying out their health literacy skills to manage healthcare for their PLWD. Considering that the overall goal of the parent study is to develop a culturally appropriate intervention to prepare health-literate Black caregivers, caregivers will soon proceed through the next phases of the DT process.

To enhance the validity of Black caregiver insights during the problem-definition stage, the next steps include inviting the same caregivers to discuss the other group’s findings and problem statements. They will be asked their thoughts on and whether they agree with the challenges and problem statement the other group came up with. They will also be tasked with combining the two overlapping problems into one concise statement, hopefully specifying it further. The goal is to further validate the qualitative data and continue the iterative process of Design Thinking in hopes that a single problem statement will be constructed, making for the development of a more specified culturally appropriate intervention.

With the problem statement in mind, the caregivers will then undergo the *Develop* phase of the DT process and use divergent thinking and brainstorming techniques to guide the ideation of different solution-focused caregiving interventions. Caregivers will collaboratively generate intervention concepts they feel will resolve their problem. During the final phase - *Deliver,* caregivers' ideas will be validated, and convergent thinking will be used to narrow down intervention concepts. A new set of criteria will be given to help facilitate the process. New Black caregivers from the same sample pool of the parent study will be invited to participate to minimize potential bias in the evaluation of possible interventions or if previous caregivers from GR1 and 2 cannot participate or have become ineligible (e.g., no longer a caregiver).

**Figure 1**

*Double Diamond Design Thinking Model Introduced by the Design Council*

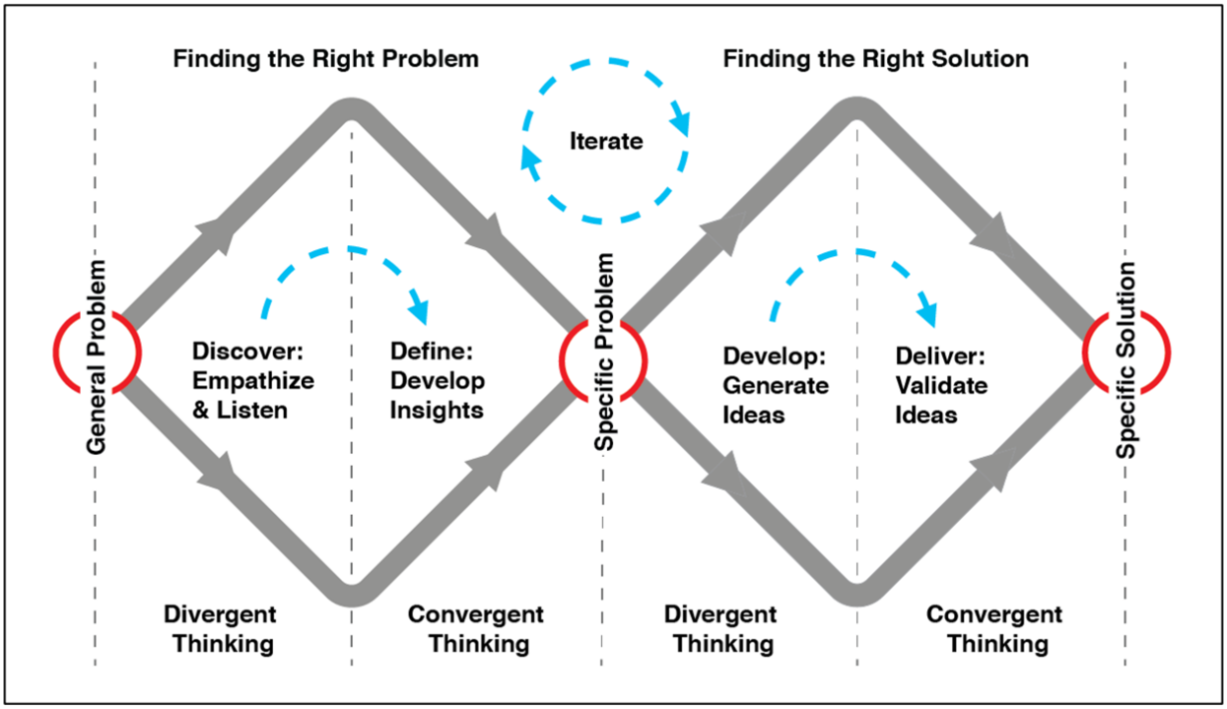


**Table 2**

*Demographics of Caregiver Focus Groups*

| | M [Range] / N (%) | |
|---|---|---|
| **Characteristic** | **Group 1** | **Group 2** |
| Age (years) | 45.4 [28-64] | 52.4 [28-64] |
| Gender Identity | | |
| (Female) | 5 (100%) | 3 (60%) |
| (Male) | 0 | 2 (40%) |
| Educational Attainment | | |
| (College Graduate) | 1 (20%) | 3 (60%) |
| (Graduate/Professional degree) | 1 (20%) | 2 (40%) |
| (Some College) | 3 (60%) | 0 |
| Person caring for | | |
| (Parent) | 3 (60%) | 4 (80%) |
| (Spouse) | 0 | 1 (20%) |
| (Other relative) | 2 (40%) | 0 |
| Care Recipient Stage of Diagnosis | | |
| (Early stage) | 0 | 0 |
| (Middle stage) | 3 (60%) | 2 (40%) |
| (Late stage) | 2 (40%) | 3 (60%) |

**Table 2.1**

*Discover Phase Pre-Determined Themes and Challenges*

| **Pre-Determined Theme** | **Caregiver Challenges** | |
|---|---|---|
| | ***Group 1*** | ***Group 2*** |
| *Print Literacy* | **1. No challenges filling out forms**<br>- has become a habit and routine<br>- rarely fill out new forms - same health system for the entire care team<br>**2. Medication management**<br>- hard to keep up with newly prescribed medications<br>- new instructions to follow<br>**3. No challenges with medication labels**<br>- familiarity and confidence with reading and understanding medication labels | **1. Medical forms are an added burden**<br>- numerous doctor appointments with a form for each<br>- anxiety from feeling rushed to complete them<br>**2. Uncertainty of newly prescribed medication(s)**<br>- questioning the benefits considering there is no cure<br>- forced to trust the prescribing provider<br>**3. No challenges with medication labels**<br>- prior knowledge due to existing conditions<br>- PLWD is not on any medications |
| *Communication* | **1. Gathering real-time health information**<br>- bombarded with a lot of information & needing time/external resources to process<br>**2. Receiving health information in medical jargon**<br>- forced to "translate" oral information to care recipients<br>**3. Forced to take extra care and caution to ensure care team is on the same page**<br>- frustration with the lack of communication between multiple providers on the care team<br>**4. Challenges with direct communication with doctors**<br>- not listening<br>- concerns not taken seriously<br>- limited time<br>lack of respect | **1. Lack of knowledge from doctors about dementia disease(s) or relevant resources**<br>- doctors discuss resources without knowing whether it's applicable to the caregiving situation<br>**2. Poor communication with healthcare providers**<br>- lack of communication between different providers on the care team<br>- expected to understand medical jargon<br>limited time |
| *System Navigation/ Information Seeking* | **1. Insurance coverage dictates navigation**<br>- what I find helpful for my care recipient versus what the insurance covers<br>**2. Challenges with the Patient Portal**<br>- questions not answered in a reasonable time frame<br>- inadequate notes captured<br>- providers not using the tool effectively | **1. Knowing where to start to find health information**<br>- where do you start when looking on your own for relevant health information?<br>- problems that come with Internet sources<br>**2. Knowing where to start when navigating care**<br>- how to learn the steps to navigate care needed from other providers (i.e., specialists) |
| *Medical Discrimination* | **1. Differential treatment as a co-caregiver**<br>- not seen as a primary caregiver<br>- not given adequate health information<br>**2. Medical Distrust**<br>- finding a trustworthy doctor<br>- challenges when trust is broken<br>**3. Discriminatory and disrespectful experiences**<br>- ageism<br>- racism<br>- discrimination based on ethnicity, gender, and the dementia diagnosis | **1. Healthcare professionals' lack of cultural competency**<br>- microaggressions<br>- culturally not relatable<br>- witness to differential treatment<br>- code-switching to avoid discrimination |

# Chapter 3: Outcomes of Data Integration in a Mixed Methods Study on Health Literacy in Black Dementia Caregivers

## Abstract

Data integration, which involves intentionally bringing together quantitative and qualitative procedures, is the core of mixed methods research. Conducting a mixed methods study and synthesizing integrated results can yield a holistic and accurate understanding of a phenomenon within a marginalized population of interest. The purpose of Chapter 3 was to integrate quantitative data (Chapter 1) and follow-up qualitative data (Chapter 2) to draw meta-inferences from this overall explanatory sequential mixed methods study on health literacy and medical discrimination in Black caregivers of persons living with dementia (PLWD). Considering that little is known about health literacy and its correlates with medical discrimination faced by Black caregivers, a mixed methods approach was warranted. Data integration was implemented at the planning stage for qualitative procedures, specifically, focus group formation and development of focus group questions. Once qualitative procedures were complete, integration was employed at the analytic and interpretation stages. Quantitative data illustrated high and low scores of various health literacy constructs measured with a multi-dimensional health literacy assessment. Quantitative data also illustrated Black caregivers' experiences of discrimination while seeking healthcare for their PLWD. The qualitative data told the 'why' behind the quantitative scores, much of which pointed to caregivers' challenges at the healthcare provider and organizational levels. Integrated findings revealed the importance of health literacy being a shared responsibility. Therefore, healthcare providers and organizations that frequently engage with Black caregivers must understand the roles caregiver health literacy and experiences of medical discrimination play in the healthcare management of Black PLWD.

# Introduction

## *Background*

Research with marginalized communities, particularly the exploration of health-related factors and outcomes of marginalized ethnic and racial populations, calls for an approach that produces a complete narrative and not solely objective data that often has underlying explanations (Ponterotto, Matthew, & Raughley, 2013; Lewis et al., 2018). Mixed methods research has been formally practiced since the 1980s and has since become increasingly popular among various disciplines (McKim, 2017). Different definitions for mixed methods have surfaced over the years, incorporating different elements of research purposes and processes, methods, and philosophy (Creswell & Plano Clark, 2017). The general agreement is that mixed methods design combines at least one quantitative method and one qualitative method in a single study (Creswell & Plano Clark, 2017). This combination is the defining attribute of mixed methods research known as data integration (Guetterman, Fetters, & Creswell, 2015; Creswell & Plano Clark, 2017). Linking together quantitative and qualitative approaches creates a more holistic understanding. Intentional integration of multiple data sources is achieved through careful design and entails "systematic attention" as to how the two forms of research can be combined (Guetterman & Breen, 2021). Integration is relevant to more than just the results of a research study, it is implemented throughout the entire process (Guetterman, Molina-Azorin, & Fetters, 2020; Guetterman & Breen, 2021). Data integration maximizes the value of mixed methodology, enriches the understanding of a particular research question, and further contributes to advancements in research topics (Guetterman & Breen, 2021). Another important aspect of mixed methods research is the justification of the methodology (Molina-Azorin, 2016). In other words, "Which research problems warrant a mixed methods approach and why?" Typically, the answer to this question encompasses research topics where one data source isn't enough and results require further explanation, multiple cases must be compared or contrasted, or an experimental design must be expanded or enhanced (Creswell & Plano Clark, 2017).

Beliefs, attitudes, and behaviors shaped by social, economic, and political forces embedded in historic power imbalances often reflect the realities of marginalized ethnic and racial groups yet are not always reflected in research outcomes (Ponterotto, Matthew, & Raughley, 2013; Lewis et al., 2018). Qualitative methods can elicit these realities, but come with another set of limitations, such as small sample size and heavy reliance on interpretation (Ochieng & Meetoo, 2015; Watson-Singleton, Lewis, & Dworkin, 2023). On the other hand, quantitative approaches elicit objective insights from data, provide an understanding of trends and patterns aligned with a topic of interest, and promote wide, representative sampling (Ochieng & Meetoo, 2015). Quantitative approaches aim to be predictive and generalizable but fall short in explaining the ‘why’, which is vital when conducting research in marginalized communities (Ochieng & Meetoo, 2015). Conducting a mixed methods study can yield a holistic and accurate understanding of a phenomenon within the marginalized population of interest (Ponterotto, Matthew, & Raughley, 2013; Watson-Singleton, Lewis, & Dworkin, 2023). By integrating both forms of data, space can be made for both testable patterns and associations between variables of interest and the in-depth understanding of the lived experiences that perhaps influence such variables and associations. That is what this mixed methods study on Black caregiver health literacy aimed to achieve.

Health literacy has been extensively explored in the family caregiving literature, particularly among caregivers of persons living with cancer, diabetes, and heart failure (Bevan & Pecchioni, 2008; Levin et al., 2014; Yuen et al., 2018). Few have examined health literacy in caregivers of persons living with dementia (PLWD) and those that have included few to no Black caregivers. Disparities in health literacy among the Black American population and disparities in healthcare management among Black caregivers are well-documented (Abramsohn et al., 2019; Muvuka et al., 2020; Alexander et al., 2022). Prior research has found that Black caregivers of PLWD view the United States (U.S.) healthcare system as “broken”, and they have reported challenges in seeking health information and resources pertinent to dementia care, communicating with healthcare providers, understanding health insurance coverage, and navigating the healthcare system (Abramsohn et al., 2019; Ali et al., 2018; Alexander et al., 2022). Such responsibilities require caregivers to be health literate, and low health literacy of family caregivers has the potential to result in poorer health outcomes for their care recipient (Abed et al., 2020). Discrimination in the healthcare setting can impede health literacy development as it influences interactions with the healthcare system, access to health-related resources, and health-related decision-making (Politi et al, 2014). The aforementioned challenges in health-related tasks reported by Black caregivers in prior research were found to be amplified by experiences of discrimination in the healthcare setting (Alexander et al., 2022).

### ***Study Purpose***

Little is known about health literacy and its correlates with medical discrimination faced by Black caregivers. Thus, it is not only warranted to assess health literacy and explore its relationship with medical discrimination but also to adopt an equitable approach to hear directly from Black caregivers about key problems in the healthcare management of PLWD. This calls for a mixed methods approach. The National Institute on Aging (NIA) Health Disparities Research Framework highlights and prioritizes health literacy and institutional racism as factors contributing to health disparities of marginalized ethnic and racial populations (Hill et al., 2015). These factors can shape important individual-level health-related decisions (Hill et al., 2015). This study examined both factors in a sample of Black caregivers of PLWD through an explanatory sequential mixed methods study with the following research aims:

1. Quantitatively examine the association between health literacy and medical discrimination.
2. Explain quantitative findings with follow-up qualitative data procedures and gain a deeper understanding of the challenges Black caregivers face while managing their PLWD's healthcare.
3. Integrate quantitative and qualitative findings to draw meta-inferences based on both data sources.

The overarching goal of this mixed methods study was to lay the groundwork for a future intervention to help prepare health-literate Black caregivers of PLWD to effectively navigate a complex healthcare environment characterized by discrimination. This study was approved by the institutional review board of Emory University (STUDY0000557). Informed consent was acquired from all caregivers participating in the study.

# Methods

## ***Research Design & Conceptual Framework***

This study employed an explanatory sequential mixed methods design that collected survey data, followed by focus group discussions. Explanatory sequential designs encompass two phases of data procedures: quantitative data collection and analysis, followed by qualitative data collection and analysis to further explain selected quantitative results (Creswell & Plano Clark, 2017). The design concludes with integrated data interpretation/meta-inferences.

A conceptual framework was created to help ground the research design and analysis (illustrated in Figure 2). Health literacy and medical discrimination were this framework's core variables of interest. Health literacy was conceptualized as a skill set as emphasized in the Health Literacy Skills (HLS) Framework (Squiers et al., 2012). The HLS framework builds on existing theoretical frameworks of health literacy, depicts how health literacy functions at the individual level, and hypothesizes the relationship between health literacy and health-related outcomes (Squiers et al., 2012). The framework is characterized by four parts: The first includes factors, such as socio-demographic characteristics, that affect the degree to which a person acquires and/or maintains health literacy skills. The next two portions of the framework include the health-related stimuli (e.g., medication label, brochure) and the following health literacy skills needed to understand and perform tasks: *print literacy*, *communication*, and *navigation/information-seeking*. The last part of the framework encompasses mediators such as self-efficacy (one’s confidence to execute the task) between health literacy and health-related outcomes (Squiers et al., 2012).

As previously mentioned, the NIA Health Disparities Research Framework theorizes institutional racism as a social factor that can shape important individual, health-related decisions (Hill et al., 2015). Institutional racism encompasses racist policies and practices perpetuated within an organization or a whole society that support the unfair or harmful treatment and disadvantage of others based on race or ethnicity (Needham et al., 2023). According to the framework, sociocultural norms and values affect individual-level self-concepts, cognition, and perceptions of bias that shape individual behavior and can influence interpersonal relationships and interactions with healthcare institutions (Hill et al., 2015). Individuals may find negative interactions with clinicians to be culturally insensitive, perceive restricted access to quality health care as institutional racism, and view this hardship as discrimination (Hill et al., 2015). Discriminatory practices have systematically restricted Black Americans' access to resources and skills needed to obtain, understand, and apply health information, resulting in ethnic and racial disparities in health literacy (Muvuka et al., 2020). Thus, experiences of discrimination in the medical setting were also examined with the health literacy skills of Black caregivers in this study. Socio-demographic factors (age, yearly household income, level of educational attainment, and health insurance status), that have been found to be predictors of health literacy and may further predict experiences of medical discrimination among Black caregivers, were also assessed.

### ***Caregiver Recruitment***

To be eligible for participation, caregivers self-identified as Black or African American, were 18 years of age or older, had internet access, and were actively caring for someone living with dementia, memory loss, or cognitive impairment and involved in their healthcare decisions. Caregivers did not have to reside with their care recipient to participate. Caregivers who were not able to clearly understand English, were former caregivers, were not yet 18 years of age, or were cognitively impaired, were not eligible to participate. The lead researcher used convenience sampling to build a network of Black caregivers and encourage study participation. The researcher sought out her research lab's established community partners with predominantly Black faith-based organizations, as well as grassroots, non-profit, and civic organizations that serve caregivers and older adults and churches. She contacted caregiver support groups, adult day care centers, and Black health organizations. Among these different organizations, the lead researcher gave informational talks on health literacy, providing rationale and importance of participating in the study, along with requested topics such as the role of diet in brain health. Recognizing the importance of community for Black families, the lead researcher also attended professional seminars to meet others in dementia care and aging. Study information was distributed through several United States (U.S.) universities' Alzheimer's Disease Research Centers and the Emory

Roybal Center for Dementia Caregiving Mastery. Informal channels of recruitment were also used to build a network of Black caregivers (Epps, Skemp, & Specht, 2015). The lead researcher sought out family members of close friends, community health events in predominantly Black communities, and social gatherings such as professional networking events and social club meetings hosted at local Historically Black Colleges and Universities. The lead researcher also used snowball sampling as many caregivers were referred by other caregivers who had participated in the study.

### ***Overview of Quantitative and Qualitative Phases***

This study builds on individual quantitative and qualitative data procedures. Quantitative data were derived from an online cross-sectional survey distributed to 99 Black caregivers of PLWD across the U.S. In addition to a socio-demographic questionnaire, the survey was comprised of the Discrimination in Medical Settings Scale (DMS) (Peek et al., 2011) and six scales from the Health Literacy Questionnaire (HLQ) (Osborne et al., 2013). The six scales included '*Feeling understood and supported by healthcare providers'; 'Appraisal of health information'; 'Ability to actively engage with healthcare providers'; 'Navigating the healthcare system'; 'Ability to find good health information';* and *'Understand health information well enough to know what to do.'* Qualitative data were based on 4 focus group discussions held with a purposeful subsample of 10 caregivers guided by the Design Thinking Process (British Design Council, 2005; Aflatoony et al., 2022). The rationale for the subsample was a result of data integration at the methods level. The focus group question guide was also developed as a result of data integration at the methods level. Further details can be found in the discussion on data integration below. Quantitative and qualitative data procedures and outcomes are detailed in Chapters 1 and 2, respectively, of this dissertation.

### ***Data Integration***

There is an array of practical approaches for achieving integration in a mixed methods study (Yin, 2006; O'Cathain et al., 2010; Fetters, Curry, & Creswell, 2013; Creamer, 2018). Fetters, Curry, & Creswell's (2013) framework was chosen for this study because it is principle-driven, practice-based, has practical application, and has been exemplified in health services research. Fetters, Curry, & Creswell's

(2013) approach demonstrates integration at three levels, the first of which takes place at the study design level, which encompasses the conceptualization of the study and the kind of design that will be carried out to address the research topic. Such designs include explanatory sequential, exploratory sequential, and convergent. The aim of sequential designs is for one form of data to be collected and analyzed, then used to inform the follow-up phase (QUAN → qual for explanatory designs; QUAL → quan for exploratory designs) (Fetters, Curry, & Creswell, 2013). Convergent designs aim to independently collect and analyze both forms of data, then merge the quantitative and qualitative results and compare (QUAN + QUAL) (Fetters, Curry, & Creswell, 2013). Data integration at the design level can influence the "researcher's decision about whether and how to use integration at the other two levels which can influence the quality of the researcher's inferences" (Creswell & Plano Clark, 2017; McCrudden & McTigue, 2019). An explanatory sequential design was best suited to address the research topic of this study. A quantitative assessment of different health literacy constructs and experiences of medical discrimination while seeking care for PLWD was first conducted and qualitative data were collected next to provide further explanation and rationale of quantitative findings. Additionally, qualitative data provided caregivers a voice to discuss how their health literacy and experiences of medical discrimination influenced healthcare management for their care recipient.

Fetters, Curry, & Creswell's (2013) framework also describes integration at the methods level. Here, methods of data collection and analysis are *linked* through one or more of the following strategies: *connecting*, *building*, *embedding*, and *merging* (Fetters, Curry, & Creswell, 2013). For this study integration was employed at the planning stage for qualitative procedures, specifically, focus group formation and the development of the focus group question guide. Quantitative results were connected to the sampling plan of the qualitative phase to determine which caregivers needed to be purposefully sampled in order to best explain the quantitative results. *Connecting* is a strategy that uses the results of one data procedure to inform the sampling plan of another (Fetters, Curry, & Creswell, 2013; Guetterman & Breen, 2021). The last question of the quantitative survey asked caregivers whether they consented to participate in a series of two focus groups and all who consented (N = 76) were considered for participation in the qualitative phase. In no particular order, two caregivers were purposefully selected based on a range of scores for each of the six HLQ scales (one with a high score and another with a low score) and varying experiences of medical discrimination. The intent was to include caregivers who had high and low scores of each health literacy construct, those who had frequent experiences of discrimination while seeking healthcare for their PLWD, and those who had few to no experiences. The rationale was to enrich the discussion by involving a mixture of Black caregivers with health literacy strengths, weaknesses, and varying experiences of discrimination. Fourteen caregivers were invited to participate in the focus groups and 10 committed. To accommodate the participating caregivers' conflicting schedules and time preferences, 2 groups, each composed of 5 caregivers, were developed. Caregivers resided in various parts of the U.S. including Georgia, South Carolina, Texas, Ohio, California, and Wisconsin. The average age of caregivers was 48.9 years and the majority identified as female (n = 8, 80%). All but one caregiver reported that their PLWD received a formal diagnosis of dementia, and all caregivers reported that their care recipient was experiencing either middle or late-stage symptoms (n = 5, 50% for each stage).

After the subsample was formed, quantitative findings were used to *build* the focus group question guide. *Building* is a strategy that relies on results from one data procedure to inform data collection of another (Guetterman & Breen, 2021). Focus group questions were constructed based on surprising findings/outliers of the health literacy constructs measured on the HLQ and the DMS assessments. Each focus group question was initiated by the related quantitative findings. A focus group question *joint display* table was developed as a framework for integration and rationale for the focus group questions for each health literacy construct of interest and medical discrimination based on quantitative findings. Table 3. *Joint display*s are visual representations, typically in the form of tables or matrices, that are used to integrate quantitative and qualitative data during data collection, as well as analysis and interpretation (Creswell & Plano Clark, 2017).

Once qualitative procedures were complete, integration was carried out at the third level highlighted in the Fetters, Curry, & Creswell (2013) framework - interpretation and reporting. At this level, the researcher “mixes” the quantitative and qualitative findings to analyze the data and draw *meta-inferences* (Fetters, Curry, & Creswell, 2013; Creswell & Plano Clark, 2017). *Meta-inferences* are conclusions that integrate understandings developed from qualitative and quantitative procedures of a study and go beyond what each procedure can explain individually (Creswell & Plano Clark, 2017). Integration at the interpretation and reporting level can be conducted through the following approaches: “*integration through narrative*; *integration through data transformation*; and *integration through joint displays”* (Fetters, Curry, & Creswell, 2013). For this study, the lead researcher employed integration through a side-by-side joint display table. Survey findings that were used for integration at the methods level were first inputted into the table. Exemplar quotes from focus groups that coincided with the respective quantitative finding and provided further explanation and details were put in the ‘explanatory quotes’ column of the table. The table was organized according to the domain of health literacy (print literacy, communication, system navigation/information seeking) and medical discrimination.

The lead researcher visualized each piece of quantitative and qualitative data, to conduct the mixed methods analytical procedure. This procedure can yield three types of findings: “confirmation, discordance, and expansion” (Fetters, Curry, & Creswell, 2013; Younas, Pedersen, & Inayat, 2022). When findings from both data sources confirm the results of each other there is data ‘confirmation’, which provides greater credibility to the study results (Fetters, Curry, & Creswell, 2013; Younas, Pedersen, & Inayat, 2022). ‘Discordance’ arises if there is inconsistency, contradiction, or conflict between findings from both data sources (Fetters, Curry, & Creswell, 2013; Younas, Pedersen, & Inayat, 2022). If qualitative findings provide further interpretations about the quantitative findings (or vice versa) or amplify insights of the phenomenon of interest there is ‘expansion’ (Fetters, Curry, & Creswell, 2013; Younas, Pedersen, & Inayat, 2022). Mixed methods findings were included in the ‘meta inferences’ column of the table. Lastly, the *weaving approach* was used to demonstrate *integration through narrative*. The weaving approach involves writing the quantitative and qualitative findings according to themes or concepts to depict the integrated findings (Fetters, Curry, & Creswell, 2013). Figure 3 describes how each stage of this explanatory sequential design was carried out.

## Results

Below are quantitative and qualitative findings woven together on a theme-by-theme basis to illustrate the meta-inferences drawn. The themes include the health literacy skills of interest and medical discrimination. Table 3.1 illustrates the side-by-side joint display that guided the mixed methods analytical process and interpretation of this study's integrated findings.

### ***Print Literacy***

The HLQ scale used to measure print literacy was '*Understand health information well enough to know what to do'* and the mean score was 3.79 (SD = 0.51) (response range: 1-cannot do/always difficult to 5- always easy). According to the HLQ, high-score interpretations of this scale indicate that *"one can understand all written information (including numerical information) about their health and write appropriately on forms where required."* Although this was the highest scored scale among caregivers, there still seemed to be some difficulty as most caregivers marked items within the range of 'sometimes difficult' to 'usually easy.' Focus group conversations around this domain indicated that the challenge is not practicing print literacy skills, as most caregivers confirmed that there was "no challenge" in actually filling out medical forms, following instructions on medication labels, and an overall understanding of written health-related text. One caregiver stated how such tasks have become such a habit for her that it has become routine. Another stated that she was already familiar with these tasks because she is a breast cancer survivor and that journey led her to develop the skills needed to take on these tasks as she cares for her mother living with dementia. Expanded findings point to external influences that can make these tasks burdensome rather than exercising the actual health literacy skill. One caregiver discussed that filling out medical forms on his wife's behalf is an added burden for him in an already taxing caregiving role. Another discussed how she often feels rushed to complete the forms before medical visits, which brings forth anxiety and can make the task even more burdensome. When discussing medication labels, issues were more so aligned with medication management rather than reading and understanding instructions. Specifically, caregivers discussed the added burden of their loved ones being prescribed new medications and how difficult it can be to manage when they already have a large medication load. Additionally, some discussed the uncertainty of newly prescribed medications given that there is no cure for dementia/dementia-related diseases.

### ***Communication***

Communication was measured with the HLQ scales ‘*Feeling understood and supported by healthcare providers’* (M = 2.81, SD = 0.41) (response range: 1-strongly disagree to 4-always easy) and ‘*Ability to actively engage with healthcare providers*’ (M = 3.46, SD = 0.49) (response range: 1-cannot do/always difficult to 5-always easy). Lower-score interpretations on ‘*Feeling understood and supported by healthcare providers’* indicate that *“individuals are unable to engage with doctors and other healthcare providers, don’t have a regular healthcare provider, and/or have difficulty trusting healthcare providers as a source of information and/or advice.”* Lower-score interpretations on ‘*Ability to actively engage with healthcare providers’* indicate that *“individuals are passive in their approach to healthcare (i.e., they do not proactively seek or clarify information and advice and/or service options).”* Additionally*, “individuals accept information without question and are unable to ask questions to get information or to clarify what they don’t understand. Individuals accept what is offered without seeking to ensure that it meets their needs and feel unable to share concerns.”*

Focus group analysis confirmed that caregivers experienced challenges with communication and engagement with healthcare providers and the fundamental problems discussed by caregivers during focus group discussions (FGDs) centered on the issue of verbal communication with healthcare providers. However, FGDs also pointed to some components of high score interpretations of the scale – ‘*Ability to actively engage with healthcare providers.’* High-score interpretations on this scale illustrate that *“the individual is proactive about their health, feels in control in relationships with healthcare providers, and is able to seek advice from additional healthcare providers when necessary. They keep going until they get what they want and are empowered.”* A mean score of 3.46 on this construct indicated that while caregivers, for the most part, found it ‘sometimes difficult’, it was not a skill they could not do or found ‘usually difficult’. The conversation about communication during FGDs was the most lengthy and numerous challenges were discussed. ‘Gathering real-time health information’, ‘lack of knowledge from doctors about dementia diseases or relevant resources', 'limited time with providers', and 'poor direct communication with caregivers' were the key challenges caregivers felt contributed to their communication problems with healthcare providers. Such challenges made it difficult for caregivers to trust providers as a source of information/and or advice and engage with them, which are components of HLQ low-score interpretations. However, some caregivers did discuss finding other doctors to discuss their concerns when faced with excessive challenges with high score interpretation.

'Receiving health information in medical jargon' was a problem frequently discussed among both groups of caregivers. They discussed having to lean on external sources after speaking with doctors and receiving an abundance of complex health information, how overwhelmed they feel when doctors use excessive jargon, and the expectation to understand the information relayed. Group 2 caregivers collectively agreed that often there is "no communication" with providers, particularly primary care physicians (PCP) because they have a limited understanding of the onset of dementia and often brush their concerns off. They collectively concluded that the PCP's lack of knowledge in how to recognize dementia was their fundamental problem in managing their PLWD's healthcare.

### ***System Navigation/Information Seeking***

System navigation/information seeking was measured with HLQ scales '*Ability to find good health information'* and *'Navigating the healthcare system.' 'Navigating the healthcare system'* had the lowest mean score (3.42, SD = 0.57) among scales with the response options of 1 (cannot do/always difficult) to 5 (always easy). Low-score interpretations of this scale indicate that *"individuals are unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Individuals do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.*" Although this scale was the lowest score, 3 = sometimes difficult which means it was not a skill that they, for the most part, could not do or 'found usually difficult.' During FGDs, caregivers explained that when it comes to navigating the healthcare system, they often "don't know where to start." Caregivers also discussed how healthcare financing and insurance often dictate how they go about system navigation, which can make things harder. Those who had health insurance where the healthcare services they wanted for their PLWD aligned with what was in-network found navigation easy. Others who found system navigation challenging discussed their limited finances and the mismatch between what healthcare services they felt would be best for their care recipient and what their insurance covered. When discussing information seeking, caregivers also stated that “knowing where to start” was a challenge. Internet sources were primarily cited as caregivers' go-to when looking up health information, however, they agreed that such sources can come with another set of problems. Ultimately, it wasn’t that caregivers did not know how to use the internet to find health information, but rather they often found themselves having to sort through the abundance of mis- and disinformation which can bring forth added strain.

### ***Medical Discrimination***

The average DMS score among the sample of caregivers was 18.35 (SD = 6.01), indicating the occurrence of medical discrimination while seeking healthcare for their PLWD. The highest overall score was 32 (max = 35). The item with the highest mean score was, ‘*You feel like a doctor or nurse is not listening to what you and your person were saying’* (2.85, SD = 0.99). The item, ‘*A doctor or nurse acts as if he or she is better than you and your person’*, was the next highest mean score (2.82, SD = 1.14). When asked what caregivers thought was the main reason for discriminatory experiences, ‘race’ was most cited (38.4%) followed by age (18.2%). Focus group quotes confirmed these findings. Discussions of caregivers’ concerns being brushed off by doctors and being disrespected were talked about when the topic of medical discrimination was posed, as well as other domains of health literacy such as communication. Racism and ageism were most frequently discussed as reasons for disrespectful treatment, confirming quantitative findings. Although racism was not experienced by all caregivers, many pondered on whether their challenges in healthcare management were also experienced by caregivers of other races and nationalities. The caregivers who had not experienced racism, all made a point to discuss measures they take to mitigate discriminatory treatment. Dressing “appropriately”, “speaking well”, and “coming prepared” were some of the actions adopted. Ageism was experienced from the role of the caregiver as well as the care recipient. One caregiver discussed feeling dismissed by her greatgrandmother's doctor, who often relayed all information to her mother, the co-caregiver. She felt it was due to her young age (28 years old). Another caregiver discussed being brushed off and disrespected by his wife's doctor when constantly trying to voice his concerns about her as she was experiencing frontotemporal dementia. He felt it was due to her young age (48 years) and the misconception that she was too young to experience dementia.

## Discussion

The quantitative and qualitative data aligned well in this study. Explanatory quotes confirmed selected quantitative results and analyses of both the quantitative and qualitative data yielded expanded findings. Direct quotes from caregivers provided a deeper narrative and the 'why' behind the quantitative scores which exemplify the benefits of using mixed methodology. We reflected on the question, "Do caregivers' views from the focus group discussions and scores on the standardized instruments converge or diverge?" If we were to solely rely on the HLQ scores to illustrate health literacy among Black caregivers of PLWD, we would find where the strengths and needs lie, which would put focus on the strengths and deficiencies in the actual health literacy skill/construct. However, with the inclusion of focus groups where caregivers were presented with the relevant quantitative findings and asked questions that aligned with the relevant health literacy construct, the context of survey findings was provided, and a more complete story was told. This is one of the justifications for using mixed methodology to address a research topic. Mixed methods research provides new insights that go beyond the individual quantitative and qualitative results (Creswell & Plano Clark, 2017).

Mixed methods approaches have become a more suitable practice and methodology when working with underserved communities and engaging them in research and problem-solving (Lewis et al., 2018; Jones, Lindquist-Grantz, & DeJonchheere, 2020). Educational research scholars have discussed the rising issue of "raced-based deficit narratives" in quantitative research which essentially attributes the presence of disparities between different racial groups to the underserved racialized group themselves without further explanation (Russell et al., 2022). For example, research narratives from quantitative studies will often state that a certain poor health outcome was higher in Black populations compared with white populations, without emphasizing or at least mentioning the actions and policies that produce the conditions that lead to the disparities. Though the statistics may depict this reality, the absence of a complete narrative can further perpetuate views of inferiority among underserved communities (Russell et al., 2022). The existing literature that has examined health literacy in Black populations and found disparities in health literacy capacity has frequently relied on quantitative health literacy measures that assess document, prose, and numeracy skills (Kutner et al., 2006; Muvuka, 2020). Some have included navigation of the healthcare system along with these skills, but not the majority (Kutner et al., 2006). Health literacy as a multi-dimensional concept rather than a single construct is being more and more emphasized among researchers and it is important to measure it as such (Beauchamp et al., 2015). The rationale for using the HLQ in this study was that it comprised a series of scales that depict a different health literacy construct that must be scored individually. Individual scores help public health professionals, practitioners, and others interested in improving health literacy pinpoint which health literacy skills must be further addressed to improve relevant health-related behaviors and outcomes (Beauchamp et al., 2015).

The construct '*Understand health information well enough to know what to do'* was the highest-scored construct among Black caregivers in this study and the item '*Read and understand written health information'* was primarily found to be 'usually easy.' This construct was assessed to evaluate caregivers' print literacy – a skill most often measured when assessing health literacy and has been found to be disproportionately lower in Black Americans compared with white Americans (Kutner et al., 2006). However, most caregivers in this study had some form of college education or higher, and this skill has a direct association with literacy levels, so that may explain why caregivers scored high. Overall, this was not a skill caregivers demonstrated deficiency in, and caregivers confirmed that during focus groups. A mean score of 3.79 is on the higher end, closer to a score of 4 (usually easy), but not quite, and a score of 3 is 'sometimes difficult.' Expanded findings provided further context as caregivers discussed how external influences can make carrying out this skill more difficult and burdensome. Additionally, the lowest scored item within this construct, *'Understand what healthcare providers are asking you to do'*, ties into the major challenge caregivers faced according to both the quantitative and qualitative data and can also explain why this construct received an average overall score just below 4.

Quantitative and qualitative findings indicated that caregivers had complexities with communication with healthcare providers. Once again, quantitative findings depicted challenges within the scales used to measure communication, thus indicating some deficiencies within the health literacy skill. However, FGDs with caregivers provided further explanation and expanded findings. Caregivers pointed to gaps in provider communication as being the source of communication challenges. Limited time spent and information provided as well as feeling dismissed and unheard were the specific experiences caregivers discussed and the reasons why they couldn't understand what healthcare professionals were asking them to do or hold effective conversations. Relaying information in medical jargon was another poor attribute of providers that caregivers felt contributed to communication issues. If doctors are using complex terminology to discuss health matters with caregivers, how can caregivers be expected to properly use their communication skills to carry on an effective conversation? The use of jargon to describe health-related information can have detrimental effects on patients and caregivers (Allen et al., 2023). The use of jargon has been thought to be related to clinicians' perceptions of patient/caregiver understanding, particularly if they exhibit high verbal fluency (Gotlieb et al., 2022). The issue of communication between healthcare providers and caregivers of PLWD is not a new one. A qualitative study that examined barriers to communication with healthcare providers and health literacy about incontinence among dementia caregivers found the biggest barrier to communication was the lack of knowledge about dementia (Mullins et al., 2016). Caregivers felt that PCPs had a "theoretical idea" about dementia but did not know how best to support them.

Communication is a commonly exercised individual health literacy skill; however, it is frequently absent from health literacy measures (Beauchamp et al., 2015). What's interesting is that challenges in communication and engagement with healthcare providers seemed not only relevant in caregivers' communication skills but also print literacy skills and experiences of medical discrimination. Items on the DMS with the highest mean scores were '*You feel like a doctor or nurse is not listening to what you and* *your person were saying'* and '*A doctor or nurse acts as if he or she is better than you and your person.'* This points to the notion that individual health literacy capacity should not only be seen as an individual responsibility but rather a shared responsibility, and healthcare providers should also be held accountable for upholding health literacy principles.

Health literacy as a shared responsibility also extends to the organizational level. *'Navigating the Healthcare system'* was the lowest-scored construct among scale responses of 1 (cannot do/always difficult) - 5 (always easy). Most caregivers found this construct to be 'sometimes difficult', and explanatory quotes pointed to system-related issues such as healthcare financing, insurance, and knowing where to start when navigating the healthcare system, as the source of difficulties. Healthy People 2030 further expanded the definition of health literacy to not only depict health literacy at the individual level but also among healthcare organizations (organizational health literacy) (U.S. Department of Health and Human Services, 2020). Organizational health literacy is "the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (U.S. Department of Health and Human Services, 2020, p. S259). Often those with strong health literacy skills can still face challenges navigating the healthcare system and exercising other health literacy skills if organizations are not health literate (U.S. Department of Health and Human Services, 2020).

### *Limitations*

Chapters 1 and 2 detail study limitations respective to the individual quantitative and qualitative procedures, respectively. These limitations are relevant to the overall mixed methods design.

### *Conclusion*

This study adopted a mixed methods approach to explore health literacy and medical discrimination in Black caregivers of PLWD. Using an explanatory sequential mixed methods design furthered knowledge and understanding of the research topic and provided a voice to caregivers. Quantitative procedures were first carried out to develop a health literacy profile and examine the association between different health literacy constructs and medical discrimination. Focus groups were then conducted to validate the results of the quantitative study and provide more insight and depth into quantitative results. Explanatory quotes pointed to healthcare providers and organizations as the source of health literacy-related challenges. It was not that caregivers had problems carrying out health literacy skills, but rather the barriers and burdens perpetuated by healthcare providers and organizations that made it challenging for caregivers to use their skills effectively. The notion of health literacy as a shared responsibility must be emphasized among healthcare professionals and organizations who frequently engage with and strive to improve care provision among Black caregivers. Specifically, they should consider integrating health literacy principles into their mission and daily operations, their commitment to identify and address the needs of all of those served and develop strategies to ensure sustainable effective communication. Additionally, healthcare providers and organizations should understand the role that medical discrimination plays among Black caregivers seeking healthcare for their PLWD. Caregivers' health literacy skills can be further challenged if such instances of disrespect are perpetuated, further compromising effective conversations and the overall healthcare of Black PLWD. This study has illustrated that health literacy and medical discrimination should be considered contributing factors to disparities in the Black dementia caregiving experience and future research should explore their roles in health-related outcomes of Black dementia patients.

**Figure 2**

*Conceptual Model*

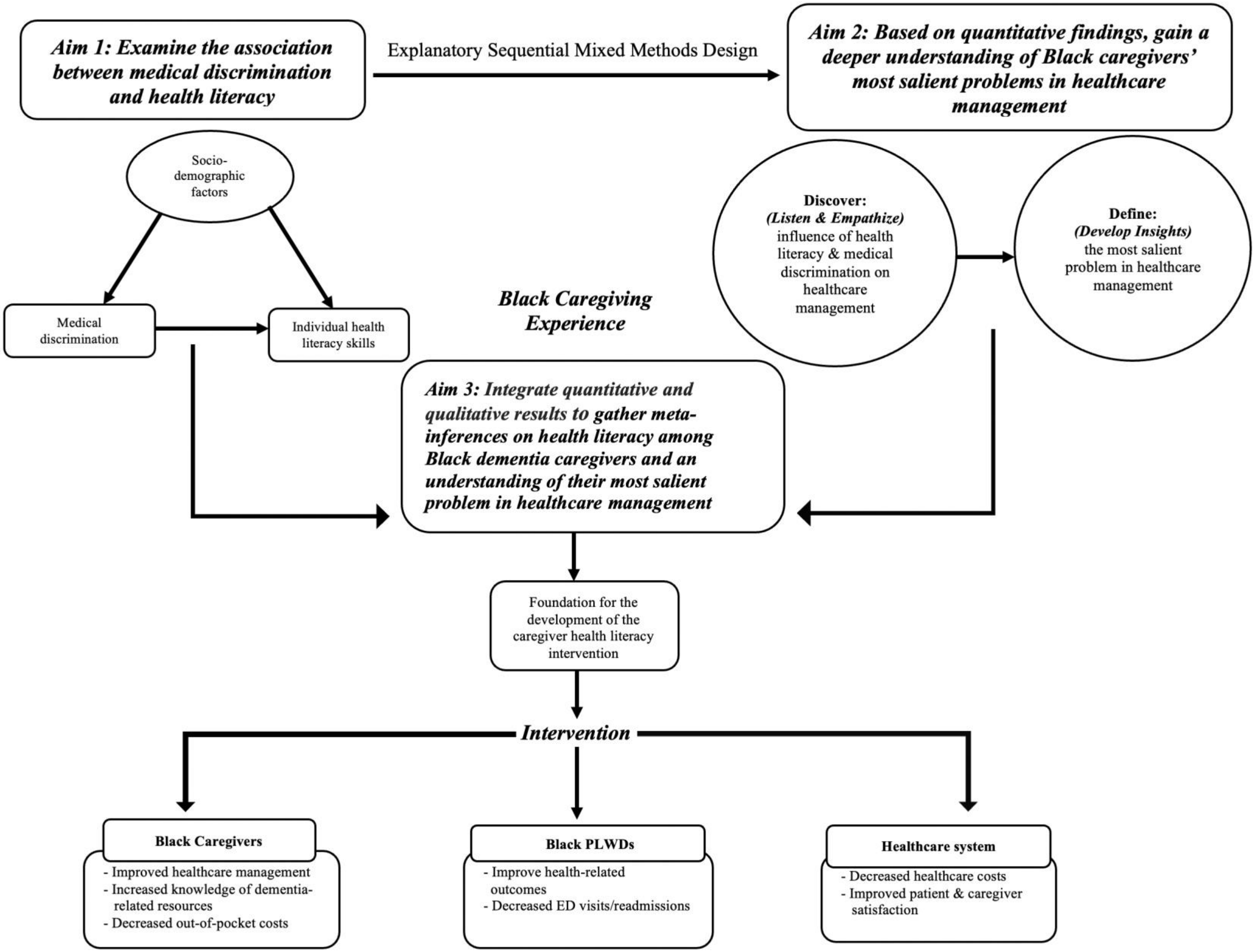
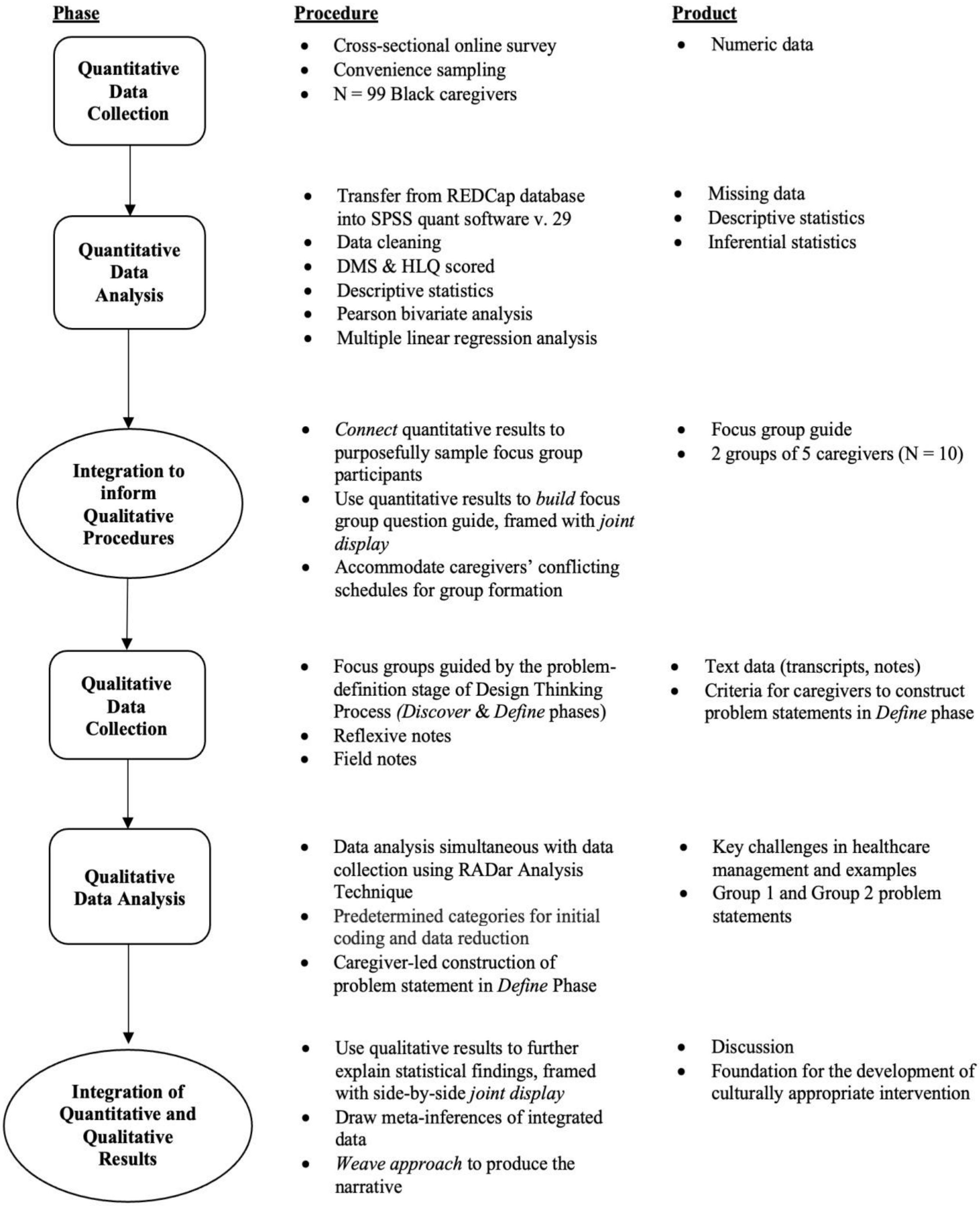


**Figure 3**

*Explanatory Sequential Design Procedures*



| Phase | Procedure | Product |
|---|---|---|
| **Quantitative Data Collection** | • Cross-sectional online survey<br>• Convenience sampling<br>• N = 99 Black caregivers | • Numeric data |
| **Quantitative Data Analysis** | • Transfer from REDCap database into SPSS quant software v. 29<br>• Data cleaning<br>• DMS & HLQ scored<br>• Descriptive statistics<br>• Pearson bivariate analysis<br>• Multiple linear regression analysis | • Missing data<br>• Descriptive statistics<br>• Inferential statistics |
| **Integration to inform Qualitative Procedures** | • *Connect* quantitative results to purposefully sample focus group participants<br>• Use quantitative results to *build* focus group question guide, framed with *joint display*<br>• Accommodate caregivers' conflicting schedules for group formation | • Focus group guide<br>• 2 groups of 5 caregivers (N = 10) |
| **Qualitative Data Collection** | • Focus groups guided by the problem-definition stage of Design Thinking Process *(Discover* & *Define* phases)<br>• Reflexive notes<br>• Field notes | • Text data (transcripts, notes)<br>• Criteria for caregivers to construct problem statements in *Define* phase |
| **Qualitative Data Analysis** | • Data analysis simultaneous with data collection using RADar Analysis Technique<br>• Predetermined categories for initial coding and data reduction<br>• Caregiver-led construction of problem statement in *Define* Phase | • Key challenges in healthcare management and examples<br>• Group 1 and Group 2 problem statements |
| **Integration of Quantitative and Qualitative Results** | • Use qualitative results to further explain statistical findings, framed with side-by-side *joint display*<br>• Draw meta-inferences of integrated data<br>• *Weave approach* to produce the narrative | • Discussion<br>• Foundation for the development of culturally appropriate intervention |

**Table 3**

*Focus Group Questions Joint Display*

| Domain | Relevant Quantitative Results | Focus Group Questions | Rationale of Questions |
|---|---|---|---|
| **Print Literacy** | HLQ scale - *Understand health information well enough to know what to do* (UHI): M = 3.79(SD = 0.51) → strongest heath literacy construct among caregivers<br>Item 1: *Confidently fill medical forms in the correct way*: M = 3.96<br>Item 4: *Read and understand all the information on medication labels*: M = 3.86<br>Item 5: *Understand what healthcare providers are asking you to do*: M = 3.81<br>→ most caregivers did not find these items *usually easy* | 1. *What are your experiences with filling out medical forms and reading medication labels?* | Gain an in-depth understanding of caregivers' experiences engaging with specific health-related information and materials commonly encountered while managing healthcare – what makes this construct a strength? Any challenges? |
| **Communication** | HLQ scale - *Feeling understood and supported by healthcare providers:* M = 2.81(SD = 0.41)<br>→ most caregivers *disagreed* with construct<br>HLQ scale - *Ability to actively engage with healthcare providers*: M = 3.46(SD = 0.49)<br>→ most caregivers found construct *sometimes difficult* | 2. *What are your primary challenges when engaging with healthcare providers?*<br>3. *What difficulties do you have when communicating with healthcare providers so that you get the information you need for your person?* | Explore reasons for limitations in understanding (connects to item 5 of scale '*Understand health information well enough to know what to do')* and communication and engagement with and understanding of healthcare providers and professionals |
| **Navigation/ Information Seeking** | HLQ scale - *Ability to find good health information*: M = 3.46(SD = 0.56)<br>HLQ scale- *Navigating the healthcare system*: M = 3.42(SD = 0.57)<br>→ Most caregivers found both constructs as *sometimes difficult* | 4. *What sources do you rely on to get health information and what makes finding information about health problems challenging?*<br>5. *What makes navigating the healthcare system for your person difficult?* | Elicit reasons for difficulties in seeking information and navigating the healthcare system |
| **Medical Discrimination** | Average DMS score: 18.35(SD = 6.01)<br>32 = highest overall score (max = 35)<br>Item 8: *What do you think the MAIN reason is for these* experiences?<br>Race - 38.4%<br>Age - 18.2%<br>Ethnicity - 14.1%<br>Other - 4%<br>Gender - 3%<br>Pearson bivariate analyses revealed DMS mean score had significant associations (moderate or weak) with all HLQ scales | 6. *What discriminatory experiences have you faced while seeking healthcare for your person? How have these experiences impacted healthcare management?* | Explore the various discriminatory experiences and the ways these experiences affect health-related tasks. |

*Note.* Abbreviations: M – mean, SD – standard deviation

**Table 3.1**

*Integrated Quantitative and Qualitative Results & Meta-Interferences*

| | Quantitative Scores | Explanatory Quotes | Meta-Interferences |
|---|---|---|---|
| **Print Literacy** | HLQ scale: *Understand health information well enough to know what to do.* M = 3.79(SD =0.51)<br>range: 1(cannot do/always difficult) – 5 (always easy)<br>Item 1: *Confidently fill medical forms in the correct way*: M = 3.96<br>Item 4: *Read and understand all the information on medication labels*: M = 3.86<br>Item 5: *Understand what healthcare providers are asking you to do*: M = 3.81 | *"ah, for me the challenge is just feeling like doing it, cause it's like everywhere you go you gotta fill out this paper… it's overwhelming to have to take care of another whole adult and you know that adult is dying, so now you gotta sit here and fill out this paperwork (R6)."*<br>*"It's not always clear when a new medicine is prescribed; how does that impact the other medicines that they're taking… Do we really need to keep taking four and five pills, if nothing's gonna change? Like, we know there's no cure is this any benefit (R8)?"* | Focus group quotes **confirmed** quantitative findings as most caregivers had no challenges with the construct. Although this was the strongest construct among those with response options of 1-5, a mean score of 3.79 indicated there may be some difficulty as a score of 4 is 'usually easy' and 3 is 'sometimes difficult.' **Expanded findings** indicated that challenges with this construct are not necessarily due to deficiencies in print literacy skills and carrying out the task but rather the external influences (intrapersonal burden, system factors perpetuating further stress) that accompany the health-related stimuli that require exercising print literacy skills. |
| **Communication** | HLQ scale: *Feeling understood and supported by healthcare providers.* M = 2.81(SD = 0.41)<br>range: 1(strongly disagree) – 4 (always easy)<br>HLQ scale: *Ability to actively engage with healthcare providers.* M= 3.46(SD = 0.49)<br>range: 1(cannot do/always difficult) – 5(always easy) | *"The challenge that I face is getting the information in real-time…That's my challenge is to get real-time information from different providers (R2)."*<br>*"I feel like with the doctors, they sort of talk as if they're talking to a fellow colleague like someone who understands what they're saying (R4)."*<br>*"I would say more the lack of knowledge about dementia, rather than the poor communication... I'd lean towards the lack of knowledge about the disease, the different diseases or the stages, especially at a PCP level (R7)."* | Focus group quotes **confirmed** caregivers' challenges engaging and communicating with healthcare providers and often not feeling understood and supported by providers. **Expanded findings** indicated that limitations in healthcare providers' communication and engagement can contribute to challenges in caregivers' ability to hold adequate discussions. |
| **System Navigation/ Information Seeking** | HLQ scale: *Ability to find good health information.* M = 3.46(SD = 0.56)<br>HLQ scale: *Navigating the healthcare system*. M= 3.42(SD = 0.57)<br>range for both scales: 1(cannot do/always difficult) – 5(always easy) | *"I think one of the barriers or why people have trouble getting information is Google… and the internet. There's a lot of misinformation out there that people sometimes take as the gospel… I think when you're trying to get information, finding information, you have to know where to start. Like* [R6] *said you don't really know where to start (R7)."*<br>*"Healthcare financing, specifically insurance dictating care and accessibility (R5)". "Sometimes it boils down to insurance coverage…what I may find helpful versus what the insurance covers (R2)."* | These were among the weaker constructs and scores indicated some challenges. Focus group quotes **confirmed** quantitative findings and provided explanations as to what affects caregivers' information seeking and system navigation skills such as not knowing where to start to find information, problems that come with using internet sources to find information, and healthcare financing and insurance dictating system navigation. |

| | | | |
|---|---|---|---|
| **Medical Discrimination** | DMS mean score: 18.35(SD = 6.01)<br>32 = highest overall score (max = 35)<br><br>item 8: *What do you think the MAIN reason is for these* experiences?<br>Race - 38.4%<br>Age - 18.2%<br>Ethnicity - 14.1%<br>Other - 4%<br>Gender - 3%<br><br>Pearson bivariate analyses revealed DMS mean score had significant associations (moderate or weak) with all HLQ scales | “*I think he* [the doctor] *just looks at me a little bit beneath my mother…I’m still doing a lot. So, that’s my thing. It’s just more so like the respect level, with the ages. He’s been working with my mom longer so I feel he’s like, ‘Oh, you’re just a kid,’ kind of thing (R1).”*<br><br>“*I do feel that other people, in other groups, don’t experience these types of things… I just don’t get it, but I feel it is a racial thing you know? I hate to even say that but sometimes they bring me to that level (R2).”*<br><br>*“come prepared (R2, R3, R7, R8)”*, *“come knowledgeable (R2, R3, R7, R8)”*, are “*dressed appropriately (R2, R3, R7, R8)”*, and/or have a *“well-established relationship with the provider (R3, R5, R8, R9, R10)”* to *“avoid facing ‘such’ experiences (R2, R3, R5, R8, R9, R10).”* | Focus group quotes **confirmed** quantitative findings which indicated that caregivers have faced discriminatory experiences while seeking healthcare for their PLWD. Race was cited as the primary reason for such experiences, followed by age. Ageism (on the caregiver end and PLWD) and racism were discussed among the focus groups.<br><br>An average overall score of 18.35 indicated that not all caregivers have faced discrimination in the medical setting which was also **confirmed** by quotes. During focus groups caregivers indicated that some adopt certain behaviors to prevent such discriminatory experiences or have a long-established relationship with their PLWD’s provider. |

*Note.* Abbreviations: M – Mean, SD – standard deviation

# Chapter 4: Integrative Summary

This study was the first step in better understanding the health literacy of Black caregivers of PLWD and the role of medical discrimination in effectively carrying out their health literacy skills. Study findings will be used to develop a future, culturally appropriate intervention to help prepare Black health-literate caregivers so that they can more effectively navigate a multifaceted healthcare environment characterized by discrimination. During the qualitative phase, caregivers were only tasked with constructing salient problem statements that encompassed their fundamental problem when managing healthcare for their PLWD, however, they began brainstorming potential solutions. Such solutions included embedding glossaries in online communication tools with healthcare providers to aid in understanding medical jargon and a web application where caregivers can correspond with various dementia care providers to enhance communication and thoroughly address concerns. Mixed methods findings indicated that a health literacy intervention should not solely take place at the individual level, but also among healthcare providers and organizations as limitations within these levels seemed to have perpetuated caregivers' health literacy-related challenges.

Individual health literacy is a shared responsibility, thus key professionals that work in the healthcare environment that caregivers navigate with their PLWD should also uphold adequate health literacy principles and meet caregivers where they are. This includes the doctors, nurses, and other healthcare workers who frequently interact with Black families affected by dementia. Quantitative data in combination with relevant explanatory quotes from caregivers in this study made it evident that an intervention is needed to shift the focus away from health literacy as an individual capacity and place more accountability on the healthcare professionals whom caregivers interact with. Perhaps such an intervention calls for more structured dialogue and time spent with a third party (e.g., medical assistant) before visiting with the primary care provider, to ensure culturally relevant dialogue is conducted to help alleviate miscommunications and improve care for the families. Perhaps an intervention is needed in health professions education, to better prepare rising clinicians and healthcare professionals. It is important to acquaint health professions students with concepts in health literacy so that they can provide effective communication and education to the patients and caregivers they will soon interact with. This includes emphasizing the use of plain language and active listening, practicing empathy, and using the often-limited time spent with patients efficiently. The Institute of Medicine and institutions that educate rising healthcare workers all agree that health literacy principles are a needed component of medical, nursing, and all other healthcare-related education (Milford et al., 2016). However, there continues to be a lack of standards, structured teaching approaches, and guidelines for educating students about health literacy - which could be due to limited knowledge and understanding of the multi-dimensional concept as well as its impact on patients and caregivers (Milford et al., 2016; Scott, 2016). Often it is left for the programs to decide how to implement content on health literacy, how many hours should be devoted to the concept, and how best to evaluate student learning (Milford et al., 2016; Scott, 2016; Hildenbrand, Perrault, & Keller, 2020).

Simulation-based teaching and learning is an effective way to carry out and evaluate health literacy education considering health literacy applies to the interaction healthcare professionals have with their patients and caregivers. Nursing students have reported that classroom simulations, where students can play not only the role of the nurse but also the patient and family member, improve their communication skills (Weekes & Phillips, 2015). Teaching health literacy, its various components - which include communication and engagement with healthcare providers, and how these components play a part in the patient and caregiver’s healthcare experience may help prioritize health literacy in nursing practice. One medical school program developed and implemented a required, specialized health literacy training for first-year medical students as part of their “Foundations of Clinical Practice” course (Hildenbrand, Perrault, & Keller, 2020). The training focused on communication strategies and using plain language. The rationale for developing the training stemmed from faculty recognizing that although basic communication skills were emphasized in the curriculum, students were not enhancing overall health literacy knowledge and learning details on various health literacy principles that go beyond how to best communicate with different patients (Hildenbrand, Perrault, & Keller, 2020). For example, understanding the power dynamics within the physician-patient relationship and system-related factors that influence patients' health-related decisions such as accessibility (Hildenbrand, Perrault, & Keller, 2020). A Doctor of Pharmacy (PharmD) program in the mid-west implemented health literacy education not only in simulation-based learning but also throughout the program curriculum (Chen et al., 2020). Perceptions, understanding, and application of and confidence in applying health literacy principles, as well as cultural competence, were consistently emphasized and evaluated (Chen et al., 2020).

Not only must healthcare professionals be held accountable to uphold health literacy principles, but also healthcare organizations because it is ultimately the organization's responsibility to ensure quality healthcare is being delivered to the patients and caregivers it serves. The RoundTable on Health Literacy (part of the National Academies of Science, Engineering, and Medicine) first brought forth the concept of a health literate healthcare organization describing it as, "an organization that makes it easy for individuals to navigate, understand, as well as use information and services to take care of their health" (Brach et al., 2012; Institute of Medicine, 2012). Healthy People 2030 further expanded the definition of health literacy to not only include personal health literacy, but also organizational health literacy - "the degree to which **organizations equitably enable individuals** to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (U.S. Department of Health and Human Services, 2020, p. S259). Effective provider communication is a key focus among the objectives of organizational health literacy (U.S. Department of Health and Human Services, 2020). In addition to challenges with healthcare providers, findings from this study also revealed organization-based challenges such as system navigation which, according to caregivers, were due to external factors and obstacles faced. Such challenges could potentially be alleviated if caregivers were served by health-literate healthcare organizations.

Even if people exhibit high individual health literacy, they can still face adverse consequences from the "ill effects" of low organizational health literacy (U.S. Department of Health and Human Services, 2020). Much like individual health literacy, the concept of organizational health literacy is still progressing, and attributes of what makes a health-literate organization are consistently operationalized and debated (U.S. Department of Health and Human Services, 2020). The Integrated Health Literate Care

Model was developed as a framework for healthcare organizations, outlining health literacy strategies to enhance patient engagement in prevention, health-related decision-making, and self-management while considering the complexities of the healthcare system (Paasche-Orlow & Wolf, 2007; Harris et al., 2013). Strategies to replace the traditional "fee-for-service" compensation models (based on amount of care provided) with "value-based" compensation (reimburses healthcare providers according to quality goals achieved) have become another plan of action for organizational health literacy initiatives (Brach, 2017). Although an optimistic plan, it will greatly help address the challenges described by caregivers in this study who cited healthcare finances and insurance as barriers to optimal system navigation. Overall, the focus on the need for organizational, rather than solely healthcare-provider-level health literacy remediation has grown and there is hope for progress (Brach, 2017).

Medical discrimination must also be factored into health literacy-focused interventions. 'Race' was the most cited reason for discrimination while seeking healthcare for PLWD among caregivers in this study. During focus groups, some caregivers felt that other racial groups did not experience the same challenges they did when interacting with the healthcare system, and others discussed personal experiences that aligned with manifestations of racism such as microaggressions. Whether caregivers had personal experiences with racism or not, all agreed that it is a problem in healthcare and can make health-related tasks more burdensome to the point some intentionally adopted behaviors to avoid such experiences. One may argue that such disrespectful ordeals do not align with racism, but rather cultural insensitivity or cultural incompetence. Consequences of perpetuating cultural insensitivity and incompetence mirror those of racism (Berger & Miller, 2021). The NIA Health Disparities Research Framework details how individuals may find negative interactions with clinicians to be culturally insensitive, perceive restricted access to quality healthcare as institutional racism, and view this hardship as discrimination (Hill et al., 2015). The framework specifically names 'racism' as a social factor that can shape important individual health-related decisions (Hill et al., 2015). Given the history of racial oppression embedded in the U.S. healthcare system, equity and bioethics scholars tend to shift from using concepts such as cultural competence as they fail to see the depth of structural inequality such as systemic racism (Berger & Miller, 2021; Ray & Davis, 2021). Given that Black Americans are more likely to mistrust or distrust the healthcare system than any other racial and ethnic group due to historical inequality and adverse experiences, including abuse in healthcare research, perhaps ‘trust’ should have been assessed in this study as well (Politi et al., 2014). Mistrust/distrust impedes health literacy development because it affects interactions with the healthcare system, access to health-related resources, and health-related decision-making (Muvuka et al., 2020). Exploring trust among Black caregivers may have provided further context around racism experienced in the healthcare space.

Although race was the most cited reason for medical discrimination other reasons such as age, gender, and the dementia disease were cited as well. This indicates that Black caregivers, as well as their care recipients, who possess other marginalized identities, can be put at further risk for discriminatory treatment in the healthcare setting. Thus, when examining and emphasizing racism as a barrier to gaining/exercising individual health literacy skills, it is also important to consider other forms of discrimination.

Caregivers did not see medical discrimination as a problem that could be feasibly addressed in a future health-literacy-focused intervention. Perhaps they are somewhat correct as the individual-level intervention is not where the concept should be addressed. If we are to further adapt a culturally appropriate intervention that emphasizes health literacy as a shared responsibility among healthcare providers and organizations, particularly one that focuses on Black patients and caregivers, the unique challenges they can face must also be incorporated. This may once again mean intervening in healthcare profession education and teaching rising healthcare workers the historical implications of current health and healthcare disparities and how to interact with diverse families based on these implications. Difficulties to effectively address racial bias and discrimination among current healthcare workers are becoming more evident given the persistent ineffectiveness of Diversity, Equity, and Inclusion training and workshops – which are commonly implemented methods of addressing the problem (Berger & Miller, 2021). Whatever the future interventions may look like, when addressing health literacy of Black patients, caregivers, and the general community, medical discrimination must also be incorporated.

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# Appendix A: Recruitment Flyer

## BLACK DEMENTIA CAREGIVERS NEEDED!

For a study exploring how health literacy and experiences of discrimination in the healthcare setting influence health-related responsibilities for persons living with dementia.

### Eligible Caregivers:

-Identify as Black/African American

-18 years of age or older

-Caring for someone living with dementia, dementia-related illness, or memory loss

-Involved in your person's healthcare decisions

-Have internet access

### What will I have to do?

1. Take ONE 45-minute survey
2. Take part in an optional focus group with other caregivers
3. Get a $25 gift card for the survey and focus group participation

### Interested in Participating?

Visit: **https://forms.office.com/r/RpmKE0se63**
**OR Scan the QR Code** to make sure you are eligible

Contact PhD Candidate:
**Karah Alexander, MPH** for more info!
**Email:** karah.lynea.alexander@emory.edu
**Phone:** (470) 223-5951

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This study has been approved by the Emory Institutional Review Board: STUDY00005570

## Appendix B: Survey

Date: ________ Subject ID: __________

### Demographic Information & Caregiving History

**1.** Your Age_____

**2.** Which of the following terms best describes your gender**? (check all that apply)**
___Female
___ Male
___ Non-binary / genderqueer
___ Not listed
___ Prefer not to answer

**3.** What is the highest level of education that you achieved?
___ Never attended
___ Less than High School
___ High School
___ Some College
___ College graduate
___ Graduate/professional

**4.** How would describe where you live?
___ urban
___ suburban
___ Rural
___ Prefer not to answer

**5.** What is your yearly household income?
___ 0 - $10,000
___ $10,001 - $25,000
___ $25,001 - $50,000
___ $50,001 - $100,000
___$100,001 - $250,000
___ $250,001+
___ Prefer not to answer

**6.** Who is the person you care for and are involved in their healthcare decisions? (circle all applicable choices)

| | | |
|---|---|---|
| Spouse | Mother | Father |
| Aunt | Uncle | Other Relative |
| If Other (please specify): | | |

**7.** Has your person received a diagnosis of dementia?
__ Yes
__ No
__ Prefer not to answer

**8.** If YES: About how long was your person diagnosed (years)?
**9.** If YES: About how long was your person diagnosed (months)?
**10.** Which stage of dementia are they in?
___ Early → **A person may function independently. They may still drive, work and be part of social activities. Despite this, the person may feel as if they are having memory lapses, such as forgetting familiar words or the location of everyday objects.)**
___ Middle → **A person may have greater difficulty performing tasks such as paying bills, but they may still remember significant details about their life. You may notice the person confusing words, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe.**
___ Late→ **A person may lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills continue to worsen, significant personality changes may take place and individuals need extensive help with daily activities.**
___ Don't Know

**11.** About how long have you been personally caring for your loved one? __ Years __ Months

**12.** Does your person have health insurance? __ Yes __ No

**13.** **If yes**, kind of health insurance do they have?
____ Medicaid
____ Medicare
____ Private
____ Other

**14.** Do YOU have health insurance?? ___ Yes ___ No

**15 If yes**, what kind of health insurance do YOU have?
____ Medicaid
____ Medicare
____ Private Health Insurance
____ Other

**16.** If Other - please describe the health insurance

## How strongly do you Agree or Disagree?

1. I have at least one healthcare provider who…
2. I have at least one healthcare provider I can…
3. I have the healthcare providers I need…
4. I can rely on at least one healthcare provider
5. I compare health information from different…
6. When I see new information about health, I…
7. I compare health information from different…
8. I know how to find out if the health…
9. I ask healthcare providers about the quality…

## How Easy or Difficult are the following tasks for you?

10. Make sure that healthcare providers understand…
11. Feel able to discuss your health concerns with a…
12. Have good discussions about your health with doctors
13. Discuss things with healthcare providers…
14. Ask healthcare providers questions to get…
15. Find the right healthcare
16. Get to see the healthcare providers you need to
17. Decide which healthcare provider you need to see
18. Find out what healthcare services…
19. Make sure you find the right place…
20. Work out what is the best care for you
21. Find information about health problems
22. Find health information from several…
23. Get information about health so you are…
24. Get health information in words you…
25. Get health information by yourself
26. Confidently fill medical forms in the correct way
27. Accurately follow the instructions from…
28. Read and understand written health information
29. Read and understand all the information on….
30. Understand what healthcare providers are…

**Full items were provided on the live survey for caregivers, however, for this re-print items are truncated. The Health Literacy Questionnaire (HLQ).**

**When receiving health care, how often have you had the following experiences as a caregiver of your person (choose one answer for each question):**

| | |
|---|---|
| 1. Your person is treated with less courtesy than other people | ○ 1. Never<br>○ 2. Rarely<br>○ 3. Sometimes<br>○ 4. Most of the time<br>○ 5. Always |
| 2. Your person is treated with less respect than other people | ○ 1. Never<br>○ 2. Rarely<br>○ 3. Sometimes<br>○ 4. Most of the time<br>○ 5. Always |
| 3. Your person receives poorer service than others | ○ 1. Never<br>○ 2. Rarely<br>○ 3. Sometimes<br>○ 4. Most of the time<br>○ 5. Always |
| 4. A doctor or nurse acts as if he or she thinks you and your person are not smart | ○ 1. Never<br>○ 2. Rarely<br>○ 3. Sometimes<br>○ 4. Most of the time<br>○ 5. Always |
| 5. A doctor or nurse acts as if he or she is afraid of you and your person | ○ 1. Never<br>○ 2. Rarely<br>○ 3. Sometimes<br>○ 4. Most of the time<br>○ 5. Always |
| 6. A doctor or nurse acts as if he or she is better than you and your person | ○ 1. Never<br>○ 2. Rarely<br>○ 3. Sometimes<br>○ 4. Most of the time<br>○ 5. Always |
| 7. You feel like a doctor or nurse is not listening to what you and your person were saying | ○ 1. Never<br>○ 2. Rarely<br>○ 3. Sometimes<br>○ 4. Most of the time<br>○ 5. Always |

**If you answered "Always", "Most of the time", "Sometimes" or "Rarely" to any of the above (anything but "Never"), please answer this question:**

| | |
|---|---|
| 8. What do you think the MAIN reason is for these experiences? (pick 1 answer) | ○ 1. Race<br>○ 2. Ethnicity<br>○ 3. Gender<br>○ 4. Age<br>○ 5. Income level<br>○ 6. Language<br>○ 7. Physical Appearance<br>○ 8. Sexual Orientation<br>○ 9. Other (fill in blank) |
| 8-other: Write in the other MAIN reason | ________________________________ |