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Adverse Childhood Experiences and its Association with Cognitive Impairment in Non-Patient Older Population

Mohini D. Dutt

University of South Florida, mohinidutt@mail.usf.edu

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Adverse Childhood Experiences and its Association with Cognitive Impairment in Non-Patient Older Population

by

Mohini D. Dutt

A thesis submitted in partial fulfillment of the requirement for the degree of Master of Arts Department of Anthropology College of Arts and Sciences University of South Florida

Major Professor: Daniel Lende, Ph.D. Theresa Crocker, Ph.D. David Himmelgreen, Ph.D.

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Keywords: memory, Alzheimer’s disease, applied anthropology, translational research, Montreal Cognitive Assessment

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DEDICATION

This thesis is dedicated to my community of supporting mentors, friends and family, without whom, the completion of my master’s degree would not have been possible. I have had the endless support of the USF Department of Anthropology, USF Health Byrd Alzheimer’s Institute and USF Department of Psychiatry and Neurosciences, who provided me a friendly space and their expertise to help build the foundation for this study. To my mentors, Dr. Daniel Lende, Dr. Theresa Crocker and Dr. David Himmelgreen, who believed in my capacity and showed unending support through all the barriers faced during the development of this study. I thank Dr. Daniel Lende for being the best advisor I could have asked for throughout my master’s program. Thank you for continuing to broaden my understanding of research in truly applied anthropology and medicine, through your mentoring as well as your own work as a researcher. I am thrilled to continue using those newly learnt perspectives in my career in research ahead. To Dr. Theresa Crocker, I could not be happier to have been first introduced to you through the memory screening program. Thank you for always showing unwavering belief in my abilities, even beyond this thesis, and continuing to inspire me with your humble yet strong leadership. I thank Dr. David Himmelgreen for his expertise in the field and his constant support in building my research idea from its initial stages. In conclusion, my parents and my sister have always been my source of strength through all my experiences. I grow to appreciate and love them more every day.
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ABSTRACT

This study explores cognitive impairment and its correlation to early-life adverse experiences in non-patient population between the ages of 50 to 65. This developmental approach and observational study design explores cognition in pre-clinical Alzheimer’s disease (AD). Using a standardized neuropsychological instrument, the Montreal Cognitive Assessment (MoCA) and clinically administered questionnaire, the ACE (Adverse Childhood Experiences), I hypothesized that participants with high ACE scores will inversely have low MoCA scores.

My goal was to use a multiple linear regression model with 3 covariates and 1 predictor of interest (ACEs). At 80% power, a sample size of 40 was calculated as needed. This would mean that the results would have 80% chance of declaring statistical significance. This corresponds to an R-squared value (percentage of variation in MoCA score explained by the predictor) of 17.2%. The desired sample size was not attained successfully due to several barriers in receiving sample data from the collaborating site and the 2017 Hurricane Irma causing a drop in participation rate. Overall 13 participants had successfully participated. The analysis of the results is demonstrated in a line graph indicating a relationship between ACE and MoCA scores. The accuracy of the descriptive statistics could be argued against due to the low sample size. The analysis of the ethnographic interviews brings out some trends in the participant responses. The focus here has been to discuss these responses as to how they advocate for the entanglement theory of aging. In other words, how
the exposure to social and environmental factors at various stages of an individual’s lifecourse can interact with one’s physiology, resulting in exposure-specific health conditions at later life stages. Among the period of exposure, my focus through this study is specifically on the early exposures in the lifecourse. This is facilitated by the use of the ACE questionnaire regarding exposures to adverse experiences such as sexual/physical abuse, familial mental health issues, alcohol/drug abuse in the family and loss or separation from parents. The entanglement theory further allows for race or culture specific exposures to adversity that raises the question of varying health consequences among cultural or racial groups and the need for a more critical approach in providing access to healthcare and healthcare policy development. Trends in ethnographic results obtained have allowed for the critical discourse in the transgenerational effects of social adversity, effects of resilience-building from adversity and the need for care-giver mental health services.

The study brought out critiques on how the ACE module could be made more inclusive of experiences specific to diverse cultures and regions, as well as the need to address the severity of individual experiences. We conclude by discussing how effects of social or environmental experiences can be used toward AD and aging research and what supporting literature and initiatives currently exist. The discussion is also inspired by the existing political discourse around the medicalization of AD and how that influences the reductionist methods in AD research. This new direction of applied and holistic approach derives its perspective from neuroanthropology and applied medical anthropology. The overall aim of this study is to ask questions challenging existing research methods with the ultimate hope to newly influence the allocation of AD research and risk reduction toward interdisciplinary focus and funding, involving early-life lived experiences and life course
perspectives.
CHAPTER ONE:
INTRODUCTION

Research in Alzheimer’s disease (AD) is moving toward addressing and understanding heterogeneous risk factors throughout one’s lifecycle. Recent literature points out that just like many other medical conditions, the nomenclature for diagnosis of AD is under constant review and shift in focus, especially over the last three decades. Research and clinical trials are refocusing on primary prevention, that is, the identification and intervention on risk factors much before the manifestation of the disease (Soloman et. al. 2014). There is thus a growing body of literature encouraging the need for development of methodologies that identify and target the populations most likely to undergo exposure to these risk factors, creating a higher chance for “therapeutic success” (Dubios et. al. 2016). More recently, focus of primary prevention has broadened into a life course approach, where the development of dementia and mild cognitive impairment (MCI) are targeted as the prior stages to the development of AD. This strategy has looked at how early and modifiable lifestyle behaviors and social experiences interact with the body’s physiology as part of the aging process, which further differs between cultures and ethnicities (Cadar 2017). My aim was to study such early interactions and encourage the use of holistic methods of investigation and interventions such as translational research and neuroanthropology methods.

One of the four new guidelines issued by the National Institute on Aging and the U.S. National Institute of Health establishes research in preclinical AD. This new guideline has
focused on research in early exposures to risk factors of the disease, during which, no clinical symptoms of AD are detected in a potential patient (Sperling et. al. 2011, “Clinical Criteria for Alzheimer's Diagnosis” 2016). A study has reported higher statistical significance in those who have experienced maternal death between the age of 11 and 17, to later develop AD. Child abuse has also been shown to be correlated with poorer physical and mental health as an adult (Albert, 2015). Another study has explored the difference in effects of early childhood adversity compared to ‘recent negative life events’ in being associated with decline in cognitive functions in ages 65 to 85 years (Korten et. al. 2014). It was reported that those who experienced early childhood adversities showed a decline in cognitive functions accelerated by 10 years in comparison to those that faced events later in life. This was especially significant in those that experienced symptoms of depression during and because of their early life event (Korten et. al. 2014).

**Early life adverse experiences and life course research**

Environmental exposures for an individual can be of three kinds, namely, pathogenic exposures, nutritional access and mortality risks (Georgiev et. al. 2014). These exposures early in life can affect the development of innate and acquired immune functions via ‘recourse allocation trade-offs’ where external exposure can affect variation in immune functions later in life. This variation may be a way of coping with the environment that the individual is exposed to and thus can be studied under an ‘evolutionary life perspective’. In other words, certain exposures can divert development of relevant function that enables the body to adapt (Georgiev et. al. 2014). The study conducted by Georgiev et. al., concluded that the early exposures tend to affect the women in terms of their innate and men in terms of their acquired immune functions.
More specifically, early life psychosocial stress such as loss of a parent/sibling or parental absence may also cause for functional trade-offs (Georgiev et al. 2014).

There has been a recent popularization of molecular epigenetics stemming from the former Baker hypothesis that has emphasized the effects of early life adversity during the gestation or early childhood period on the health consequences in the adult (Gowland 2015). Molecular epigenetics has been concerned with the exploration of such effects and consequences of developmental stressors. The consequences leading to “phenotypic plasticity” has also been stated to travel across generations due to “epigenetic modifications”. Studies investigating such effects could aim to understand the origin and progression of a disease from a life course standpoint. Just like socio-economic circumstances can affect across generations, experiences and risk factor exposures early in life could lead to changes in physiology (Gowland 2015). Evolutionary and life course perspective on trade-offs between exposures and health outcomes has also been applied to research in osteoporosis. This has been studied based on the exchanges between the bone health of a woman and her reproductive health (Madimenos 2015). Thus, studies like the ones cited above have recently utilized the concepts of life course trade-offs to study the origins and progressions of a health outcome based on recognition of risk factors.

‘The Impact of Early Life Trauma on Health and Disease: The Hidden Epidemic’ examines the connections between childhood trauma and conditions such as cardiovascular diseases, obesity, liver disease, depression to name a few (Lanius et al. 2011). These conditions among others have contributed the most to current rates of mortality and morbidity in the USA. Researchers have been increasingly exploring neuroregulatory systems that are hypothesized to form connections between emotional trauma and molecular level pathways. The ACE study was carried on a large scale supported by the Center for Disease Control...
(CDC) at the Kaiser Permanente’s Department of Preventative Medicine, San Diego as a prospective study (Lanius et. al. 2011).

The ACE study, today a major and growing epidemiological study, originally was part of a weight loss program that used non-surgical methods to help its participants lose a large amount of weight (Lanius et. al. 2011). On experiencing substantial amounts of study dropouts and on digging deeper, it was recognized that weight loss was associated with much more than just a visual success or failure. One of reasons why obesity has become a growing public health issue extends to social and psychological reasons, including set social guidelines of beauty, taboo and sexuality. Continued research in this area could create opportunities for real world collaboration and application of medical practice, health care policies and applied anthropology (Lanius et. al. 2011).

The ACE questionnaire adopted from the above original study is used to determine the scale and consequences of separate categories of adverse social and mental health experiences on health outcomes with increasing age (Murphy et. al. 2016, Howe et. al. 2015, The ACE Pyramid, 2016). The scale determines the presence and quantifies the following categories of childhood trauma faced before 18 years of age:

- Emotional abuse
- Physical abuse
- Sexual abuse
- Parental separation or divorce
- Intimate partner violence
- Mental illness of a household member
- Substance abuse by a household member (Murphy et. al. 2016, Howe et. al. 2015, The ACE Pyramid, 2016).
The CDC has roughly determined the framework by which ACE categories affect an individual through their lifecourse. This is demonstrated in the ACE pyramid (See Figure 1) (Murphy et. al. 2016, Howe et. al. 2015, The ACE Pyramid 2016)

![ACE Pyramid](image)

**Figure 1.** “The ACE Pyramid represents the conceptual framework for the ACE Study.”

(The ACE Pyramid 2016)

**Theories that pathologized AD and aging**

Gerontology and the world of Alzheimer’s research was not always as much a disease of interest, government grant-funding and media attention, as seen today (Lock 2013). Margaret Lock, a medical anthropologist, has beautifully gathered the historical assent of medical attention in the late 20th century in AD and the process of aging. *The Alzheimer Conundrum notes* has explained how investigators viewed the process of aging and the conditions that occur along the way, as belonging to a normal or inevitable set occurring in all individuals. However, over time
with the realization of an increasingly growing population of older individuals, studies have predicted that government and insurance company costs toward age-related healthcare will begin peaking. This encouraged researchers to consider the medicalization of those age-related conditions to begin the scientific process of finding a cure. However, theorists and researchers have had two main theories surrounding the need and extent of research power needed toward conditions such as dementia (Lock 2013).

According to researchers that base their investigations on the localization theory, AD and other age-related disorders are inevitable consequences of aging irrespective of the difference in outer environmental factors (Lock 2013). This is popular among those researchers that strictly have a clinically based or basic science related mode of thinking. This mode of thinking is based on a search for a “silver bullet” or standard connection between the brain and manifestation of the disease. Medical anthropologists like Lock have pointed out the dangers of believing in such a search for an ultimate cure. Slightly different, the entanglement theory is based on a complex interplay of environment, society, genetics and pathology. Lock has called the clash of these two theories as a “revitalized and reformulated nature/nurture debate” (Lock 2013).

**The gradual move toward prevention**

Conditions like dementia, at some point had a partial pathological identity where some investigators believed it to be a natural result of aging that could not be cured or controlled (Lock 2013). However, there was a growing group of investigators that looked more deeply into findings that suggested a difference in aging outcomes based on exposures during one’s life course. The gap in knowledge lied in the fact that not all individuals that were found to contain plaques (beta-amyloid plaques are linked to the causation of AD) went on to develop cognitive
impairment or AD (Lock 2013). Thus, the question of what protects those individuals remained unanswered. Here we have noticed a shift in attention from looking for a cure to searching for ways to age in a healthier way, by focusing efforts to create a body of knowledge in prevention.

The age group of the subject population for research thus shifted to the young and middle-aged individuals. Researchers began looking for biomarkers, or molecular substances that predict the possible formation of those diseases. Biomarkers gave way for large screening programs and the hopes for early detection and interventions globally (Lock 2013).

**Making Alzheimer’s disease popular**

Efforts to popularize the importance of such programs however, faced the same issues that efforts in breast and prostate cancer had faced (Lock 2013). Advocates thus began shifting the conversation, to create a sense of taking control of the disease rather than submitting to one’s fate. Efforts were then put into popularizing such an attitude. Here the entanglement theory advocates for attention to external factors throughout one's lifecourse (Lock 2013). Even though the localization theory does call attention to early life risk factors and a specific neurological pathway of disease formation, Lock argued that, the entanglement theory views the disease as an ongoing construction based on continued ‘entanglement’ of life experiences and one’s physiology throughout the life course.

Efforts to grow attention toward the risk of developing AD and to increase government-grants for research recognized the need for plans to politicize the disease. Studies emphasized that the growing older population ran the risk of growth in the number of individuals that required access to healthcare for AD and age-related conditions, creating an increasing social and economic burden on government institutions (Lock 2013). Lock rightly pointed out that political
and public attention to such a cause could only be achieved by popularization in professional and media publications. Newly organized Alzheimer’s advocacy groups started out with their main goal as making AD a disease that called for more public and political attention and not be ignored as an inevitable result of aging. The past four decades had thus seen the increase in medicalization of the disease resulting in an increase in government funded research efforts and an attitude of clinical priority.

**Drawbacks to medicalization of age-related disorders**

This move toward progress in attention has however seen some drawbacks due to the promotion of reductionist viewpoints on the understanding of the disease and the approach for disease research that is promoted by the pharmaceutical companies (Lock 2013). As discussed above, the entanglement theory is widely supported due to its consideration of all factors, internal and external. However, pharmaceutical companies and their sponsored clinical research groups tend to believe in a more localized theory of finding that one answer to cause, prevention and cure. This is done with the outlook and overall agenda to standardize those methods of prevention or cure, to sell them to the masses as a product. This narrow approach takes away from the consideration of “better management” of the risk factors that cause the disease over one’s lifetime of exposure (Lock 2013). More often than never, clinical research sponsored by such companies, knowingly or unknowingly, become part of the system that only believes true medicine to be that which produces replicable solutions to diseases. Researchers have thus, shied away from the thought of risk factors such as social and environmental experiences because these tend to be more variable in nature and non-standardized (Lock 2013). Lock pointed out that this narrow way of understanding can be dangerous in an era that is moving toward the
prevention of disease symptoms, because it keeps taking us farther away from interventions that target the early life risk social, environmental and biological risk factors that negatively affect the continued process of aging, more prominent in populations that are lower on the socio-economic and are not racially privileged.

The collaborated understandings of the neuroanthropologist, evolutionary biologist, clinicians and advocates are needed to promote the understanding of the aging process as continuous throughout one’s lifecourse. This can be used to encourage basic science research and fund- raising activities of advocate groups to broaden their focus on early life experiences. What truly needs to be understood here is that prevention may not necessarily mean a “cure” or an ultimate solution to the disease. Prevention can also be looked upon as an effort to reduce the pace of onset of the age-related conditions by screenings and interventions throughout the lifecycle.

The purpose of this study was to explore pre-symptomatic (preclinical) AD, by looking for potential correlations between early life traumas with impairment in cognitive functions of an individual. This could help bolster the significance of social adversities and truly operationalize the individual lived experience to biological manifestation of diseases. The broader goal was to ask important questions on how research focus and funding in AD may be reallocated to involve interdisciplinary collaboration. In simple terms, this was an observational study to find potential link between adverse childhood experiences and cognitive functioning in non-patient geriatric population, by comparing obtained MoCA and ACE scores.

Combining my own experiences from methods applied in basic sciences research and applied medical anthropology research, my overarching aim for this study was to strive to ask scientific questions differently. By looking through my neuroanthropology glasses, I hope to
challenge the strictly standardizing methods of Alzheimer’s and aging research, who prefer to comfortable shy away from considering the non-standardizable reality of early environmental and social influences on the life course.
CHAPTER TWO:
LITERATURE REVIEW

Introduction

This chapter focuses on bringing together a history of Alzheimer’s disease to provide the reader a background to the arguments made. I believe, from my own experiences in obtaining an education in the basic sciences, that it is common to leave out the history behind the medicalization of a pathological condition. My recently obtained experience in applied medical anthropology was proof enough to encourage me to provide an extensive understanding of how and what have been motivations behind the current status in AD research. My goal is to show how medicalization of a disease is not bereft of politics and biases, and how it all has a place along with society, the environment and individual experiences. My attempt is not only to provide a background of AD, but to open a discussion about its key role as part of the aging process and how AD and other age-related conditions are resultant of an entanglement of exposed factors throughout one’s life course.

Allostatic load / overload in response to adverse childhood experience (ACE)

Chronic exposures to acute stress that give rise to damaging effects are being increasingly studied by researchers through concepts like allostasis and allostatic load. Fields of study such as
aging, epigenetics and effects of socioeconomic inequalities on healthcare are working on understanding the application of these concepts in terms of long-term and short-term implication of adverse childhood experiences (Danese and McEwen 2012).

The current study similarly aims at contributing to cognitive changes associated with varied levels of psychosocial experiences during childhood and adolescents. This area of study is the basis for understanding the effects of allostasis, the extreme or chronic nature of which leads to allostatic load (Danese and McEwen 2012). Daily external and internal changes have the ability to affect adaptive responses in the body triggering changes within a network of neurobiological systems in the body. This network mainly consists of the thalamus, the sensory cortex and amygdala. The most common example of such triggered change is commonly found in the hypothalamus-pituitary-adrenal or the HPA axis giving rise to necessary physiological responses and adaptations connected with the immune system, the endocrine and the nervous systems. Such adaptation is frequent and short-term. A prolonged exposure and adaptive responses by the allostatic systems could have harming consequences (Danese and McEwen 2012).

Research has shown that chronic exposure to allostatic load can have behavioral consequences, negative effects of attention and increase in sensitivity to fear-based emotions. Overall, this chronic exposure to stressful situations and constant activation of the HPA axis has been known to be related to higher output of cortisol, a hormone associated with exposure to stress. Important physiological functions developed under the acquired immune system such as inflammatory pathways and a decreased rate of secretion of insulin have also been known to be progressively affected with prolonged exposures to stress inducing experiences. Most importantly and in-focus with the current study, is past research on neurodegeneration supporting
increasing cognitive decline and dementia resulting from prolonged elevated levels of cortisol secretions (Danese and McEwen 2012).

My focus here is to primarily exposure the exposure to chronic stress during the developmental stages in life, that is, before the age of 18 and if these exposures can cause lasting effects on one’s cognitive health later in life. Such developmental stages vital for the development of the nervous endocrine and immune systems after birth. Research indicates the increase in myelination therefore progressively developing the white matter volume of the brain during childhood and adolescence. Similarly, the cortical area matures in the initial few years of life taking a prefixed developmental trajectory of sensory and motor skills, basic language, attention and other executive functions. Even though these developments are led by passed- on genetic information, research has proven an intricate interplay of genetic information and environmental factors, resulting in a display of developed functions, unique to every individual (Danese and McEwen 2012).

Further, as mentioned above, experiences have the ability to modify allostatic systems or each individual’s response to their environment in the form of adaptive responses. In some cases, prolonged exposure to adverse childhood experiences can affect change that go beyond providing adaptive advantages and become detrimental instead. This physiological response is called biological embedding (Danese and McEwen 2012).

Research data has shown adverse childhood experiences such as childhood maltreatment, socio-economic distress, social isolation and sexual abuse can work as risk factors for age-related diseases such as type- 2 diabetes and cardiovascular diseases. Such exposures have shown to cause a reduction in telomere length due to recurrent threat to allostatic and aging systems thus supporting biological embedding of social experiences (Danese and McEwen 2012).
Other studies have found chronic exposure to stress hormones from childhood abuse and family mental illness to be associated with shortened telomere lengths and consequently age-related illnesses. Evidence also suggests an association to higher inflammatory conditions, cardiovascular diseases, arthritis, osteoporosis, type 2 diabetes and Alzheimer’s disease (Kiecolt-Glaser et. al. 2011, Oliveira et. al. 2016, Price et. al. 2013). Some future recommendations by Danese and McEwen encourage more extensive and longitudinal research involving a well distributed population exposed to various risk factors (Danese and McEwen 2012). Repeated research and collection of differently exposed biological consequences and the diversity in epigenetic mechanisms need to be encouraged, for this line of research to be further translated into therapeutic practices and healthcare policies (Danese and McEwen 2012).

From the perspective of adverse life experiences early in life affecting the immunity of an individual, the “life history theory” concentrates on the shifting focus of the body toward development of the innate versus the acquired immunity. This changing concentration is theorized to be based upon exposures to pathogens, nutrition and adverse life experiences, all within an early developmental window in life. The study concluded that innate and acquired immunity of an individual shows “adaptive plasticity” based on the early life exposures (Georgiev et. al. 2016). More supporting research by biological anthropologists is discussed below on the significant effects of adverse childhood experiences on biological and psychological functionalities leading to a decline in cognitive processing speed, when compared to more recently experienced traumas (Korten et. al. 2014).
Plasticity explained by biological anthropology

For more literature focusing on the role of social and environmental change on the adaptive lifecourse we turn to evidence as presented by biological anthropologists. When looked at from the perspective of evolution, the life cycle of *Homo sapiens* is characterized by infantile care-dependency, periods of physical and mental growth and fertility/reproductive activities (Kuzawa and Bragg 2012). These designated paths of growth and reproduction are known to be specifically lengthy among humans. Within these set paths, the life history of an individual is adaptive to variation based on the intragenerational exposures to environmental, nutritional and social change. Such “within- and between-population” adaptation is described as “phenotypic and developmental plasticity” (Kuzawa and Bragg 2012). Plasticity brings adaptation to growth in terms of rate and trajectory, to nutritional profiles in terms of availability and reproductive strategies, playing a distinct role in every individual or population in response to risks of mortality. Kuzawa and Bragg (2012) have described such adaptation and variability in their “phenotypic – first” model based on the influencing role of social and environmental adaptation on growth, nutrition and reproduction, and their resulting “evolutionary diversification” within the species itself (Kuzawa and Bragg 2012).

The importance of consideration of the role of environmental and social factors on the lifecourse was initially advocated for by Chisholm in his 1993 publication of ‘Death, Hope, and Sex’. He advocated for the greater collaboration in evolutionary biologists and social scientists, to broaden their views beyond the belief that genetics is the only determining factors in the creation of one’s physiology and health conditions. He argues that early life stress exposures have a larger role to play in the shaping of varying traits in one’s life-history (Chisholm 1993).
The mechanism of induced variation could be explained in terms of “early- late life trade-offs” (Lemaitre at. al. 2015). The process of aging is said to be based on a maintenance of balance and compromise between different elements of life course. This is theorized by the principle of allocation, according to which energy is used to facilitate this balance between components such as growth and reproduction. Such trade-offs could take place due to the limitation in resources in an individual’s environment that facilitates that life component, such as “growth, reproduction and maintenance” (Lemaitre at. al. 2015). When the larger distribution of energy goes toward reproduction, there is said to be a compromise in the maintenance of the physiology, leading to a promotion of faster rate of aging. On the other hand, maintenance is controlled to ensure the optimum lifespan given the risks of mortality posed by the environment. These researchers have further suggested the future implications of the trade-off theory to be integral in explaining the environmental factors that affect perinatally and the development of sex-specific traits during aging (Lemaitre at. al. 2015).

**Adverse childhood experiences and public health implications**

So why does childhood healthcare need more attention from a broader public health and societal perspective? As explained above adverse exposures early in life can affect development of a child and may increase morbidity throughout one’s lifetime. The exchange between the inner and outer biological and social landscape is crucial in shaping the health base of an individual through allostatic or stress response systems. On a global and national platform, diverse socioeconomic exposures produce varying stress responses. Such varying health outcomes on a community or racial level can have varied public health implications demanding more community-specific healthcare policies (Bauer and Boyce 2004). Not just socioeconomic
exposures, but early parental care quality can have varied impact on an individual’s mental health. A 2010 article studied the impact of varied exposures to the sculpting of an individual’s or community’s epigenetic pattern. They hypothesized the correlated impact of environmental exposures to epigenetic alterations and how such imposed changes can affect one’s behavior and thus neurological consequences later in life. These neurological consequences are diseases and conditions that may develop later in life such as mild cognitive impairment (MCI), Alzheimer’s disease, dementia to name a few. Adverse exposures early in life, are found to dictate the course of epigenetic mechanisms, producing exposure-specific epigenetic markings. Such studies make it imperative for further research for more supporting evidence and interventions that focus on mitigating the effects of such exposures via community-based programs early in life (McGowan and Szyf 2010).

With the recent incline in attention toward ACE, the WHO and the National Center for Chronic Disease Prevention and Health Promotion pushed to broaden the research by bringing together a framework of public health surveillance on a global scale. This effort was spanned Canada, China, the former Yugoslav Republic of Macedonia, Philippines, Saudi Arabia, South Africa, Switzerland and Thailand. This was with the intention of expanding the global understanding and categories of adverse childhood experiences in both developed and developing countries. Currently the ACE module consists of childhood abuse, neglect and related experiences caused by other individuals under the influence of drugs/alcohol or due to the presence of a mental health condition. When expanded to include adverse social experiences in developing countries, forced marriage, witnessing or being part of an organized violent incident, emotional violence and other aspects of cultural-specific experiences were found to be appropriate to be added within the module (Anda et. al. 2010).
**AD and primary prevention**

Current medical practice focuses its efforts and funding largely into secondary prevention, that is, the identification of present risk of developing the disease and treatment to reduce or halt disease progression. Although fewer research efforts have been made, evidence exists of early life adversity and a strong correlation to development of mid-life risk factors that are precursors to developing dementia and AD (Albert 2015). Here, primary prevention would be identifying and targeting those early life risk factors, much before the biological manifestation of the disease. In this case, the area of focus would broaden beyond the field of medicine into public health and medical anthropology. Steven Albert discusses the importance of a “lifespan primary prevention” where interventions early in life focus on a population or community as a whole (Albert 2015). Here the “critical window model” suggests that adverse childhood experiences within a certain window of time works to have the move biological impact and risk the development of cognitive issues later in life. A study shows the development of AD in individuals who experienced maternal death between the ages of 11 and 17 years. Similarly abuse and other adverse experiences before the age of 18 can affect physical and mental health (Albert, 2015). The ACE module works in such social adversity to understand their connection to public health issues later in life, making it overall possible for organizations like the Center for Disease Control (CDC) and the World Health Organization (WHO) to build a framework of primary care solutions. Ignoring the role of social adversity in public healthcare services can perpetuate the risk of risky behaviors in distressed communities. Based on the increasing importance of social adversities, acts of violence like intimate partner violence, intra-parental violence, sexual or physical child abuse are areas that need attention especially in low socioeconomic communities (Anda et al. 2010). Based on such evidence and the need to shift
focus on early life risk factors, epidemiologic and medical anthropology research would require more attention and collaboration from the medical community promoting the culture of a translational form of research.

**Translational research and medical anthropology today**

What can a medical anthropologist do to help? Lock’s work brings attention to the growing popularity of environmental epigenetics, especially due to the progress in understanding DNA methylation and the growing evidence in support of its relationship between the environment, genotypes and phenotypes. These innovative approaches when translated bring about new directions on political attention and more “realistic demands” in policy making in the presence of social inequities. The late policy making approaches in healthcare, as warned by Lock, have severe reductionist undertones. The advanced technology and biological knowledge used to develop therapeutic approaches for patients at risk of Alzheimer’s disease, fail to consider the diversity of impacting environments. Epigenetics combined with ethnographic research is fit to appropriately utilize diverse “local narrative accounts” in terms of social and economic adverse experiences. A community based approach for this purpose can be used to reallocate political and economic interests that help advance AD research (Lock 2013).

More researchers have shown support for interdisciplinary collaboration between epigenetic and anthropological methods. Instead of drawing a wide and unadaptable conclusion to conditions of the brain, these researchers are pushing to get to the early roots of the risk factors we know to be involved directly and indirectly. That source of adverse experiences in one’s life stem from social inequities and various other environmental exposures. Research
encompassing these sources of risk factors pushes to look for the early preventable/controllable risk factors (Thayer 2015). Conclusions drawn from these approaches ultimately translate into more suiting public policies and healthcare bills. This hierarchical ladder from risk factor to disease/illness to healthcare policies/services need to be all studied with equal detail at every step with such translational research.

Neuroanthropology of AD

The gradual medicalization of any disease or condition undergoes various phases of research and recognition by the public and government (Lock 2013). As discussed in chapter 1, efforts in AD have been to find a medical standard for prevention of the disease. The popular path taken, however, is argued by applied anthropologists such as Lock to be taking us away from the understanding of AD as part of the continuous process of aging that differs in every individual throughout one’s lifecourse. Just before the popularization of the age of prevention, true diagnosis of AD was considered only after the autopsy of a deceased individual. Families had to withstand long waiting periods for accurate results and those belonging to a low socio-economic background were unable to afford the costs for autopsy, leaving questions regarding the prevalence of AD in their family unanswered (Lock, 2013).

In the later years, when AD was considered a more serious reality of the growing population, efforts moved toward finding a mode of clinically diagnosing AD or the possibility of its development (Lock 2013). The lack of a perfect and standardized method to do so left many over – or underdiagnosed of dementia or AD. This issue was taken care of by socialized healthcare system in Canada, where physicians often worked out ways to diagnose the patient even on minor speculation of dementia, so as to provide access to medication to individuals.
Further, the increase in risk was open to dispute due to the lack of a database the prevalence of the disease in the population (Lock 2013).

This encouraged efforts to grow the body of knowledge around diagnosis and the creation of diagnostic criteria. Many advocating institutions including the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, published criteria for physicians to diagnose their patients with AD (Lock 2013). These criteria have remained subject to review and change as additional information and research arises. Popular among psychological evaluations has been the Mini-Mental State Examination (MMSE) that is conducted for 10 minutes by a trained clinician to scale the cognitive functions of the individual at the time of evaluation (Lock 2013). The evaluation is repeated over the course of a few months to keep a track in any cognitive changes. With growing clinical efforts to diagnose dementia as a precursor to AD, it was realized that dementia expressed itself as spectrum among patients. Thus, terms used to provide some diagnostic structure were “mixed dementia, atypical dementias and ‘cognitive impairment no dementia’”. Further, an exclusion strategy has been used to rule out all other condition or disease before arriving at an AD conclusion. This was due to the realization that aging and dementia common in other conditions such as stroke, head trauma, Parkinson’s disease and Huntington’s disease, labelling AD as a “wastebasket” disease. This further gave rise to the realization that AD could not be studied as an isolated disease (Lock 2013). There have been some noted drawbacks to MMSE, the more prominent one being the lack of inclusivity of individuals that do not speak English. Physicians are known to prefer diagnosing such patients with a medically verifiable disease such as diabetes, so as to provide them with medication and encourage their return to follow-up visits. Thus, the knowledge gathered in literature form so far were thought to be only good enough for text rather than real human
physiology (Lock 2013). An article consisting of new criteria was introduced in the 2005 in a workshop in Florence held to discuss revised criteria. The article emphasized the clinical diagnosis of gradual memory change is given priority. The tools used to support such diagnosis could be a combination of psychological testing and MRI scan, cerebrospinal fluid analysis, positron emission tomography (PET) scans (Lock 2013). The main goal of such clinical work must be to detect factors in the brain that can act as biomarkers indicating the presence or future development of AD or dementia. Retroactive analysis of the causative links in the brain can also be done with existing patient’s (Lock 2013).

The efforts toward prevention of AD shifts focus on the detection of mild cognitive impairment (MCI) in the following years. Meanwhile, biomarkers eventually begin to be speculated to be unreliable due to the realization that there may not be any one or two reasons why AD is formed. The question also remains as to why some individuals do not go on to develop the disease even when they exhibit the same signs as those that do. The interest in detection of MCI quickly picked up in popularity and more scales for its detection began to be developed (Lock 2013). The shift in focus to detecting memory loss became prominent when in 2001, the Food and Drug Administration (FDA) formally recognized MCI as a condition that can be diagnosis, calling for pharmaceutical companies to work toward developing drugs and research for memory loss. Although in all of this, a clear definition of MCI remained slightly unclear (Lock 2013).

The support for MCI diagnosis was also favored in clinics as physicians found it less stressful to tell their patients they have a certain amount of MCI rather than an AD diagnosis. This meant that the patients were made aware of a potential for causation of the disease or otherwise. Thus, patients were provided with counselling and ways to improve their quality of
life from there on and asked to follow-up with routine checkups (Lock 2013). This also saved those individuals from the societal stigma that is attached with being diagnosed with AD. Among screening tools that became popular, the Montreal Cognitive Assessment (MoCA) was found to be most reliable in sensitivity and specificity in memory decline detection. Based on the subjective complaints of memory difficulties, this scale assessed visuospatial or executive memory, naming, memory, attention, language, abstraction, delayed recall and orientation (Lock 2013). The diagnosis and understanding of the condition is easier on patients along with administration and follow-up. Lock argues that a drawback to routinized prediction of AD via diagnosis of MCI can cause anxiety among the population.

From the information above, one might realize how there has been a slow and gradual shift in interest in the stages of AD and aging among researchers and advocates (Lock 2013). The shift began from focus on post mortal diagnosis of AD to stages of dementia and mild forms of memory impairment. This is evident of our shift toward a more preventative world of approach to the disease overtime. Eventually in 2008, the AAIC (Alzheimer’s Association International Conference) released a new list of revised criteria that focused on only “in-vivo clinico-biological expression” of the disease in the form of memory impairment and supporting biomarkers, making post mortal evidence no longer a requirement (Lock 2013). Terms such as prodromal or predementia AD were now acceptable and in some cases AD dementia was used to diagnose dementia that was severe enough to turn into AD. Some researchers have pointed out that due to the unspecific definition of MCI, it can have a “limited utility” in producing a gold standard in clinical diagnosis. The need for a gold standard as understood by some researchers is to give a sense of uniformity so as to help the comparison of results across clinics.

Overtime, the definition of AD went through further change where instead of being at as
a single entity with clear borders, it was understood as a continued process consisting of a cascade of events. This way of thinking was intentionally introduced so as to work on producing a future population with lower cases of dementia, calling it a “paradigm shift”. Biomarkers, especially the beta-amyloid plaque biomarkers remained a dominant area of research with a good share of support and criticism from many due to its narrow but dominant approach. This gave way to the national strategic goal “Campaign to Prevent Alzheimer’s Disease by 2020”, partly due to the realization of a financial crisis approaching the US national healthcare system in the coming future. Alzheimer’s disease Neuroimaging Initiative (ADNI) is a 2004 public-private partnership as part of the national strategic plan to promote development of technologies to detect memory impairments (Lock 2013). Some technologies used have been PET, MRI scans, CRF and blood biomarkers. However, there have been a few significant drawbacks to this initiative. It has been critiqued to not represent a fair epidemiological sample, one that does not exclude patients with comorbidities such as cancer, heart disease, substance abuse or stroke. It includes only a limited age range of 55 to 90 years, not covering a younger age range that does not yet show signs to plaque deposition (Lock 2013). Qualitative information of patient’s lifestyle is not taken into consideration as an affecting factor, yet leaving out the impacts of social and environmental exposures. Although the initiative is said to be a work in progress, it is largely discouraging for patients that feel the load of having repeated high costs for such tests (Lock 2013).

In support of the biological anthropology theories discussed in the above pages, recent literature on Neuroanthropology have also shown support for the inclusion of factors besides genetics. This understood in the literature on ‘encultured brains’ which explains how the nervous systems and its cellular development is influenced in the early years through language, social and
environmenal exposures (Lende and Downy 2012). Experiences, interactions specific to cultures and communities, thus, work to shape the individual’s behavior as part of what is described as “dynamic infolding of an encultured nervous system” throughout one’s lifecourse (Lende and Downy 2012). The understanding that the brain is prone to plasticity and experience induced variation, is critical to aging research. Arguments were made by researchers such as Manson and his colleagues, where they theorized the concept of degeneracy to explain the development of multiple connections within an individual’s brain that result in specific resulting health conditions. This approach varies from the trade-off and energy allocation theory as it believes in the formation of multiple pathway in comparison to the latter which is based on the trade and balance of energy between two or more life components like reproduction and growth (Mason et. al. 2017). Another group of researchers in their work on Frontotemporal Dementia had based their approach on what they called “reverse engineering of the social mind”. This concept is based on the methodology to determine the process of aging backward from the determined condition. This relies on the understanding that determination of social behavior is based on the individual’s understanding of the external motivation that arise through “socially-relevant interactions”. Supporting researchers have advocated for the use of such evolutionary based understanding of behavioral development through individual or cultural experience, as a key method of discourse in neuroanthropology (Lende 2010).

Developmental Origins of Health and Disease (DOHaD)

A world of research beyond Alzheimer’s that took initiative in the effects of early environmental exposures began with a 2011 research that found Japan to have a consistency in
low-birth-weight infants for over 20 years of data (Sata F 2016). This was speculated to be resultant of the societal pressures over Japanese women to be unhealthy thin. Epidemiological studies conducted by Prof. David J. Barker of Southampton University gave way to popular theory of DOHaD that focused on the “developmental plasticity” and effects of social and environmental exposures on development of fetuses. This is broadly seen as a new paradigm of “preemptive medicine”, encouraging interdisciplinary collaborations for large-scale epidemiological studies (Sata F 2016, Heindel et. al. 2017, Kubota et. al. 2015). Currently, there exists The International Society for Developmental Origins of Health and Disease that was set up to promote the interdisciplinary collaborations to study the “fetal and developmental origins of disease”. Figure 2. displays a summary of their aims. (“Learn more about DOHaD” 2017).

**Aims of the DOHaD Society**

- To promote co-ordination of a research strategy in different countries, for the scientific exploration of early human development in relation to chronic disease in later life
- To promote the development and application of public health strategies to prevent chronic disease
- To advocate for the need for funds from governmental and non-governmental sources for research in the developmental origins of health and disease
- To champion training opportunities for scientists and clinicians
- To foster regular meetings to discuss research findings and potential intervention
- To promote the interchange of ideas, staff and expertise between laboratories across the world
- To make representations to government, NGOs and other relevant agencies concerning the health implications of DOHaD

**Figure 2.** A summary of the aims of the DOHaD Society. (“Learn more about DOHaD” 2017)

The importance of such initiatives could have a strong influence on aging studies due to their consideration of perinatal and postnatal factors. This could have a strong collaboration with researchers working in aging-related disorders. Given the move of AD research toward prevention, researchers for DOHaD are the potentially the best group of people to collaborate
with on furthering the promotion of early life experiences research with respect to AD and aging.

**Summary**

My attempt throughout this chapter has been to provide a diversity in information on both existing biomedical and neuroanthropological research. The concept of allostatic load explains the accumulative effects of external and internal toxins over an extended period. Due to its extended effects on the HPA axis, it could even alter behavior and physiology. This can be applied to studies in childhood experiences, where repeated adverse events can mold the body’s response to such factors bringing to attention the plasticity of the brain. Such studies by epidemiologists, evolutionary biologists and social scientists make translational research in AD more individualized experiences can be taken into consideration and results can be applied for real world solutions in public policies and healthcare bills. The section in neuroanthropology above provides an overview of the flow in historical scientific events and decisions that made AD research what it is today. As Margeret Lock describes it, it is for sure a “paradigm shift” to have moved from cure to prevention, however, our approach to prevention requires more critical thinking and a more holistic approach. The overview of these historical decisions is an attempt to open the young scientist’s minds to how the scientific world as we see today has been shaped with biases and individuals with enough funding who could push those biased outlooks to research onto the larger scientific community. All hope is not lost to ask critical questions to reductionist views as, initiatives such as DOHaD are pushing to emphasize the importance of “preemptive medicine”, or research that considers the inclusion of social and environmental factors. There have been evidences supporting the use of the same, as noted above, however we require more collaborative research to multiply supporting evidence. The aim of this study has
been to contribute to the growing body of literature that advocates for interdisciplinary research in Neuroanthropology and biomedical sciences. Theories surrounding life-course research and initiatives such as DOHaD give a space for studies like this to broaden the critical discourse surrounding the role of social and environmental exposures on mental health outcomes and age-related conditions and how they must be an integral part of AD and cognition research. The theory in focus in this study is the entanglement theory that advocates for the interplay of social and environmental factors at various stages in one’s life course. I believe the mixed methods of neuropsychological assessments, neuroanthropology theories and ethnography can play a key role in informing the raised critical questions.
CHAPTER THREE:

METHODS

Introduction

This chapter provides a technical overview of the qualitative and quantitative methodologies used in this study. 13 participants had successfully recorded data presented below after eliminating those that were lost to follow-up or did not show up for their visit. Participants were between the ages of 50 and 65 and were recruited via phone calls made due to their consent to be contacted if they are eligible for any other studies on AD or aging. Visits were scheduled in the Memory Disorders Clinic of the USF Psychiatry and Behavioral Neuroscience in collaboration with the Yvonne Bannon, director of the Memory Disorders Clinic.

On their visits, participants were given an explanation of the study and all their questions were answered before they gave their written consent to move forward with the study. Each visit lasted one hour where I had them provide some basic medical history. Neuropsychological assessments such as the Montreal Cognitive Assessment (MOCA) and the Adverse Childhood Questionnaire (ACE) were used to access various components of the participants cognition and obtain an account of their degree of exposure to adverse experiences before the age of 18. Further, a semi-structured ethnographic interview was conducted to obtain an even further detailed account of their adverse experience and how those experiences, according to their perception, shaped their behavior or personality as an adult. The interview also attempted to capture their experiences
seeking mental healthcare in the current system and their critique on it. Details of the methodologies are explained further below.

Participants

- **Inclusion criteria**: Age 50 to 65 (Manly et. al. 2008, Berchtold et. al. 2014).
- **Exclusion criteria**: Presence of any of the following conditions: Visually impaired, learning disability, Alzheimer's disease, corticobasal degeneration, frontotemporal dementia, Huntington’s disease, Lewy body dementia, progressive supranuclear palsy, vascular dementia.

Sampling procedure

Participants will be recruited via two methods, each of which are discussed as follows:

1. **Memory Care Registry**

   A database of participants who have consented to be contacted for other studies in memory were contacted by study coordinator. The purpose of the call was to briefly explain the study, schedule their visit and provide the PI’s contact information in case they have any questions/concerns at another time.

2. **Recruitment from other studies on site**

   A database of participants who have consented to be contacted for other studies in memory were contacted by study coordinator. The purpose of the call was to briefly explain the study,
schedule their visit and provide the coordinator’s contact information in case they have any questions/ concerns at another time.

3. **Waiting room recruitment**

   We recruited participants from waiting room areas at Psychiatry and Behavioral Neurosciences, USF. Waiting rooms at the Psychiatry and Behavioral Neurosciences, USF were also used to recruit and distribute fliers. Participants were given a brief description and purpose of the study and scheduled for a visit.

4. **Fliers**

   Fliers were handed out to all potential participants within the waiting room and not specifically current participants of other ongoing clinical studies at the Psychiatry and Behavioral Neurosciences, USF and Byrd Institute, USF. Once interested participants contacted the study coordinator on the number provided, they were given a brief description and purpose of the study and scheduled for a visit.

**Sample size**

A sample size of 40 or more participants was the original goal. However, due to barriers discussed further, a sample of 13 participants were used. We used the following SAS code to predict the sample size:

```sas
proc power;
   multreg
   model = fixed
```

31
nfullpredictors = 3
ntestpredictors = 1
partialcorr = 0.415
ntotal = 40
power = .;
plot x=n min=10 max=100;
run;

We have used a multiple linear regression model with 3 covariates and 1 predictor of interest (ACEs). At 80% power, we can detect a partial correlation coefficient of 0.415. This corresponds to an R-squared value (percentage of variation in MoCA score explained by the predictor) of 17.2%. In other words, if the predictor (ACE category) uniquely explains 17.2% of the variation in MoCA scores, a sample size of 40 will have an 80% chance of declaring statistical significance. The confounding variables or covariates considered are age, gender and disease summary. The following were the SAS results used to obtain a significant sample size.
The POWER Procedure
Type III F Test in Multiple Regression

Fixed Scenario Elements

<table>
<thead>
<tr>
<th>Method</th>
<th>Exact</th>
</tr>
</thead>
</table>

Fixed Scenario Elements

<table>
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<th>Model</th>
<th>Fixed X</th>
</tr>
</thead>
<tbody>
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<td>Number of Predictors in Full Model</td>
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</tr>
<tr>
<td>Number of Test Predictors</td>
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</tr>
<tr>
<td>Partial Correlation</td>
<td>0.415</td>
</tr>
<tr>
<td>Total Sample Size</td>
<td>40</td>
</tr>
<tr>
<td>Alpha</td>
<td>0.05</td>
</tr>
</tbody>
</table>

Computed Power

| Power     | 0.802   |
Figure 3. The relationship between total sample size and power in a Type III F Test in Multiple Regression model

Duration of data collection: March 2017 - September 2017

Ethical checklist:

- The research design is adequate to answer the proposed hypothesis without unethical exposure of subjects to research.
- The participant population being studied is categorized as vulnerable due to age. Thus, participants were recruited after consent from existing participant population.
- All involved researchers were trained to conduct screenings included in the study.
- To ensure confidentiality of participants, all involved researchers are trained and certified in USF Health HIPAA compliance.
All involved researchers have completed and certified in the Collaborative Institutional Training Initiative (CITI) Program.

Psychological risks, social risks and physical harm caused through this study were minimal.

Research site: Psychiatry and Behavioral Neurosciences, USF.

Medical consultant: Dr. Glenn Currier, Psychiatry and Behavioral Neurosciences, USF

Research committee:

- Mohini Dutt, USF
- Dr. Theresa Crocker, USF
- Dr. Daniel Lende, USF
- Dr. David Himmelgreen, USF

Study Instruments:

1. Demographic and medical history questionnaire (Refer to Appendix A)
2. Informed consent form (Refer to Appendix B)
3. Montreal Cognitive Assessment (MoCA) (Refer to Appendix C)
4. Adverse Childhood Experiences (ACE) Questionnaire (Refer to Appendix D)
5. Ethnographic semi-structured interview questionnaire (audio recorded)
**MoCA (Montreal Cognitive Assessment)**

The MoCA is used to screen patients with cognitive complaints. This tool does not provide a diagnosis of AD, but is used to detect measure and track cognitive impairment (Nasreddine et. al. 2005, Roalf et. al. 2013). This assessment is conducted by trained professionals and consists of sensitive and ‘easy-to- administer cognitive tasks.’ It has been especially used in cases that have been later diagnosed (using other neuropsychological tools) with MCI or mild AD. The structure of the MoCA is one page with a total score of 30 where a score above disease- specific cutoff score is considered healthy cognition (HC) (Roalf et. al. 2013). It can be administered approximately in 10 minutes. Overall this tool is used to test one’s visuospatial abilities, executive function, attention, concentration, short- term memory, working memory, language and orientation to time / space (Nasreddine et. al. 2005). Research has proved the MoCA to be more sensitive and comprehensive than the MMSE (Mini Mental State Examination; widely recognized screener for MCI) in early assessment of cognitive impairment (Freitas et. al. 2013, Roalf et. al. 2013).

A 2014 retrospective chart study to assess the accuracy of MoCA along with MoCA Total Score (MoCA-TS) and the MoCA- Index Score (MoCA-IS) was conducted. (Julayanont 2014) This was done to access accuracy in detecting the prognosis of MCI into AD. MCI is known to be symptomatic in patients that often go on to develop AD in the later years. The early detection of those individuals with MCI that will develop AD could give way to early therapeutic interventions and an increase in supervision of the prognosis. From a total of 114 participants, 90.5% of participants predicted through these scales went on to develop AD (Julayanont 2014). Another study investigates the sensitivity in detecting AD early in 25 patients with mild to moderate cognitive decline. The results proved that MoCA is a tool with the
sensitivity to track changes in memory in early AD (Costa 2014). Other screening tools such as the Mini –Mental State Examination (MMSE) has been a tool often used to detect changes in cognition in patients, however studies have shown the MoCA to be more accurate and sensitive compared to the MMSE for indication cognitive decline (DeBros 2015).

Most importantly, research has indicated that the MoCA could be useful in ‘improving diagnostic accuracy’ for MCI and its sub- types. Although not used as a stand- alone tool for detection of AD or MCI, a MoCA cutoff of 23 and 25 has helped in differentiating between HC and AD/MCI respectively (Roalf et. al. 2013).

ACE (Adverse Childhood Experiences) questionnaire

The ACE questionnaire was developed by the Centers for Disease Control and Prevention. This tool includes five categories involving different types of childhood abuse and household dysfunctions faced as a child. These questions are in reference to events in the first 18 years of an individual. The categories of exposure can range from 0 (no exposure) to 10 (exposed to all) (Korten et. al 2010). The original ACE study was first published in 1998 where a large cohort of 13,494 adults were assessed with the ACE questionnaire (Felitti et. al. 1998). The results obtained were used to draw comparisons between ACE categories such as substance abuse, family mental health, sexual/physical abuse or imprisonment, and the risk of participating in risky behavior. These risky behaviors involved sexual risk taking, drug/alcohol abuse, suicidal ideation and health conditions later in life. There was an increased risk of such behavior found in those that had two or more exposures to ACE categories (Felitti et. al. 1998).

A 2015 study investigating the relation between adverse childhood experiences and allostatic load (AL) was carried out to understand the effects of social adversities on adult mental
health (Solis et. al. 2015). AL, as described in more detail in chapter 2, is the gradual accumulation of external and internal stressors over the life course, and is theorized to be consequentially lead to health conditions. This study was done with a larger cohort of 3,782 women and 3,753 men, where they were assessed with scales at various ages of 7, 11 and 16. The results concluded the ACE to be higher in those adults that showed a higher AL level at the ages of 23 and 33 (Solis et. al. 2015). Thus, early exposure to adversities such as abuse, trauma or neglect can impact the physiological systems that are equipped to respond to such situations. The ill effects of which could lead to increased risky behavior such as sexual risk-taking, increase alcohol consumption or drug abuse. The period that these adversities make the most impact, however remains understudied (Solis et. al. 2015).

Researchers have further investigated the period in one’s early years that is most vulnerable to exposures such as physical or sexual abuse (Dunn et. al. 2016). This study was done to see their effects on short term or working memory during adulthood. Although there was no statistical significance found in the relation between abuse and cognitive impairment in adulthood, periods that are most likely to be affected were found. It was found that individuals that were exposed to such abuse during adolescence (age 14-17) had greater memory impairment than those that were exposed during early childhood (age 3-5) (Dunn et. al. 2016). Such research calls for more investigation into the study of memory impairment and developmental periods in one’s lifecourse that is most vulnerable to exposures to adversity. A 2013 study has investigated the association between childhood sexual abuse and the resulting cognitive status of adult individuals in 6,912 aged 50 years or older (Feeny et. al. 2013). The assessment of memory involved executive function, attention, processing speed and memory. The results however did not show an association between childhood sexual abuse and memory.
impairment. Thus, due to such competing evidence of the correlation between ACE and negative health conditions in adulthood, researchers encourage further investigation (Feeny et. al. 2013).

The ACE categories in Figure 4 and respective questions were asked to participants with respect to their experiences before the age of 18.

<table>
<thead>
<tr>
<th>ACE Category</th>
<th>BRFSS Question</th>
<th>Response That Resulted in an ACE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical abuse</td>
<td>“How often did a parent or adult in your home ever hit, beat, kick, or physically hurt you in any way? Do not include spanking.”</td>
<td>“Once” or “More than once”</td>
</tr>
</tbody>
</table>
| Sexual abuse                  | 1. “How often did anyone at least five years older than you or an adult ever touch you sexually?”  
2. “How often did anyone at least five years older than you or an adult try to make you touch them sexually?”  
3. “How often did anyone at least five years older than you or an adult force you to have sex?”                                                                                                              | “Once” or “More than once” to any question                                                       |
| Verbal abuse                  | “How often did a parent or adult in your home ever swear at you, insult you, or put you down?”                                                                                                                                                                                                                                    | “More than once”                                                                                |
| Mental illness in a household member | “Did you live with anyone who was depressed, mentally ill, or suicidal?”                                                                                                                                                                                                                                                     | “Yes”                                                                                           |
| Substance abuse in a household member | 1. “Did you live with anyone who used illegal street drugs or who abused prescription medications?”  
2. “Did you live with anyone who was a problem drinker or alcoholic?”                                                                                                                                            | “Yes” to either question                                                                       |
| Divorce                       | “Were your parents separated or divorced?”                                                                                                                                                                                                                                                                                       | “Yes”                                                                                           |
| Witnessed abuse               | “How often did your parents or adults in your home ever slap, hit, kick, punch, or beat each other up?”                                                                                                                                                                                                                           | “Once” or “More than once”                                                                       |
| Incarceration of a household member | “Did you live with anyone who served time or was sentenced to serve time in a prison, jail, or other correctional facility?”                                                                                                                                                                                                 | “Yes”                                                                                           |

**Figure 4.** Categories and question on the BRFSS ACE module (Adverse Childhood Experiences in Alaska 2015).
**Ethnographic semi-structured interview**

The aim of this interview is to obtain further information related to the responses on the ACE questionnaire. The semi-structured interview used here is based on a person-centered approach that aims to explore the individual’s relation to his/her surroundings based on input and output within their sociocultural context. Thus, attempting to understand the cognitive and emotional interaction with external exposures building a social and cultural-behavioral model. Here the ‘social complexity’ and ‘degree of embeddedness’ are brought out by the constructed questionnaire, directing the narrative of the interviewee based on their experiences. The questions are framed in a way to lead the respondent into identifying their perceptions based on their behavior and experiences (Bernard, H. R. 2015). The inclusion criteria for this interview within the participant pool will be an education of high school and above so as to keep skews in responses to a minimum. In the case of that participant not meeting the education criteria mentioned above, we will select the successive participant to him/her. The questions are asked with the goal of understanding the individual participant’s adverse experience and how they think those experiences have shaped them in their adult life. Further, I attempt to understand their experience with the mental healthcare system and where they think it is lacking.

**Collection of Data**

Once participants arrived at study site, consent for this current study was taken. After the participant had filled out the demographic questionnaire, he/she was walked into the testing room where the MoCA, ACE and semi-structured interview were administered. To obtain a randomized sample for the ethnographic semi-structured interview, we interviewed every second participant we scheduled for a visit. The screening results were provided at the end of the appointment in the
form of a packet containing the results and recommendation on how to practice memory exercises. Participants were also given recommendation on next steps, based on the MoCA score they received.

Data monitoring plan

The following are elements of our data safety monitoring plan:

- Who is responsible for performing the data monitoring? - All components of the data were monitored by study PI, Mohini Dutt. Analysis and discussion of results involved other listed members within the research.

- How often will monitoring be performed? - The following documents were weekly monitored: protocol, subject research records, informed consent documentation and safety information. A checklist of the subject's schedule and data were maintained per visit, to ensure collection of all required data and following of protocol procedures.

- How will monitored data responded to appropriately? - The study coordinator discussed the findings with other listed members of the study and took actions in required areas such as:
  - amending the protocol or consent form
  - re- considering participants
  - additional data collection from participants
  - withdrawal of participants from the study

Any changes made to the IRB-approved documents or information were submitted to the IRB via an amendment application.
**Statistical analysis** (Software- IBM SPSS)

**Multiple linear regression**

This method of statistical method of analysis was used to model the relationship between the MoCA results as continuous dependent variables and the ACE results as the primary independent variables. The confounding variables considered were age, gender and disease summary.

**Cognitive schemata**

This method of analysis adds to the mixed-methods dimension of this study. Going beyond statistical analysis, have attempted to determine the patterns and variabilities in how the exposure to early adversity is behaviorally embedded over time. This is done keeping in mind that individuals do base decision-making on life history and all exposed circumstances and events. Cognitive schemata is a method derived from cognitive anthropology where its overall approach is to identify patterns of performance by organizing the participant’s narrative (Bernard, H. R. 2015).

Audio recorded responses were transcribed. Based on those transcriptions, we have attempted to filter out data patterns in experiences and decision making. Internalized feelings like fear, anxiety, self-confidence, loss of interest or isolation were areas of focus with a desire to chart the behavioral embodiment of their respective exposures.
Limitations

Just like every research study, this study has its own limitations. Being part of a master’s program, the time and resources used for this project has been limited. Thus, a population beyond Tampa could not be recruited and more than one study site could not be utilized to gather a more diverse population of participants. The disadvantage to ACE is that the questions included in the module are not inclusive of languages other than English and Spanish. The questionnaire could be more specific with question specific to cultural or racial groups. Further the intensity of the adversity faced by the individual is difficult to gauge by the options provided for each question. Individuals also may differ on how those adversities actually affected them later in life and if they had to seek mental healthcare services to cope with the experience. The limitation to the language is also applicable to the MoCA tool.

Dissemination plan

Findings of the approved study will be shared through presentations in conferences, web and print publications; and other on-line media approaches.
CHAPTER FOUR:

RESULTS AND ANALYSIS

Introduction

This chapter provides a detailed review of the results obtained and their analysis. I begin with the responses obtained in demographic and medical history questionnaire and the scores obtained on the MoCA and the ACE. This is followed with the discussion of the results obtained in the quantitative and qualitative section. The main focus with the results obtained in the ethnographic interview is the discussion of each individual participant response and the analogy of the common themes that occur.

Demographic and Medical History Questionnaire

The following Table 1 is the summation of the responses obtained for participant demographic and medical history.
Table 1. Results for Demographic and Medical History Questionnaire

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<tr>
<th>Participant ID#</th>
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<th>11</th>
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<td>58</td>
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<td>59</td>
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</tr>
<tr>
<td>2. Gender</td>
<td>F</td>
<td>M</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>M</td>
<td>F</td>
<td>F</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>F</td>
<td>M</td>
</tr>
<tr>
<td>3. Family History</td>
<td>F-</td>
<td>F-</td>
<td>M-</td>
<td>R-</td>
<td>M-</td>
<td>A</td>
<td>D;</td>
<td>F-</td>
<td>M-</td>
<td>M-</td>
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<td>A</td>
<td>D;</td>
<td>AD</td>
<td>tw</td>
<td>M-</td>
<td>A</td>
<td>D;</td>
<td>FT</td>
<td>D;</td>
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<td>AD</td>
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<td>4. Tobacco</td>
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<td>N</td>
<td>N</td>
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<td>N</td>
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<td>N</td>
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</tr>
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<td>5. Alcohol</td>
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<td>6. Drugs</td>
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<td>7. Learning Disability</td>
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<td>8. Hearing Disability</td>
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<td>Hospitalized in past 2 years</td>
<td>Heart attack/ failure</td>
<td>Stoke/ TIA</td>
<td>Cancers</td>
<td>Sleep Apnea</td>
<td>Parkinson’s Disease</td>
<td>Diabetes</td>
<td>Thyroid conditions</td>
<td>Sleeping difficulty</td>
<td>Psychiatric conditions</td>
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Table 1 (Continued)
### Table 1 (Continued)

<table>
<thead>
<tr>
<th></th>
<th>Medications for memory-related conditions:</th>
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<tr>
<td>a.</td>
<td>Namenda</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>b.</td>
<td>Axona</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>c.</td>
<td>Gingko Biloba</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>d.</td>
<td>Exelon/Exelon Path</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>e.</td>
<td>Aricept</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>f.</td>
<td>Razadyne</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>g.</td>
<td>Any other memory-enhancing supplements</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
</tbody>
</table>

Note: AD- Alzheimer’s Disease; D- Dementia; TIA- Transient Ischemic attack; LBD- Lewy Body Dementia; FTD- Frontotemporal Dementia; F- Father; M- Mother; S-Sibling; R-Relative; Y- Yes; N-No
This questionnaire aimed at obtaining existing co-morbidities of the participant along with their age, gender and family mental health history. Information on family history was obtained to ensure the disclosure of possibility of genetic inheritance between generations. Information on learning disability, hearing disability and visual impairment was obtained. This was to ensure the disclosure of individual factors that affect the understanding, processing and response to questions asked, due to conditions besides cognition or memory. Medical history of heart attack, sleep apnea, Parkinson’s, diabetes, thyroid issues, cancer or hospitalization was obtained to understand if these conditions were the cause of faced memory issues rather than ACE categories. I had also asked for the participant to make a note if they were consuming any of the following medication that are usually taken for memory-related disorders: Namenda, Axona, Gingko Biloba, Exelon/Exelon Path, Aricept and Razadyne. The intent of collecting this data was to use it to analyze descriptive statistics in understanding the relationship between the MoCA and the ACE scores. However, the data collected was not used to make any analysis due to the incompleteness of the collected sample size. More details on why the sample size remains incomplete is explained in the following paragraphs.

Desired sample size was not attained

Every research comes with some uncertainty. The goal of recruiting 40 participants to determine a statistical correlation of the study was not achieved due to constraints faced in time. This population of older individuals between the ages of 50 and 65 makes it more difficult and an overall slower recruitment goal to achieve. Out of all the recruitment calls, some were lost to follow-up, some did not show up to their scheduled visits and 13 successfully completed their visits. Other possible hindrances to the recruitment may have been due the unavailability of
individuals during the months of June and July, due to these being the sort of time where schools are on summer break and families are away from their homes. Another possible hindrance to the recruitment may have been the September 2017 Hurricane Irma that passed through a large section of south Florida. Older participants were thus not available to travel to the study site before in preparation of the hurricane and after the hurricane when individuals were working on returning to their homes and returning to their everyday lives. The low number of participants thus makes it difficult to statistically analyze. The study overall consists of a quantitative and qualitative goal, and hence the remainder of this report focuses on the application of applied anthropology theories and the analysis of our ethnographic findings and discusses the history, current affairs and future goals in AD research.

Results of the MoCA, ACE and semi-structured ethnographic interviews

The following are some of the notable responses obtained from participants and their respective ACE and MoCA scores. Our attempt here was to gauge how the participant’s experiences before the age of 18 has shaped his/ her lifecourse, attempting to map cognitive schemata leading to the participant’s current memory (MoCA) score. This approach, as discussed in the previous chapter, is based on an individualized approach of best estimating the primary risk factors. The goal here is to show how this epigenetic method of taking both early-life social and biological risk factors into consideration can play a role in understanding some commonly occurring themes and the trajectory of developing memory -related conditions later in life and advocate for early -life mental health interventions. Based on these reports and scores, recommendations are discussed in chapter five, conclusions, discussions and future directions as
to how such findings can be translated into integrated strategies for child mental healthcare interventions in existing and new accessible systems.

The following table 2. consists of the MoCA and ACE scores obtained for each participant.

**Table 2. Results for the MoCA and ACE**

<table>
<thead>
<tr>
<th>Participant ID#</th>
<th>59</th>
<th>9</th>
<th>38</th>
<th>28</th>
<th>11</th>
<th>34</th>
<th>25</th>
<th>50</th>
<th>30</th>
<th>68</th>
<th>72</th>
<th>81</th>
<th>58</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE</td>
<td>1</td>
<td>7</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>MoCA</td>
<td>29</td>
<td>28</td>
<td>30</td>
<td>27</td>
<td>29</td>
<td>28</td>
<td>28</td>
<td>27</td>
<td>29</td>
<td>27</td>
<td>30</td>
<td>30</td>
<td>27</td>
</tr>
</tbody>
</table>

Note:

ACE- 0 (lowest) – 11 (highest) (CDC, 2016)

MoCA- 0 point (lowest) - 30 points (highest) (Nasreddine 2010)

Using the data obtained in Table 2, in the following paragraphs, every participant response is discussed individually to provide an overview of the responses I had obtained. Further, my attempt has been to analyze common themes that have commonly occurred and what literature is out there to provide support in my arguments.

**Participant #11**

The participant reported no categorized ACE experiences and has a current MoCA score of 29 out of a possible 30. She reported cases of isolation before the age of 18 due to her home being in a low populated region and due to her being the youngest of many siblings. She however credited her isolation for her problem-solving abilities as an adult. Isolation pushed her
to be self-reliant, acting as a source of resilience, she also notes in all the other women in her family. She further responds that her recent memory issues most likely are due to her “stresses as a care-giver” for her mother, who is ailing from early onset AD. She further notes the lack of access to support for care-givers and their management of the various aspects that come into play while caring for an AD patient. The “exhaustion” resulting from her care-giving responsibilities and responsibilities for her own family, according to her have become causes for her to forget simple and everyday tasks. Thus, although she does not show symptoms of cognitive impairment, there is a question as to how these care-giver related stresses might act as risk factors for her development of cognitive impairment. Could care-giver related stresses act as epigenetic risk factors for development of MCI or other memory-related conditions?

**Participant #25**

The participant reported an ACE score of 2 and a MoCA score of 28 out of a possible 30. In her adult life, she reports to be good at problem solving and paying attention to detail. Her reasons for being interested in participating in memory related research is her recent concerns with her own memory. She reports to more difficulty in remembering short tasks and has been concerned with developing symptoms of AD as she is currently of the same age as her sister when she developed symptoms of AD. Her ACE categories consist of substance abuse by a family member and sexual abuse before the age of 18. Both those experiences, according to her have shaped her personality as non-confrontational and often a “peacekeeper” in conflicts. This, she says, is due to her experiences with her father and his alcoholism. She was often the one to feel the pressure of protecting her mother and her family’s peace from the stress that her father’s alcoholism brought. This she says has been a point of stress for herself in her workplace, due to her behavior of always being the peacekeeper and wanting to please those around her.
Participant #28

The participant reported an ACE score of 2 and a MoCA score of 28 out of a possible 30. In her interview, she reported the experience of ACE categories – sexual abuse and verbal abuse. According to her, the latter, verbal abuse by her mother has affected her personality as an adult. What stood out in her interview is her perception that the abuse might have been “transgenerational”, as her mother faced both physical and verbal abuse from her own parents and was also diagnosed with depression around the age of 40. Could abuse be passed on via transgenerational epigenetic inheritance? Early detection of the same in school systems might open up an area of early-life interventions for children under the age of 18.

Participant #38

This participant reported an ACE score of 7 and a highest possible MoCA score of 30. She reported ACE categories of physical abuse, sexual abuse, verbal abuse, mental illness in household member, substance abuse and incarceration of household member. She was diagnosed with endometriosis and diagnosed infertile in her 20s, which she believes to be the result of the repeated sexual abuse she faced from her father from the age of 3 to 16. She decided to undergo group therapy at the Tampa Bay Crisis Center at the age of 25, which she believes had helped her emotionally recover from abuse and suicidal ideation. She notes that the affordability of therapy is solely due to the sliding scale fee method the center uses. Based on the patient’s income the treatment is made affordable with the help of various grant funds they receive. She credits the crisis center for her emotional recovery and the ability to maintain a successful
marriage. She also credits her line of work - massage therapy, to have helped her gain back the ability to make normal physical contact with individuals in her everyday life. It is easy to understand here how much early therapy has helped in her recovery and how much it can help more like her if more centers like the Crisis Center are easily accessible to many.

Table 3. Summary of response trends

<table>
<thead>
<tr>
<th>Participant #11:</th>
<th>Participant #25:</th>
<th>Participant #28:</th>
<th>Participant #38:</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE =0; MoCA= 29</td>
<td>ACE =2; MoCA=28</td>
<td>ACE= 2; MoCA= 27</td>
<td>ACE=7; MoCA= 30</td>
</tr>
<tr>
<td>• Does not report on any of the categories in the ACE module.</td>
<td>• ACE categories of substance abuse by a family member and sexual abuse.</td>
<td>• ACE categories of sexual abuse and verbal abuse.</td>
<td>• ACE categories of physical abuse, sexual abuse, verbal abuse, mental illness in household member, substance abuse and incarceration of household member.</td>
</tr>
<tr>
<td>Experience of childhood isolation and neglect (not categorized in ACE module)</td>
<td>Experience of alcoholic father helped instill a protective personality.</td>
<td>Reports building behavioral resilience as an adult.</td>
<td>Transgenerational effects reported from above exposure/</td>
</tr>
<tr>
<td>Reports building behavioral resilience as an adult.</td>
<td>Reports on mother’s experience of verbal and sexual abuse herself.</td>
<td>Diagnosed with endometriosis and diagnosed infertile in her 20s. Reports its cause to be repeated childhood sexual abuse.</td>
<td>Credits the crisis center for her emotional recovery and the ability to maintain a successful marriage.</td>
</tr>
<tr>
<td>Reports lack of care giver mental health services.</td>
<td></td>
<td>Also credits her line of work as a massage therapist that helped her overcome fears associated with physical contact.</td>
<td></td>
</tr>
</tbody>
</table>
Figure 5 below displays a relationship between the obtained MoCA and ACE scores through descriptive statistics.

The line graph below shows the MoCA scores to be increasing with the ACE scores. This means that with more the adverse experience, the less the cognitive decline (an increasing MoCA score would signify a low cognitive decline). This is an argument opposite to the point being made in comparison to the qualitative analysis. One would expect the cognitive decline to be more (i.e. low MoCA scores) when the adverse childhood experiences are more. Although, it can be argued that not everyone is affected by adversity in the same way. There can be cases, such participant #11 and #25, who in their ethnographic interview reported below that their
experiences did help them develop coping mechanisms as an adult. #11 notes that her experiences of isolation and neglect helped her build socio-behavioral qualities of being self-reliant as an adult. #25 has reported below that her experiences with an alcoholic helped with issues in keeping the peace in the family and protecting her mother. Thus, such form of socio-behavioral resilience might also be resultant in some cases with adverse childhood experiences. However, socio-behavioral resilience might not necessarily be advantageous to the aging mechanism. It may be difficult to determine what effects these might have on the pathology. This brings up the discussion on the connection between the body and the mind and between socio-behavioral qualities and disease progression. All said, the graph could still be argued against, as the data it used had participants from only that pool which had individuals with high MoCA scores of 25 and above. This is because there was a misunderstanding in communication while obtaining participant information from the database. My goal during the contacting of potential participants by accessing a larger database, was to exclude participants that have already been diagnosed with AD or MCI. The misunderstanding of the collaborating institution administrator during the export of relevant data from the larger database, was in assuming that I was looking to exclude participants with low MoCA scores. Low MoCA scores however, did not necessarily mean those individuals were diagnosed at that time. The misunderstanding in assuming that only having low MoCA scores was somehow equivalent to a diagnosis led to providing me with only half the required potential participant information. Hence the potential participants I was able to recruit were not inclusive of those with low MoCA scores leading to incomplete results. This misunderstanding was one of the main reasons for the unreliability of the quantitative results I have obtained.
Analysis of trends in ethnographic responses

ACE questions and their severity

These ethnographic interviews are discussions of real people’s experience with AD as a caregiver or with their own cognitive decline. Their experience with early childhood adversity, their parent’s AD and their own cognitive decline plays into how Lock talks about aging being a continuum. Experiences such as neglect, isolation, sexual abuse and familial history of mental health issues and substance abuse may be the only some of the few influencing factors that entangled with the overall aging process. Question remains as to what may constitute a high ACE score and what could be the cut off for a low score for the purposes of an epidemiologist. The cut off would however not be very fitting to the real experiences of these individuals as the degree of impact of each experience may differ between individuals. Thus, more number of accumulated experiences may not have necessarily been as impactful as that one experience of another individual. Thus, severity of experience also plays an essential role in its impact. The ACE module hence needs to be more comprehensive in levels of severity of each experience.

Culture or region- specific ACE questions

The version of ACE module present in English and Spanish may not work in another country with another main language. Further, the type of question asked here may not be applicable when it comes to other cultures. The role of a neuroanthropologist is crucial here to understand the culturally relevant ways to frame those ACE questions. Some cultures may have their own specific type of social adversity such as forced genital mutilation in certain African
countries (Jina et. al. 2013), extreme societal beauty standards in Japan (Sata F 2016) or child marriage in rural India (“District- level..” 2017). Involving culture- or region- specific questions in the ACE module as well as making it inclusive for other languages would make such studies more applicable on a global scale. This can also be helpful to the formation of a global longitudinal study aiming to build a database of culturally based aging studies. These can further help advocate for a political and economic solution to those specific adversities as well.

**Entanglement of adverse experiences**

AD research from an entanglement theory standpoint needs to be looked at as part of a continuous aging process. From the responses explained above, those adverse experiences began socially affecting the participants from even before they were 18 years of age. That may be due to isolation due to neglect, a parent’s harmful relationship with alcohol, a parent’s mental health issues or even repeated sexual abuse by a family member. The interviews reveal how those experiences shaped the participants as adults. “I truly believe that I was not able to have kids or keep my trust in men because he raped me as such a young girl.. When it happened I was able to almost mentally come out of my body just so I did not have to feel it when it was going on.. Being a massage therapist helped me feel good in my own skin again.. I don’t feel like tearing it off anymore” One might argue that this participant and few participants like her might be only extreme cases and unfortunately I was unable to retrieve the numbers in the study to prove otherwise. However, as explained in chapter 2 there have been several longitudinal studies that prove the effects of social adversity on the aging outcomes of individuals. Thus, I would encourage more medical anthropologists to continue contributing to this line of work in collaboration with professionals in medicine, epidemiologists and governmental bodies. The
more collaborations you have with individuals from other fields, the more widely distributed the study results and ideas will be. In other words, the more the importance of social factors, environmental factors and qualitative research as a whole is collaborated between different fields, the more it will be recognized by those other fields that currently have a more popularized reductionist outlook on research.

**Could the aging process be transgenerational?**

Aging patterns as a transgenerational study could also be another method to research aging as a continuous process. The participants for this study have narrated how experiences with their own parents have shaped them and their mental health as an adult. The study of Japanese women having low fetal birth-weight (Sata F 2016) is yet another example of how aging patterns can be transgenerational, adding more weight to AD being looked at as an aging process than a singular entity of disease. The idea of the brain being shaped via various internal and external variables advocates for the neuroplasticity of the brain, a concept that further supports the entanglement theory. One common theme among all the participants given above is the fact that one or both their parents had one or more issues of alcohol abuse, sexual abuse, mental health issues. The participant’s experience with these issues where much before they were 18.

Could there be a certain window of time during one’s childhood where social and environmental influences make the most impact on the developmental process? The entanglement of these experiences with the aging process of these individuals may have contributed in the development of repeated feelings of isolation and distress which accumulated
as allostatic load over time shaping the participant’s behavior along the way and eventually manifesting into memory issues much later in the life course. The degree of effect might differ between individuals, but in general, cumulative experiences may be absorbed into the individual’s behavior and may shape the way they choose to lead their own lives. For example, participant#25 reports how her behavior as an adult might be shaped because of her childhood experiences with her father’s alcoholism. She learned how to be the “peacekeeper” of the household and as an adult in her relationships and her workplace. Experiences before the age of 18 may have enough of an effect to shape all aspects of one’s life, that is, their nutritional habits, habits of self-care, work ethics, their own relationship with others etc. These consequent habits and personality formed results into what health conditions one might have or not have, thus all trickling down to the way the individual’s body and mind ages. In other words, the experiences one has are the exposures to the physiology and mind, both latter in turn playing a role in shaping each other. This is seen in participant#28, where sexual and verbal abuse she experienced as a child, she believes, had manifested into diagnosed depression at the age of 40. Thus, the body and mind might not be as separate as it is assumed to be.

**Building resilience from adverse experiences**

As mentioned above and from the responses we got from participant#25 and #11, adverse experiences may not have all harmful mental health consequences. Just like #25 built an understanding on how to maintain peace during demanding situations, such as her father’s alcohol abuse. #11’s experience of childhood isolation and neglect made her self-reliant and independent as an adult. Thus, certain experiences can also build a resilient and self-protective behavior that might prove beneficial as an adult. Although the question still remains, does this
resilience necessarily prove beneficial in terms of slowing down the aging process long-term? In other words, it could be argued that socio-behavioral resilience built may not necessarily mean pathological resilience. Thus, research in this aspect of adverse experience-consequences may be another interesting area in aging research.

Care-giver mental health

Something we do not often see talked about is the health of those family members that take care of the AD patients. Participant#11 believes her recent memory problems have been circumstantial due to her mother’s AD. The pressure and exhaustion that comes with having to take care of a parent with AD may one of the biggest long-term stress inducers. The long period of high stress may affect the care giver’s mental health and it can be argued that it could also be a trigger leading to the decline of the care-giver’s own health. Thus, counselling interventions that protect the care-givers themselves could be essential along with services for those with diagnosed AD.

Perceptions on experiencing memory decline and AD of a loved one

The overall common theme throughout the conversation I have had with the participants has been about the accumulation of experiences. The accumulation of their experiences before the age of the18, their experiences with family mental health and substance/sexual abuse, all have a significant place in their narratives. During their ethnographic interview, on being asked why they were interested in this study, one frequent response was because they have never had anyone ask them about how their ACE experiences have affected them as adults and they were
excited to share their perception of how those experiences may have affected their behavior and health as an adult. Their experiences have affected them from their childhood by issues faced by those of the previous generation, that is, their parents or siblings, thus they all had responses where they believed the constant exposure to high stress throughout their life could have been responsible for their current memory issues.

Participant #11 and #25 noted that there is a lack of conversation about mental health with their primary care physicians. Behavioral differences such as possible chronic depression or frequent mood swings are often overlooked by them as situational and temporary. This lack of conversation about the need for mental healthcare often leads to a late diagnosis of dementia or the complete ignorance of mental health of the care-giver. This makes things more difficult for the care-giver as often times they are in situations where they need to take care of their own issues with memory as well as their rapidly declining parent or sibling.

The motivation for individuals to participate in research is most commonly because of their long experience with AD and memory impairment, most important reason being is that they want to help so their children have better access to help early on. Participants with a MoCA score of 30 feel motivated to participate because they want to be involved and become familiar with the current research findings to be prepared and informed for themselves. These are some of the general perceptions as to why participants were interested in this study and how their experiences might have played a key role in their healthcare.
Summary

The ethnographic responses along with the individual MoCA and ACE scores, when analyzed brought out some interesting trends in responses and critiques. All participants with one or more ACE experiences had faced adverse conditions before the age of 18. Among those reported were experiences of neglect and repeated sexual abuse all experiences that had a lasting effect in respondents into their adult age. The entanglement of these experiences with their early experiences worked to shape their behavior and personalities as an adult. Thus, the aging process and individuality of that process could be due to the entanglement of every individual’s experiences through one’s lifecourse resulting into a unique pace of aging and age-related conditions for every individual. Some responses also raised the question of the aging process to be potentially transgenerational. Some participants whose parents experienced alcohol abuse or sexual assault had lasting effects on their own early experiences. This further brings the neuroplasticity and development of the brain into focus. This would require further research into periods of brain development in early years that the brain is most likely to be affected by exposed experiences. However, some responses also showed to build resilience in some respondents. The argument remains as to whether resilience in behavior also means resilience in the aging process and pathology of that individual. Among critiques, there were responses where the lack of mental health services for care givers were pointed out. These individuals were one’s that had to take care of a parent suffering from AD or dementia along with their own issues in memory. Further, the ACE questionnaire was found to be lacking inclusivity for culture or region- specific experiences. Inclusion of diverse categories of adverse experiences could expand the use of the ACE module globally, advocating for more research in adverse childhood experiences and their health outcomes.
In the next chapter, I go more into depth into how such findings can be used to further research in AD, our current findings and my recommendations for potential future research and their implications.
CHAPTER FIVE:

CONCLUSION, DISCUSSION AND FUTURE DIRECTIONS

Conclusion and discussion

The results obtained brought out some drawbacks of the ACE module in terms of what might be missing and how it can be made more culturally, regionally and racially -inclusive. That may help broaden the ACE and DOHaD initiatives to a global scale, furthering the existing body of knowledge. The results obtained were used to advocate for the entanglement theory as explained by Lock in chapter 2. Further, chapter four provides a detailed review of commonly occurring themes such as the entanglement theory, transgenerational aging, and resilience from adverse experiences and care- giver mental health. Chapter five furthers the discussion by providing a look into current research related to the discussed themes. An informed and larger drive to critically view current research in AD and aging.

The MoCA, ACE and interview results cumulatively brought out the significant role of adversity in the early years of one’s experiences. Experiences of childhood isolation and neglect were not reported as a category in the ACE module, however, it brought out the possibility of resilience- building from adverse experiences. The ACE experience of alcohol abuse by a family member and repeated sexual abuse also developed qualities of behavioral resilience in another respondent. The contribution of such behavioral resilience, however could be debatable as only
more focused research could determine if such resilience has any positive effects on the process of aging and age-related conditions. Other responses of sexual and verbal abuse on the other hand, had transgenerational effects between mother and daughter’s early experiences. Mental illness and incarceration for another respondent resulted into reproductive conditions that lead to diagnosis of infertility. Thus, in these common and as well as varied experiences, the entanglement of adversity with environmental and social exposures early in life did have behavioral and physiological consequences later in life for all respondents.

Due to the lack of adequate statistical data this study was unable to determine a significant correlation between these adverse experiences and memory impairment. However, a correlation could determine the role of the trade-off theory and the principle of allocation of energy to be true. In other words, it would show that adversity faced early in life could have led to allocation of energy in areas significant to early life coping mechanisms and a compromise on allocating for development of cognitive growth. The results obtained overall signify the need for utilization of neuroanthropology and mixed methods research by utilizing all aspects of environmental, social and biological exposures during one’s lifecourse. This could help broaden currently held reductionist methods of research where unquantifiable factors are not considered to have a significant role in the development and progression of a disease. More specifically, the life course approach can help aging research understand the process of aging as a continued process that is affected by an entanglement of early and later life exposures.

Looking back, a significant parameter to use in this study would have been scales to determine the severity of each ACE category. This would further inform the individuality in effects of those experiences on responses. This severity scale along with the age at which the respondent experienced the adversity could also be another significant parameter that could be
used. Adverse experiences faced during groups like early childhood (age 3-10) and adolescence (age 11-18), when compared to the results of the respondent’s MoCA score could determine a possible developmental period that is most susceptible and could have impacts on the cognitive profile later in life. I would encourage more researchers to further investigate these ideas.

**Where we stand now and what challenges us**

The world of Alzheimer’s disease research has seen some slow but significant strides in understanding prevention and treatment approaches. The 2012 “Alzheimer’s Disease Research Summit 2012: Path to Treatment and Prevention” presented speakers like Kathleen Sebelius, the secretary for US Health and Human Services. By 2050, about 16 million people in the US will be affected by AD (Lock 2013). This information was emphasized with the goal of capturing the attention of governmental authorities and most importantly create a “sense of urgency.” There was a steady growth in mentions on governmental websites focusing on disseminating information to the public about AD and age-related dementia. These websites were built with the goal of informing the public of available resources and encouraging them to sign up to be research subjects (Lock 2013).

There have also been media reporting with headlines such as “Obama Administration’s War on Alzheimer’s” to gain attention but also critique about the unavailability of adequate funds (Lock 2013). Further, efforts to sequence AD genome further narrows down efforts to a reductionist approach, all in search of that perfect answer or cure. Along with the above-mentioned summit, there had also been an increase in a global calling for translational efforts in research to be integrated globally (Lock 2013). Lock critiques that it is clear how throughout all
these efforts, even though calling for prevention, seeks a solution with “definable stages”, willfully being oblivious to the “continuum” of AD. This maybe largely due to the broader emphasis set on the race toward a finish line, without even knowing where that line exits. Researchers even called for shortening of the period for development of clinical and diagnostic technologies worldwide, calling for a fast development of systems worldwide (Lock 2013).

Some limitations to setting up a global infrastructure of clinical and diagnostic technologies may have some limitations that could be overlooked. In most countries there is a prevalent lack of access to such research studies (Lock 2013). In many others, the younger generation prefer to stay away from volunteering for routine invasive tests such as neuroimaging and spinal tap. Studies often give monetary concessions for those that volunteer as subjects, however large sums of money rewarded in socio-economically poorer communities attracted more participants (Lock 2013). This gave rise to ethical dilemmas where one could argue that the research study was exploitative of the population’s poor conditions. All these efforts are based on the localization theory, emphasizing the search for biomarkers and their associated treatments, especially that of amyloid plaques (Lock 2013). This is an effort based on incomplete knowledge, that not all individuals diagnosed have the same amount of amyloid and the actual role of the plaques are still unknown. It is notable though, that years of research has brought us to a period where AD and some aging-related conditions are manageable diseases and “no longer a death sentence”.

At this juncture the urgency of taking AD as a critical concern, has been widely recognized due to predictions of major future economic, healthcare burdens. Some researchers have noted a shift toward molecular genomics and epigenetic ways of looking at the impact of the environment and external factors on the aging generation (Lock 2013). The grips of genetic
determinism have been strong within the scientific community; however, one must note that there are researchers across disciplines who understand the role of “non-genetic factors” on the physiology (Lock 2013). “The Developmental Biology Systems theory” is built with the understanding that the environment and the physiological systems are in constant interaction altering the DNA to a certain extent throughout the lifecourse. At this point the understanding of how that exactly happens is very limited (Lock 2013).

The hope remains in the younger generation of scientists and applied anthropologists to increasingly work toward including environmental and societal variables. This hope is seen due to the fact that social media and modern control over lifestyle has made everyone aware how nutrition, exercise and social interactions affect one’s behavior and ultimately, health and development. Some concrete research has focused on bringing forth evidence that the environment and other external factors do affect the methylation of sites on the DNA ultimately affecting cellular changes (Lock 2013). Memory has been one of such topics of interest when it comes to its connection and modes of change with respect to epigenetics. All being said there is still a majority of researchers that do believe in the reductionist approaches of strictly studying the role of genetic mutations to find a cure (Lock 2013).

There is an increasing need of advocacy for translational research in the field of mental healthcare. Collaborations between neuroscience, medical anthropology and public health experts can work together to build interventions that have the long-term capacity to detect those populations most vulnerable to social adversities early in life. Such detection can identify those in need to early intervention through already existing systems like schools, churches and pediatric facilities. Implementation may receive more support if screening services are available and mandatory in these institutions, similar to the mandatory requirement of vaccinations.
The challenge for support exists in the political world, where political attention keep shifting according to the interests of supporting funding sources like pharmaceutical companies. Thus, to build attention towards the need for policy making, the target audience for such ACE research needs to be both those parties, as having research data is not enough to get the attention of policy makers. Climate change is a well-studied example in this case where various strategies are used to attain public and political attention to issues like global warming and climate change that have opposing views within the conservative and liberal mindsets. It is seen that support is more likely to be given when such issues are brought to people’s attention via education, focus groups, short films and imagery, all beginning in communities that need these interventions the most (Hart et. al. 2015, Smith et. al. 2013)

Some drawbacks to ethnography and ACE

Self-reporting and retrospective data collection methods have often faced criticism in terms of their accuracy and reliance in research. Here collection of reports of ACE categories have also been obtained from child protective services. However, both are reported to be reliant increasingly as attention to mixed methods and qualitative research has grown. Further, years of longitudinal ACE research has quantitative proof of having significant correlation between ACE categories and increased risk of diseases, hospitalizations and drugs/alcohol abuse (Anda et. al. 2010).

Another drawback of ACE studies is the time takes for exposures to become outcomes and the uncertainty of what severe consequences of one or a combination of adversities might have. Although the solution would not be short term, it does not take away from the importance
of developing a broader primary-preventative interventions. Support of biological data does exist in the form of both human and rat experiments where early traumatic exposures have altered the neurobiology of the brain and have caused dysregulation in emotion, memory, arousal, aggression etc. (Anda et. al. 2010). Our goal now must be to not just produce interdisciplinary collaborated results further supporting this, but also translate those into broader public health programs implemented early in life.

**Should we dare to ask questions differently?**

I believe the more we continue to ask only the convenient questions, the deeper we continue boxing our creativity. This is reflective of how inherently rooted AD research is in the localization theory. Even though recent research conversation does bring up social experiences as influencing factors in aging, it only does so in passing. The important shift toward prevention is a good direction, however, the reductionist approach of asking questions only seems to be revealing more convoluted information, making this more about the race to find the perfect answer than the overall agenda to prevent AD.

Research in AD-related neuropathology emphasizes finding the stages that lie between normality and dementia where individuals do not yet show any visible symptoms of cognitive impairment. This is highly researched with amyloid plaques as the popular biomarker and conveniently denies environmental or social influences. This is another example of research based on a localized mindset (Lock 2013) To find evidence of influencing social and political factors AD research may be based cross-culturally or between different racial groups. The different life course experiences between these groups could be good comparison to prove that
difference in experiences, especially levels of disparities between groups can influence aging outcomes. Naturally, this is where collaborations between neuroanthropologists, medical professionals and epidemiologists can work toward a longitudinal cross-cultural research. However, it may not be limited to these professionals, experts in politics and socio-behavioral sciences can provide additional input, to understand the role of social, economic and political factors between those cultures, races or sexes. This may be at the expense of discomfort in not having an outcome with neat boundaries, but it does push us to truly investigate aging as a continuous and entangled process influenced throughout the life course by internal and external variables. I believe we need to ask the question of how susceptible we are to cognitive decline with culturally specific social adversities and environmental changes. In other words, the brain’s plasticity must be understood with respect to response to various stimuli over time (Lock 2013).

The ethnographic results obtained in this study successfully bring out aspects of the ACE effect that question the brain’s early development and plasticity. My arguments and participant quotes in support for the entanglement theory discusses how prolonged exposure to negative experiences below the age of 18 could influence the molding of one’s behavior and ultimately their physiology. This gives way to discussions about the complexity in connection between the mind and the physiology. I believe this initiates the discussion of how the process of aging might be influenced by such a connection between the mind and the physiology. Thus, I would encourage more socio-behavioral studies to ask more of such questions and investigate what might not necessarily be quantifiable but could give way to the use of ethnographic methods to gather a database of trends in such a connection. The plasticity of the brain is also discussed in questioning whether the effects of experiences can transcend generations. Could experiences of parents experiencing issues with alcohol or drug use shape the behavior and mind during the
exposed child’s development? The role of the parent’s experiences in affecting the child’s development is yet another example of the entanglement of various experiences and their role in shaping the behavior and physiology during the individual’s aging process. This also brings into question whether there is a window of period where the individual is the most influenced by their experiences. All adverse experiences may not affect every individual in the same way. Some responses to the semi-structured interview showed trends of building behavioral resilience from experiences like isolation or neglect. Although as I have argued, this may not necessarily mean that resilience can slow down or have any form of protective quality in the aging process. This may give way to another research question about the correlation between such behavioral resilience and the aging brain. Further, public health, adverse experiences, and political arguments must also be equally part of the AD prevention effort. These exchanges could help ask questions that go beyond the confines of a lab into the real-world influencing factors on the aging brain.

Lock in her book notes that there are researchers that believe AD to be a syndrome rather than a single disease. Further, AD could be looked at as part of a personalized aging process based on their experiences. Calling it a syndrome also helps with curbing the stigma that lies with diagnosis or potential treatment. Another mode of comparison is education (Lock 2013). The number of years in education can help determine if it acts as a source of slowing does or protecting the individual from getting cognitive decline early in life. There may not be a direct correlation, but education may overall help improve the lifestyle of the individual by improving their socioeconomic status or simply the way they take care of their health. It may overall decrease the toxic stress that works in entanglement with one’s cognition at every stage in the life course. However, this may not mean that genetics does not play a role in any way. Genetics,
although, may undergo upregulation and downregulation based on the external factors it comes into contact with through the years. Thus, the entanglement theory works best here to explain how it is the interconnection of several risk factors with each other that pave the way for aging over the years. Based on that entanglement, an individual who is predisposed to having AD, may not end up with the disease at the end of his/ her lifecycle based on the combination of several internal and external variables. It may fail to comfort researchers that are looking to find a standardized answer. However, emphasizing the results of political and social impacts on one’s brain physiology can encourage a newly strengthened dialogue on the changes to those systems. Such a holistic approach targets the overall lifestyle and stressors exposed to all generations of youths to older individuals globally. Research in AD may not be limited to only aging, it can also indirectly create initiatives of social, political and economic change in a nation and on a global scale.
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doi:10.1265/jjh.71.41

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APPENDICES

Appendix A: Demographic and Medical History Questionnaire

1) Name:_____________________________________

2) Sex: M/ F

3) Address:___________________________________________________________________
________________________________________________________________________
________________________________________________________

4) Date of birth:__________________Age:________________

5) Phone:____________________________________________________

6) Email:_____________________________________________________

7) How many people do you live with?__________________________

8) Ethnicity:_______________________________________________

9) Name of primary care physician: ________________________________
    Office phone number :____________City and State:____________

10) Please list all medications you are currently taking:
    ____________________________________________________________
    ____________________________________________________________
    ____________________________________________________________
    ____________________________________________________________
11) Family history of Alzheimer’s disease (AD) and other mental health conditions:
   a) Relationship with individual:__________________Name of condition:
      
      Was the condition: Suspected / Diagnosed (Circle answer)

   b) Relationship with individual:__________________Name of condition:
      
      Was the condition: Suspected / Diagnosed (Circle answer)

   c) Relationship with individual:__________________Name of condition:
      
      Was the condition: Suspected / Diagnosed (Circle answer)

Notes:

_____________________________________________________________________

____________________
_________________________________________________

12) Tobacco use: Yes / No; Number of times per week:_________

   Received treatment or therapy: Yes/ No
13) Alcohol use: Yes /No; Number of times per week:__________

Received treatment or therapy: Yes/ No

14) Drug use: Yes /No; Number of times per week:__________

Received treatment or therapy: Yes/ No

15) Circle yes or no for the following conditions (current/ past) listed:

<table>
<thead>
<tr>
<th>Condition</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visually impaired</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you had to seek treatment in a hospital in the last 2 years?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>If yes, name why_____________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you suffered a heart attack or a congestive heart failure?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Have you suffered a stroke / transient ischemic attack (TIA)?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Have you suffered any type of cancer in the last 5 years?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Sleep Apnea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thyroid problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleeping difficulty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatric condition/s</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Are you on any of the following list of medications:

<table>
<thead>
<tr>
<th>Medication</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Namenda</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Axona</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Gingko Biloba</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Exelon/ Exelon Path</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Aricept</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Razadyne</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Any other memory enhancing supplements</td>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>

Thank you for taking the time to fill out this questionnaire.
Appendix B: Informed Consent Form

Informed Consent to Participate in Research Involving Minimal Risk and Authorization to Collect, Use and Share Your Health Information

IRB Study # Pro00029715

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:
Adverse childhood experiences and its association with cognitive impairment in non-patient older population
The person who is in charge of this research study is Mohini Dutt. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Dr. Daniel Lende.

The research will be conducted at Psychiatry and Behavioral Neurosciences, USF.

**Purpose of the study**

The purpose of the study is to find out if your life experiences before the age of 18 has played a role in affecting your memory at your current age.

**Why are you being asked to take part?**

We are asking you to take part in this research study because:

- Your age is 50 -65 years.
- You have been interested in the memory screening due to your current concerns about your memory.

**Study Procedures: What will happen during this study?**

If you take part in this study, you will be asked to provide:
• Demographics and medical history

• MoCA

• ACE and

• A semi-structured interview that will be audio recorded.

**Total Number of Participants**

Minimum of 100 individuals will take part in this study at USF.

**Alternatives / Voluntary Participation / Withdrawal**

You do not have to participate in this research study. You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study.

You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

**Benefits**

The potential benefits of participating in this research study include:

• Participants can use the MoCA score to be aware of a baseline score. This score can be taken home and used to track changes in the score by having retaking the MoCA tool with a memory care specialist, nurse practitioner or neurologist anytime in the future if the
participant wishes. This helps to track changes in memory in a regular and effective way.

- Participants are provided with results of the screening to share with other primary healthcare provider.

- Interested participants will be referred to clinical research trials USF Psychiatry and Behavioral Neurosciences. This is in case the participant feels the need to speak to a medical professional after the completion of the visit, as some questions might have the participants recall difficult memories.

- The participant may contribute to long term benefits in research and increase scope for socio-behavioral relevance of adverse childhood experiences in development – epigenetics.

Benefits to primary healthcare: This study may add relevance to consideration of mental healthcare early in life, especially to disadvantaged groups belonging to low socio-economic backgrounds and lower rate of access to mental healthcare. Supporting results of this study can further research in primary prevention of mental conditions thus bolstering the advocacy for a stronger mental healthcare component in current primary healthcare system.

**Risks or Discomfort**

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. The result of the MoCA tool will be shared
at the end of the visit. Here, we emphasize that this study will not be used to make any form of medical diagnosis. There are no known additional risks to those who take part in this study.

**Compensation**

You will receive no payment or other compensation for taking part in this study.

**Costs**

It will not cost you anything to take part in the study.

**Privacy and Confidentiality**

We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, study advisors, and all other research staff.

- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
o Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).

o The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, call Mohini Dutt at 267-356-7041.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638 or contact by email at RSCH-IRB@usf.edu.

Authorization to Use and Disclose Protected Health Information (HIPAA Language)

The federal privacy regulations of the Health Insurance Portability & Accountability Act
(HIPAA) protect your identifiable health information. By signing this form, you are permitting the University of South Florida to use your health information for research purposes. You are also allowing us to share your health information with individuals or organizations other than USF who are also involved in the research and listed below.

The following groups of people may also be able to see your health information and may use that information to conduct this research:

- The medical staff that takes care of you and those who are part of this research study;
- Each research site for this study including Psychiatry and Behavioral Neurosciences, USF.
- The USF Institutional Review Board (IRB), its related staff who have oversight responsibilities for this study, including staff in USF Research Integrity and Compliance and the USF Health Office of Clinical Research.
- Data Safety Monitoring Boards or others who monitor the data and safety of the study;

Anyone listed above may use consultants in this research study, and may share your information with them. If you have questions about who they are, you should ask the study team. Individuals who receive your health information for this research study may not be required by the HIPAA Privacy Rule to protect it and may share your information with others without your permission. They can only do so if permitted by law. If your information is shared, it may no longer be protected by the HIPAA Privacy Rule.

By signing this form, you are giving your permission to use and/or share your health information
as described in this document. As part of this research, USF may collect, use, and share the following information:

- Your research records
- All of your past, current or future medical and other health records held by USF, other health care providers or any other site affiliated with this study as they relate to this research project. This includes, but is not limited to records related to HIV/AIDs, mental health, substance abuse, and/or genetic information.

You can refuse to sign this form. If you do not sign this form you will not be able to take part in this research study. However, your care outside of this study and benefits will not change. Your authorization to use your health information will not expire unless you revoke (withdraw) it in writing. You can revoke this form at any time by sending a letter clearly stating that you wish to withdraw your authorization to use your health information in the research. If you revoke your permission:

- You will no longer be a participant in this research study;
- We will stop collecting new information about you;
- We will use the information collected prior to the revocation of your authorization. This information may already have been used or shared with others, or we may need it to complete and protect the validity of the research; and
- Staff may need to follow-up with you if there is a medical reason to do so.

To revoke this form, please write to:

Principal Investigator

For IRB Study # Pro00029715
While we are conducting the research study, we cannot let you see or copy the research information we have about you. After the research is completed, you have a right to see the information about you, as allowed by USF policies. You will receive a signed copy of this form.

Consent to Take Part in this Research Study

And Authorization to Collect, Use and Share Your Health Information for Research

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

_____________________________________________  ____________
Signature of Person Taking Part in Study           Date

_____________________________________________
Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.
Signature of Person obtaining Informed Consent  Date

Printed Name of Person Obtaining Informed Consent
Appendix C: Montreal Cognitive Assessment (MoCA)

### Montreal Cognitive Assessment (MoCA)

#### Visual-Spatial / Executive
- Copy cube
- Draw clock (ten past eleven)

#### Naming
- Contour
- Numbers
- Hands

#### Memory
- Read a list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

#### Attention
- Read list of digits (1 digit/sec.). Subject has to repeat them in the forward order.
- Read list of digits (1 digit/sec.). Subject has to repeat them in the backward order.

#### Serial 7 Subtraction Starting at 100
- 93
- 86
- 79
- 72
- 65
- 4 or 5 correct subtractions: 3 pts., 2 or 3 correct: 2 pts., 1 correct: 1 pt., 0 correct: 0 pts.

#### Language
- Repeat: I only know that John is the one to help today.
- The cat always hid under the couch when dogs were in the room.

#### Abstraction
- Similarity between e.g. banana - orange or fruit - leaf

#### Delayed Recall
- Has to recall words with no cue.
- Optional category cue
- Multiple choice cue

#### Orientation
- Date
- Month
- Year
- Day
- Place
- City

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www.mocatest.org

Normal’s 26 / 30

Add 1 point if ≤ 12 yr old

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TOTAL __ / 30
Letter Fluency - F

Directions: "I want you to tell me all the words you can think of that begin with a certain letter. Don’t tell me names of people or places, just words. Try not to repeat yourself. Now tell me all the words you can think of that start with the letter F."

1. __________________________  16. __________________________
2. __________________________  17. __________________________
3. __________________________  18. __________________________
4. __________________________  19. __________________________
5. __________________________  20. __________________________
6. __________________________  21. __________________________
7. __________________________  22. __________________________
8. __________________________  23. __________________________
9. __________________________  24. __________________________
10. __________________________  25. __________________________
11. __________________________  26. __________________________
12. __________________________  27. __________________________
13. __________________________  28. __________________________
14. __________________________  29. __________________________
15. __________________________  30. __________________________

No credit for repetitions or words that start with another letter. If subjects get 11 words, they score 1 point on the MOCA.
Appendix D: Adverse Childhood Experiences (ACE) Module

BRFSS Adverse Childhood Experience (ACE) Module

Prologue: I’d like to ask you some questions about events that happened during your childhood. This information will allow us to better understand problems that may occur early in life, and may help others in the future. This is a sensitive topic and some people may feel uncomfortable with these questions. At the end of this section, I will give you a phone number for an organization that can provide information and referral for these issues. Please keep in mind that you can ask me to skip any question you do not want to answer. All questions refer to the time period before you were 18 years of age. Now, looking back before you were 18 years of age—

1) Did you live with anyone who was depressed, mentally ill, or suicidal?

2) Did you live with anyone who was a problem drinker or alcoholic?

3) Did you live with anyone who used illegal street drugs or who abused prescription medications?

4) Did you live with anyone who served time or was sentenced to serve time in a prison, jail, or other correctional facility?

5) Were your parents separated or divorced?

6) How often did your parents or adults in your home ever slap, hit, kick, punch or beat each other up?

7) Before age 18, how often did a parent or adult in your home ever hit, beat, kick, or physically hurt you in any way? Do not include spanking. Would you say—

8) How often did a parent or adult in your home ever swear at you, insult you, or put you down?

9) How often did anyone at least 5 years older than you or an adult, ever touch you sexually?

10) How often did anyone at least 5 years older than you or an adult, try to make you touch sexually?

11) How often did anyone at least 5 years older than you or an adult, force you to have sex?

Response Options

<table>
<thead>
<tr>
<th>Questions 1-4</th>
<th>Question 5</th>
<th>Questions 6-11</th>
</tr>
</thead>
<tbody>
<tr>
<td>1=Yes</td>
<td>1=Yes</td>
<td>1=Never</td>
</tr>
<tr>
<td>2=No</td>
<td>2=No</td>
<td>2=Once</td>
</tr>
<tr>
<td>7=DK/NS</td>
<td>8=Parents not married</td>
<td>3=More than once</td>
</tr>
<tr>
<td>9=Refused</td>
<td>7=DK/NS</td>
<td>7=DK/NS</td>
</tr>
<tr>
<td></td>
<td>9=Refused</td>
<td>9=Refused</td>
</tr>
</tbody>
</table>
Appendix E: Follow-up Questionnaire to BRFSS Adverse Childhood Experience (ACE) Module

NOTE: Only for education of High School and above

• Education:

• List of questions numbers that have positive ACE response:

______________________________________________________________________

• Obtain response to questions A and B below with respect to each positive ACE response:

A: When and how did you decide to come in for a memory screening?

(Probe points: recent changes in memory; encouraged by friends/ family or healthcare provider)

B: What age (or recall year) were you when you first noticed an irregularity in everyday activities?

C: Before that age, describe yourself in such an activity or situation focusing on these following areas: (ask individually)
Memory
Concentration
Attention
Problem solving

**D:** Try to locate and recall how your memory, concentration and attention have been influenced by your ACE experiences in terms of internalized feelings like fear, anxiety, loss of interest, self-confidence or isolation?

**E:** Have you noticed a change in frequency or progression of the memory problems since you first said you noticed it up till now?

**F:** Was there any other individual or individuals who helped you or motivated you to come in?
Appendix F: USF IRB approval letter

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-9638 • FAX(813)974-7091

April 3, 2017

Mohini Dutt
Anthropology
Tampa, FL 33612

RE: Expedited Approval for Initial Review
IRB#: Pro00029715
Title: Adverse childhood experiences and its association with cognitive impairment in non-patient older population

Study Approval Period: 4/2/2017 to 4/2/2018

Dear M. Dutt:

On 4/2/2017, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within, including those outlined below.

Approved Item(s):
Protocol Document(s):
Pro00029715_Version#1_3.6.2017.rtf

Consent/Assent Document(s)*:
Adult w_HIPAA Consent Version #1.docx.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent documents are valid until the consent document is amended and approved.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110. The research proposed in this study is categorized under the following expedited review category:
(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your study qualifies for a waiver of the requirements for the process of informed consent as outlined in the federal regulations at 45 CFR 46.116(d) which states that an IRB may approve a consent procedure which does not include, or which alters, some or all of the elements of informed consent, or waive the requirements to obtain informed consent provided the IRB finds and documents that (1) the research involves no more than minimal risk to the subjects; (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects; (3) the research could not practicably be carried out without the waiver or alteration; and (4) whenever appropriate, the subjects will be provided with additional pertinent information after participation. (Recruitment database)

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Board