INTENTIONS TO UNDERGO DEMENTIA SCREENING

AMONG OLDER BLACK ADULTS

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ABSTRACT

Stark health disparities exist between Black and White Americans including dementia risk. Black Americans are up to three times more likely to develop dementia compared to their White counterparts. These disparities can be attributed to other health inequalities that increase the risk of dementia. Despite the `higher prevalence of dementia among Black Americans, rates of dementia screening remain low and diagnosis often occurs at more advanced stages of the disease. Consequently, those living with dementia and their families lose valuable time planning for care and for interventions. There is a dire need to address this disparity in multi-faceted ways and a better understanding of the decision-making process for dementia screening among older Black adults may be a springboard to close this gap. The current study aimed to investigate intent to undergo dementia screening and was the first of its kind to do so in a faith-based sample of older Black adults. The researchers drew on the Health Belief Model (HBM) as a framework, given its successful application in understanding screening behavior for other health concerns. Altogether, the study examined six factors in their ability to predict dementia screening intent: perceived benefits, perceived barriers, perceived severity (guided by the HBM), as well as dementia knowledge, dementia stigma, and expectations regarding aging through hierarchical regression modeling. Results

support stigma as an especially important predictor for dementia screening intent among older Black adults. Addressing dementia stigma should be a priority in interventions aimed at increasing screening rates among older Black adults. Moreover, findings are particularly relevant to future faith-based dementia screening interventions as churches may be pivotal in closing this health disparity.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Education, Social Work and Psychological Sciences examined a dissertation titled “Intentions to Undergo Dementia Screening Among Older Black Adults” presented by Jensen Emily Davis, candidate for the Doctor of Philosophy degree, and certify that in their opinion it is worthy of acceptance.

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ABBREVIATIONS

Alzheimer's Disease=AD

Expectations Regarding Aging-12= ERA-12

Health Belief Model=HBM

Dementia Knowledge Assessment Scale= DKAS

Mild Cognitive Impairment=MCI

Neurocognitive Disorder= NCD

Patient Health Questionnaire-9=PHQ-9

Perceptions Regarding Investigational Screening for Memory in Primary Care =PRIMS-PC

Socioeconomic Status=SES

Stigma Impact Scale=SIS

Theory of Planned Behavior=TPB

Vascular Dementia=VAD

CHAPTER 1

REVIEW OF THE LITERATURE

Overview of Dementia

Dementia is a syndrome characterized by a significant decline in an individual's previous level of cognition with accompanied functional impairment. As it is a clinical diagnosis, classification guidelines are outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). The manual presents the term neurocognitive disorder (NCD) to represent a continuum of changes or impairment in cognitive abilities. NCD represents cognitive decline spanning from mild NCD, otherwise known as mild cognitive impairment (MCI), to major NCD, otherwise known as dementia. Further, the DSM-5 defines major NCD as "significant cognitive decline from a previous level of function" in one or more cognitive domains, such as: attention, executive function, learning and memory, language, perceptual-motor function, or social cognition, preferably as evidenced by standardized neuropsychological or neurocognitive testing (American Psychiatric Association, 2013). At this end of the continuum, cognitive deficits interfere with independence in everyday activities, and specifiers—mild, moderate, or severe—further denote the degree of one's functional impairment. Minor neurocognitive disorder is characterized by a milder decline from an individual's previous level of functioning in one or more of the same cognitive domains. Contrastingly, in mild NCD, cognitive deficits do not significantly interfere with one's ability to live independently.

Though the DSM-5 specifies the term neurocognitive disorder for diagnostic purposes, the research literature often refers to major NCD as dementia. Dementia, and neurocognitive disorders, encompass many causes. Causes include but are not limited to

various neurodegenerative conditions like Alzheimer's or Parkinson's disease, traumatic brain injury, stroke, organ failure, vitamin deficiency, or effects from a history of excessive substance use, all specified within DSM-5 criteria for NCD (Corrada et al., 2010; Jorm & Jolley, 1998; Muangpaisan et al., 2012). Though many causes can contribute to the development of dementia, the leading causes are neurodegenerative and typically occur after the age of 65.

As the leading risk factor for developing dementia is age, the growing number of Americans aged 65 and older will result in a higher prevalence of dementia. In fact, the population of Americans aged 65 and older is projected to nearly double what it is now by 2050 (Ortman et al., 2014). This same trend is reflected worldwide, too (Jones, 2021). As a result, larger proportions of the global population will be living with dementia than ever before. Further, one's risk of developing dementia doubles every five years after 65 (Corrada et al., 2010; Jorm & Jolley, 1998). Given the dynamics of a population that will be proportionately older, compounded by the exponential rate of dementia risk with increasing age, the number of people living with dementia in the year 2050 could be nearly 15 million in the U.S. alone (Hebert et al., 2013). However, this is merely an estimation. According to Lang and colleagues (2017), dementia is greatly under-detected.

As mentioned, most of the underlying disease processes that cause dementia are progressive illnesses for which changes are not reversible. The most common cause of dementia is Alzheimer's disease (AD), which is thought to account for nearly half of all diagnoses. It is also currently the fifth leading cause of death among those over age 65 (Alzheimer's Association, 2016). Vascular dementia (VaD), caused by insufficient blood flow and damaged blood vessels within the brain, accounts for another 25% of cases, while

mixed type, or co-occurring VaD and AD pathologies, account for roughly 20% of cases. Other neurodegenerative conditions occurring in older adulthood that underlie dementia include frontotemporal dementia, dementia due to Lewy body disease, and dementia due to Parkinson's disease, among many others (Brunnström et al., 2009; De Reuck et al., 2016).

Although the true prevalence of dementia is difficult to quantify, its economic impact is well-documented and significant. Dementia leads not only to increased costs for individuals and families but broader systems as well. The duration of illness before death and eventual functional difficulties of those affected by dementia leads to loss of productivity and high costs of care. Currently, individuals in the U.S. living with dementia require nearly $60,000 more in care annually than those without (Hurd et al., 2013). More still, a person with dementia receives more than $250,000 worth of care in their last five years of life (Kelley et al., 2015). Further, to address the growing demands for necessary services to prevent, diagnose, treat, and care for individuals living with dementia, an estimated 18 million additional healthcare workers will be needed by 2030 (Prince et al., 2016). Early identification and subsequent enactment of disease-modifying behaviors and dementia symptom management will be imperative in reducing costs (Fillit & Hill, 2005).

Due to the increasing prevalence and imminent health system/economic burden, calls to action have been made to address issues related to dementia. Doing so could bring better preparedness for its impact. Coordinated initiatives aim to meet these needs nationally and globally. The World Health Organization [WHO], for example, has announced a campaign to increase public awareness and foster a better understanding of the disease through the year 2025. The call has outlined seven principles for action:

> "…human rights of people with dementia, empowerment and engagement of people with dementia and their careers, evidence-based practice for dementia risk reduction and care, multisectoral collaboration on the public health response to dementia, universal health and social care coverage for dementia, equity, and appropriate attention to dementia prevention, cure and care…" (WHO, 2017)."

In short, as the makeup of the global population becomes older, dementia's impact will reach even further. The disease, again, is characterized by a change in cognitive function so great that an individual can no longer live independently. A Conservative estimate of 8 million Americans living with the disease by 2030 poses a dire need for prevention, detection, and support efforts to accommodate the demands placed on individuals, families, and broader public health responses. To support those living with the disease and create necessary caregiving infrastructure for dementia patients, widespread efforts are being established.

Dementia Risk in Older Black Adults

As the global population continues to age and rates of dementia increase, it is important to consider communities that are more significantly impacted by dementia. In fact, WHO's global initiative aims to focus specifically on communities with higher rates of dementia. Though rates of dementia are rising for all older groups, some older adults will be impacted to a greater extent. Epidemiological research has examined the differential risk for dementia among racial/ethnic groups and has long established a higher prevalence among older Black adults.

Earlier research conducted in rural community samples estimated 4x greater prevalence in Black relative to White older adults within the same geographical area. The

former had higher rates of cardiovascular risk factors which contributed to dementia risk (Heyman et al., 1991). Gurland and colleagues (1999) also researched dementia prevalence differences among ethnic groups: non-Hispanic White, Hispanic, and Black/African Americans. Prevalence of dementia was higher in Hispanic and Black older adults than in non-Hispanic Whites (Gurland et al., 1999). Dementia type did not differ significantly between the Black and Hispanic groups.

More recent prevalence and incidence estimates again show older Black adults are at decidedly higher risk for developing dementia in their lifetime compared to their White counterparts, perhaps in large part due to being disproportionately affected by diseases that cause or contribute to its development, such as diabetes and heart disease. Still, many estimates suggest a lifetime risk that is 3x higher in Black Americans than among non-Hispanic Whites (Mehta & Yeo, 2017; Potter et al., 2009). Even among those over age 90, this trend persists.

Other risk models estimate that older Black adults have a 30% increased risk of developing dementia compared to White older adults, even after adjusting for comorbidities implicated in dementia susceptibility (Gilsanz, Corrada, et al., 2019). Again, a recent systematic review shows higher prevalence of dementia in older Black adults compared to older White adults, but not between White and Latino ethnic groups (Shiekh et al., 2021). Taken together, research suggests Black Americans are at markedly enhanced risk for developing dementia in their lifetime relative to other older adult groups, especially Whites. These disparities may soon be felt to an ever-greater extent. The older Black population is expected to grow even faster than the older White population (Shrestha & Heisler, 2011), further widening dementia health disparities already existing.

Heretofore, as more resources are directed to the crisis posed by dementia, particular attention should be given to older adults with higher prevalence rates of the disease. Decades of research have established older Black adults as deserving of that focused attention due to their heightened risk compared to other older groups (Gilsanz, Corrada, et al., 2019; Gurland et al., 1999; Heyman et al., 1991; Shiekh, et al., 2021). Moreover, the challenges of dementia in older Black adults will be exacerbated further by the fact that this population is growing even faster than other older groups (Plassman et al., 2007).

Factors Placing Older Black Adults at Enhanced Risk for Dementia

The increased risk of dementia in minority groups, especially older Black adults, likely involves a complex interplay among a multitude of factors. Research suggests that differences in education, socioeconomic status (SES), and health factors can attenuate these disparities. Some studies indicate slight differences in underlying pathologies between older Black adults and other ethnicities, even after accounting for sociodemographic factors. However, these studies may have not fully considered historical, cultural, political, sociological, and psychological dynamics that contribute to overall health outcomes.

It is also important to note that issues of recruitment and participation in dementia research further hinder the understanding of dementia disparities. Older Black adults are consistently underrepresented in such studies (Ighodaro et al., 2017). For instance, Alzheimer's disease, the most prevalent cause of dementia, has received more investigation than other types. However, many in the field cite the underrepresentation of older Black adults in Alzheimer's disease research as a complicating factor in understanding genetic risk differences (Bardach et al., 2021; Lambe et al., 2011).

Nevertheless, there are risk factors, both health and psychosocial, that increase susceptibility to developing dementia. These risk factors tend to be more prevalent in Black older adults. A brief discussion of these risk factors for dementia is provided below.

Genetic Risks

Though dementia is not a normal part of aging, the most significant risk factor for developing Alzheimer's disease and other dementias is increasing age. Also, having a family member with AD increases one's risk, and the risk may be compounded with more affected family members (Handley et al., 2006). The enhanced risk with age and familial history does not appear to differ by race/ethnicity (Matthews et al., 2019).

Perhaps the most researched and established genetic risk factor for AD is Apolipoprotein E gene, or APOE e4. Particularly, the presence of one or more APOE e4 alleles is associated with the formation of amyloid plaques and neurofibrillary tangles that underlie AD pathology (Evans et al., 1997; Mayeux et al., 1993). Interestingly, some research shows APOE e4 leads to an increased risk of AD among White subjects but not Black subjects, despite that the allele is more prevalent in Black adults (Evans et al., 2003). However, more recent research, namely the genome-wide association study (GWAS) which used several Black cohorts concludes that the combination of the APOE e4 allele with ABCA7, another gene associated with the formation of amyloid plaques, translates into a similarly increased risk of late-onset AD in Black subjects as they are in those individuals of European ancestry (Reitz et al., 2013).

Possible differences between ethnic groups regarding underlying dementia pathologies have also been observed as well. Katz and colleagues (2012) matched older Black and White enrollees of the Rush Alzheimer's Disease Clinical Core on age at death,

sex, education, and cognition proximate to death. The frequency of brain pathologies was examined (e.g., AD, Lewy body disease, and cerebrovascular disease). Alzheimer's disease pathology, again the leading cause of dementia, was found in both groups at roughly 90%, but older Black adults were less likely to have AD alone than were their White counterparts; 19% vs. 42.0%, respectively. AD with Lewy body disease and AD with mixed vascular and Lewy body disease is more prevalent in Black than in White subjects (Barnes et al., 2015; Katz et al., 2012). Though this may suggest differences in underlying pathologies exist between ethnic groups, these findings may be impacted by the sampling bias highlighted before.

Socioeconomic Status and Education

As suggested, other social factors also place Black Americans at enhanced risk for various diseases. For example, epidemiological studies establish that level of education influences one's risk for dementia in later life. Some studies estimate a 7% decrease in dementia risk for each year of schooling through graduate study (Xu et al., 2016). Moreover, education is independently related to dementia due to AD and VaD, even when lifestyle and health habits contributions are controlled for (Caamaño-Isorna et al., 2006).

It is important to note however that the Einstein Aging Study, a longitudinal study of aging conducted among a sample of older adults from an urban community-dwelling population, found race a weaker risk predictor of dementia after adjusting for educational attainment, particularly for dementia due to Alzheimer’s disease (Katz et al., 2012). Relatedly, other findings suggest what may be viewed as a faster rate of decline is more aptly explained by lower baseline performance on cognitive testing persisting throughout

observation periods (Weuve et al., 2018). In that regard, historical disparities in educational attainment play a role in disparate risk/diagnosis between the groups (Weuve et al., 2018).

A possible explanation for the protective factor of education is cognitive reserve, or individual differences in susceptibility to brain changes (Meng & D'arcy, 2012). Hayward et al. (2021) assessed Black American educational attainment and dementia risk from 2000-2014 and found significant declines in dementia prevalence with increased cohort education levels. Socioeconomic status (i.e. income, education, and literacy) may in fact explain much of the unequal prevalence of dementia between Black and White older adults. Yaffe and colleagues (2013) found that risk lessened somewhat after adjustment for physical fitness chronic conditions, but risk per group no longer differed when controlling for SES.

Cardiovascular/Cerebrovascular Health

Vascular dysfunction is highly implicated in cognitive impairment, AD, and other forms of dementia (Kapasi & Schneider, 2016). As such, delays in treatment for hypertension and high cholesterol experienced by Black Americans are even more concerning. Soden and colleagues (2018) found that Black patients presented with more advanced vascular disease at the time of initial major vascular operation compared to Whites. Moreover, Black Americans are at higher risk for dementia within five years of ischemic stroke (Clark et al., 2018).

Individuals with diabetes are as much as twice as likely to develop dementia. This is true for not only vascular dementia but also dementia due to AD as well (Ninomiya, 2019). As diabetes is more prevalent in Black Americans, consequently, the enhanced risk for dementia could be explained in part by the diabetes-related brain changes that underlie dementia development (Geiss et al., 2014; Ojo & Brooke, 2015; Peek et al.,

2007). Moreover, the Diabetes and Aging Study observed patients with type 2 diabetes over a 10-year period, Black Americans had a 50% greater incidence of dementia when adjusting for SES variables (Mayeda et al., 2014).

Other research has investigated the role obesity, or body mass index (BMI), may have in dementia development. Existing literature suggests a higher BMI poses an enhanced risk for dementia (Atti et al., 2008; Gao et al., 2011; Loef & Walach, 2013). Thus, it could also represent a particular risk for Black adults due to higher rates of overweight and obesity (Beydoun & Wang, 2009).

Lifestyle

The benefits that exercise and a healthy lifestyle (i.e., judicious alcohol use and healthy diet) have on preventing dementia and slowing the rate of progression are well documented (Dhana et al., 2020). Certainly, a more active lifestyle can help mitigate the impact chronic illnesses, such as diabetes, has on dementia risk. This is perhaps by way of limiting brain volume loss (Marseglia et al., 2020). Black Americans are less likely to meet exercise guidelines and as such enhanced risk may also be partially explained by this disparity (August & Sorkin, 2011). Focus groups have sought to better characterize barriers to physical activity which include lesser reported time to exercise, physical limitations, family responsibilities, and poorer neighborhood conditions (Gothe & Kendall, 2016).

Mental Health

Mental health also plays a role in one's dementia risk. Depression and anxiety can contribute to dementia in later life at approximately a threefold greater risk than those without prior history (Burton et al., 2013; Santabárbara et al., 2019). As well, having depression can produce cognitive changes like those seen in early dementia processes.

Controlling for age, education, reading level, and sex, older adults who endorse more depression symptoms score lower on measures of memory, language, processing speed, and executive functioning performance (Hamilton et al., 2014).

Relatedly, Gilsanz, Quesenberry, et al. (2019) observed the effects of stressors in midlife, e.g., resources, drug, and family problems, on dementia later in life. Findings suggested differential impacts of the experience of stressors on later dementia development between Black and White adults. In the overall sample, having at least one midlife stressor was associated with 17% greater dementia risk versus no midlife stressors. However, compared to Whites without stressors, Whites with ≥1 stressor had a 13% greater dementia risk. Black adults without stressors had 19% greater risk, and Black adults with ≥1 stressor 47% greater risk. Moreover, older Black Americans with higher perceived stress may have faster functional decline after diagnosis independent of concurrent depression, vascular diseases, and age (Turner et al., 2017).

Stigma toward mental illnesses and mental health services, and lesser access to mental health resources, present as barriers to seeking help for these concerns. More specifically, factors contributing to delayed help for mental health concerns include perceptions of mental health, views toward treatment, and lack of culturally appropriate treatments (Campbell & Mowbray, 2016). As a result, psychotherapy is not as available for and underutilized by Black Americans. Unfortunately, this also lessens the opportunity to ameliorate the effects of depression, anxiety, and trauma and thus their implication in dementia development (Ward & Mengesha, 2013).

Beliefs about Dementia and Aging Expectations

Existing literature has also explored the beliefs older adults have about dementia. A particularly striking finding is that Black Americans endorse dementia as a normal part of aging more than other groups do (Gray et al., 2009). Additionally, Roberts and colleagues (2003) found that in comparison to Whites, Black Americans report the following regarding AD: fewer sources of information, lesser knowledge about the disease, and lesser perceived threat from the disorder. Similarly, Connell and colleagues (2009) examined racial differences in knowledge and beliefs about AD and found significant differences between White and Black Americans even when controlling for age, marital status, education, and financial status. Lesser knowledge about the impact of head injury, mental illness/stressors, alcohol use, and smoking on AD risk was observed more often in the group. As well, Black adults more often attribute dementia to God's will. The two groups also differ in their perceptions of how dementia is diagnosed, with a greater percentage of older Black adults incorrectly identifying that AD can be diagnosed with a blood sample (Connell et al., 2009).

Beliefs about risk and severity are disparate, too. For example, Black Americans are less likely to worry about developing AD in their lifetime, less likely to view AD as debilitating, and less likely to believe that having AD would be stressful for their families, according to Connell and colleagues (2009). However, a family history of the disease attenuates these sentiments. Conversely, however, the higher percentages of older Black adults believe staying mentally active, controlling stress levels, and participating in physical activity, are effective preventative measures.

Relatedly, misconceptions and beliefs about aging held early in life are risk factors for the decline in later life. Those holding more ageist beliefs are at greater risk to develop

dementia, while holding a more positive view has been linked to lesser risk (Levy et al., 2018). How this affects Black Americans is unclear, however, as research in this area shows two perhaps opposing views towards aging. More than non-Hispanic White older adults, Black older adults expect lesser functional decline with aging (Menkin et al., 2017a). In contrast, they more often endorse the belief that dementia is a normal part of aging. Thus, in some respects, current research suggests Black Americans may be more optimistic towards the aging process (e.g., do not expect as much functional change) while also holding the belief that dementia is to be expected with getting older.

The latter may be particularly harmful in delaying treatment-seeking and engaging in disease-modifying behaviors. Having lower expectations regarding aging has been independently associated with poorer health behaviors (Sarkisian et al., 2002). For example, Andrews and colleagues (2017) studied the effect of aging expectations on physical activity in a predominantly Black sample (N=446; 92.6% Black, mean age=66). Lower overall expectations regarding aging (e.g., physical, cognitive, and psychological aging) were associated with lesser exercise engagement. This finding is concerning given the strong benefits of physical exercise in the prevention of cognitive decline, particularly for dementia due to AD and VaD or slower progression of decline (Alty et al., 2020; Gregory et al., 2012; Müllers et al., 2019).

Relatedly, others suggest that socially acquired positive beliefs about aging and/or less stigma towards dementia may decrease dementia risk as one ages. For example, those with more positive beliefs about aging (i.e., believing it is not a period of decline) tend to have lesser incidence of dementia after age 65, even among those with APOE e4 (Levy et al., 2018). Other longitudinal research suggests that such beliefs can impact the development of

dementia-causing disease processes as well. Those who hold more negative beliefs about aging in early life have a significantly greater accumulation of neurofibrillary tangles and amyloid plaques and more significant volume loss in the brain areas important for memory, hallmarks of AD. (Levy et al., 2016). Contrastingly though, one study suggests that lower expectations may have a paradoxical effect. That is, lower expectations for one's future psychical and cognitive health earlier in life are related to higher subjective well-being later (Cheng et al., 2009).

Heretofore, the dementia stigma and knowledge among Black adults is not well understood as it relates to risk and dementia care seeking. Research suggests the group is more likely to attribute cognitive changes to normal aging while endorsing lesser concern about cognitive decline. These two coexisting beliefs may have effects on dementia treatment-seeking. Because the population is at enhanced risk, it will become increasingly important to examine such beliefs, particularly, how beliefs and knowledge influence one's decision to get screened for dementia and initiate help-seeking.

Dementia Diagnostic Delays

As mentioned previously, Black Americans have higher rates of dementia compared to other older groups, influenced by various factors. Unfortunately, they also encounter delays in receiving timely diagnoses. Research indicates that older Black adults are twice as likely to be underdiagnosed compared to non-Hispanic White Americans (Gianattasio et al., 2019). Detecting cognitive changes early and ensuring timely diagnoses can offer numerous advantages to individuals with dementia, as well as their families or caregivers. While widely available pharmacological treatments like donepezil and memantine have shown very modest effectiveness in attenuating cognitive decline, the recent approval of aducanumab and

lecanemab has instilled hope for a disease-modifying therapies by removing or blocking the formation of amyloid plaques respectively (Wiley, 2021). Although ongoing research seeks to further understand and establish how plaque reduction translates into slower progression, these treatments hold promise for the future of AD interventions (Vaz et al., 2022). Importantly though, lecanemab and aducanumab are most effective in earlier stages of Alzheimer's diseases, making early detection even more critical to maximize their potential benefits.

Additionally, timely diagnosis plays a critical role in maximizing the benefits and effectiveness of other interventions and prompts preparation for disease progression. Foremost, it provides valuable time for care planning, which allows individuals to play a more active role in important decisions including advance care directives and legal/financial arrangements (Chandler et al., 2016). Behavioral and emotional interventions, such as those targeting depression and anxiety, are also more effective when diagnosis is timely.

There are also benefits to be had by physicians treating those with dementia: better management of comorbidities, ruling out treatable contributory conditions, and deprescribing medications that could further impact cognition (Dubois et al., 2016). Furthermore, early diagnosis allows for a thorough examination to identify and treat reversible causes that mimic the early stages of dementia, such as sleep apnea, vitamin deficiencies, and mood disorders (Dubois et al., 2016). Seeking help as cognitive changes arise makes it more likely relevant contributors are addressed appropriately. As it stands, older Black Americans face a disadvantage in receiving timely diagnosis and therefore its many benefits. This underscores the urgent need for action to reduce delays in diagnosis and improve dementia care and overall outcomes for this population.

Calls have been made by the Global Disease Burden Study (2016) for the early detection of dementia before underlying pathologies manifest as significant impairment in day-to-day activities. Twenty years ago, the time between the initial onset of symptoms and diagnosis was around three years (Boise et al., 1999). Despite calls mentioned above to expedite diagnosis, this remains relatively unchanged for all dementia subtypes, except vascular dementia, which is on average two years from onset to diagnosis and is often easily recognized post-stroke (Van Vliet et al., 2013). Ethnic minorities have even greater delays between symptom onset and diagnosis. Tsoy and colleagues (2021) examined the difference in the timeliness of dementia diagnosis between older White and Black adults. They found that those identifying as Asian, Black, or Hispanic Americans were more likely to be diagnosed with dementia, as opposed to MCI, at first examination. Moreover, though available risk estimates vary in the literature, yearly minor to major NCD conversion rates range between 5% to 20% (Langa & Levine, 2014), further emphasizing the pressing need to timely detection.

More broadly, and as alluded to before, low public awareness of warning signs, misperceptions about dementia's impact, and the emotional distress of diagnosis are routinely cited as contributing to reluctance to seek help (Blendon et al., 2012; Boustani et al., 2011). For example, a survey conducted across 12 countries found that 60 percent of respondents believe AD is a normal part of aging, and nearly half are unaware that AD is a fatal disease. These beliefs may play a significant role in delayed diagnosis (Alzheimer's Association, 2016; Clark et al., 2005).

According to data gathered from the Behavioral Risk Factor Surveillance System, only half of those aged 45 and older with subjective memory decline within the last year had

disclosed those observations to a healthcare provider. Moreover, only 60% of those surveyed who endorsed functional impairment had discussed those concerns with a provider (Anderson et al., 2015). To perhaps complicate the timeliness of diagnosis and care planning further, U.K. memory clinic physicians emphasized to patients that their symptoms as mild while failing to highlight disease progression. Moreover, some physicians reported avoiding discussing diagnoses altogether with patients whose dementia was not yet in moderate to severe stages (Dooley et al., 2018).

As current evidence suggests, many patients are reached later in the dementia processes than would be preferable for effective interventions. This is especially true for older minorities, specifically older Black adults. Beliefs, stigma, knowledge, and attributions to age contribute to these disparities. As such, the role these factors play in the willingness to pursue dementia screening and diagnosis should be examined more closely.

Attitudes Toward Screening for Dementia

Myriad reasons account for the uncertainty surrounding when one should pursue a diagnostic assessment for cognitive changes or a suspected underlying dementia process. Attitudes toward the screening and diagnostic processes in and of themselves may also pose a threat to timely diagnosis. Some research has considered patient, caregiver, and provider beliefs toward assessment/screening procedures. These studies have sought a better understanding of the decision to seek diagnosis and help for dementia concerns. Acceptability and eventual pursuit of diagnostic clarity may depend upon many things including age, presence of subjective complaints, decline observed by others, setting, and expected outcomes of diagnosis (Martin et al., 2015).

Seeking out dementia screening may be somewhat predictable from demographic factors. Some research suggests women are more likely to endorse memory complaints and in turn are more likely to agree to dementia screening (Tang et al., 2017). Another factor may be age, though findings to date surrounding its influences on willingness to undergo dementia screening are mixed. One interesting finding by Fowler and colleagues (2012) is that participants aged 65-69 and over 80 are more open to getting screened for dementia in primary care than those aged 70-79. However, a more recent study contradicts this, as increasing age predicted willingness to undergo the dementia screening process in an older Japanese sample (Aihara & Maeda, 2020b). Black adults over 80 are more likely to refuse dementia screening than those 80 and younger (Boustani et al., 2006). Thus, the role age plays in willingness to be screened for dementia is not well understood.

Also, educational attainment has been an established predictor of openness to dementia screening. Particularly, those with less than a high school education refuse screening for dementia at higher rates than those with education beyond high school (Fowler et al., 2015). Relatedly, greater knowledge about dementia has been associated with seeking dementia diagnosis and care as well (Aihara & Maeda, 2020a; Werner, 2003). These associations are shared with other health and screening behaviors. The role health literacy plays in health outcomes in illnesses such as cancer, diabetes, and heart disease are well established (Berkman et al., 2011; Fernandez et al., 2016; Koay et al., 2012; Kobayashi et al., 2014; Peterson et al., 2011).

Family history of a disease is also a likely influence on health screening behavior. In fact, those with a greater family history of dementia have been found to be more likely to seek dementia diagnosis for themselves (Fowler et al., 2015; Werner, 2003). Other research

has looked at subjective complaints of memory changes as they relate to cognitive testing performance and screening behavior. Subjective cognitive decline generally predicts both poorer performance on cognitive testing and later dementia diagnosis (Abner et al., 2015). However, it should be noted that subjective complaints are associated highly with depressive symptoms regardless of cognitive status (Lehrner et al., 2014). In fact, "worried well" patients, or those with subjective complaints but intact cognition, more commonly have a history of depression and other psychiatric symptoms (Verity et al., 2018).

Subjective complaints have also been observed to negatively predict screening behavior acceptance (Dale et al., 2008). One study by Lundquist and Ready (2015) may provide insights into these mixed findings. Their research suggests dementia anxiety moderates the relationship between dementia knowledge and willingness to undergo screening for dementia. At lower dementia anxiety levels, willingness increases with knowledge. In contrast, at higher anxiety levels, willingness decreased with knowledge. Thus, anxiety about developing dementia may be highly influential on whether screening is pursued.

Little research has explored the dementia screening behavior in diverse samples but what exists shows that the benefits of screening must be emphasized. Those who perceive more benefits from screening are less likely to refuse it (Sayegh & Knight, 2013). Gleason and colleagues (2016) applied the Commonsense Model (CSM) of Illness Perception to dementia screening/diagnosis seeking in Black adults (n=187). This model posits that perceptions of a disease dictate coping strategies, and thus outcomes. Their survey compiled questions focused on willingness to discuss memory concerns with their doctor and to screen. Anticipation of benefits and low harm associated with diagnostic clarity predicted

willingness to discuss memory concerns with a physician. This suggests that relieving concerns about the undesirable effects while emphasizing potential benefits could influence willingness to discuss cognitive concerns with a provider among older Black adults.

Qualitative research with Black older adults living in the U.K. may provide additional insight into diagnostic disparities, though may be less applicable to older Black Americans. Many participants perceived little utility in seeing a general practitioner outside of severe memory problems. When considering discussions about dementia with medical providers, many spoke about privacy concerns, fears about how others would perceive a diagnosis, and fears about the possibility of institutionalization (Berwald et al., 2016).

When more direct conversations with providers are had about the benefits of diagnosis, particularly when provider-initiated, higher acceptability of screening for dementia is achieved. For example, Holsinger and colleagues (2011) applied the interview-based Dementia Screening and Perceived Harms questionnaire to Veteran primary care populations. Questions included inquiries about personal experience with a person living with dementia, subjective memory functioning, opinions on treatment for dementia, and perceptions of risks and advantages of early diagnosis. Findings indicated that after discussions with health care professionals, an overwhelming majority (80%) of participants (n=345, mean age=65) reported they would like to be screened to rule out dementia risk. Here again, perceived benefits to screening were predictors of screening acceptability (Fowler et al., 2012; Holsinger et al., 2011). These findings in which risk and benefits, among other aspects of screening, are discussed is a stark contrast to early research in which only half of those in retirement community settings agree to screen for dementia (Boustani et al., 2003), underscoring the role discussions with a provider can play. Likewise, Takeda et

al. (2017) compared perceptions between people with strong and weak intentions to screen for dementia. The two groups differed significantly in perceptions of seriousness, preventability, and lifestyle knowledge— all higher in those with a stronger intent to screen.

Other research by Wong and Jacova (2018) investigated preferences for where one is screened and informed of results. Interestingly, though most have no preference for home or office-based screening, a third of those asked did prefer to be screened in their home. Moreover, preferences for feedback were dependent on results. If results are consistent with cognitive impairment/dementia, patients were more likely to prefer an office visit for their feedback. Accordingly, patient preference should be considered while screening for dementia concerns for better treatment buy-in.

Existing research into how patients use screening results is of concern as well. Some estimates suggest that only about half of those who screen positive for dementia agree to further testing and follow-up to confirm the diagnosis (Boustani et al., 2006). Among older Black adults, those over 80 are even more likely to refuse than those 80 and younger. More recently, Galvin and colleagues (2020) conducted interviews with patients newly diagnosed with mild or major NCD about their compliance with recommendations and the discussions they had with others about their diagnosis. Two months after diagnosis, only half had spoken about it with family, one-third shared with other providers, and half acted on recommendations. It should also be noted that better overall mental health predicted sharing with family and following recommendations for behavioral changes (Galvin et al., 2020).

Intent to Undergo Dementia Screening: Guiding Models

Despite the higher risk for dementia among older Black adults and calls to action to close disparities in timely detection, knowledge and population gaps about factors that make

one willing or intend to undergo screening remain. Though some nascent research has focused on factors leading to delayed help-seeking, giving some insights, less information is available with diverse samples despite their enhanced risk. Therefore, it would be valuable to consider social cognitive theories as a framework for understanding the decision-making process of older Black adults regarding dementia screening.

One theory well studied in Black samples is the Health Belief Model (HBM). Developed in the 1950s, the HBM helps explain behavior and decision-making surrounding preventive medicine. Hochbaum (1958) researched the relationship between beliefs and participation in public tuberculosis screening and observed striking predictive utility in this application of the model. The theory has gone through different iterations but comprises the following components: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action (see figure 1).

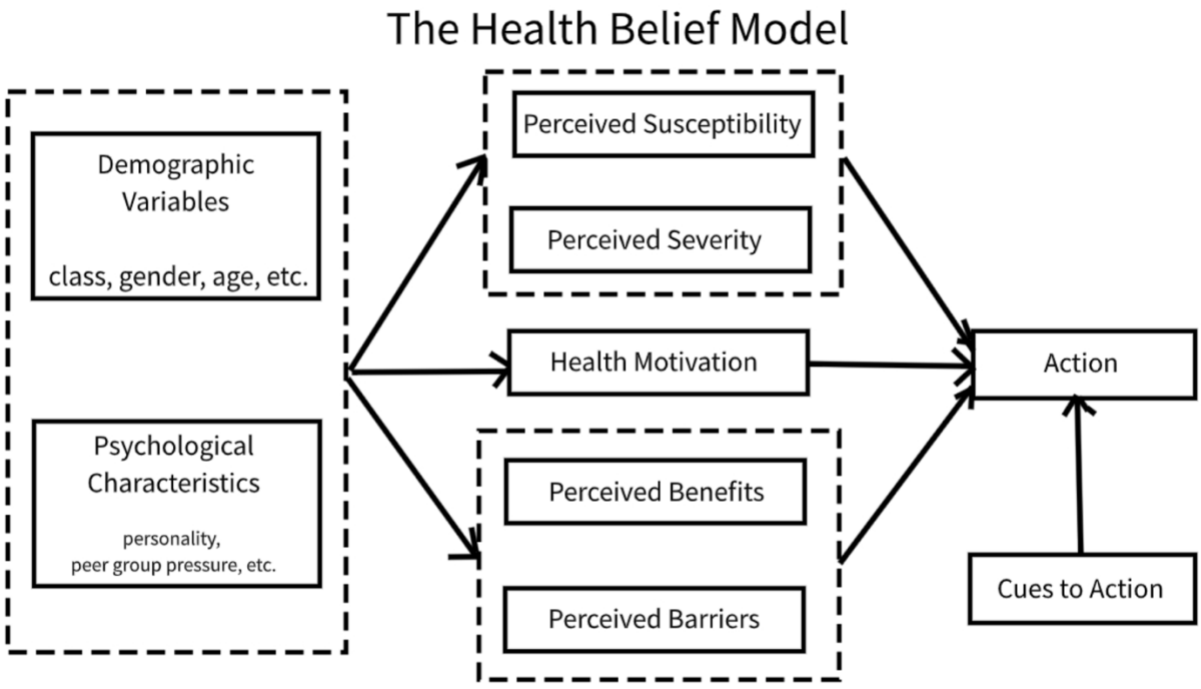


Figure 1. The Health Belief Model

Perceptions of susceptibility is the belief that one is vulnerable to acquiring an illness. (Strecher & Rosenstock, 1997). As mentioned earlier, this is largely dependent on one's knowledge about the respective illness (e.g. AD changes are a normal part of aging) (Menkin et al., 2017b). Susceptibility perceptions may be particularly salient early in the dementia process as Black Americans tend to attribute changes to age more than other older groups (Connell et al., 2009).

Perceptions of severity are another construct within HBM. This concept deals with the assessment of how great an impact to quality of life an illness will have. An assessment of the health and social consequences of not seeking help is weighed by the individual (Strecher & Rosenstock, 1997).

Other constructs include perceived benefits and barriers to acting. Perceived benefits are the belief that acting will produce desirable results. As mentioned before, the benefits of dementia screening/diagnosis have been established as a particularly important factor when older adults are deciding whether to seek dementia diagnostic services (Gleason et al., 2016; Sayegh & Knight, 2013). Conversely, perceived barriers represent factors that may deter or hinder an individual from taking a particular health action (Strecher & Rosenstock, 1997). Examples of barriers may include income status or lack of access to specialty care. Stigma is also considered a barrier (Ighodaro et al., 2017). To produce action, the benefits of acting must outweigh the barriers.

The belief that one has the skills and resources to act on a health behavior, or self-efficacy, is also included in the HBM (Strecher & Rosenstock, 1997). As an aside, self-efficacy has been explored in dementia caregiving among Black caregivers. Black caregivers may have a greater sense of caregiver mastery, higher levels of self-efficacy, and lower levels

of caregiver burden when compared to their White counterparts (Dilworth-Anderson et al., 2002; Fortinsky et al., 2002).

The final component of the HBM is cues to action. Hochbaum (1958) considered that the decision to act on a health behavior is influenced by external cueing (e.g., concerns from others or advertisements) or prior experiences (e.g., family history of the illness or subjective complaints). A cue to seeking dementia diagnosis for a family member or oneself could be cognitive and personality changes beyond what could be reasonably attributed to age. Thus, the HBM captures many variables that likely impact screening behaviors as reviewed above. As the model has been effectively applied to Black adult samples regarding other health behaviors such as weight loss programs (Romano & Scott, 2014) and cancer screenings (Consedine et al., 2005; Davis, 2020; Davis et al., 2013; Plowden, 1999), it might also be useful for examining dementia screening intent among older Black adults.

Theories Applied to Dementia Screening

Only a handful of studies have investigated intent to undergo screening for dementia. To our knowledge, one study has applied the HBM to dementia diagnosis procedures in a Black population, albeit retrospective in nature and with dementia caregivers. Hughes and colleagues (2009) examined the experiences of 17 Black dementia caregivers when their loved one received a diagnosis of dementia due to AD. The researchers conducted semi-structured interviews based on HBM components.

Most caregivers in the study had limited knowledge about dementia before their loved one was diagnosed. Regarding perceived severity, many attributed changes in functioning to age and were surprised by the diagnosis, though many were aware of the lack of a cure for dementia. Likewise, upon diagnosis, the perceived susceptibility to developing it themselves

also increased after their loved one's diagnosis—many caregivers were siblings or children (Hughes et al., 2009). Responses to perceived facilitators and barriers revealed disagreement between other family members. While some caregivers reported support when bringing up concerns and thus possible medical care and interventions, others reported experiencing resistance from their family, namely siblings. Both family reactions influenced seeking a diagnosis in the expected directions.

Others reported frustration with navigating the health care system, finding many physicians downplayed cognitive concerns and focused more on other conditions instead; other physicians were reported not to have discussed dementia with the family despite giving the patient a diagnosis. Knowing what to expect prognostically, confirming their suspicions of cognitive decline, and access to treatment were among the most cited benefits of seeking dementia diagnosis for their loved one. Lastly, marked changes to the patient's personality and changes in daily tasks were common cues to action (Hughes et al., 2009).

This study gives much needed insight into the unique interactions of HBM principles as they relate to seeking dementia diagnosis and treatment within a Black sample. However, it only explores retrospective views of those who eventually sought care on behalf of someone else and ostensibly only after significant changes in functioning were observed. It does not give needed insights into beliefs about help-seeking before or as cognitive changes begin to emerge for the individual experiencing changes.

Other studies have applied HBM to answer this question, albeit in predominantly White samples. Galvin and colleagues (2008) studied dementia screening intentions in a large sample of 1039 older adults (86% White). The Behavioral Model of Health Services Use (see Figure 2 below) was used to develop a questionnaire, including constructs from the

Health Belief Model and Theory of Reasoned Action. Of the tenets applied from these theories on intention to undergo screening, perceived benefits, knowledge of dementia, preventive health behaviors, and perceived susceptibility were most predictive of outcomes. Moreover, knowledge was positively correlated with perceived benefits and susceptibility. Though promising in constructing community-based interventions, the study may not generalize to older Black adults' dementia screening intentions.

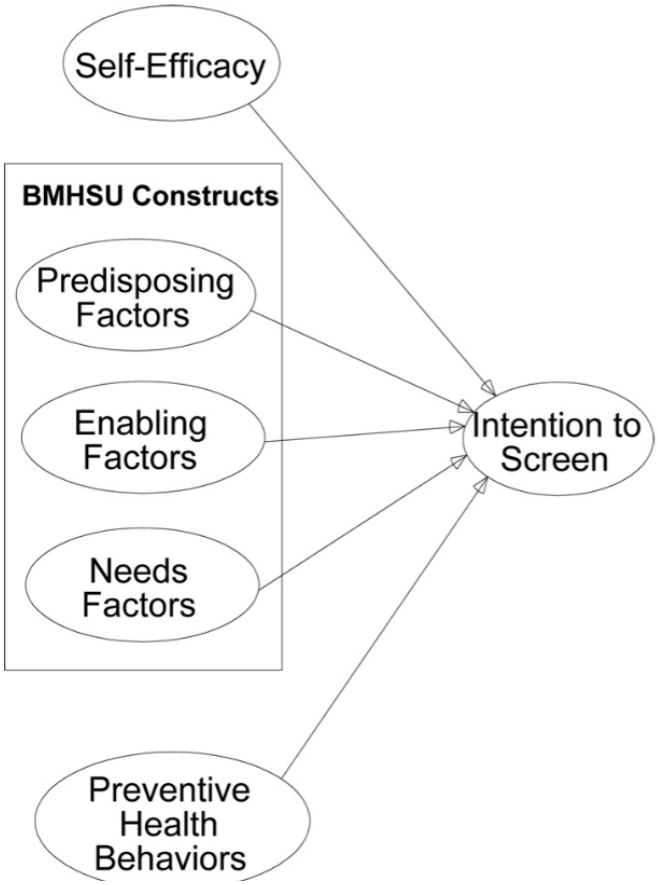


Figure 2. Behavioral Model of Health Services Use

Other research has looked at perceptions of dementia screening in primary care settings, more specifically. Fowler and colleagues (2012) examined 554 primary care patients (65.5% age 70 and older; 56.5% older Black adults). Participants completed the Perceptions Regarding Investigational Screening for Memory in Primary Care Questionnaire (PRISM-

PC), a questionnaire modeled after HBM principles, and then asked whether they intended to undergo dementia screening. Most (89.7%) agreed to be screened, and 63 (12.7%) screened positive. When adjusting for age, perceptions of screening for other illnesses, and the belief that there are no treatments, the odds of agreeing to be screened were greater in participants who endorsed higher perceived benefits.

Similarly, the PRISM-PC has also been used to predict willingness to undergo telephone-based dementia screening in those 65 and older with no prior dementia diagnosis, 20.9% and 2.5 % Black respectively for two participating Indianapolis, IN, hospitals. Again, higher endorsement of screening benefits was associated with decreased odds of refusing to screen. Additionally, those who refused screening endorsed significantly lower perceived benefits of getting screened for dementia and more often refused to screen for other conditions (Fowler et al., 2015).

Sayegh and Knight (2013) suggest modifying the HBM to be more applicable to minority ethnic groups after extensive literature reviews on factors influencing diagnostic delays in minorities. Notably, they suggest adding not only knowledge about dementia to the model, but also cultural beliefs about dementia. Their Sociocultural Health Belief Model (SHBM) emphasizes cultural factors and posits they have indirect effects on pursuing help for dementia concerns. Specifically, the model asserts that cultural values directly affect beliefs and knowledge about dementia. Consequently, perceptions of one's risk, dementia's potential impact, and barriers to care then influence the decision to seek care. Much like the HBM, cues to action directly influence dementia care-seeking behavior, as do perceptions of barriers. However, self-efficacy is not included in the SHBM (Sayegh & Knight, 2013).

Current Study

Despite calls to action to increase timely and accurate dementia diagnosis from many organizations like WHO, NIH, and the Alzheimer's Association, many barriers to timely detection and care initiation continue to exist. These issues are even more salient for older Black adults as they have a heightened risk of dementia at rates of up to 3x that of their White counterparts (Potter et al., 2009), and help is received much later into disease progression (Clark et al., 2005; Pham et al., 2018).

Existing literature lacks sufficient information regarding what informs decisions to screen for dementia among older Black adults. As more individuals enter later life, it has become crucial to develop interventions to increase dementia screening. However, before implementing such initiatives more widely, a better understanding of the factors that influence decisions about seeking dementia diagnosis in older Black adults is needed.

To date, some research has utilized social cognitive models to examine dementia screening intentions, as evidenced by studies conducted by Fowler et al. (2015), Hughes et al. (2009), and Sayegh and Knight (2013). Current research suggests that aspects of the Health Belief Model can provide valuable insights into understanding screening behavior, particularly regarding the perceived benefits. However, only one study has explored these factors in a Black sample, and that study focused on dementia caregivers.

The unique relationships between benefits, barriers, severity, beliefs about aging, knowledge about dementia, and screening intentions among older Black adults should be better understood. Though existing literature on intentions to be screened for dementia is scarce, it suggests that the impact these factors have on intentions to be screened could differ from older White adults, necessitating different approaches to increase the uptake of

screening. Exploring these factors could further inform effective interventions, which was the principal aim of the study. In that endeavor, the HBM was used as a guiding theoretical framework due to its applicability in understanding both how individuals view their health, and how their perception of a health issue influences action. It may provide a valuable lens through which to examine various factors that may impact intentions to get screened for dementia.

Aims and Hypotheses

The current study had both hypothesis-driven and exploratory components. Specifically, the principal aim of this study was to examine the utility of the HBM constructs perceived benefits, perceived barriers, and perceived severity in predicting intention to screen for dementia in a sample of older Black adults. Furthermore, the study explored the ability of dementia stigma, dementia knowledge, and aging expectations to predict intent to screen. See Figure 3 below for the conceptual framework of the study. These questions and hypotheses are detailed further below:

Aim 1: The first aim of the study was exploratory in nature and sought to examine the impact multiple demographic and other characteristics had on intent to screen in older Black adults.

1a. Is age-related to intent to screen for dementia in older Black adults?

1b. Does intent to screen for dementia vary by age in older Black adults?

1c. Does intent to screen vary by age group in older Black adults?

1d. Do those who identify as female have greater dementia screening intentions than those who identify as male?

1e. Does intent to screen for dementia vary by income in older Black adults?

1f. Does intent to screen for dementia vary by level of education in older Black adults?

1g. Does intent to screen for dementia vary between older Black adults who are related to or know someone with dementia and those who do not?

1h. Does intent to screen for dementia vary between older Black adults who believe they are at greater risk for dementia and those who do not?

1i. Does intent to screen for dementia vary between older Black adults who have subjective memory complaints and those who do not?

1j. Are depression symptoms related to intent to screen in older Black adults?

Aim 2: Identify HBM constructs that are related to dementia screening intentions in older Black adults and determine how much variance is explained by these factors on intent to screen.

Hypothesis 1. It was hypothesized that perceived benefits, barriers, and severity would be correlated with intent to screen.

Hypothesis 2. It was hypothesized that the linear combination of perceived benefits, barriers, and severity would significantly predict intent to screen. That is, greater perceived benefits, lower perceived barriers, and higher perceived severity would predict screening intentions. Perceived benefits were hypothesized to explain the most variance in intent to screen for dementia.

Aim 3: Identify if dementia stigma, expectations regarding aging, and knowledge about dementia were related to dementia screening intent. Determine how much variance in intent to screen is explained when these variables are added to the above model of HBM constructs.

Hypothesis 3. It was hypothesized dementia stigma, expectations regarding aging, and knowledge about dementia would be correlated with intent to screen.

Hypothesis 4. It was hypothesized that the addition of dementia stigma, expectations regarding aging, and knowledge about dementia would significantly predict intent to screen above and beyond perceived benefits, barriers, and severity. That is, lower dementia stigma, higher expectations regarding aging, and higher knowledge about dementia would predict screening intentions after controlling for HBM constructs.

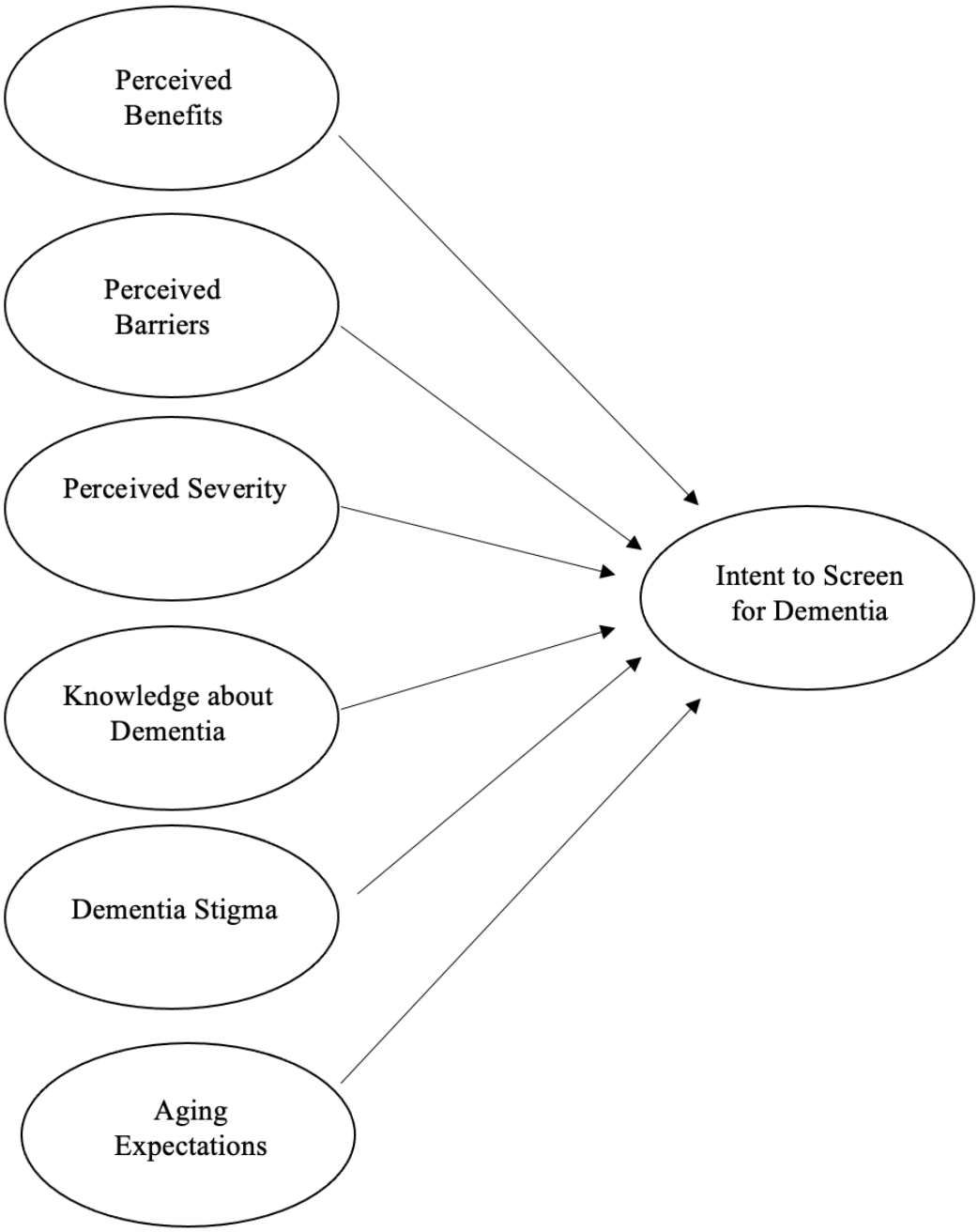


Figure 3. Conceptual Framework: Constructs from HBM, Knowledge, Aging Expectations, Stigma, and Intent to Screen

CHAPTER 2

RESEARCH DESIGN AND METHODOLOGY

The current study was part of a larger randomized controlled trial exploring the feasibility of implementing a culturally and religiously tailored dementia education intervention. This pilot intervention aimed to foster opportunities for dementia screening and linkage to care in predominantly Black churches in the Kansas City, Missouri metropolitan area. Black churches serve as valuable channels for implementing dementia education and screening interventions. As previously mentioned, medical distrust can discourage Black Americans from seeking help for dementia concerns. However, they place significant trust in medical information received through their churches or faith centers. Notably, Black churches have played vital roles in promoting many health behaviors ranging from increased physical activity to diabetes and HIV screening (Berkley-Patton et al., 2013; Derose et al., 2019). Apart from being trusted sources, Black faith organizations have a wide-reaching influence, especially among older Black adults, as church attendance is prevalent in Black communities. Indeed, a majority of Black Americans, particularly older adults, attend church at least weekly (Pew Research Center, 2009). Given this extensive reach and overall esteem, Black churches present an ideal setting for implementing dementia education and screening interventions for older Black adults.

The current study, guided in part by the Health Belief Model, explored possible predictors of dementia screening intent before this intervention was implemented. Namely, relationships between HBM constructs, knowledge about dementia, expectations regarding aging, stigma towards dementia, and intention to screen among older Black adults were examined with regression modeling.

Participants

Due to disparate research despite greater dementia risk, participation in the study included only those who self-identified as Black and/or African American. Moreover, though a diagnosis of NCD can be given across the lifespan, the greatest risk factor for developing dementia is increased age, with onset of symptoms occurring most often after age 65, though Black adults may experience symptoms earlier. Accordingly, this study was also limited to only include those who were 55 and older. Recruitment was facilitated through long-standing partnerships with Dr. Berkley-Patton's faith-based studies. The eligibility criteria were: (1) self-identified as African American/Black, (2) aged 55 and older, (3) attended church at least monthly. As recruitment took place during the COVID-19 pandemic, regular virtual attendance reported by each respective church service fulfilled the attendance criterion. Prior screening for dementia did not exclude one from participation.

The projected sample size of this study was 150 older Black adults. In terms of the criteria for sample size needed for linear modeling, Babyak (2004) suggests a minimum of 10 to 15 observations per predictor variable. Another widely accepted heuristic is a minimum base sample size of 50 observations and eight additional observations per predictor (Tabachnick & Fidell, 2013). The most complex hypothesized regression model in the current study contains six predictors (see Figure 1). Thus, sampling at least 90-100 older Black adults ensured that there would be adequate power to glean meaningful interpretations.

Procedure

Recruitment. Before participant recruitment, the study was approved by UMKC's Social Sciences Institutional Review Board. Four churches in the Kansas City, Missouri urban area were contacted for their interest in participating in the pilot. The churches varied

in denomination, size, and location within the area to diversify this church-population sample. Investigators met with representatives from each respective church and explained project logistics. Criteria for church participation included: a) a minimum of 150 adult church members who regularly attend Sunday services; b) an active church outreach ministry (e.g., food/clothing pantry, social services, daycare); c) commitment from the pastor and two church health liaisons (CHLs) to assist in study activities; and d) willingness to promote dementia information and dementia screening opportunities. One church withdrew from the study due to difficulty fulfilling the CHL requirement.

Participants were recruited through their churches by both pre-recorded video announcement and flyer (see Appendix A). Prior to recruitment, researchers met with CHL's and pastors from each respective church to provide study materials to be disseminated for virtual or hard copy use. The pre-recorded video was shown during service and/or shared on church social media platforms (e.g. Facebook) at study commencement. Within the pre-recorded video, the principal investigator of the larger pilot study provided information about the research project, eligibility for participation, and incentives. In addition to the video announcement, the same information was provided in an electronic flyer format. This was also shared with CHL's and distributed in hard copy or electronic format in the church, on website or bulletin, through email, and/or on social media.

Participant Procedure. The current study was a non-experimental, self-report, survey-based design conducted at a single point in time. Church members were able to participate by phone, mail, or online. The survey was hosted by UMKC's Research Electronic Data Capture (REDCap), a web-based application that captures data for clinical

research and creates databases for projects. It is Health Insurance Portability and Accountability Act (HIPAA)–compliant, secure, and intuitive to use for participants.

Those interested in participation contacted the research team by way of three options, all of which were provided in the recruitment materials distributed by their respective church: survey link, phone call, or email. Those who followed the link directed to the eligibility screener (see Appendix B), completed it completely online. Those opting to contact the team by phone or email were contacted by that respective method and given the choice to screen for eligibility via direct link as described above, or while on the phone with a research team member. Participants who did not meet eligibility criteria were directed to a debriefing. Those who met eligibility criteria were given the option to complete the survey through one of three formats: via scheduled phone-administered survey, via unique REDCap survey link sent to their email address, or via hard-copy survey sent directly to their home by mail with return postage provided. Participants read and were required to agree to an informed consent document before moving forward with the survey.

The survey began with a brief demographic questionnaire used to collect participants' age, gender, ethnicity, sexual orientation, educational attainment, marital status, employment status, health insurance status, housing status, and monthly income as well as church membership status/role and length of affiliation with their church. Questions relating their family history of dementia and the belief they themselves were experiencing changes in thinking abilities were also asked. The remaining pages in the study consisted of constructs of interest: intention and acceptance of dementia screening, measures of HBM constructs, expectations regarding aging, knowledge about dementia, and dementia stigma. Other measures were also administered the purposes of larger pilot study. Regardless of format,

study measures were administered in the same order. The survey took 30-45 minutes to complete depending on format selected. A debriefing statement, including contact information for the researchers, was provided at the end of the survey. Participants were compensated with a $25 gift card for their time.

Measures

Demographic data. Demographic information was collected by use of a questionnaire designed by the researchers. The survey asked participants to disclose their age, gender, ethnicity, sexual orientation, educational attainment, marital status, employment status, health insurance status, housing status, and monthly income (see Appendix C).

Attitudes Toward Dementia Screening (HBM). The Perceptions Regarding Investigational Screening for Memory in Primary Care, PRISM-PC (Boustani et al., 2008) was used to measure HBM constructs of perceived benefits, barriers, and severity. The Health Belief Model guided the development of the PRISM-PC questionnaire which includes the following subscales: acceptance of dementia screening (6 items), benefits of dementia screening (HBM benefits; 8 items), stigma of dementia screening (10 items), negative impacts of dementia on independence (HBM severity; 6 items), and suffering related to dementia (HBM barriers; 4 items). Other subscales include screening acceptance for other conditions—colon cancer and depression, and other dementia beliefs. Example items include "I would like a doctor to examine me every year to know if I have developed memory problems." (acceptance scale) or "It would motivate me to have a healthier lifestyle." (benefits scale). All items are scored on a 5-point Likert scale, with responses ranging from 1= *strongly agree* to 5=*strongly disagree*. Responses to items were reverse coded so that a higher score indicate stronger agreement with the items in the respective scale. In a sample of

315 older adults in primary care settings—mean age 72.8, 70% female, 44% Black—Cronbach's alpha for subscales ranged of 0.73 to 0.85 (Boustani et al., 2008). See Appendix D for a copy of this measure.

Aging Expectations. The Expectations Regarding Aging-12 (ERA-12) was used to operationalize participants' beliefs about changes that come with aging. The ERA-12 is 12-item measure of physical health, mental health, and cognitive function expectations, all with 4-items respectively (Sarkisian et al., 2005). The measure asks responders to rate how true they believe statements about aging to be on a 4-point scale: 1=*definitely true*, 2= *somewhat true*, 3= *somewhat false*, 4=*definitely false*. Some items include: "Having more aches and pains is an accepted part of aging." (physical health subscale), "It's normal to be depressed when you are old." (mental health subscale), "It is impossible to escape the mental slowness that happens with aging." (cognitive health subscale). The ERA-12 total scale score range from 0-100 and is calculated using an algorithm published by the developers. Higher ERA-12 scores indicate believing that high physical, social, and mental function can be maintained with age. Contrastingly, lower scores indicate that decline is seen as a normal part of the aging process. The ERA-12 sub scale scores also range from 0-100 derived from a similar algorithm. Its developers found that the ERA-12 subscales had acceptable levels of reliability and construct validity in a sample of community-residing adults aged older than 65 years (N = 429; 16% Black). Each subscale had an internal consistency of at least .75 and was .80 for the total score. Moreover, test–retest reliability over a 2-week interval was at least 0.78 for the three subscales and 0.94 for the total ERA-12 score. See Appendix E for a copy of this measure.

Dementia Stigma. The Burgener and Berger version of the Stigma Impact Scale (SIS) was used to measure dementia stigma in this study. The original version, created by Fife and Wright (2000) for those with HIV/AID had been previously amended by Burgener and Berger (2008) to measure stigma for persons living dementia and their caregivers. Previous studies in samples of those with a diagnosis of dementia and/or their caregivers show the measure to have good internal consistency. In a sample 50 persons with dementia (mean age of 78.3; 48% female, 38% Black), internal consistency for the total SIS was .88 (Burgener & Berger, 2008). As the SIS was designed for those with a diagnosis of dementia, the scale was reworded to reflect the prospect of having dementia for the purposes of this study. For example, the item "Others avoid me because of my illness." was changed to "Others *would* avoid me because of my illness.". Response choices range from 1= *strongly agree* to 4=*strongly disagree* and it is comprised of 21 items. Scores were reverse coded such that higher scores indicate higher stigma towards dementia diagnosis. See Appendix F for a copy of this measure.

Knowledge about Dementia. The Dementia Knowledge Assessment Scale (DKAS) was used to assess participant's knowledge related to dementia. The DKAS 25 -item True/False test was developed by Annear and colleagues (2015) and consists of four subscales, including causes and characteristics (7 items), communication and behavior (6 items), care considerations (6 items), and risks and health promotion (6 items). A list of statements is presented, and responders must choose if each is true or false (e.g. "Dementia is a normal part of aging."). One point is awarded for each correct response and summed for a total score. Higher scores represent greater knowledge about dementia. In an international sample of over 3,000 participants, the DKAS effectively discriminated between different

levels of knowledge based on education or experience related to dementia. Health care professionals obtained the highest scores. Comparatively, lower scores are observed in health students, other care workers, and family caregivers. Lowest scores were observed in the general population. The 25-item DKAS had good reliability (α = .85), with acceptable subscale internal consistency (Annear et al., 2015). See Appendix G for a copy of this measure.

Depression. The Patient Health Questionnaire 9 (PHQ-9; Kroenke et al., 2001) was used to measure depressive symptoms. The PHQ-9 is a 9-item screening tool assessing symptoms of depression. Participants endorse how often in the past two weeks they have experienced common depression symptoms (e.g., little interest in doing things or trouble sleeping). Responders rate the frequency of these symptoms on the following 4-point response scale: 0=*not at all*, 1=*several days*, 2=*more than half of the days*, 3= *nearly every day*. It is validated and widely used screener for patients aged 18-99 years, with good internal consistency (α=.89) (Huang, et al., 2006; Kroenke et al., 2001). See Appendix H for a copy of this measure.

Intention to Screen. For the current study, intention is a measure of a person's willingness to be screened for dementia. According to Ajzen (1991), intention is often an immediate antecedent of behavior and therefore has often been used as a proxy for behavior in research when an actual behavior cannot be observed (Sheeran et al., 2016). Ajzen's proposes that intention be measured with the following three statement stems: "I expect to . . .," "I want to . . . ," and "I intend to. . . " (Francis et al., 2004). For the current study, four questions assessed the intention to undergo dementia screening within 3 months if offered through their church: "I want..", "I am ready…", "I intend…", and "I am

committed… to get a dementia screening at my church". Response options for each question range from 0=*not at all* to 6=*very much*. Total scores were used to indicate intention to screen for dementia, with higher scores indicating stronger intent. See Appendix I for a copy of this measure.

Positionality Statement

In my research on health disparities, I want to be transparent about my positionality and how it shapes my perspective. I am a cis-gendered, White female of rural background. My experiences growing up in a highly rural area taught me how factors such as health literacy, medical distrust, and access to healthcare can impact health outcomes. However, I also acknowledge that my identity and social location have shaped the way I approach research in Black health disparities. I am aware that my perspective is inherently limited by not sharing the experiences of the population I am studying.

I recognize that my social location comes with power and privilege, which can limit my ability to consider all relevant aspects of this topic. Further, I also understand that my position may affect how participants and others perceived me during the study, including the church members I collaborated with throughout the study period. I strive to be aware of my limitations and biases and approach my research with humility and a willingness to learn from those with different experiences and perspectives.

As a researcher studying health inequities that affect Black individuals disproportionately, I am committed to using my position and privilege as a researcher to contribute to the dismantling of systemic racism that shaped these inequities. As such, I am committed to engaging in ethical research practices and will actively seek out and collaborate

with Black scholars and community members. I will use this research to advocate for policies and interventions that promote health equity.

CHAPTER 3

RESULTS

Preliminary Analyses

Missing Data & Multiple Imputation

In total, 112 individuals accessed the screening survey. Nine participants did not complete the eligibility screener and thus were not matriculated to the study survey. One participant was excluded as they were not 55 or older. Finally, three participants were removed for skipping multiple pages of the survey or for suspicious response patterns (e.g., indicated the same value for each item across multiple different measures). Therefore, 99 cases were included in final data analyses. Although 150 participants, or about 50 participants per church, were desired for the study, a sample size of 99 was deemed sufficient as it met generally accepted sample size heuristic for the planned analyses (Babyak, 2004; Tabachnick & Fidell, 2013).

Authors of statistical guidance articles have made suggestions for acceptable proportions of missing data ranging from 10% to 40% (Jakobsen et al., 2017; McNeish, 2017). In the current study, no variable was missing more than 9% of data aside from one, stigma towards dementia as measured by the Stigma Impact Scale. This was due to one item on the SIS in which participants were asked the degree to which they agreed with the following statement “My employer or coworkers would discriminate against me.” Over half of the participants answered “not applicable” to this question. Indeed, many participants were retired or unemployed. As this question was not critical to the measure, it was removed. The deletion of this item from the total score of this scale resulted in a more acceptable level of missingness, 23%. Other missingness was due to item nonresponse (e.g., skipping items or

selecting “choose not to answer”). Altogether, listwise deletion of incomplete cases would have resulted in the deletion of 57 cases and was untenable with an already minimally adequate acquired sample size. Multiple imputation (MI) was used to impute missing data at the scale-level data instead.

Data were examined for nonignorable patterns of missing responses, and none were found. After examining Little’s Missing Completely at Random (MCAR) test ($\chi 2 = 3633.15$, df=334, p=.13), which provided evidence data were missing completely at random, we addressed the problem of missing data using the MI technique with all variables to be included in analysis. The default MI options were chosen which generated five imputed datasets. The imputed values compared reasonably to observed values, thus imputed data are presented.

Participant Characteristics

This faith-based sample comprised 99 participants identifying as Black or African American. Table 1 below presents descriptive information on the study sample. Participants ranged in age from 55 to 94 years old, with a mean age of 68.74 (SD = 8.43) years. In the sample, 82.8% identified as female; 17.2% of the sample identified as male. Participants tended to be well-established in their respective place of worship. Years of attendance in their respective church ranged from 0-70 with a mean of 30.26 (SD=18.51). Education levels varied but in general, the sample was highly educated, 40% having completed a college degree or higher. Most participants were retired or not working, owned a home, and had a monthly household income of over $3,000.

Many participants (44.4%) reported *“do not know”* on whether they thought they were at higher risk for AD or other dementias relative to others their age. Nearly half

reported having either a family member or friend with Alzheimer's disease or other form of dementia. Most participants (67.7%) denied believing they themselves had more memory problems than their peers. Lastly, eleven participants reported a previous dementia screening.

Table 1.
Participant Characteristics (N=99)

	M	*SD*
Age	68.7	8.4
	N	*%*
Gender		
Female	82	82.8
Male	17	17.2
Sexual Orientation		
Heterosexual	93	93.9
Homosexual	1	1.0
Not disclosed	5	5.1
Education		
9-11th	3	3.0
High School/GED	18	18.2
Some College/Technical School	25	25.3
Associate's Degree/Technical Cert.	8	8.1
College Degree or Higher	40	40.4
Not disclosed	5	5.1
Marital Status		
Partnered	48	48.5
Not partnered	48	48.5
Not disclosed	3	3.0
Financial Support		
Work part-time	15	15.2
Working full-time	22	22.2
Self-employed	1	1.0
Private disability	1	1.0
SSDI	9	9.1
Pension/SS/savings	58	58.6
Insurance		
Medicare	59	59.6
Medicaid	7	7.1
Private	45	45.5
Other	15	15.2
Housing		
Own a home	75	75.8
Renting	21	21.2
Staying with family/friends	1	1.0

Not disclosed	2	2.0
Average monthly household income		
0-$1,000	1	1.0
$1,001-$2,000	12	12.1
$2,001-2,500	10	10.1
$2,501-$3,000	16	16.2
More than $3,000	38	38.4
Not disclosed	22	22.3
Current Tobacco User		
Yes	5	5.1
No	92	91.9
Not Disclosed	3	3.0
Currently Overweight		
Yes	54	54.5
No	40	40.4
Not disclosed	5	5.1
Believe at Higher Risk for dementia		
Yes	20	20.2
No	35	35.4
Do not know	44	44.4
Know Someone with Dementia		
Yes	43	43.4
No	42	42.4
Do not know	14	14.1
Subjective Memory Complaints		
Yes	9	9.1
No	67	67.7
Do not know	23	23.2
Personal History of Dementia Screening (ever)		
Yes	11	11.1
No	82	82.8
Do not know	6	6.1

Data Screening

Prior to conducting study analyses, the relevant assumptions for multivariate regression were tested, using SPSS 28.0 (IBM Corp, 2021). Histograms, skew, and kurtosis values were reviewed. No univariate outliers were observed, and variables were roughly normally distributed. Assumptions of multicollinearity were deemed satisfactory after inspection of collinearity statistics (i.e., Tolerance and VIF). Mahalonobis values and

residual and scatter plots indicated the assumptions of normality, linearity and homoscedasticity were met (Hair, 2009). Descriptive statistics for study variables can be found in Table 2.

Table 2.
Descriptive statistics for study variables

Measures	Possible Range	M	SD	Coefficient Alpha
Perceptions Regarding Investigational Screening for Memory in Primary Care				
Acceptance Of Screening	6-30	22.99	5.09	.89
Benefits (HBM Benefits)	8-40	34.89	4.55	.91
Negative Impact (HBM Barriers)	6-30	15.47	4.86	.84
Suffering (HBM Severity)	4-20	11.44	3.65	.84
Stigma	9-45	17.62	5.59	.79
Expectations Regarding Aging-12	0-100	55.59	16.82	.85
Physical Expectations	0-100	48.53	22.09	.71
Psychological Expectations	0-100	71.46	23.76	.79
Cognitive Expectations	0-100	46.49	21.45	.80
Stigma Impact Scale	20-80	44.27	10.53	.93
Dementia Knowledge Assessment Scale	0-25	16.53	3.24	.59
Patient Health Questionnaire-9	0-13	3.15	3.36	.81
Intent to Screen	0-24	13.00	9.10	.98

Aim 1

The first aim of the study was exploratory in nature and sought to determine the impact of demographic and other characteristics previously shown to impact intent to screen. As such, possible covariates were explored. No statistical significance was found.

1a. Correlation analyses were used to determine if age was related to intent to screen. Age was not significantly related to intent to screen, r=.03, p=.97.

1b. We also used between subjects one-way ANOVA to determine if intent to screen differed by age group (55-59; 60-69; 70-79; 80+). We found no statistically significant differences between age groups, $F(4,94)$=.68, p=.61.

1c. An independent samples t-test was used to determine if participants identifying as female differed in screening intentions as compared to participants identifying as male. There were no significant differences between intent to screen for females (M=13.10, SD=8.97) and males (M=12.52, SD=9.98), $t(97)=.23$, $p=.40$.

1d. We used one-way ANOVA to determine if intent to screen varied by income level. We found no statistically significant differences between income level on intent to screen, $F(7,91)=.86$, $p=.54$.

1e. We used one-way ANOVA to determine if intent to screen varied by education level. We found no statistically significant differences between education level on intent to screen, $F(4,89)=.56$, $p=.69$.

1f. We used one-way ANOVA to determine if intent to screen varied between those who have a relative or friend with AD or other dementia, those who do not, and those who did not know. We found no statistically significant differences between these groups on intent to screen $F(2,96)=.30$, $p=.74$.

1g. We used one-way ANOVA to determine if intent to screen varied between those who believe they are at higher risk for AD or other dementia, those who do not believe they were at higher risk, and those who did not know their risk. We found no statistically significant differences between these groups on intent to screen $F(2,96)=.14$, $p=.87$.

1h. We used one-way ANOVA to determine if intent to screen varied between those who endorsed subjective complaints of memory, who denied subjective complaints of memory, and those who did not know if they had more problems with memory than others their same age. We found no statistically significant differences between these groups on intent to screen $F(2,96)=.42$, $p=.66$.

1i. Correlation analyses were used to determine if symptoms of depression were related to intent to screen. Symptoms of depression were not significantly related to intent to screen r=.01, p=.94).

Aims 2 & 3: Hierarchical Regression

As no covariates were identified in above analyses, a two-stage hierarchical multiple regression was conducted with intention to screen for dementia as the dependent variable. The HBM constructs of perceived benefits, barriers, and severity were entered into the first block. Dementia knowledge, dementia stigma, and expectations regarding aging were entered into the second block. Regressions analyses were completed using SPSS V.28. Correlations between the study variables and the regression models are represented in Tables 3 and 4.

Table 3.

Correlations for study predictors and intent to screen (N=99)

	1	2	3	4	5	6	7
1. Intent to Screen							
2 Benefits (PRISM-PC)	.12						
3 Suffering (PRSIM-PC; HBM barriers)	-.09	-.01					
4 Negative Impact (PRSIMP-PC) (HBM severity)	-.10	.03	.64***				
5 Stigma (PRISM-PC)	-0.37***	-.18	.49***	.46***			
6 ERA-12	.01	.15	-.15	-.12	-.13		
7 SIS	-.33**	-.03	.66***	.60***	.64***	-.09	
8. DKAS	.11	.15	.23*	.40***	.33***	-.28**	.23*

Note ***P<.001; ** p < 0.01; * p < .05

Aim 2: Identify HBM constructs that are related to dementia screening intentions in older Black adults and determine how much variance is explained by these factors on intent to screen.

Hypothesis 1. It was hypothesized that perceived benefits, barriers and severity would be correlated with intent to screen. This hypothesis was not supported, Pearson's correlations among the HBM variables and intention to screen for dementia were not significant. See Table 3.

Hypothesis 2. It was hypothesized that the linear combination of perceived benefits, barriers and severity would significantly predict intent to screen. That is, greater perceived benefits, lower perceived barriers, and higher perceived severity would predict screening intentions. Moreover, perceived benefits were hypothesized to explain the most variance in intent to screen for dementia. The hierarchical multiple regression examining the predictors for intentions to screen for dementia revealed that in block one, perceived benefits, barriers, and severity were not significant predictors of screening intentions, $F(3,95) = .81$, $p = .49$, $R^2 = .01$ (see Table 4). As such, we did not find support for this hypothesis.

Aim 3: Identify if dementia stigma, expectations regarding aging, and knowledge about dementia were related dementia screening intent. Determine how much variance in intent to screen is explained when these variables are added to the above model of HBM constructs.

Hypothesis 3. It was hypothesized that dementia stigma, expectations regarding aging, and knowledge about dementia would be correlated with intent to screen. In the current study, correlations between intent to screen and knowledge and aging expectations were small and not significant (knowledge $r = .11$. aging expectations $r = .01$). However, the

relationship between intent to screen and stigma was significant (r=-.33, p<.01). That is, stigma was negatively related to screening intention. See Table 3.

Hypothesis 4. It was hypothesized that the addition of dementia stigma, expectations regarding aging, and knowledge about dementia to HBM constructs would significantly predict intent to screen. That is, lower dementia stigma, higher expectations regarding aging, and higher knowledge about dementia would predict screening intentions above and beyond HBM factors. By adding these variables, there was a significant improvement $\Delta F(3,92)$ = 5.47, $p< .01$, ΔR^2=.12 from the first block. However, only dementia stigma was a significant negative predictor (β =-.50, $t(92)$= -3.73, $p< .001$, pr^2=.13) of intention to screen; those with lower dementia stigma indicated greater screening intent. Overall, the final model with all six predictors explained 11.8% of the variance in screening intentions. See Table 4 below.

Table 4.
Regression analysis between dementia screening intention and study predictors and statistical parameter results of the model (n = 99)

Predictors	Model 1			Model 2		
	ß	*t*	P-value	ß	*t*	P-value
Perceived Benefits	0.12	1.18	0.24	0.09	0.93	0.36
Perceived Barriers	-0.04	-0.29	0.78	0.20	1.47	015
Perceived Severity	-0.08	-0.58	0.57	0.01	0.02	0.90
Dementia Knowledge				0.18	1.64	0.10
Dementia Stigma				-0.50	-3.73	<0.001***
Expectations Regarding Aging				0.53	0.53	0.60
Adjusted R^2	0.01			0.12		
ΔR^2	0.03			0.15		
ΔF	0.81			5.47		
Significant F	0.49			<0.01**		

Note ***P<.001; ** p < 0.01; * p < .05

Exploratory Analysis

A related construct to intent to screen, dementia screening acceptance, was embedded in one of the measures used. Indeed, acceptance and intention were moderately to strongly

correlated (r=.49, p<.001). Exploratory analyses mirroring those used to examine screening intention were conducted to assess possible relationships between screening acceptance with HBM constructs, dementia knowledge, aging expectations, and stigma among older Black adults. As with intent to screen, possible covariates to include in the dementia screening acceptance model were explored first.

1a. Correlation analyses were used to determine if age was related to screening acceptance. Age was not significantly related to screening acceptance, r=.08, p=.39.

1b. We also used between subjects one-way ANOVA to determine if screening acceptance differed by age group (55-59; 60-69; 70-79; 80+). We found no statistically significant differences between age groups $F(4,94)=1.9$, p=.12).

1c. An independent samples t-test was used to determine if participants identifying as female differed in screening acceptance as compared to participants identifying as male. There were no significant differences between females (M=22.83, SD=5.03) and males (M=23.72, SD=5.49), $t(97)=-.65$, p=.41 on screening acceptance.

1d. We used one-way ANOVA to determine if screening acceptance varied by income level. We found no statistically significant differences between income level on screening acceptance $F(7,91)=2.07$, p=.06.

1e. We used one-way ANOVA to determine if screening acceptance varied by education level. We found no statistically significant differences between education screening acceptance $F(4,89)=.39$, p=.94.

1f. We used one-way ANOVA to determine if screening acceptance varied between those who have a relative or friend with AD or other form of dementia, those who do not, and

those who did not know. We found no statistically significant differences between these groups on screening acceptance $F(2,96)=.79$, $p=.46$.

1g. We used one-way ANOVA to determine if screening acceptance varied between those who believe they are at higher risk for AD or other dementia, those who do not believe they were at higher risk, and those who did not know their risk. We found no statistically significant differences between these groups on screening acceptance $F(2,96)=2.40$, $p=.09$.

1h. We used one-way ANOVA to determine screening acceptance varied between those who endorsed subjective complaints of memory, who denied subjective complaints, of memory, and those who did not know if they had more problems with memory than others their same age. We found no statistically significant differences between these groups on screening acceptance $F(2,96)=.29$, p=.79).

1i. Correlation analyses were used to determine if symptoms of depression were related to screening acceptance. Symptoms of depression were not significantly related to screening acceptance, $r=.17$, $p=.08$.

Exploratory Hierarchical Regression

As no covariates were identified in above analyses, a two-stage hierarchical multiple regression was conducted with dementia screening acceptance as the predictor variable. The HBM constructs of perceived benefits, barriers, and severity were entered into the first block. Dementia knowledge, dementia stigma, and expectations regarding aging were entered into the second block. Regressions analyses were completed using SPSS V.28. Correlations between the study variables and the regression models are represented in Tables 5 and 6.

Table 5.

Correlations for study predictors and acceptance of dementia screening (N=99)

	1	2	3	4	5	6	7
1. Acceptance of Dementia Screening							
2 Benefits (PRISM-PC; HBM benefits)	.29**						
3 Suffering (PRSIM-PC; HBM barriers)	.16	-.01					
4 Negative Impact (PRSIMP-PC) (HBM severity)	.20*	.03	.64**				
5 Stigma (PRISM-PC)	-0.09	-.18	.49***	.46***			
6 ERA-12	-.10	-.15	-.14	-.12	-.13		
7 SIS	.11	.03	.66***	.60***	.64***	-.09	
8. DKAS	.19*	.15	.23*	.40***	.33***	-.28**	.23*

Note ***p<.001; ** p < 0.01; * p < .05

Aim 2: Identify HBM constructs that are related to dementia screening acceptance in older Black adults and determine how much variance is explained by these factors on dementia screening acceptance.

It was hypothesized that perceived benefits, barriers, and severity would be correlated with dementia screening acceptance. This hypothesis partially supported. Indeed, there was significant positive correlation between dementia screening acceptance and perceived benefits (r=.29, p<.01). There was also a positive correlation between perceived severity and dementia screening acceptance (r=.20, p<.05). The relationship between perceived barriers and acceptance was not significant (r = .16). See Table 5.

It was also hypothesized that the linear combination of perceived benefits, barriers and severity would significantly predict dementia screening acceptance. That is, greater perceived benefits, lower perceived barriers, and higher perceived severity would predict dementia screening acceptance. Moreover, perceived benefits were hypothesized to explain the most variance in dementia screening acceptance. The hierarchical multiple regression examining the HBM predictors for dementia screening acceptance was significant, $F(3,95) = 4.43$, p<.01, R^2=.10. However, only perceived benefits was a significant predictor in the model (β =.28, $t(92)= 2.95$, p< .01, pr^2=.08). That is, those with greater perceptions of benefits of screening for dementia indicated greater dementia screening acceptance. Overall, the first model explained 9.5% of the variance in dementia screening acceptance. See Table 6.

Aim 3: Identify if dementia stigma, expectations regarding aging, and knowledge about dementia were related dementia screening acceptance. Determine how much variance in

dementia screening acceptance is explained when these variables are added to the above model of HBM constructs.

It was hypothesized that dementia stigma, expectations regarding aging, and knowledge about dementia would be correlated dementia screening acceptance. Correlations between dementia screening acceptance and stigma and aging expectations were small and not significant (stigma r=.11. aging expectations r=-.10). Th relationship between dementia screening acceptance and knowledge was significant (r=.19, p<.05). That is, higher knowledge was positively related to screening acceptance. (See Table 5).

It was also hypothesized that the addition of dementia stigma, expectations regarding aging, and knowledge about dementia to HBM constructs would significantly predict dementia screening acceptance That is, lower dementia stigma, higher expectations regarding aging, and higher knowledge about dementia would predict dementia screening acceptance above and beyond HBM constructs. However, the addition of these three variable did not significantly improve the prediction of dementia screening acceptance $\Delta F(3,92) = .28$, p= .84, ΔR^2=.01 from the first block. See Table 6.

Table 6.
Regression analysis between dementia screening acceptance and study predictors and statistical parameter results of the model (n = 99)

Predictors	Model 1			Model 2		
	ß	*t*	P-value	ß	*t*	P-value
Perceived Benefits	0.28	2.95	<0.01**	0.28	2.95	0.04*
Perceived Barriers	0.07	0.59	0.56	0.07	0.59	0.56
Perceived Severity	0.15	1.16	0.25	0.15	1.16	0.25
Dementia Knowledge				0.09	0.82	0.42
Dementia Stigma				-0.04	-0.28	0.77
Expectations Regarding Aging				-0.01	-0.09	0.92
Adjusted R^2	0.10			0.07		
ΔR^2	0.12			0.01		
ΔF	4.43			0.28		
Significant F	<0.01**			0.84		

*P < 0.05 and **P < 0.01; P<.001

CHAPTER 4

DISCUSSION

While the prevalence rate of dementia is projected to increase substantially in the coming years, screening rates remain quite low. This is particularly concerning for older Black adults who are at greater risk of developing dementia and often receive a diagnosis at a later stage. Given these circumstances, the current study examined how constructs of HBM, expectations regarding aging, knowledge about dementia, and stigma impacted dementia screening intent in a faith-based sample of older Black adults. This chapter presents findings from the current study and discusses their implications for faith and community-based dementia interventions and screening initiatives. Recommendations for future research in this area are also provided.

The Health Belief Model and Screening Intentions

The Health Belief Model includes various components that relate to individuals' assessment of their health. It has been extensively used to explore factors influencing health-related decisions across different diseases, making it a valuable tool for developing health interventions. We did not explore all components of the model in the present study, rather only perceived benefits, barriers, and severity to determine their ability to predict intention to undergo dementia screening. Also, the focus of the current was on intent to screen as it is routinely used as a proxy for, and highly predictive of, actual behavior. Contrary to our initial hypotheses, which asserted that these three components would predict intent to screen, the results of correlation analyses and regression modeling indicated no significant relationships. This finding differs from the existing literature on dementia screening and may point the

importance of other factors in predicting screening intentions among older Black adults specifically.

Contrastingly, many components of HBM have proven useful tools in predicting various other screening behaviors among older Black adults, particularly in the context of cancer screenings. For instance, a study conducted by Frank and colleagues (2004) demonstrated that Black women who perceived fewer barriers, greater benefits, higher susceptibility to the disease, and had confidence in the accuracy of screening were more likely to undergo a colonoscopy. More recently, the HBM model has also been successful in predicting COVID-19 vaccination acceptance among older Black Americans. Here, perceptions of susceptibility, severity, barriers, and, notably, the benefits of vaccination played significant roles in the decision to vaccinate (Bass, 2023).

Again however, research to date has largely failed to investigate dementia diagnosis seeking behavior in diverse samples, namely older Black adults. Recent metanalytic review, albeit in less diverse samples, suggests multiple HBM constructs are important to one's decision for seeking dementia diagnosis, both for carers and for self, too. In their review of existing literature on barriers and facilitators for seeking help for dementia, Parker et al. (2020) gleaned themes aligned with HBM principals. Perceived susceptibility (e.g., lack of knowledge about risk or signs) and perceived severity (i.e., noticing cognitive abilities have changed but not considering changes sufficient enough to seek help) were found in 19 studies. Barriers (i.e., threats to autonomy and independence, lack of clarity on where to seek help, or lack of support from social networks) were found in 16 studies.

Moreover, in many studies of HBM principals, benefits are often the most important predictor, if not the sole predictor, of dementia screening intentions or actual receipt of

screening (Fowler et al., 2012). For example, the perception of screening benefits was more important than perceived susceptibility, severity, or barriers for predicting intentions and subsequent actual screening in a sample of Japanese older adults (Harada et al., 2017).

However, in this first study of intent to screen in and older, Black, faith-based sample, the HBM constructs examined do not seem to capture relevant factors dictating this decision. Given the Health Belief Model's effectiveness in predicting various health screening behaviors among Black samples, and growing evidence of its potential for predicting dementia diagnosis seeking, the current findings are unexpected. However, it should be noted that many of the aforementioned studies relating screening behavior and HBM offered screening concurrently with other study procedures, or immediately after. The current study asks about the prospect of screening in the future. This extended timeline may have also impacted how participants answered intention questions.

Nonetheless, though intentions may be an important antecedent to actual behavior, results suggest that other factors aside from benefits, barriers, and perceived severity are important for screening intent among this population. In this first study, to our knowledge, in a faith-based sample of older Black adults, it appears that there is specific nuance in the decision-making processes for this health behavior in this specific group.

Stigma

In this study, the researchers initially expected that stigma would have an additional impact on the intention to undergo dementia screening beyond the effects Health Belief Model (HBM) constructs. While the HBM constructs tested did not yield significant results, stigma did emerge as a significant predictor of screening intent, partially supporting this hypothesis. Specifically, screening intent increased with lower levels of stigma. This finding

aligns with existing literature that emphasizes the influence of stigma on screening intentions and the pursuit of further diagnostic assessment for dementia. Moreover, it underscores the significance of stigma in shaping the behavior of seeking a dementia diagnosis, particularly among older Black adults.

In the United States, dementia is widely perceived as one of the most feared conditions, ranking second only to cancer. This fear, fueled by stigma, significantly influences the willingness of individuals to seek help when concerns related to dementia arise (Blinka et al., 2023; Nguyen & Li, 2020; Sayegh & Knight, 2013). Supporting this notion, a study conducted by Fowler and colleagues (2015) focused on individuals who tested positive for dementia through the Mini Mental Status exam. Among older primary care patients who screened positive for dementia and were referred for further testing, stigma emerged as the primary reason for declining. Similarly, Phillipson, et al. (2015) found that stigma played a critical role in the decision-making process regarding whether to seek or delay screening for early-onset dementia, both for oneself and for a significant other.

The present study's finding, indicating that stigma was the sole significant predictor of intention to undergo dementia screening, further underscores the role of dementia-related stigma in the help-seeking process. This finding is made more relevant for older Black adults as dementia stigma may be more prevalent among the group. Indeed, this was the case in this sample compared to previous, more predominantly White samples (Burgener et al., 2013). Consequently, interventions aimed at promoting early detection of dementia should prioritize approaches that effectively reduce the stigma associated with the diagnosis.

Dementia Knowledge

The expectation that knowledge would predict the intention to undergo dementia screening was not supported. To our awareness, no previous studies have utilized the DKAS as the primary measure of knowledge about dementia specifically in older Black samples, nor when examining the relationship between knowledge and willingness to undergo screening. Also of note is that the DKAS has most often been used to differentiate between health professions on their level of knowledge. Therefore, the suitability of the DKAS for use in older Black samples is called into question.

Additionally, the influence of stigma on answering DKAS questions should be considered. Gerontological research suggests that bias and knowledge about aging are inextricable (Palmore, 2005). That is, aging bias, positive or negative, greatly influences one's answers to questions about dementia and/or aspects about aging. Thus, it is possible that the DKAS is multidimensional. A stigma factor may underly its structure, perhaps especially in those with lesser dementia health literacy. If so, this also could be why the measure was previously shown to be highly reliable and distinguished well between different knowledge groups (e.g., physicians vs medical students) while it was not as reliable in the current study. Indeed, moderate correlations between the DKAS and the SIS (r=0.23, $p< 0.05$) as well as the stigma subscale on the PRISM-PC (r=.40, $p< 0.001$) were found in our sample.

Ultimately, the study did not provide clarity regarding the role of dementia knowledge in predicting screening intention among older Black adults and further research is needed to explore the relationship between knowledge and screening intentions in this population. Nevertheless, global health initiatives and interventions have emphasized the

importance of increasing awareness and public knowledge to improve the lives of individuals with dementia, their caregivers, and to reduce the community-wide impacts of the disease. The World Health Organization (WHO) has announced the "global action plan on the public health response to dementia 2017-2025," which highlights raising dementia knowledge as a critical strategy (WHO, 2017). Disseminating information about dementia is believed to increase early detection by reducing stigma and increasing willingness to undergo screening, as seen in other health behaviors.

The existing literature supports such initiatives and shows poorer health outcomes and lower utilization of preventive screenings among individuals with lower health literacy (Chesser et al., 2016; MacLeod et al., 2017). Regarding dementia screening, knowledge has been found to be a factor in help-seeking for concerns about cognitive changes. Werner and Davidson (2004) found that higher levels of knowledge about dementia symptoms were associated with increased help-seeking such as from primary care physicians or neurologists.

It is also important to consider that it may not be overall knowledge about dementia that is related to willingness to undergo screening, but rather awareness of specific aspects of the disease that impact intention. For example, Edwards, Cherry, and Peterson (2000) found that while a majority know there is no cure for Alzheimer's disease, many lack awareness about the services and resources available to help those living with dementia. Similarly, findings from focus groups by Devoy and Simpson (2016) suggested that although people may be familiar with dementia symptoms, there is a knowledge gap regarding available treatments and factors contributing to the development of dementia. Future studies should aim to discern what, in terms of factual knowledge about dementia, is more influential on perceptions of screening. It is possible that knowledge about specific aspects of the disease,

such as treatment options, may have a greater impact on intent. To this end, future research should also explore the use of other knowledge measures to determine which aspects of knowledge about dementia relate most strongly to the dementia help-seeking. Understanding where knowledge gaps exist and how they influence help-seeking behavior will inform the educational interventions called for by the organizations.

Expectations Regarding Aging

Contrary to hypotheses, the study findings did not support the assumption that aging expectations would contribute to the prediction of screening intentions. This finding is somewhat inconsistent with existing literature which has demonstrated the influence of aging beliefs on older adults' healthcare-seeking behaviors for age-related conditions (Sarkisian et al., 2002). Numerous studies have shown that higher expectations of aging are associated with a greater likelihood of engaging in health behaviors.

For example, older adults with higher expectations of aging tend to engage in more physical activity and have larger social networks (Andrews et al., 2017; Breda & Watts, 2017; Menkin et al., 2017b). Additionally, higher expectations have been linked to willingness to seek help for memory concerns (Sarkisian et al., 2002). Moreover, recent research has highlighted the role of self-efficacy, or one's belief in one’s own abilities, as a potential mediator between aging expectations and healthier lifestyles in older adulthood (Yao Jr, 2019). This suggests that beliefs about maintaining health in older age can enhance self-efficacy, leading to the adoption of healthier behaviors. Coincidentally, adoption of such behaviors reduces the risk of developing dementia.

Interestingly, the current sample exhibited greater overall aging expectations compared to previous research with Black samples (Menkin et al., 2017a). However, these

higher expectations did not translate into higher intentions or acceptance of dementia screening, as would have been suggested from existing literature. All in all, expectations regarding aging may not have as significant an impact on dementia screening behavior among older Black adults, further highlighting the role of dementia stigma in help-seeking for the group.

Acceptance of Dementia Screening vs. Intention to Screen for Dementia

Exploratory analyses conducted in the study revealed surprising results when examining acceptance of dementia screening, supporting the constructs of the Health Belief Model (HBM). Specifically, perceived benefits and barriers were found to be related to the acceptance of dementia screening. However, regression analyses showed that perceived benefits were the sole significant predictor of screening acceptance with all six predictors, including non-HBM constructs, in the model.

The discrepancies in findings between acceptance and intention suggests that these constructs connoted different meanings and thus different considerations for the participants, though one might assume considerable overlap between the two. Indeed, acceptance and intention were moderately to highly correlated (r=.49), p<.001) in the current study and the respective measures share similar questions. The intention scale of the current study contains the item “I want (or would like) to get a dementia screening at church.” while the acceptance of screening subscale on the PRISM-PC contains the items “I would like to be tested for Alzheimer's disease with a short questionnaire; I would like to be tested for Alzheimer's disease with a blood sample.” Where they diverge is perhaps the urgency implied by the intentions measure; “I am ready… I intend… I am committed to getting a screening.”

Additionally, the terminology used to denote changes in cognition (Alzheimer's disease vs. dementia) and the target settings (primary care vs. church) differ and likely further influenced participants' responses. It has been noted that participants may be more familiar with the term "Alzheimer's disease" compared to "dementia" according to previous research (Fowler et al., 2012). Moreover, the difference in target settings may have raised privacy concerns, especially considering the role stigma had in predicting screening intentions in the sample. As intentions to undergo screening were prefaced by "at church" participants may have contemplated privacy issues more when indicating their intent to undergo screening as posed by the current study.

Cues to Action

A limitation of the study is that did not explore the Health Belief Model in its entirety. The model also incorporates cues to action in initiating the decision-making process to accept recommended health actions. These cues can be either internal or external. Regarding dementia, internal cues to help-seeking may include subjective cognitive changes or symptoms experienced by the individuals themselves, while external cues involve feedback or observations from family members or other external sources. Although the current study did not explicitly explore cues to action, a question regarding subjective complaints was asked. Out of the 99 participants, only 11 endorsed complaints. Further, there was no significant difference in intent to screen or screening acceptance between those who endorsed memory complaints and those who denied complaints.

Internal cues may not always be a reliable indicator for action, particularly in dementia. A common symptom in cognitive impairment and dementia is a lack of insight into one's own difficulties, known as anosognosia. This symptom affects as many as 25-40% of

individuals with Alzheimer's disease, even in the milder stages (Wilson et al., 2016). Consequently, diagnoses for dementia are often prompted by family members or other external sources such has primary care physicians. Significant changes in behavior or functioning or incidents may serve as "tipping points" that trigger the recognition for further evaluation. For instance, getting lost while driving or missed bills can prompt family members to seek a diagnosis for their loved ones. Altogether, this suggests that relying solely on internal cues, such as subjective cognitive changes, may not always be a reliable indicator for individuals to act. Thus, a limitation of the study is not including more questions about possible external cues (e.g., if friends or family have raised concerns for cognitive changes).

Theory of Planned Behavior

Though perceived benefits predicted acceptability for screening, no support for the role of the examined HBM constructs on the intention to screen for dementia was observed in the current study. It may also be helpful to look at other social cognitive models in future studies within older Black samples. The Theory of Planned Behavior (TPB), for example, could also be a valuable lens through which to view willingness to be screened for dementia. TPB asserts that health decisions are formed by perceived control (much like perceptions of benefits and barriers), attitudes (formed by knowledge and experience), and finally subjective norms (the degree to which others might approve of the action) (Ajzen, 1991).

Many components of TPB overlap with both the HBM and non-HBM factors presented in the current study. However, the concept of subjective norms is unique to TPB and could be particularly relevant to faith-based samples. Regarding dementia screening behavior, the TPB has recently been used to predict intentions to seek an early dementia diagnosis, albeit in a sample of Irish older adults. Content analysis revealed facilitators to

seeking help for dementia were support from family and friends as well as good relationships with health professionals (subjective norms) (Devoy & Simpson, 2016). Indeed, exploratory analyses in the current study also revealed relationships between intention, acceptance, and subjective norms. Participants answered on a scale of 0=*not at all likely* to 6=*very much likely* others would support their getting screened for dementia (e.g., My friends…My spouse…My church members…. My pastor… My doctor would support me getting a dementia screening). Answers to each item were summed to obtain a total score. Moderate to strong correlations with both intent (r=. 55; p<.001) and acceptance (r=. 38; p<.01) were found. Given the observed impact of social network encouragement on intention in the current study, it will be important to consider subjective norms on the intention to screen for dementia in future studies.

Limitations

In addition to the previously acknowledged issues with missing data, we also acknowledge that the current study had a minimally adequate sample size of 99 participants. The smaller sample size increased the likelihood of a type II error and limited the generalizability of the findings. Nevertheless, despite the reduced statistical power resulting from the small sample, several relationships were found to be statistically significant. Particularly, stigma was found to be influential on intent to screen as were perceived benefits are acceptability of screening.

Additionally, the current study was conducted during the peak of the COVID-19 global health crisis, which likely introduced stress and unforeseen influences on the participants. We recruited Black adults ages 55 and older during a pandemic that disproportionately affected them. As mentioned before, Black Americans experience higher

rates of health challenges such as diabetes, hypertension, and asthma, which are associated with higher rates of mortality from COVID-19 (Centers for Disease Control and Prevention [CDC], 2020). Age-adjusted COVID-19 mortality rates show that at one point, the mortality rate for Black Americans was 3.4 times higher than that of non-Hispanic Whites, although this gap has reduced over the course of the pandemic, according to updated CDC data (2023). Accordingly, older Black adults were particularly encouraged to socially distance. Participating churches took this risk and recommended precautions seriously.

Like many other faith communities, the participating churches strictly enforced social distancing guidelines during the study to reduce community spread. Therefore, they had to adapt their services to comply with these guidelines. Various media platforms and communication technologies like YouTube and Zoom were utilized to stream services to members' homes, and our recruiting strategies were dependent on these platforms and technologies. Church members may have had challenges accessing virtual services and other materials due to a lack of knowledge and skills about utilizing technology (Gecewicz, 2020). Consequently, the recruitment for the current study may have resulted in a sample with higher media and technology literacy, and by extension, perhaps a higher level of functioning overall. Simply, although participants of various ages were enrolled, those who may have been at the highest risk for dementia and of particular interest for the study, might not have been reached through these modified services and recruitment procedures.

Conclusion and Future Research

The aim of the current study was to examine the Health Belief Model, as well as knowledge, stigma, and aging expectations, on the intent to undergo screening for dementia. The overall goal was to provide insights for community-based dementia interventions that

aim to increase dementia screening and subsequent linkage to care for older Black adults. Notably, this is the first study to our knowledge that investigates dementia screening intentions using the framework of the Health Belief Model within a faith-based sample of older Black adults. This is despite the considerable potential of this setting, as a cornerstone of support within the older Black community, to promote dementia screening.

Partial support for our hypotheses were found. Though the study did not explore all elements of HBM, it did not support benefits, barriers, or severity as predictors of screening intentions, nor did it support knowledge or aging expectations. However, stigma was indicated as a significant factor influencing willingness to undergo dementia screening. Therefore, addressing stigma appears to be of paramount importance for interventions in this population and setting moving forward. Though not a central question, exploration into screening acceptance suggests different decision-making processes between acceptability of screening procedures and intention. The latter was related to perceived benefits, but not stigma. Tailoring future faith-based interventions to align with the cultural nuances of older Black adults is of paramount importance, as pointed out by Sayegh and Knight (2013). The way in which dementia information is sourced and presented directly impacts knowledge about the disease consequently influencing perceptions of risk and its impact, thereby affecting willingness to seek help for dementia-related concerns (Sayegh & Knight, 2013).

In addition to addressing stigma, the study also revealed the importance of community connectedness. Exploratory findings showed the impact on perceived support from others on intent. That is, screening intention increased with higher perception of support from others. This finding is even more relevant given that the pursuit of dementia diagnosis is often initiated by someone other than the individual affected. Indeed, research regarding

social support and other health screening with Black samples bears this out as well. For example, research in faith-based samples found that Black men and women who engaged in communication about various cancer screening, such as breast and prostate cancers, with family and friends were more likely to pursue screening (Pratt et al., 2017).

Additionally, future research could consider expanding the targeted age ranges of community-based interventions in this area. The decision to screen for dementia is unique in that it may involve the influence of others to pursue the behavior. This differs from other health behavior research in adults. Younger individuals, such as adult children with parents over 65, will be an important population to consider in this line of research. Furthermore, since there are currently no effective, data-driven approaches to combating dementia stigma, further studies might pursue whether intergenerational approaches can modify dementia beliefs. To this pursuit, examining health behaviors on behalf of someone else could serve as a useful framework for studying dementia screening or diagnosis-seeking behaviors.

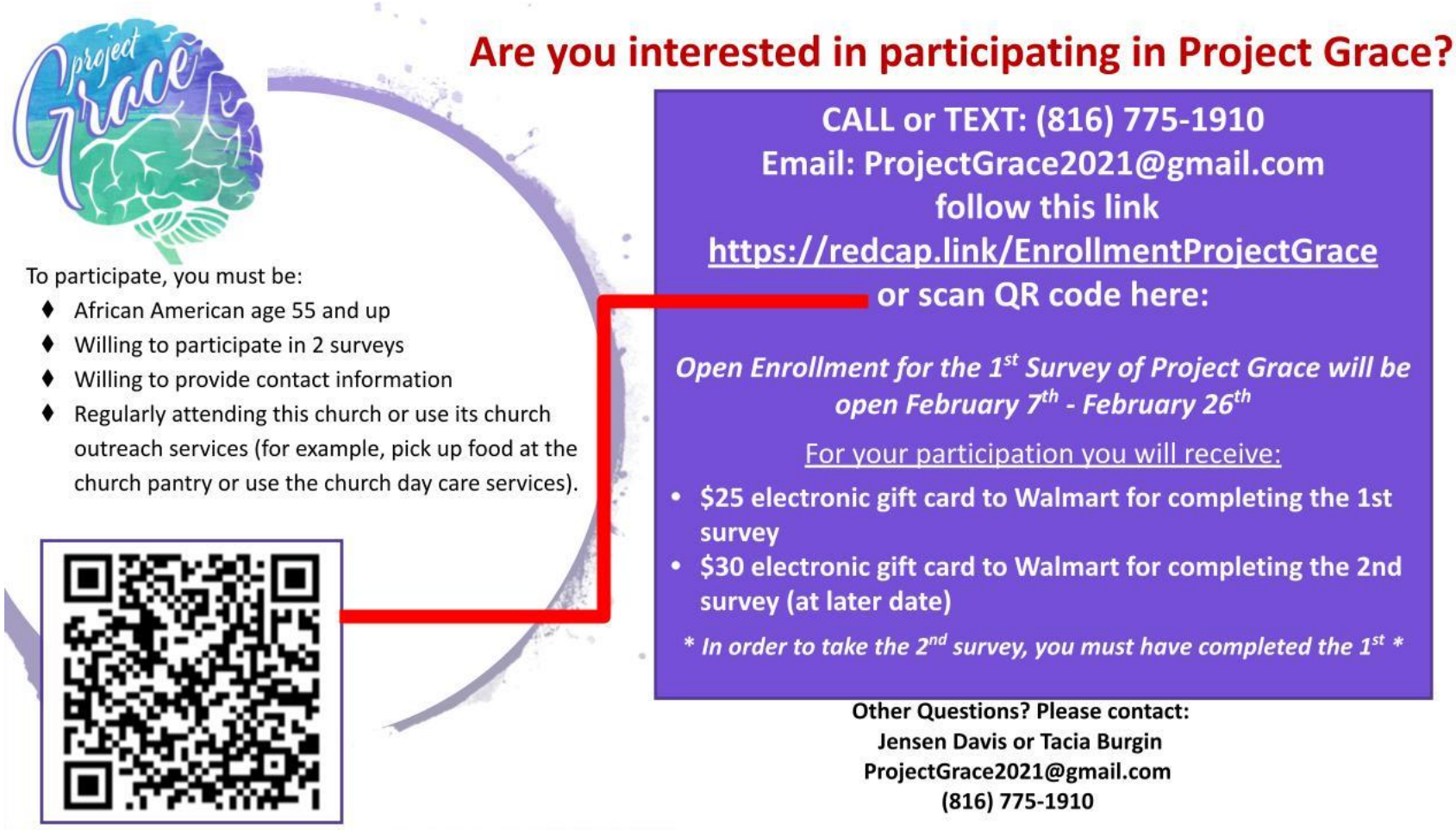
In short, considering a broader scope of conversations about dementia by including a larger portion of the church population could prove beneficial in future dementia screening interventions. Moreover, integrating dementia education into existing health ministries within churches might facilitate ongoing discussions and stress the importance of screening and follow-up. To further enhance understanding of the decision-making process regarding dementia screening, it may also be beneficial to employ mixed methods approaches. Conducting participant interviews could provide additional insights into the role played by stigma and other factors in the decision to pursue or forgo dementia diagnostic procedures.

All in all, the findings suggest that stigma plays a significant role on intention to undergo screening among older Black adults. With advancements in disease-modifying

medications for Alzheimer's disease, this research offers timely strategies to increase early dementia screening, which is needed to maximize the effectiveness of such treatments. Findings also highlight the need for further research to better understand the factors that influence screening intentions and acceptance including measurement nuances, terminology, and target screening settings/age groups. Specifically, the involvement of family members and other external sources may have a crucial impact on recognizing and initiating the process of seeking a dementia diagnosis. Ultimately, Black churches can play a significant role in providing culturally appropriate dementia education and creating supportive spaces to encourage the use of medical services for dementia concerns. The study's examination of screening intentions within a faith-based setting provides valuable insights for future interventions aimed a closing dementia health disparity.

Appendix A.

RECRUITMENT FLYER



Appendix B.

SCREENING QUESTIONNAIRE

	Inclusion/Exclusion Criteria Item	Survey Question	Response Options
1.	Age	Are you 55 years of age or older?	Yes/No
2.	Ethnicity	Do you consider yourself Black or African American	Yes/No
3.	Church Attendance	Do you attend church either (virtually or in person) at least once per month?	Yes/No
4.	Participation	Are you willing to participated in 2 surveys? You will b paid $25 for the first survey and $30 for the second survey in the form of an electronic gift card.	Yes/No

Appendix C.

DEMOGRAPHIC AND OTHER CHARACTERISTICS QUESTIONNAIRE

	Category	Survey Question	Response Options
1.	Age	_How old are you?	Fill in the blank
2.	Sex	Are you?	1=male 2=female
3.	Zip	What is the zip code where you live	Fill in the blank
4.	Ethnicity	Do you identify your ethnicity as being of Hispanic or Latino origin?	1=No, not of Hispanic or Latino origin 2=Yes, Mexican, Puerto Rican, Cuban, or another Hispanic, Latino, or Spanish origin
5.	Sexual Orientation	How do you identify?	1=Heterosexual (straight) 2=Homosexual (gay/lesbian) 3= Bi-sexual (attracted to both men and women)
6.	Education	What is your highest level of education?	1=8th grade or below 2=11th grade 3= High school graduate or GED 4=Post high school technical training 5=Some college (but no degree) 6=Associate's degree/Technical school certificate 7=College degree 8= Graduate courses 9=Graduate degree
7.	Relationship Status	What is your current marital status?	1=Single, never married 2=Living with partner, but not married 3=In a relationship, but not living together 4= Married 5=Separated 6=Divorced 7=Widowed

8.	Church Connection	How are you connected with your church?	1=Member 2=Guest 3= Person who received food services |4=Person who received health screening or participated in a health fair 5=Person who received a COVID-19 test 6=Person who received drug rehab services 7=Person who received clothing 8= Parent of a child in church daycare, summer school, after-school program, or mentoring program
9.	Church Membership	How long have you been a member or attended services at this church?	Fill in the blank
10.	Church Leadership	Are you in a leadership role at this church?	Check all that apply: Pastor Pastor's wife Deacon Elder Sunday school teacher Ministry leader
11.	Employment Status	How do you support yourself?	1=No income 2=Working part-time 3=Working full-time 4= Self-employed in your own business |5=Private disability insurance 6=(SSDI) Social Security Disability Insurance 7= Financial support from family/friends 8=Unemployment compensation 9= General assistance/relief 10=Pension, social security, savings
12.	Insurance Status	Do you have health insurance or coverage that helps pay for part of your medical bill	Check all that apply… No health insurance Medicare

			Medicaid | Private Insurance (Such as Blue Cross/ Blue Shield, Kaiser, etc.)
13.	Housing Status	What is your current housing status?	1=Own a home | 2=Renting 3=Staying with family or friend 4=Living in temporary or emergency housing 5=Homeless
14.	Income	For the past 12 months, please estimate the average monthly income of your household?	1= $0 - $1,000 2= $1,001 - $2,000 3=$2,001 - $2,500 4= $2,501 - $3,000 5= More than $3,000
15.		Do you have a relative or friend with Alzheimer's disease or other form of dementia?	1=Yes 2=No 3=Don’t Know
16.		Do you believe that you are at a higher risk for Alzheimer's disease or other forms of dementia than others your same age?	1=Yes 2=No 3=Don’t Know
17.		Do you think you have more memory problems than others your same age?	1=Yes 2=No 3=Don’t Know
18.		Has a doctor told you that you have memory problems?	1=Yes 2=No 3=Don’t Know
19.		Are you taking medications to help with memory?	1=Yes 2=No 3=Don’t Know

Appendix D.

PERCEPTIONS REGARDING INVESTIGATIONAL SCREENING FOR MEMORY IN PRIMARY CARE

PRISM-PC		
Instructions: The following questions ask about your feelings about getting screened for Alzheimer's disease. Indicate how much you agree or disagree with the following statements.		
Acceptance of Screening		
1	I would like to know if I am at higher risk than others of developing Alzheimer's disease.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
2	I would like to know if I have Alzheimer's disease.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
3	I would like to be tested for Alzheimer's disease with a short questionnaire.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
4	I would like to be tested for Alzheimer's disease with a blood sample.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
5	I would like to be tested for Alzheimer's disease on a with pictures of my head or brain (CT-scan or MRI).	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
6	I would like a doctor to examine me every year to know if I have developed memory problems.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree

Benefits of Screening		
1	It would increase the chance to treat the disease better.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
2	It would give my family a better chance of caring for me.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
3	It would give me more time to plan my future.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
4	It would give me more time to talk with my family about my health care.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
5	It would give more time to talk with my family about my finances.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
6	It would motivate me to sign my advance directive or my living will.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
7	It would motivate me to have a healthier lifestyle.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
8	It would make more willing to participate in research about this disease.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree

Stigma		
1	I would not want my family to know.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
2	I would feel humiliated by my family members or other who would treat me poorly or laugh at me.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
3	I would be considered stupid and unable to do things.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
4	I would feel ashamed or embarrassed.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
5	I would give up on life.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
6	My doctor would not provide the best care for my other medical conditions	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
7	My doctor and other health professionals would not listen to me.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
8	I would be concerned that my health insurance company would find out.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree

Negative Impact of Screening		
1	I would not be able to get health insurance.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
2	I would not be able to get life insurance.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
3	I would not be able to get long-term care insurance.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
4	I would lose my home.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
5	I would be living in a nursing home.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
6	I would lose my driver's license and other privileges.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree

Suffering		
1	My family would suffer financially.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
2	My family would suffer emotionally.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
3	I would be depressed.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
4	I would be anxious.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
Acceptance of Screening for Other Conditions		
1	I would like a doctor to examine me yearly for colon cancer.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
2	I would like a doctor to examine me yearly for depression.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
Other AD Beliefs		
1	I believe that a treatment for Alzheimer's disease is currently available.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree
2	I believe that early detection of Alzheimer's disease increases treatment chances.	1=strongly agree 2=agree 3= don't know 4=disagree 5=strongly disagree

Appendix E.

EXPECTATIONS REGARDING AGING-12

ERA-12 Instructions: The following questions are about aging. Indicate to what degree the following statements are true.		
Physical Health Expectations		
1	When people get older, they need to lower their expectations of how healthy they can be.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
2	The human body is like a car: when it gets old, it gets worn out.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
3	Having more aches and pains is an accepted part of aging.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
4	Every year that people age, their energy levels go down a little more.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
Psychological Health Expectations		
5	I expect that as I get older, I will spend less time with friends and family.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
6	Being lonely is just something that happens when people get old.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
7	As people get older, they worry more.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false

8	It's normal to be depressed when you are old.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
Cognitive Health Expectations		
9	I expect that as I get older, I will become more forgetful.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
10	It's an accepted part of aging to have trouble remembering names.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
11	Forgetfulness is a natural occurrence just from growing old.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false
12	It is impossible to escape the mental slowness that happens with aging.	1=Definitely true 2=Somewhat true 3=Somewhat false 4=Definitely false

Appendix F.

STIGMA IMPACT SCALE

Stigma Impact Scale Instructions: The following questions are specifically about how you would feel IF you had dementia. Indicate how much you agree with the following statements IF you had dementia.		
Deleted Item	My employer or coworkers would discriminate against me. (If you are not currently employed, choose not applicable).	1=strongly agree 2=agree 3=disagree 4=strongly disagree 5=not applicable
1	Some people would act as though I am less competent than usual.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
2	I will be treated with less respect than usual by others.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
3	Others would be concerned that they could "catch" my illness through contact like a handshake or eating food I prepare.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
4	Others would avoid me because of my illness.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
5	Some family members would reject me because of my illness.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
6	Some friends would reject me because of my illness.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
7	Others would feel awkward and tense when they are around me.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
8	Changes to my appearance would affect my social relationships.	1=strongly agree 2=agree 3=disagree 4=strongly disagree

9	I would feel that others think I am to blame for my illness.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
10	I would feel I could not be open with others about my illness.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
11	I would fear that someone would tell others about my illness without my permission.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
12	I would feel I need to keep my illness a secret.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
13	I would feel I was at least partially to blame for my illness.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
14	I would feel set apart from others who are well.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
15	I would have a greater need than usual for reassurance that others care about me.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
16	I would feel lonely more often than usual.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
17	I would have a sense of being unequal in my relationships with others.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
18	I would feel less competent than I did before my illness.	1=strongly agree 2=agree 3=disagree 4=strongly disagree
19	I would sometimes feel useless.	1=strongly agree 2=agree 3=disagree 4=strongly disagree

20	I would encounter embarrassing situations as a result of my illness.	1=strongly agree 2=agree 3=disagree 4=strongly disagree

Appendix G.

DEMENTIA KNOWLEDGE ASSESSMENT SCALE

DKAS		
Instructions: Answer the following to the best of your knowledge about dementia. If not sure, give your best guess.		
1	Most forms of dementia do not generally shorten a person's life.	1=True 0=False
2	Blood vessel disease (vascular dementia) is the most common form of dementia.	1=True 0=False
3	People can recover from the most common forms of dementia.	1=True 0=False
4	Dementia is a normal part of the aging process.	1=True 0=False
5	Dementia results from physical changes in the brain.	1=True 0=False
6	Planning for end of life care is generally necessary following a diagnosis of dementia.	1=True 0=False
7	h. People experiencing dementia generally have problems making decisions.	1=True 0=False
8	Alzheimer's disease is the most common form of dementia.	1=True 0=False
9	It is impossible to communicate with a person who has advanced dementia.	1=True 0=False
10	A person experiencing advanced dementia will respond to changes in their physical environment.	1=True 0=False
11	It is important to correct a person with dementia when they are confused.	1=True 0=False
12	People experiencing advanced dementia often communicate through body language.	1=True 0=False
13	People with dementia are unlikely to experience depression.	1=True 0=False
14	Medications are the most effective way of treating behavioral symptoms of dementia.	1=True 0=False
15	Movement is generally affected in the later stages of dementia.	1=True 0=False
16	Difficulty eating and drinking generally occurs in the later stages of dementia.	1=True 0=False
17	People with advanced dementia may have difficulty speaking.	1=True 0=False
18	People experiencing dementia often have difficulty learning new skills.	1=True 0=False
19	Daily care for a person with advanced dementia is effective when it focuses on providing comfort.	1=True 0=False

20	Having high blood pressure increases a person's risk of developing dementia.	1=True 0=False
21	Maintaining a healthy lifestyle reduces the risk of developing the most common forms of dementia.	1=True 0=False
22	Symptoms of depression can be mistaken for symptoms of dementia.	1=True 0=False
23	The sudden onset of cognitive problems is characteristic of common forms of dementia.	1=True 0=False
24	Exercise is generally beneficial for people experiencing dementia	1=True 0=False
25	Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition.	1=True 0=False

*Shaded questions were reversed-coded to reflect correct responses.

Appendix H.

PATIENT HEALTH QUESTIONNAIRE-9

PHQ-9 Instructions: Over the last two weeks, how often have you been bothered by any of the following problems?		
1	Little interest or pleasure in doing things.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day
2	Feeling down, depressed, or hopeless.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day
3	Trouble falling or staying asleep or sleeping too much.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day
4	Feeling tired or having little energy.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day
5	Poor appetite or overeating.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day
6	Feeling bad about yourself - or that you are a failure or have let yourself or your family down.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day
7	Trouble concentrating on things, such as reading the newspaper or watching television.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day
8	Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day
9	Thoughts that you would be better off dead, or of hurting yourself in some way.	0 =Not at all 1=Several days 2=More than half the days 3=Nearly every day

Appendix I.

DEMENTIA SCREENING INTENTIONS

Instructions: The following questions are to better understand your feelings about getting a dementia screening (over the next 3 months). Some of the questions are quite similar, but do your best to respond to each one as a separate question.		
1	I want (or would like) to get a dementia screening at church.	0=Not at all likely 1 2 3 4 5 6=Very Much Likely
2	I am ready to get a dementia screening at church.	0=Not at all likely 1 2 3 4 5 6=Very Much Likely
3	I intend to get a dementia screening at church.	0=Not at all likely 1 2 3 4 5 6=Very Much Likely
4	I am committed to getting a dementia screening at church.	0=Not at all likely 1 2 3 4 5 6=Very Much Likely

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