Early screening for Alzheimer's disease in Persons of the African Diaspora

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Early Screening for Alzheimer’s Disease in Persons of the African Diaspora

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Abstract

African Americans are frequently identified as a cohort of the population at a high risk for developing Alzheimer’s disease. This quality improvement project was developed to assess the feasibility of an intervention to a small group of African Americans about modifiable and nonmodifiable risk factors, early signs and symptoms, benefits of early detection and treatment of cognitive impairment or Alzheimer’s disease. The project provided understanding regarding health promotion and health maintenance initiatives designed for dissemination among African Americans who may be at increased risk for developing Alzheimer’s disease. **Purpose:** The Beat Alzheimer’s Disease by Knowing your Risk and Early Detection initiative was designed to pilot test the self-created pre/posttests and evaluation tool (Watson, 2017) used to educate African Americans about risk factors, the importance of early screening, and the detection of cognitive impairment. **Methods:** This Project was a piloted educational quality improvement initiative in which participants were educated about cognitive impairment. A pretest was given, followed by the educational intervention, then a posttest, and program evaluation. The project was conducted in collaboration with a community health district and a church in Hamden, Connecticut. **Results:** Scores on the posttest ($M = 13.1$, $SD = 1.45$) were higher than the scores on the pretest ($M = 11.5$, $SD = 3.21$). The knowledge scores were not significant, with the one-tail $t$ test ($9) = 1.35$, and $p = .105$. **Conclusion:** The Beat Alzheimer’s Disease by Knowing your Risk and Early Detection and the program evaluation tool completed by the project participants provides positive guidance for a larger project in the future.

**Keywords:** African American and dementia, Alzheimer’s disease, cognitive impairment, Alzheimer’s disease treatment, African Diaspora, prevention of Alzheimer’s disease and cultural difference
Introduction

Intermittent moments of forgetfulness are occurrences that happen in the normal process of aging, but cognitive impairment is not normal aging (Alzheimer Society Canada [ASC], 2015). Alzheimer’s disease has become one of the diseases that disproportionately affects African American more than any other ethnic group in the United State of American (Chin, Negash, & Hamilton, 2012; Prince, Prina, & Guerchet, 2013).

The literature shows African Americans are significantly more at risk for cognitive impairment than White Americans (Prince et al., 2013). Although the incident of Alzheimer’s disease is 13.9% for all Americans age 71 and older, it is 21.3% in individuals of the African Diaspora, and 11.2% among Whites (Chin, Negash, & Hamilton, 2012). In comparison to other races and ethnic groups, people of African descent and Latinos (many of whom are descendants of people from the African Diaspora) are affected with an earlier onset of this disease at a younger age (Griffith & Lopez, 2009; Rajan, Wilson, Weuve, Barnes, & Evans, 2015; Schneider, Kennedy, Wang, & Cutter, 2015). In addition, the signs and symptoms of Alzheimer’s disease are reported to be more severe in individuals who are affected by the disease at an age younger than age 65 (Schneider et al., 2015). Although the disease is reported to be more rampant in the African American population (Alzheimer’s Association, n.d.), some African Americans believe Alzheimer’s disease is primarily a White disease (Howell et al., 2015). Additionally, the literature indicates that although religious beliefs play a significant role in the lives of African Americans coping with and caring for a loved one with an illness, these beliefs also make some less likely to seek appropriate medical care for diseases such as Alzheimer’s disease and cancer (Howell et al., 2015; Ochoa-Frongia, Thompson, Lewis-Kelly, Deans-McFarlane, & Jandorf, 2012). Alzheimer’s disease is considered an invisible epidemic among some African Americans.
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(Alzheimer’s Association, n.d.). In addition, even cognitive impairment experts have reported difficulties identifying Alzheimer’s disease in this cohort of individuals (Clark et al., 2005; Griffith & Lopez, 2009).

The population of interest for this quality improvement project is African Americans living in the Quinnipiack Valley Health District (QVHD) of Hamden, Connecticut, USA. African Americans include individuals who are descent from Africa and the movement in historic time of people from Africa, predominantly to the Americas and other areas around the globe. This population will be referred to interchangeably as African Americans, persons, people or individuals of the African Diaspora.

**Background**

The disease is identified interchangeably as dementia, cognitive impairment or Alzheimer’s disease (Alzheimer’s Disease International [ADI], 2015). The first known patient was diagnosed in 1901 with a lack of short-term memory or cognitive impairment by Alois Alzheimer. She was 51 years of age (Biography [Bio], 2016). Her diagnosis was confirmed by a brain biopsy to be “senile dementia” (Bio, 2016, p. 1). The diagnosis was confirmed by a brain autopsy following her death in 1906, which demonstrated shrinkage of her cerebral cortex and the presentation and formation of tangles and plaques (Bio, 2016). The research finding of “senile dementia” was confirmed by Solomon Carter Fuller, a medical student researcher (Alzheimer’s Association, n.d.; BlackPast, 2017).

There are greater than five million individuals living in the United States with Alzheimer’s disease (Alzheimer’s Disease Association [ALZ], 2016). In 2013, Alzheimer’s disease became the sixth leading cause of death in the United States (U.S. Department of Health and Human Services [HHS], 2010). In 1995, it was the 14th leading cause of death for all Americans combined.
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(Hoyert & Rosenberg, 1997). The prevalence of Alzheimer’s disease is projected to steadily increase through 2050 to more than 15 million (Prince, Prina, & Guerchet, 2013; ALZ, 2016; ALZ 2017). Additionally, the rate of increase is greater among African Americans (Prince et al., 2013; ALZ, 2016). The Alzheimer’s Association (n.d.) identified Alzheimer’s disease among African Americans as a “silent epidemic” (Alzheimer’s Association, n.d., p. 2).

Moreover, many persons of the African Diaspora lack basic knowledge about cognitive impairment (Clark et al., 2005; Griffith & Lopez, 2009; Howell et al., 2015). Individuals with the disease are often stigmatized and seen as psychiatric patients because of the prominent personality changes which are dissimilar to the presentation of the disease in their White counterparts (Griffith & Lopez, 2009; Holston, 2005). Also, the difference in presentation makes it more difficult for them to participate in clinical trials about cognitive impairment (Holston, 2005). African Americans are more frequently misdiagnosed, and research has shown that it takes an average of two to seven years for them to be correctly diagnosed with the disease, even when assessed by neurologists, and experts in the field (Clark et al., 2005; Griffith & Lopez, 2009). They are also more likely to be placed on psychiatric medications than on the U.S. Food and Drug Administration approved medications used to treat the symptoms of Alzheimer’s disease (Filshtein, Beckett, Godwin, Hinton & Xiong, 2016). Research data indicate that this practice is more prevalent among persons of color who receive their care in national Alzheimer’s disease clinical centers (Filshtein et al., 2016). For those patients who are diagnosed, only approximately 40% are correctly and timely placed on approved cognitive impairment medications (Clark et al., 2005; Griffith & Lopez, 2009). One study showed that African Americans and Hispanics with Alzheimer’s disease are overwhelmingly prescribed Aricept instead of Exelon when compared with their White counterpart (Perryman, Lewis, & Rivers,
In addition, African Americans prescribed Aricept are also routinely diagnosed with diabetes and psychiatric disorders as well (Perryman et al., 2009).

Bassil and Grossberg, 2009 found many individuals of the African Diaspora were not knowledgeable about their risk factors for the disease associated to genetics, one’s environment and lifestyle. African Americans are reported to have more arteriolar sclerosis and atherosclerosis than their White counterparts which has the potential for placing persons of African descent at a greater risk for cognitive impairment (Barnes et al., 2015). The cardiac profile of African Americans which include hypertension, cardiovascular disease, and diabetes are reported to be potentially associated with a greater rate of the disease. The cardiac profile of a large segment of the African American population predisposes them to two types of Alzheimer’s disease one that is associated to vascular disease, and another called a mixed presentation (Akinleye et al., 2011; Barnes et al., 2015). The mixed presentation type of Alzheimer’s disease includes the evidence of Lewy body dementia, infarctions and other cardiovascular abnormalities (Akinleye et al., 2011; Barnes et al., 2015) such as “more severe arteriolar sclerosis and atherosclerosis” (Barnes et al., 2015, p. 528).

In addition, healthcare providers are reported not to be well informed about the increased risk or the unique presentation of cognitive impairment in individuals of the African Diaspora (Griffith & Lopez, 2009). Healthcare professional are also unfamiliar with the early personality changes exhibited by persons of the African Diaspora with cognitive impairment (Holston, 2005), which is one of the reasons for the misdiagnosis with psychiatric conditions such as depression, schizophrenia and anxiety disorder (Griffith & Lopez, 2009).

The Affordable Care Act (ACA) of 2011 mandates an annual cognitive impairment assessment of Medicare recipients at their annual wellness visit (AWV). There is also an
established standard of care for individuals age 65 and older with cognitive impairment (Agency for Healthcare Research and Quality [AHRQ], 2014), but there is no approved standard of care for populations with Alzheimer’s disease younger than age 65 (AHRQ, 2014). In addition, there is no systematic process established to educate African Americans and Hispanics who are predisposed to the disease or programs promoting prevention of the disease among these populations. The World Health Organization (WHO) assesses prevention to be the vital link in health and disease management (The Alzheimer’s Disease/CDC Health Brain Initiative, 2013-2018; WHO, 2017). Similar to, the American Cancer Society (ACS) which has demonstrated the importance of early screening and detection aligned with timely treatment increased survival rates among many types of commonly occurring cancers (ACS 2015; WHO, 2017). Also, outcomes from other projects indicated that early screening and detection, education, modification of lifestyle may slow or delay the onset of cognitive impairment and the addition of appropriate treatment has the potential to delay the progression of the disease (MCC, 2004). In addition, Eichler et al., (2015) confirmed that early screening and diagnosis of cognitive impairment has the potential to improve the quality of life for individuals that are at risk for cognitive impairment. The evidence also stressed the importance of connecting patients and their caregivers with available community resources (Danner, Smith, Jessa & Hudson, 2008).

**Problem Statement**

The increased risk for the early onset of Alzheimer’s disease among those of the African Diaspora is indicated by health data confirming that their quality of life is affected by rapid cognitive impairment, inability to plan for their future, increased family stress and denial of the disease. This risk is mediated by increased patient, caregiver, and health provider knowledge of population-specific risk factors and earlier screening starting before the age of 65.
Organizational “Gap” analysis of project site.

Alzheimer’s disease among individuals of the African Diaspora is associated to their less than healthy cardiovascular profile (Barnes et al., 2015; Chin et al., 2012) and genetic factors (ALZ, 2016). The high prevalence of hypertension, diabetes, and obesity are some of the modifiable risk factors that place African Americans at an increased risk for cognitive impairment (Barnes et al., 2015). When all races and ethnic groups in the United States are combined and compared, older African Americans have the highest rate of Alzheimer’s disease or cognitive impairment, which is 21.3% vs. 11.2% for all cases in the United States (Chin et al., 2012). African Americans have an earlier onset of cognitive impairment than their White counterparts, and their symptoms are more severe (Griffith & Lopez, 2009; Schneider, Kennedy, Wang, & Cutter, 2015). The disease has reached epidemic level among people of African descent (Alzheimer’s Association, n.d.), Yet, many African Americans lack the awareness about cognitive impairment and the early signs and symptoms of Alzheimer’s disease (Clark et al., 2005; Griffith & Lopez, 2009). In African American communities Alzheimer’s disease is typically not openly discussed because of the stigma related to the disease (Holston, 2005). The incident of Alzheimer’s disease seems to be associated with the people of African Diaspora’ less than optimal cardiac health profile that includes high rates of heart disease, stroke, hypertension, diabetes, and obesity (Barnes & Bennett, 2014; Chin et al., 2012).

The annual death rate from heart disease is 23.8% among African Americans compared to 23.5% for all races and ethnicities in the United States (CDC, 2015). Also, approximately 40% of persons of African descent have uncontrolled hypertension and high cholesterol (Centers for Disease Control and Prevention [CDC], 2014). The rate of diabetes is about 77% higher among African Americans when compared to White Americans (Centers for Disease Control and
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Prevention [CDC], 2016). Data indicate that about one-third of African Americans with Alzheimer’s disease is attributed to diabetes mellitus (Luchsinger, Tang, Stern, Shea, & Mayeux, 2001). Obesity is also reported to be significantly represented among the African American population. Greater than 74% of African Americans are overweight or obese (The State of Obesity [The State of Obesity], 2014). Heart disease, hypertension, diabetes, obesity, and stroke are modifiable risk factors which are overrepresented among individuals of the African Diaspora and are all associated with Alzheimer’s disease (Barnes et al., 2015).

The health disparity related to Alzheimer’s disease diagnosis and treatment are complex and multifactorial (Clark et al., 2005; Griffith & Lopez, 2009). The complexities for the health disparity include but not limited to a lack of healthcare providers’ knowledge about cognitive impairment among persons of the African Diaspora, the presenting signs and symptoms of the disease, racism, misdiagnosis, delay initiation of appropriate treatment, and a lack of a defined standard of care for persons younger than age 65 having Alzheimer’s disease (AHRQ, 2013; Clark et al., 2005; Danner et al., 2008; Griffith & Lopez, 2009). The current cost for treating Alzheimer’s disease is greater than 230 billion dollars annually, which is projected to more than double by 2050 (ALZ, 2016). For persons of the African Diaspora that makes up slightly over 13% of the United States population in 2012, the financial burden for cognitive impairment was greater than 71 billion dollars. (Gaskin, LaVeist, & Richard, 2013). The evidence shows Medicare cost for providing medical care to African Americans associated with Alzheimer’s disease is significantly higher than the cost for White Americans with the disease because African American patients live longer with the disease (US Health and Human Services [HHS], 2014).

This quality improvement project (Watson, 2017) was developed to educate the selected population about the early onset of signs and symptoms, modifiable risk factors for the disease
EARLY DETECTION OF ALZHEIMER’S DISEASE (Bassil & Grossberg, 2009), and the importance of early screening and detection. This quality improvement project aimed to enhance awareness about Alzheimer’s disease to a small group of African Americans and to determine the feasibility of the intervention for future application to practice. The outcomes from previous projects affirmed that a program involved in community outreach, early screening, and advocacy might be an excellent approach to increase awareness about cognitive impairment in the African American community (Chin et al., 2012; Chin, Walters, Cook, & Huang, 2013; Danner et al., 2008). The outcomes from this initiative will also lay the groundwork for the implementation of a larger quality improvement project that may lead to the development of a standard of care for African Americans and other populations affected with Alzheimer’s disease before the age of 65.

This quality improvement project is appropriate for the Christian Tabernacle Baptist Church (CTBC) and the surrounding neighborhood because of the impact of Alzheimer’s disease on the congregation. The pastor and other members of the congregation have or had family members who are living or have passed after several years of living with Alzheimer’s disease, K. King and K. Martin (personal communication, June 27, 2017). The African American church has a long tradition of promoting health, self-advocacy, community outreach and alliances with community resources (Barnes, 2011) to enhance the lives and well-being of its members. In contrast, the QVHD, last community health assessment, conducted in 2016 revealed that this African American community was not engaged with the Department of Health’s wellness promotional programs (Quinnipiack Valley Health District, 2017).

One ways of promoting and instilling change is the involvement of an internal or external change agent (Barnes, 2011). The African American church was selected for the implementation of this project, because of the vital role this entity plays in the lives of African
Americans (Trader-Leigh, 2008). The African American church has been an effective change agency that promotes personal, social, political, and health-related changes in the lives of African Americans (Trader-Leigh, 2008); for this reason, the CTBC was selected for this pilot quality improvement initiative. The initiative was designed to educate and promote behavioral changes in African Americans related to their risk for cognitive impairment and Alzheimer’s disease. The use of the CTBC was an appropriate venue, because of its location and the church’s involvement in the community.

**Review of the Literature**

A search of the literature was conducted for Alzheimer’s disease in combination with African Americans and dementia, Alzheimer’s disease, cognitive impairment, Alzheimer’s disease treatment and people of the African Diaspora, prevention of Alzheimer’s disease and cultural differences. Also, a search for evidence-based preventative interventions was done using the following databases: The Institute of Medicine, Cochrane, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, and Allied Health Literature. The terms used for all the searches separately and in combination included: African American and dementia, Alzheimer’s disease, cognitive impairment, Alzheimer’s disease treatment, prevention of Alzheimer’s disease, African Diaspora, and cultural differences.

Data specific to persons of African descent, cognitive impairment, dementia and Alzheimer’s disease was limited. Several of the articles were old, one English title appeared appropriate, but came from a study conducted in Brazil, and the results were published in Portuguese. Another study that appeared ideal which involved diverse ethnic and cultural populations had to be eliminated because it was a Chinese study and no English translation was found. Based on the body of recent knowledge about dementia and Alzheimer’s disease
and new biomarkers specific to the disease, attempts were made to use research articles from 2006 through 2017. All the articles used were in English. Three older articles (Clark et al., 2005; Hoyert & Rosenberg, 1997; Luchsinger et al., 2001) were selected for inclusion, because of the pertinent research evidence addressed. The Clark et al., (2005) article highlighted the hindrances to diagnosis of cognitive impairment in African Americans. One of the significant impediments identified was the knowledge deficit about the disease by healthcare professionals (Clark et al., 2005). These healthcare providers were said to be unaware of the early onset of Alzheimer’s disease as well, and the specific signs and symptoms in African Americans (Clark et al., 2005). The correlation of diabetes to Alzheimer’s disease and other dementias was affirmed by (Luchsinger et al., 2001). The Luchsinger et al. (2001) work was considered significant because of the early evidence and association of diabetes to cognitive impairment in the 4.3-year follow-up longitudinal study (Luchsinger et al., 2001). The work by Hoyert and Rosenberg (1997) is included because of the historical timeline it gives related to the rapid rise of Alzheimer’s disease to the sixth leading cause of death in the United States. No editorials or op-ed articles were included.

In summary, 31 articles were retrieved, of which 14 were eliminated, because they did not seem relevant to the subject of interest. Approximately 75% (N = 23) of the articles were primary research while the other 25% (N = 8) were classified as secondary research.

The 17 articles selected for inclusion in this project are associated with risk factors related to dementia, Alzheimer’s disease, and disparities associated with diagnosis and treatment of cognitive impairment among people of the African Diaspora (Clark et al., 2005; Chin et al., 2012; Griffith & Lopez, 2009). One of the studies shows people of African descent tend to have more severe arteriolar sclerosis and atherosclerosis. However, they are more likely to have mixed
brain pathologies (Barnes et al., 2015). One of the studies confirmed the use of antipsychotic medications in Alzheimer’s disease type treatment setting was 10% higher among individuals of African and Hispanic descents, especially among young males (Filsheim et al., 2016).

The works of the American Cancer Society (2015), Eichler et al. (2015), MCC, (2004), and Weimer and Sager (2009) are included because they supported the benefits of early screening, diagnosis and treatment for patients, the loved ones, and the society. The annual cancer statistical values and trend magnify importance of early detection and treatment (American Cancer Society, 2015), related to the execution of early screening, diagnosis, and treatment that have changed the survival rates and the quality of life for persons with cancer. Schneider et al., 2015 and Eichler et al., 2015 stressed the importance of early screening and detection for individuals with a younger age of onset of Alzheimer’s disease. The research also revealed a slower decline for persons who get the disease when they are more advanced in age, whereas the younger the person with the disease the more severe the symptoms (Musicco et al., 2009; Schneider et al., 2015). The outcome of this study underscores the need for early screening, diagnosis and implementation of appropriate Alzheimer’s disease treatment (Schneider et al., 2015). The article from the World Health Organization focus was on prevention and wellness; it explained the different levels of prevention and their definitions is a part of the selected articles (World Health Organization [WHO], 2015).

The research by Clark et al., (2005) was the first study of its kind to comprehensively look at the impediments to treatment for African Americans with Alzheimer’s disease or cognitive impairment. The study stated that it takes about two years before being correctly diagnosed (Clark et al., 2005). However, Griffin and Lopez (2009), found the duration before diagnosis was approximately seven years. They also confirmed that the misdiagnosis occurred
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even when patients were seen by neurologists who are said to be experts in the field (Griffith & Lopez, 2009; Clark et al., 2005). Significant time was given by Griffith and Lopez (2009), about healthcare professionals who are unaware about the presenting signs and symptoms of people of the African Diaspora with cognitive impairment. The study confirmed that this population is frequently diagnosed with psychiatric disorders and are not promptly placed on appropriate treatment, if medically indicated (Griffith & Lopez, 2009).

Bassil and Grossberg (2009) focused their reviews on risk factors for Alzheimer’s disease relating to genetics, environment, and lifestyle. They reported that the component of one’s mental, social and the level activity of an individual is positively associated with an increased risk for dementia or Alzheimer’s disease. The cancer factors and figure document reported the annual figures related to the incidence and prevalence of different types of cancer and their survival rates. The outcome of this work affirmed the importance of early screening, diagnosis, and treatment and the remarkable potential these activities have had in the increase of cancer survival rates for many cancers, especially breast cancer (American Cancer Society, 2015). The same process applied to cognitive impairment, have the potential to increase the quality of life for individuals affected by the disease (Peterson, 2009). The other article (World Health Organization [WHO], 2015) provided definition and explanation about the different levels of prevention, which are primary, secondary and tertiary. Griffith and Lopez (2009) went through a data review process and delineated where the gaps were in relationship to care and health disparities being faced by Hispanics and persons of African descent with dementia or Alzheimer’s disease.

The Schneider et al., (2015) work discussed one of the significant limitations of the Mini Mental Status Examination (MMSE), which is reported not to be sensitive to educational
attainment as noted in the works of Clark et al., (2005) and Griffith & Lopez, (2009). Getting a lower score on the MMSE also confirmed a positive correlation to developing Alzheimer’s disease as noted by both Rajan et al. (2015) and Schneider et al. (2014). These studies showed that lower MMSE scores were predictors of who would get Alzheimer over a period of 18 years (Guerrero-Berroa et al., 2009; Rajan et al., 2015). The incident of Alzheimer’s disease was also higher for the African descent study participants who acquired the disease which was at 23% while the persons of European descent study participants only reflected a 17% rate of the disease (Rajan et al., 2015). An interesting element about the study is the population ages ranged from between ages 61-85 because younger persons of African and Hispanic descents are having cognitive impairment at an alarming rate at a younger age (Alzheimer’s Association, n.d.; ALZ, 2016; Schneider et al., 2015). The results inferred that the younger study participants who did not do well could also have been treatment resistant, while the older study participants were treatment responsive (Schneider et al., 2015).

Based on the health disparity that exists among the two largest ethnic populations in the United States with this disease, Perryman et al., (2009) set out to validate whether patients of African and Hispanic descents are treated differently regarding how Alzheimer’s medications are prescribed to them. This study identified that Blacks and Hispanics might not be given all the medications that are federally approved for the treatment of cognitive impairment (Perryman et al., 2009). These two groups of patients were more frequently given Aricept and not Exelon or other dementia medications (Perryman et al., 2009). The use of psychiatric medications was noted to be more frequent with persons of African descent who receive their treatment from community clinics. The Filshtein et al., (2016) study confirmed that about 10% of African American patients are routinely placed on psychiatric medication, although they have
Alzheimer’s disease or cognitive impairment (Filshtein et al., 2016). Also, it was noted that African American patients who were younger and were males received a higher percentage of psychiatric medication (Filshtein et al., 2016).

The selected participants were reported to have lower knowledge attainment about Alzheimer’s and their risk factors are higher than their White counterparts (Holston, 2005). Some older people of African descent tend to believe Alzheimer’s disease is a part of normal aging and have the attitude, that it is God’s will for them to have the disease (Howell et al., 2015). Therefore, individuals of the African Diaspora may be more accepting of taking care of a family member with the illness instead of placing them in a skilled nursing facility (Howell et al., 2015).

This population’s extensive less than robust cardiac profile place them at increased risk for cognitive impairment. The vascular medical conditions such as diabetes, cardiovascular disease, hypertension, heart disease, obesity and other social determinants of health might have an association to the high prevalence of this disease in this population (Barnes et al., 2015). Compounding the situation is the lack of a documented standard of care for early screening and diagnosis of this disease in the persons of African descent or other ethnic groups and populations that get Alzheimer’s disease or cognitive impairment at an age younger than 65 years of age (AHRQ, 2013).

In summary, the evidence demonstrates that persons of the African Diaspora have (a) a higher prevalence of cognitive impairment at an earlier age and the symptoms are more severe (Perryman et al., 2009; Rajan et al., 2015; Schneider et al., 2015) (b) African Americans tend to lack knowledge about the disease and the early signs and symptoms (Howell et al., 2015), and (c)
there is no mandate for early screening, diagnosis and treatment, although doing so may increase the quality of life for individuals at high risk for cognitive impairment (Schneider et al., 2015). This project was vital in educating individuals of the African Diaspora in Hamden, Connecticut of regarding their risk factors for cognitive impairment, the importance of early screening and diagnosis, initiation of treatment and how-to advocacy for themselves and their families relates to this life-altering disease (ALZ, 2016).

**Evidence-Based Practice: Verification of Chosen Option**

The project, Beat Alzheimer’s Disease by Knowing your Risk, and Early Detection started with the introduction of the Doctor of Nursing Practice (DNP) student identifying herself to the potential project participants as the facilitator of the quality improvement initiative. The initiative was explained in full regarding why they were being asked to participate (see Appendix G). All persons (N = 12) presented to participate in the initiative were allowed to take part, because they met the project inclusion criteria. The informed consent was then reviewed with the participants and they were individually asked to sign the consent if they still wanted to participate after all their questions were answered. The consent was obtained from all (N =12) participants. They then completed the participant enrollment sheet which collected selected demographic and health information (see Appendix H). The project participants were then instructed to complete a pretest to determine their knowledge of cognitive impairment/Alzheimer’s disease. Next, a 45-minute Power Point educational presentation was presented to inform the participants about modifiable and non-modifiable risk factors, and signs and symptoms associated with cognitive impairment. They were also provided a brief overview about Alzheimer’s disease treatment and community resources such as the Alzheimer’s Disease Association and QVHD. A posttest was administered within 30 minutes after-completion of the
educational Power Point presentation to assess participants’ knowledge about Alzheimer’s disease. After completing the posttest, participants were asked to complete a project evaluation. At the conclusion of the project, each participant was presented with a $10.00 supermarket gift card in appreciation for their time and participation.

**Theoretical Framework/Evidence-Based Practice Model**

The goal of Beat Alzheimer’s Disease by Knowing your Risk, and Early Detection is to improve the awareness, screening and early detection of cognitive impairment in the selected community of individuals of the African Diaspora, while also encouraging these individuals to make healthier choices pertaining to their modifiable risk factors for the disease (Bassil & Grossberg, 2009). The White’s (1982) Construct for Public Health Nursing conceptual model was selected for use based on the model’s broad base reach about population-focused practice (Bigbee & Issel, 2012). This public health nursing theory embodies the framework of public health. The theory promotes healthy living, and the implementation of interventions that protect or delay the onset of diseases, and activities that aim at the restoration of health, as feasible (Bigbee & Issel, 2012). The focus is on four distinct categories which are: human biology, environmental determinants of health, “medical/technological/organizational” (Current Nursing, 2012, p. 5) and the social construct (Current Nursing, 2012). This pilot initiative served to evaluate the evidence and feasibility of implementing a larger community-based project. The educational presentation informed the participants about specific early signs and symptoms of Alzheimer’s disease, their risk factors for the disease, those that are modifiable (Bassil & Grossberg, 2009) and those that cannot be changed (Alzheimer’s Association, n.d.; ALZ, 2016). The participants were informed about the importance of annual cognitive impairment assessment by their primary healthcare provider. The literature indicates that as this and any group becomes
more comfortable in speaking about an illness openly it is likely that the stigma associated with the disease may decrease and early detected increase (American Cancer Society, 2015; Holston, 2005). The participants also learned how to advocate for themselves and their family within the healthcare system and were informed of valuable community resources such as the Alzheimer’s Association, American Heart Association, American Diabetes Association, and the services they provide to individuals, groups, and communities. This model served as the underpinning for implementing the strategy of Plan/ Do/Study/Act (PDSA).

**Goals, Objectives and Expected Outcomes**

The outcome of this project is to educate and increase the awareness of African Americans regarding Alzheimer’s disease, using the pre/posttests Alzheimer’s knowledge assessment tool (Watson, 2017) and the program evaluation survey. The participants’ knowledge of the early signs and symptoms of cognitive impairment was assessed with a pretest before the Alzheimer’s disease educational intervention. A posttest was administered within one-half hour following the implementation of the educational intervention. Participants were informed regarding the process and importance of early screening and detection of cognitive impairment. The project was implemented in one two and one-half hour meeting. There were no official breaks, but participants were encouraged to get up, move about and have some refreshments. The outcome of the project is the results from the pre/posttests and satisfaction evaluation survey.

**Project Design**

The Shewhart cycle or the Plan Do Study Act (PDSA) model was used to implement this quality improvement project. This plan is widely used for its problem-solving and quality
improvement assessment capabilities (Joshi et al., 2014). The quality project “Plan” was to implement a process of empowering persons of the African Diaspora ages 50 through 64 to be knowledgeable about their risk factor for Alzheimer’s disease and to know the early signs and symptoms of the disease. The approach focused on three areas; outreach, screening and advocacy based on the nursing intervention wheel (Minnesota Department of Health Division of Community Health Services Public Health Nursing Section [MDH], 2001). The population of focus was African Americans between 50-64 years of age, based on the earlier onset of the disease in this cohort (Griffith & Lopez, 2009; Schneider et al., 2015). The behavioral change of the African American participants would demonstrate more openness in speaking about cognitive impairment in a public setting and committing to request an annual cognitive assessment evaluation from their primary healthcare provider. The “Do” was aimed at increasing participants’ awareness about the importance of early screening and diagnosis of persons of African descent with cognitive impairment. The “Study” (Improvement Initiative) was done in collaboration with the Quinnipiac Valley Health District (QVHD), Christian Tabernacle Baptist Church (CTBC), residents of city of Hamden or members of the CTBC which is located in Hamden. The successful implementation of the project and analysis of the outcome was done over approximately five months. The “Act” of this project was to modify the initiative tools if indicated by the outcome of the implementation of the piloted project (Joshi et al., 2014). The benchmark was done by comparing pretest and post test results and determining whether or not the evaluation tool captured the essence of the program accurately. This process will be in alignment with the patient/caregiver Health Risk Assessment (HRA) at the patient’s Medicare/Medicaid Annual Well Visit (AWV) for patients’ age greater than 65 years of age (Cordell et al., 2013).
The relationship to optimal health and wellbeing is early screening and diagnosis of any disease (Satizabal et al., 2016; Schneider et al., 2015). The need for early screening, diagnosis and treatment is essential for Alzheimer’s disease as well, especially since cognitive impairment starts greater than ten years before the disease has visible evidence (Rajan et al., 2015; Satizabal et al., 2016; Schneider et al., 2015). Therefore, having an ongoing project like this initiative may prove helpful in informing and educating African Americans about cognitive impairment, beyond the implementation of this project. At this time, there is currently no established standard of care to address the early onset of cognitive impairment/Alzheimer’s disease in this population. The approach used in this initiative may help make African Americans more comfortable in speaking about cognitive impairment while increasing their knowledge about the disease process versus normal aging, self-advocacy, early screening and diagnosis and the initiation of treatment when indicated (Vickrey et al., 2006).

The Project Participant Enrollment Sheet was used to collect selective demographic and medical data from the project participants. A facilitator developed Alzheimer’s disease knowledge assessment pre- and posttests and a program evaluation survey. See (Appendices B, C, G, and H).

**Project Site and Population**

The project was piloted in collaboration with the QVHD, and implemented at the CTBC, in Hamden, CT., in the community where the population resides or attends church. The project was facilitated by a Doctor of Nursing Practice (DNP) student from the University of Massachusetts-Amherst in partnership with the Director of the QVHD. The program was implemented in a large conference room, with tables placed in a square so that participants could
see and interact with each other. The conference room equipment was used to project the Power Point Presentation during the implementation of the initiative. The Power Point Presentation took approximately 35 minutes, and the entire project was implemented in about two hours and 15 minutes. The topics covered included the signs and symptoms of Alzheimer’s disease, modifiable and non-modifiable risk factors for the disease, the reasons for early screening and detection, treatment, and discussion QVHD and the Alzheimer’s Disease Association as community resources.

This initiative was implemented in Hamden, CT, one of the four towns that make up the QVHD. The city has approximately 60,000 residents of which almost 19.5% (11,869) are persons of African descent (City Data, 2015). Hamden is the most populous of the four towns in the health district. In the region of the town where the initiative was implemented, most individuals of African descent are clustered along the border of the city line closer to New Haven, CT where most of the individuals receive their hospital and specialized healthcare services (Connecticut Official State Website [CT.gov], n.d.). The median annual income for the area most populated by the persons of African descent is approximately $66,000. The cost of living index is greater than 139 which is estimated to be high since it is 100 for the country (City Data, 2015).

This quality improvement project represents a pilot initiative to determine the feasibility of implementing this project in the future with a larger population. The target population was individuals of the African Diaspora, ages 50-64 who were residents of Hamden CT or attended the CTBC located in Hamden, CT. The sample size for this project was 12 participants, based on previous recommendations for pilot studies of using 10% or 10-40% of the population intended for a future larger initiative (Hertzog, 2008; Connelly, 2008). The major ethnic groups in the town
of Hamden include White 64%, African Americans 19.5, Hispanics 8.7% and Asians 5.4% (City Data, 2015). Education attainment for the cohort reflects 27.3% graduated from high school, 34.3% has some college or an associate college degree, while 28.3% has an undergraduate degree or higher. Hamden is primarily a city that relies on retail and a thriving restaurant industry. There is one community college and one University in Hamden, and there are no major industries beyond nursing homes and doctors’ offices (City Data, 2015).

The inclusion criteria for participation in this project included: the ability to give written or verbal consent, being a person of African descent; being between the ages of 50-64; resides in Hamden or attends the CTBC, can commit to a two and one-half hour program; and are able to complete the pre/posttests, and the end of program evaluation survey independently or with minimal assistance. For minimal assistance, questions were read to participants who required assistance. Exclusion criteria were: persons who do not identify themselves as persons of the African Diaspora; younger or older than age 50-64 for project participants; does not live in Hamden, CT or attend the CTBC; and cannot complete the pre/posttests and the end of program evaluation survey independently or with minimal assistance. All project activities were completed in about two hours and 15 minutes.

**Setting Facilitators and barriers.** This quality improvement project was conducted at the CTBC located at 425 Newhall Street, Hamden, Connecticut 06517. The church is a significant entity in the African American community and the promotion of health and healthy lifestyle changes (Trader-Leigh, 2008). This church is also in the center of the African American community and is engaged in many types of health promotional activities for the members of the church and the community. The facilitators for the project were a doctoral student from the University of Massachusetts-Amherst, for the fulfillment of her DNP graduation requirement
along with the Director of the QVHD and the CTBC Health Coordinator Deacon Kimberly Martin. A verbal announcement about the pilot quality improvement project was made in several Sunday morning services, after IRB approval. The project was also advertised in the church bulletin. The church’s Health Coordinator also kept a running list of individuals who had expressed and interested to participate in the initiative. Not having direct contact with the project participants until the date of implementation of the project was a significant barrier.

Leslie Balch, Director of QVHD who served as mentor for the project was supportive of the initiative A meeting was held on July 15, 2017, with Deacon Kimberly Martin, Health Coordinator and Reverent Keith King, Senior Minister of the CTBC. They expressed excitement about the proposed pilot Alzheimer’s disease initiative because of the number of families in the church and the church community dealing with the disease.

**Implementation Plan/Procedures**

After receiving IRB approval, project specific documents such as the informed consent, participants’ information sheet, pre/posttests, and the program evaluation survey were duplicated. The QVHD and the CTBC were contacted and informed of the IRB approval which had been obtained on November 6, 2017, to conduct the pilot quality project. Although the project’s duration was projected to take approximately 12 weeks, from IRB approval to the dissemination of the outcome it took about eight weeks longer than projected. Therefore, the project timelines were modified to accurately reflect the duration of the project. All program tasks with project participants were completed in a single visit. The visit lasted approximately two hours and 15 minutes. All 12 participants were informed about the quality improvement project and if they had no questions or concerns about the project they were invited
to sign the informed consent. After signing the informed consent, the quality improvement project activities were implemented. Participants were asked to complete the participants’ information sheet followed by the administration of the 15-item Alzheimer’s disease pretest. The educational Power Point presentation about Alzheimer’s disease was presented with time given for questions and answers and impromptu discussions initiated by the participants.

The Power Point presentation took approximately 35-minutes to inform the participants and potential caregivers about the risk factors, signs and symptoms and their association to common disease processes which have plagued the African Americans population at disproportional rates such as heart disease, cardiovascular accidents, hypertension, diabetes, and obesity for many years (Barnes et al., 2015). The presentation addressed the difference between normal aging and dementia, the importance of early screening and detection (Nauert, 2015), and the importance self-advocacy. This was paramount considering the early onsent of the disease and the lack of a standard of care for individuals getting Alzheimer’s disease before age 65 (AHRQ, 2013; Clark et al., 2005; Griffith & Lopez, 2009). The initiative participants were made aware of the QVHD and the Alzheimer’s Disease Association for connection and continued support after the project was over.

The 15-item posttest was administered within 30 minutes after the educational presentation to assess participants’ knowledge of cognitive impairment. Lastly, the participants were asked to complete a 10-item Likert program evaluation survey.

The evaluation phase includes the review and official documentation of the quality improvement project in a scholarly paper to fulfill the graduation requirement of the DNP student of the University of Massachusetts-Amherst.
Budget

This project was implemented over a period of five months or 20 weeks and involved a total of two healthcare professionals: the Doctor of Nursing Practice (DNP) student who was the facilitator of the quality improvement project and the Director of the QVHD, and the DNP student’s practicum preceptor. The largest cost associated with this project task/item was the $10.00 supermarket gift certificates and copying of the project-specific documented used in the implementation of the initiative. All contributed by the DNP student. Refreshments were made available by the CTBC and QVHD for participants to serve themselves. Please see Appendix D (Budget) for associated project cost.

Timelines

The timelines covered approximately five months from IRB approval, the project’s initiation, data collection, evaluation of initiative outcome, sharing of the information and publication of a scholarly paper. See (Appendix F).

Ethics and Human Subjects Protection

The project received IRB approval on November 6, 2017, from the University of Massachusetts-Amherst Institutional Review Board (IRB). The protection, privacy, and rights of each participant was ensured from the consenting of each participant and throughout the data collection process, review, and analysis. All data collected are maintained in a secured locked file with access only to the DNP student who was the primary facilitator of the project. All actions were implemented to maintain the security and confidentiality of the participants’ collected information for the project. Please see the informed consent form in Appendix G, and the project participant’ enrollment sheet in Appendix H.
Outcomes

Project Participants Demographic Data

The demographic data are reflected in Table 1, and subsequent tables. Eleven participants were female (91.7%) and one male (8.3%), and all identified themselves as African American as specified by the inclusion criteria. It was encouraging that 66.7% of the participants were college graduates. However, from this small group 41.7% reported having hypertension and 66.7% were overweight.

Table 1

*Frequency Distributions for Age, Gender, Marital Status, Education, and Medical Conditions (N=12)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-54</td>
<td>3</td>
<td>25.0</td>
</tr>
<tr>
<td>55-59</td>
<td>5</td>
<td>41.7</td>
</tr>
<tr>
<td>60-64</td>
<td>4</td>
<td>33.3</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Women</td>
<td>11</td>
<td>91.7</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>3</td>
<td>25.0</td>
</tr>
<tr>
<td>Married</td>
<td>6</td>
<td>50.0</td>
</tr>
<tr>
<td>Divorced or separated</td>
<td>3</td>
<td>25.0</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Some college</td>
<td>3</td>
<td>25.0</td>
</tr>
<tr>
<td>College graduate</td>
<td>8</td>
<td>66.7</td>
</tr>
<tr>
<td>Medical conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High blood pressure</td>
<td>5</td>
<td>41.7</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Heart disease</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Overweight</td>
<td>8</td>
<td>66.7</td>
</tr>
</tbody>
</table>
Data Analysis

A paired $t$-test was conducted to determine if participants’ knowledge scores increased after the educational intervention. The one-tail $t$-test showed a slight increase in knowledge scores on the post test, but the increase was not significant, $t (9) = 1.35, p = .105$. The analysis included 10 paired pre/posttest. Although the difference was not statistically significant, participants’ scores on the posttest ($M = 13.1, SD = 1.45$) were higher than their scores on the pretest ($M = 11.5, SD = 3.21$). Two factors may have made statistical significance less likely. First, the sample size was small and second the average scores on the pretest were high (11.5 out of a possible 15). One participant did not complete the pretest and one participant did not complete the posttest, therefore there were only ten matched pairs.

Pilot Initiative Evaluation

The evaluation questions were divided into items that evaluated knowledge and items that evaluated the effectiveness of the educational intervention. The average distribution for both knowledge and effectiveness of the educational intervention was positive from all participants that responded ($N=11$).

Table 2

*Frequency Distributions for Questions Evaluating Knowledge ($N=12$)*

<table>
<thead>
<tr>
<th>Knowledge Evaluation Questions</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I learned a lot about Alzheimer’s disease and dementia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Agree</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>10</td>
<td>83.3</td>
</tr>
<tr>
<td>There are risk factors for Alzheimer’s disease that one can change or delay</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Agree</td>
<td>2</td>
<td>16.7</td>
</tr>
</tbody>
</table>
I can now list some of the risk factors for Alzheimer’s disease.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9</td>
<td>75.0</td>
</tr>
</tbody>
</table>

Being active, maintaining a normal blood pressure and making proper food selection might decrease or delay the onset of Alzheimer’s disease.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>8.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Agree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
<td>16.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9</td>
<td>75.0</td>
</tr>
</tbody>
</table>

There is a cure for Alzheimer’s disease.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9</td>
<td>75.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
<td>16.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>8.3</td>
</tr>
</tbody>
</table>

Early detection of Alzheimer’s disease is just as important as detecting or knowing you have any other diseases.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>8.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Agree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
<td>16.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9</td>
<td>75.0</td>
</tr>
</tbody>
</table>

Signs and symptoms of Alzheimer’s disease in African Americans and Hispanics may be different from other races with the disease.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
<td>16.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>8.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Neutral</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
<td>16.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Agree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>41.7</td>
</tr>
</tbody>
</table>

Average knowledge evaluation

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>8.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Neutral</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>8.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Agree</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10</td>
<td>83.3</td>
</tr>
</tbody>
</table>

Table 3

Frequency Distributions for Questions Evaluating Effectiveness of Educational Intervention (N=12)

<table>
<thead>
<tr>
<th>Effectiveness Evaluation Questions</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The topics and presentations covered were relevant to my family and me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Disagree</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Neutral</td>
<td>2</td>
<td>16.7</td>
</tr>
</tbody>
</table>
Agree 1 8.3
Strongly Agree 7 58.3
This program makes me feel more comfortable to speak about Alzheimer’s disease.
Neutral 1 8.3
Agree 6 50.0
Strongly Agree 5 41.7
I will speak to my healthcare providers about being screened each year for Alzheimer’s disease.
Strongly Disagree 1 8.3
Neutral 2 16.7
Agree 1 8.3
Strongly Agree 8 66.7
Average effectiveness evaluation
Disagree 1 8.3
Neutral 1 8.3
Agree 5 41.7
Strongly Agree 5 41.7

Discussion

The purpose of this quality improvement initiative, Beat Alzheimer’s Disease by Knowing your Risk and Early Detection was to educate African Americans about their potential risk factors for Alzheimer’s disease and the importance of early screening, detection and treatment. The project outcome will provide insight into educating African Americans about cognitive impairment in the implementation of the project in a larger population of African Americans. As noted in the literature review African Americans tend to be more comfortable in caring for their loved ones with Alzheimer’s disease at home, rather than placing them in the nursing home (Howell et al., 2015). The participants expressed their appreciation for the information they were provided. The project also allowed them to ask questions and speak openly in a safe and nonjudgement environment about cognitive impairment and about dealing with family members with cognitive impairment. The interaction of the participants appeared to
have affirmed the outcome of one work reviewed which indicated that this type of forum enriches the learnings of African Americans about Alzheimer’s disease (Schneider et al., 2015). The opportunity to collaborate with the church to provide education and health promotion was an excellent way to empower a population about a disease in an environment that is safe and assuring to African Americans.

Ten of the participants are members of or attend the CTBC regularly, but initially, they were not aware of the magnitude of what each other was dealing with as it pertains to cognitive impairment. Some were dealing with family members while others had fears about themselves becoming forgetful. The remaining two participants live in the town of Hamden but do not attended the church. They heard about the project through the facilitator of the initiative. The program participants spoke openly and freely about their specific situation.

The sample was small, but the data indicated a slight increase in knowledge gained following the educational intervention. Only ten matched pairs of scores were available for analysis, because one participant did not complete the pretest and another did not complete the posttest. The outcome was not statistically significant $t(9) = 1.35, p = .105$. The participants’ scores on the posttest ($M = 13.1, SD = 1.45$) were higher than their scores on the pretest ($M =11.5, SD = 3.21$). Two factors that may have made a statistical significance less likely were; first, the sample size was small, and second, the average scores on the pretest were high (11.5 out of a possible 15).

**Limitations**

The sample size was a limitation, there were 12 participants. One participant did not complete the pretest and one participant did not complete the posttest. This further decreased the
sample size to only ten matched pairs, which might have impacted the robustness the project outcome. The educational intervention could have been enhanced with the distribution of culturally appropriate Alzheimer’s disease materials prepared by the Alzheimer’s Association. To bridge this gap, the PowerPoint educational presentation used in the initiation of project was sent to Deacon Kimberly Martin electronically, for distribution to the ten participants who attend the CTBC. The two participants who live in Hamden, but do not attend the CTBC did not receive a copy of the presentation, because the church does not have their contact information. The project evaluation tool needs to be revised and weighted more on the educational intervention and less on the effectiveness of the presentation of the intervention. Although, the outcomes cannot be generalized, they may provide insight for the development and implementation of a larger project in the future.

Other limitations include the short timeframe within which the project was implemented and evaluated, approximately two hours and 15 minutes. The short time in which the project was conducted did not allow for the evaluation of the participants’ behavioral change toward Alzheimer’s disease over time.

**Conclusion**

Cognitive impairment continues to be a major issue among people of the African Diaspora. Therefore, informing and educating this group about their risk factors and the importance of early screening are important in increasing community awareness which has the potential to improve the quality of life for individuals who might be at risk for the disease (Schneider et al., 2015). Alzheimer’s disease is considered the “silent epidemic” (Alzheimer’s Association, n.d., p. 3) among individuals of African descent (Alzheimer’s Association, n.d.). In
recent years, data have suggested that having a less than ideal cardiac health profile, evident by diabetes, poorly managed hypertension, cardiovascular accidents, and obesity are health conditions which are reported to be associated with the high rate of Alzheimer’s disease among this population (Barnes et al., 2015).

The statistics are compelling related to the earlier onset of cognitive impairment in African Americans (Schneider et al., 2015). In addition, the symptoms are said to be more severe in younger African Americans with the disease (Nauert, 2015; Schneider et al., 2015). Therefore, efforts should be focused on risk awareness programs, promotion of early screening, detection of the disease, and the establishment of a standard of care to address the early onset of the illness (AHRQ, 2013; Eichler et al., 2015; Nauert, 2015). If such a process is established the author believes this could create a groundswell for public discussion and awareness regarding cognitive impairment in African Americans (Nauert, 2015) and help mitigate the impact of Alzheimer’s Disease.
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https://doi.org/10.1056/NEJMoai504327


Appendix A

Theoretical/Conceptual Framework

The Construct of Public Health Model (White, 1982)

- **Societal focus on health to:**
  - Protect
  - Promote
  - Restore

- **Nursing Focus**
  - Achieving &
  - Health maintenance

- **Practice Priorities:**
  - Disease prevention
  - Disease protection
  - Health Promotion

- **Nursing Interventions**
  - Health education
  - Management of risk factors
  - Standard of care for better health
## Appendix B
### Pretest (Assessment)

Alzheimer’s disease Knowledge Assessment: Individuals of the African Diaspora

Please circle True or False to each of the Statements Listed Below

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>True</td>
<td>False</td>
<td>More Whites have Alzheimer’s disease than people who are African Americans.</td>
</tr>
<tr>
<td>2</td>
<td>True</td>
<td>False</td>
<td>Alzheimer’s disease is a part of getting older and happens to people 65 years of age and older only.</td>
</tr>
<tr>
<td>3</td>
<td>True</td>
<td>False</td>
<td>People as young as 30 years old can have Alzheimer’s disease.</td>
</tr>
<tr>
<td>4</td>
<td>True</td>
<td>False</td>
<td>Having high blood pressure might increase a person’s risk for Alzheimer’s disease.</td>
</tr>
<tr>
<td>5</td>
<td>True</td>
<td>False</td>
<td>Having high cholesterol might increase the risk of having Alzheimer’s disease.</td>
</tr>
<tr>
<td>6</td>
<td>True</td>
<td>False</td>
<td>Alzheimer disease may run in families</td>
</tr>
<tr>
<td>7</td>
<td>True</td>
<td>False</td>
<td>There is a cure for Alzheimer’s disease.</td>
</tr>
<tr>
<td>8</td>
<td>True</td>
<td>False</td>
<td>Most African Americans with Alzheimer’s disease live in a nursing home.</td>
</tr>
<tr>
<td>9</td>
<td>True</td>
<td>False</td>
<td>Some medical or dietary problems might make a person act as if he/she has Alzheimer’s disease.</td>
</tr>
<tr>
<td>10</td>
<td>True</td>
<td>False</td>
<td>A person can change some risk factors for Alzheimer’s disease.</td>
</tr>
<tr>
<td>11</td>
<td>True</td>
<td>False</td>
<td>There is no medicine to treat the symptoms of Alzheimer’s disease.</td>
</tr>
<tr>
<td>12</td>
<td>True</td>
<td>False</td>
<td>The early signs and symptoms of Alzheimer’s disease are the same for Whites African Americans and Hispanics.</td>
</tr>
<tr>
<td>13</td>
<td>True</td>
<td>False</td>
<td>Alzheimer’s disease does not run in families.</td>
</tr>
<tr>
<td>14</td>
<td>True</td>
<td>False</td>
<td>Alzheimer’s disease is God’s will for everyone who has it, so there is nothing one can do about it.</td>
</tr>
<tr>
<td>15</td>
<td>True</td>
<td>False</td>
<td>Someone with Alzheimer’s disease might believe a person is trying to hurt them, hiding or stealing their belongings.</td>
</tr>
</tbody>
</table>
Appendix C
Posttest (Assessment)

Alzheimer’s disease Knowledge Assessment: Individuals of the African Diaspora
Please circle True or False to each of the Statements Listed Below

<table>
<thead>
<tr>
<th>Post-Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong></td>
</tr>
<tr>
<td><strong>2</strong></td>
</tr>
<tr>
<td><strong>3</strong></td>
</tr>
<tr>
<td><strong>4</strong></td>
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<tr>
<td><strong>5</strong></td>
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<tr>
<td><strong>6</strong></td>
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<tr>
<td><strong>7</strong></td>
</tr>
<tr>
<td><strong>8</strong></td>
</tr>
<tr>
<td><strong>9</strong></td>
</tr>
<tr>
<td><strong>10</strong></td>
</tr>
<tr>
<td><strong>11</strong></td>
</tr>
<tr>
<td><strong>12</strong></td>
</tr>
<tr>
<td><strong>13</strong></td>
</tr>
<tr>
<td><strong>14</strong></td>
</tr>
<tr>
<td><strong>15</strong></td>
</tr>
</tbody>
</table>
Appendix D
Budget

All costs, direct or indirect are included in the cost-analysis below:

- One DNP student 10 hours = $0.00
- $10.00 Supermarket gift cards x 12 = 120.00 (one for each participant)
  Light refreshments contributed by the CTBC and QVHD

**Grand Total = $127.62** (tax included)

The materials needed include: Coping
- Participants’ Information Sheet 2 x 0.10 x 12 = $2.40
- Informed consent 4 x 0.10 x 12 = $4.80
- Pretest 12 x 0.10 = $1.20
- Posttest 0.10 x 12 = $1.20
- Satisfaction survey 12 x 0.10 = $1.20

**Total = $10.80**

Data collection and entry cost associated with the completion of the consenting of participants:
- One DNP student 5 hours = $0.00

**Total = $0.00**

Mileage traveling back and forth from Wallingford, CT to Hamden, CT (contributed)
- **Total = 0.00**

**Grand Total = $138.42**
## Appendix E
### Simplified Project Timelines

<table>
<thead>
<tr>
<th>Task</th>
<th>Wks. 1-9</th>
<th>Wk.10</th>
<th>Wks. 11-13</th>
<th>Wks. 14-15</th>
<th>Wks.16-20</th>
</tr>
</thead>
<tbody>
<tr>
<td>IRB Approval</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administrative Activities</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recruitment of eligible participants</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtaining of Informed consent if indicated</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-test</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-Minute Power Point Presentation</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-test</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction Evaluation Survey</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analyze Collected Data</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Present Topline Result to QVHD</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Write Scholarly Paper</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Appendix F
Project Evaluation Survey

Next to each item below, please circle the number that best shows your satisfaction with the Alzheimer’s Disease by Knowing your Risk Factors and Early Detection” presentation.

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>The topics and presentations covered were relevant to my family and me.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>I learned a lot about Alzheimer’s disease and dementia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>There are risk factors for Alzheimer’s disease that one can change or delay.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>This program makes me feel more comfortable to speak about Alzheimer’s disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>I can now list some of the risk factors for Alzheimer’s disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>Being active, maintaining a normal blood pressure and making proper food selection might decrease or delay the onset of Alzheimer’s disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>There is a cure for Alzheimer’s disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>Early detection of Alzheimer’s disease is just as important as detecting or knowing you have any other diseases.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>I will speak to my healthcare providers about being screening each year for Alzheimer’s disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number</th>
<th>Meaning</th>
<th>Signs and symptoms Alzheimer’s disease in African Americans and Hispanics may be different from other races with the disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Strongly Disagree</td>
<td>1.</td>
</tr>
<tr>
<td>2</td>
<td>Disagree</td>
<td>2.</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
<td>3.</td>
</tr>
<tr>
<td>4</td>
<td>Agree</td>
<td>4.</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Agree</td>
<td>5.</td>
</tr>
</tbody>
</table>
Appendix G
Consent Form for Participation in a Quality Improvement Project
University of Massachusetts Amherst

Researcher(s): Jean Swinney, Ph.D., RN, FAAN, Faculty Sponsor, and Olive Joyce Watson, RN, MPH, UMass-Amherst DNP Student, and Leslie Balch, RN, MPH, Director of Quinnipiack Valley Health District (Clinical Practicum Site)

Quality Improvement Project Title: Early Screening for Alzheimer’s Disease in Persons of the African Diaspora

Funding Agency: N/A

1. WHAT IS THIS FORM?
This form is called an Informed Consent Form. It will give you information about the quality improvement project so you may decide if you wanted to take part or not in this quality improvement project. This quality improvement project is being done to come up with an easy way to inform African Americans about Alzheimer’s disease. This project will be done in partnership with the Quinnipiack Valley Health District (QVHD), located at 1151 Hartford Turnpike, North Haven, CT 06473. The quality improvement project will be conducted at the Christian Tabernacle Baptist Church, located at 425 Newhall Street, Hamden, CT 06517. Throughout this informed consent, the word project will be used to identify ”quality improvement project.”

This informed consent form will give you the information you need to know about why this project is being done and why you are being asked to take part. It will also describe what you need to do to participate and any known risks, inconveniences or discomforts that you may experience while taking part. Please take some time to think this over and ask questions before you decide to participate and at any other time afterward. If you choose to participate, you will be invited to sign this form, and you will be given a copy for your record.

2. WHO IS ELIGIBLE TO PARTICIPATE?
The project participants will be a total of 10 adults, male and female who are:

- 50-64 years of age,
- Be of African descent,
- Live in Hamden, CT or attends the Christian Baptist Tabernacle Church in Hamden, CT,
- Can complete the pre-and post-tests and survey or response to each test/survey questions if read by someone.

3. WHAT IS THE PURPOSE OF THIS PROJECT?
The purpose of this project is to assess the participants' knowledge about Alzheimer’s disease using a new pre/posttests developed for African Americans and to have the participants evaluate the project. These activities will help the creator of this project to determine if this project can be implemented with African Americans who may be at risk to have Alzheimer’s disease.
4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?
This project will take place at the Christian Tabernacle Baptist Church, located at 425 Newhall Street, Hamden, CT 06517. You will be asked to commit to one (1) two and one half-hour timeslot from the beginning to the completion of this project.

5. WHAT WILL I BE ASKED TO DO?
If you agree to participate, you will be asked to give your permission by signing this document called an informed consent before you can take part in the project. You will then be assigned a number that will be used to identify you in this project. No personal information that can identify you will be collected. You will be asked for the following:

- The year you were born
- Your race
- Your gender/sex
- Your marital status
- The highest grade of school completed.
- If you live in Hamden or attends the Christian Tabernacle Baptist Church

You will be asked to do the following:

- Read and sign this informed consent form
- Complete a 15-item true and false quiz about Alzheimer’s disease
- Listen/watch a 45-minute slide presentation about Alzheimer’s disease
- Complete the same 15-item true and false quiz about Alzheimer’s disease
- Complete a 10-item multiple choice project evaluation.

Note: You may skip any question you feel uncomfortable to answer.

You can choose to or not to participate in this educational project.

6. WHAT ARE MY BENEFITS OF BEING IN THIS PROJECT?
You may not directly benefit from this project; however, the hope is, your participation may provide valuable information for the conduct of a larger project that could improve how African Americans are educated about Alzheimer’s disease.

7. WHAT ARE my RISKS OF BEING IN THIS PROJECT?
There are no known risks associated with this project. However, the 2½ hours needed to complete this project might be an inconvenience for you. There is also the likely risk of loss of privacy and potential for a breach in confidentiality by taking part in this project.

8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?
The following procedures will be used to protect the confidentiality of your records. Each project participant will be assigned a three-digit identification (ID) number that will be affixed to all documents associated with each project participant. The ID numbers will be assigned in order
EARLY DETECTION OF ALZHEIMER'S DISEASE

(example: 001, 002, and 003). No identifiable personal information will be collected. All information will be collected on paper which will be kept in a locked file cabinet with access only to the University of Massachusetts-Amherst DNP student. The DNP student will maintain the project records including, the signed informed consent forms, subject ID code, enrollment sheet, completed pre/posttests and project evaluation and data codes in a securely locked cabinet with access only to the DNP student. The paper documents will be destroyed after the review of the outcome of the project. All electronic files such as databases and spreadsheets will contain no identifiable information and will be password protected. The computer hosting these files will also be password protected to prevent access by unauthorized users. Only the Massachusetts-Amherst DNP student will have access to the project records. After this project, the DNP student and team may publish the findings. Information will be presented in summary format, and you will not be identified in any publications or presentations. The outcome of the project will be released to the University of Massachusetts-Amherst School of Nursing in a formal paper for the fulfillment of the DNP student requirement for graduation, the Quinnipiack Valley Health District (QVHD), and the CTBC for their records.

9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THIS PROJECT?
You will not receive payment. You will receive a $10.00 Price Right gift certificate at the end of the project for participating in appreciate to you sharing your time. Refreshments (water, soda, and chips) will be available for you to serve yourself, as desired.

10. WHAT IF I HAVE QUESTIONS?
Please take your time in deciding if you want to take part in this project. All your questions will be answered before you participate in this project. If you have further questions about this project or if you have a project-related problem, please contact Olive Watson at 203-627-9946 or Jean Swinney at 413-545-2703. If you have any questions concerning your rights as a project participant, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.

11. CAN I STOP BEING IN THIS PROJECT?
Yes, you can stop taking part in this project at any time. If you agree to take part, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide to no longer participate.

12. WHAT IF I AM INJURED?
The University of Massachusetts-Amherst does not have a policy for compensating project participants for injury or complications related to human project participation. If needed, project personnel will assist you in getting assistance/treatment.

13. SUBJECT STATEMENT OF VOLUNTARY CONSENT
By signing this form, I agree to enter this project voluntarily. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.
Participant Signature  Print Name  Date

By signing below, I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

Signature of Person  Print Name  Date
Obtaining Consent
Appendix H
Project Participant Enrollment Sheet

Project Name: Early Screening for Alzheimer’s Disease in Persons of the African Diaspora

Participant’s Year of Birth ____________  Project Assigned ID: ____________

Have you given consent to participate in this study (select one)?

0 = Yes
1 = No

Age: (Select one age range):

1 = 50-54
2 = 55-59
3 = 60-64

Gender (Sex – Select one):

0 = Male
1 = Female

Ethnicity/Race (select one):

1 = African American/Black
2 = White/Caucasian
3 = Hispanic
4 = Other

Marital Status (select one):

1 = Never married
2 = Married
3 = Divorce or separated
4 = Widow/widower

Level of education completed

0 = Did not complete high school
1 = High school graduate
2 = Some college
3 = College graduate

Do you have any of the following medical conditions (select all that apply)?

1 = High blood pressure
2 = Diabetes
3 = Heart disease
4 = Stroke
5 = Overweight
Appendix I
University of Massachusetts Amherst IRB Approval

Certification of Human Subjects Approval

Date: November 6, 2017
To: Olive Watson-Coleman, Nursing
Other Investigator: Jean Elizabeth Swinney, Nursing
From: Lynnette Leidy Sievert, Chair, UMASS IRB

Protocol Title: Early Screening for Alzheimer's Disease in Persons of the African Diaspora Protocol ID: 2017-4307
Review Type: EXEMPT - NEW Paragraph ID: 2
Approval Date: 11/06/2017 Expiration Date: 11/05/2020
OGCA #: 00003909

This study has been reviewed and approved by the University of Massachusetts Amherst IRB, Federal Wide Assurance # 00003909. Approval is granted with the understanding that investigator(s) are responsible for:

Modifications - All changes to the study (e.g. protocol, recruitment materials, consent form, additional key personnel), must be submitted for approval in e-protocol before instituting the changes. New personnel must have completed CITI training.

Consent forms - A copy of the approved, validated, consent form (with the IRB stamp) must be used to consent each subject. Investigators must retain copies of signed consent documents for six (6) years after close of the grant, or three (3) years if the study is unfunded.

Adverse Event Reporting - Adverse events occurring in the course of the protocol must be reported in e-protocol as soon as possible, but no later than five (5) working days.

Completion Reports - Notify the IRB when your study is complete by submitting a Final Report Form in e-protocol.

Consent form (when applicable) will be stamped and sent in a separate e-mail. Use only IRB approved copies of the consent forms, questionnaires, letters, advertisements etc. in your research.

Please contact the Human Research Protection Office if you have any further questions. Best wishes for a successful project.
EARLY DETECTION OF ALZHEIMER'S DISEASE

Objective
- What is Cognitive Impairment
- Risk Factors for the Cognitive Impairment
- Signs and Symptoms vs. Normal Aging
- Importance of Early Screening and Detection
- Diagnosis and Treatment
- A Call to Action
- Community Resources

What is Cognitive Impairment
Cognitive impairment is a mental stage when someone has a problem remembering new information, thinking, or making decisions about daily living. Someone could have mild or very bad memory problems (Centers for Disease Control and Prevention [CDC], 2011).

Risk Factors for the Cognitive Impairment
- Unchangeable risk factors for cognitive impairment:
  - Age: Developing this disease doubles every five years after one reaches 65 years of age.
  - Family history and genetics - If your mother/father or sister/brother has the disease your risk of getting the disease is two to three times more likely.
  - Genetic risk increases when more than one primary family member has Alzheimer’s disease (CDC, 2011).

What is Cognitive Impairment
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Risk Factors for the Cognitive Impairment
- There are risk factors that we can work on to delay the getting cognitive impairment and here are others we cannot change.
- Changeable risk factors are:
  - Diet:
    - Medical conditions (diabetes, stroke, heart disease and etc.)
    - Lifestyle (physical and mental inactivity)
  - Social/environmental factors
  - Possible education deprived population (Baile & Grossberg, 2009, CDC, 2011).

Risk Factors for the Cognitive Impairment
- Evidence indicates the high blood pressure, stroke, diabetes and being overweight might be some of the reasons why cognitive impairment is high among Blacks, Alzheimer’s Disease Association (ALZ, 2016).
- The rate of the disease ranges from 14% to almost 100% higher in people of color when compared to whites (ALZ, 2016).
- There is a greater familial risk association among people color vs. than among Whites (ALZ, 2016).
- An individual with a history of high cholesterol or high blood pressure is twice as likely to develop cognitive impairment after the age of 45 (ALZ, 2016).
EARLY DETECTION OF ALZHEIMER'S DISEASE

Risk Factors for the Cognitive Impairment

- High cholesterol & blood pressure are speculated as significant risk factors for cognitive impairment in Blacks (ALZ, 2016).
- In persons with both high cholesterol & blood pressure, it may be necessary to achieve lower levels of blood pressure to become healthier (ALZ, 2016).
- Level of education: People who have not completed a college level and higher level of education are at a higher risk for cognitive impairment (ALZ, 2016).

Signs and Symptoms of Cognitive Impairment

- African Americans tend to present with more Parkinson's symptoms such as:
  - Tremors
  - Hallucinations
  - Poor sleeping pattern (Barnes et al., 2015).

Cognitive Impairment vs. Normal Aging

- Poor judgment and decision making vs. making a bad decision once in a while.
- Inability to manage a budget/money vs. missing a bill or monthly payment.
- Losing track of time and/or seasons vs. forgetting what date it is and remembering later.
- Problems with word finding in speaking and writing vs. sometimes forgetting which word to use (ALZ, 2016).

Cognitive Impairment vs. Normal Aging

- Mislaying things and unable to retrace steps to find them vs. losing things from time to time.
- Difficulty understanding visual images and spatial relationships vs. vision changes related eye problems (cataracts).
- Difficulty completing familiar tasks at home, work, church and/or activities associated with hobbies vs. the occasional need for assistance with such things like the TV and/or microwave (ALZ, 2016).

Cognitive Impairment vs. Normal Aging

- Having memory changes which disrupt daily life: especially in recent learned information vs. sometimes forgetting names or appointments but remembering them later.
- Withdrawal from work or social activities vs. sometimes feeling weary about work, family and other social obligations.
- Note changes in mood and personality vs. some flexibility with changes (ALZ, 2016).

Screening and Detection

- Discover treatable medication conditions that contribute to the disease:
  - Vitamin B12 deficiency
  - Thyroid problem
  - Mood change
  - Anxiety and depression etc.
- Knowing allow patients and their family to be more protective about:
  - The way forward plan of care
  - Behavioral changes (Barnes et al., 2015).
**Screening and Detection**
- Knowing allow patients and their family to be more proactive about (Cont.)
  - Development of management plan
  - Financial planning
  - Development of end of life plan
  - Loss the flow of patients and family members
- Having a complete medical and mental check up
- Initiation of the right treatment (Benson et al., 2013)

**Diagnosis and Treatment**
- There are no definitive imaging or laboratory tests for the diagnosis of Alzheimer's disease when a patient is alive.
- Definitive diagnosis is made by an autopsy of the brain, which occurs after the patient's death.
- The autopsy will reveal brain changes that take more like the normal disease in the brain, tendons, and muscles in the body.
- In 2013, the U.S. Food and Drug Administration drug Advisory Panel approved Avonex (interferon beta-1b), a beta interferon that can help to delay the onset of symptoms.

**Diagnosis and Treatment**
- Alzheimer's disease is currently diagnosed by a process of elimination. The team might include:
  - Primary care doctor
  - Neurologist (neurologist): doctor
  - Interpreter who deals with aging (geriatrician)
  - Psychiatrist and social worker (multidisciplinary team)
- The team will collect and review information from the following sources to determine the diagnosis:
  - A thorough medical history of the patient and their family history
  - An assessment of the patient's mental and physical status
  - Psychological assessment and testing
  - A neurological examination and assessment
  - Lab tests and brain scans.

**Diagnosis and Treatment**
- Currently, there is no cure or any drug to modify the course of Alzheimer's. But drug and non-drug treatments may help with both cognitive and behavioral symptoms.
- The U.S. Food and Drug Administration (FDA) has approved two types of medications for cognitive impairment: (a) for cognitive impairment, symptoms (but not the disease itself).
- These drugs affect the activity of two different chemicals involved in carrying messages between the nerve cells of the brain (Alz. Org. Research Center [Alz.Org.], 2017).

**Approved medications for Cognitive Impairment**
EARLY DETECTION OF ALZHEIMER'S DISEASE

Approved Medications for Cognitive Impairment

- Donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl) are all donepezil-type acetylcholinesterase inhibitors.
- Donepezil decreases the process that transfers memory from the hippocampus to other areas of the brain.
- Galantamine targets the hippocampus and improves memory function.

Stages of Cognitive Impairment

1. Normal: mild cognitive impairment, the disease becomes more severe over time.
2. Mild: moderate cognitive impairment, the disease becomes more severe over time.
3. Moderate: severe cognitive impairment, the disease becomes more severe over time.

A Call to Action

- The National Alzheimer's Association is a national organization that provides resources and support for families affected by Alzheimer's disease.
- The Alzheimer's Association provides a range of services, including support groups, educational resources, and funding for research.
- Family members affected by Alzheimer's disease are encouraged to join support groups and seek resources from the Alzheimer's Association.

People of African Descent in the Field of Alzheimer's Disease Researchers

- Dr. Collie Byrd is the Nathan P. Sims Endowed professor of biology at North Carolina A&T State University.
- Dr. Collie Byrd is a prominent researcher in the field of Alzheimer's disease.

A Call to Action

- We need to increase awareness in our communities of the signs and symptoms of Alzheimer's disease.
- We need to demand that professionals develop and expand affordable culturally appropriate services, including assessment tools.
EARLY DETECTION OF ALZHEIMER'S DISEASE