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Motivation differences of males and females in the PACT Study: An exploratory study

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Motivation Differences of Males and Females in the PACT Study
An Exploratory Study.

by

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in partial fulfillment of the requirements for the degree of
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ABSTRACT

A cure for Alzheimer's disease (AD) is not yet a reality, however, research on preventative interventions for AD has demonstrated promise. An issue this research has encountered and will continue to contend with is the recruitment of a generalizable sample. There are several randomized clinical trials (RCTs) in various disciplines that do not reach their target sample or must extend their recruitment period to reach their sample size. Challenges like this will aid in the delay of finding an AD prevention method. That impedes the help it could provide future generations. The current study explores research participants' (2,617) open-ended responses to the Motivation Questionnaire that is administered during the visit one appointment of the Preventing Alzheimer's with Cognitive Training, (PACT) randomized clinical trial. The purpose of this study is to explore what motivates an individual to participate in a longitudinal AD prevention study. Specifically, do females and males differ on what motivates them to participate in the PACT study. The PACT study is testing different types of brain games to see if computerized cognitive training (CCT) can delay the onset of Alzheimer's disease or other related dementias (ADRD). The findings suggest that there is a difference in what motivates females compared to males. While both genders are concerned about our brain health and aging, males are more likely to participate for the benefit of others. Whereas women are more likely to participate in the hopes of benefitting personally from the efforts.

CHAPTER 1: INTRODUCTION

Why is AD research necessary?

Research suggests that most individuals aged 65 years or older have some risk level of developing Alzheimer's disease (AD) or other forms of related dementia (ADRD) and that risk will continue to increase as they age (Alzheimer's Association [AA], 2021). The apolipoprotein e4 gene (APOE-e4) increases that risk and so does a family history of AD (AA, 2021). Females are more likely than males to develop cognitive decline (AA, 2021; Mielke, Vemur, & Rocca, 2014). Females are more likely to be the caretaker of someone with cognitive decline (Mielke et al., 2014). In 2020, most of the baby boomer generation turned 75 years old (AA, 2021). This means more of the population falls in the age demographic that increases the risk for developing ADRD (AA, 2021). AD has higher rates of prevalence in the African American and Hispanic populations compared to the White population (AA, 2021). African Americans are almost two times more likely to have ADRD and Hispanics are almost one and half times more likely compared to white Americans (Alzheimer's Impact Movement [AIM], AA, 2020).

The research to determine why two thirds of ADRD diagnoses are female is limited and not entirely clear (AA, 2017; Mielke, 2018; Nebel, Aggarwal, Barnes, Gallagher, Goldstein, Kantarci, Mallampalli, Mormino, Scott, Yu, Maki & Mielke, 2018). The single biggest risk factor to the development of ADRD is age, and females outlive males by a considerable amount. The Center for Disease Control (CDC) reported that in 2020 the life expectancy for males was 75.1 years of age and for females 80.5 years (Arias, Tejada-Vera, & Ahmad, 2021). That five-year difference creates additional time to develop a form of dementia for females comparatively to males.

Another reason for the increased risk for females to develop ADRD is due to the higher prevalence in depression amongst females. Mielke (2018) reports, "Depression has implications for cognition across the lifespan because mood and memory map to some of the same brain regions"(p. 2). Higher rates of depression, biological sex of being female, and age are all explanations as to why women make up about two thirds of the ADRD diagnoses. However, recent literature offers a new perspective. Low education was also considered a risk factor for ADRD diagnosis (AA, 2017; Mielke, 2018; Nebel et al., 2018). Previously females were more likely to have lower education levels due to being the caretakers of the household. In recent decades this trend is changing since more females are pursuing higher levels of education (Mielke, 2018). Although females are listed as more likely to develop ADRD there are circumstantial factors that may result in a shift in trends in the future. These reasons are all factors in the importance of researching the differences in gender differences when it comes to motivation to participate in ADRD prevention research.

Alzheimer's disease is the seventh leading cause of death in the United States (National Institute of Aging [NIA], 2019). The baby boomer generation is now approaching 80 years old (AA, 2021). The baby boomer generation makes up almost a quarter of the population. The leading risk factors for being diagnosed with ADRD is age, being female, and having depression (Mielke, 2018; Arias, et al., 2021). Our population is aging and the prevalence of ADRD will continue to rise unless there are effective prevention methods that are accessible to most. In this study significantly more females participated than men. The gender differences in motivation could help explain the discrepancy and provide insights to develop effective recruitment strategies and efficient retention approaches so that both genders are represented equally.

Costs to family and government

There is a considerable amount of tax dollars and personal costs from the caretaking of an individual with AD. The medical and social care costs were about \$1.3 trillion (about \$4,000 per person in the US) US dollars worldwide in 2019, this is expected to increase over two times that amount to \$2.8 trillion (about \$8,600 per person in the US) US dollars by 2030 (World Health Organization [WHO], 2022). Aside from the cost of care, it is noted that “more than 11 million Americans provide unpaid care for people with Alzheimer’s or other dementias” (AA, 2021, p.724). The Alzheimer’s Association estimates the lifetime cost to someone with a form of dementia is around \$373,527 US dollars and that does not factor in all the unpaid care that loved ones provide (AA, 2021).

In review of the costs associated with ADRD it is necessary to mention that the Alzheimer’s Association (AA) notes on their website, “...Alzheimer’s is a progressive disease and the person’s needs will change over time” (AA, 2023). Meaning, that the care an individual with a form of dementia needs, especially if that form is AD, then the care will continue to increase as the disease progresses. They go on to report that home care with non-medical personnel is \$28 per hour, adult day care is \$80 per day, and a private room in a nursing home is \$306 per day (AA, 2023). The overall cost to an individual with AD or other related dementia is expensive to start off care and continues to increase in expense as the disease progresses and the care needs increase. The expense of the disease on society is felt both in the loss of life, in the monetary cost, and the time loved ones spend on care taking. These reasons are all components in the decision for the US government to invest in ADRD prevention research, such as the Preventing Alzheimer’s with Cognitive Training (PACT) clinical trial. PACT was awarded a 44-

million-dollar grant by the National Institutes of Health (NIH) to research if computerized cognitive training can delay or prevent onset of ADRD.

Alzheimer's Disease and other related Dementia prevention strategies

There are a few treatment options on the market for dementia. Many medication options provide up to six months of symptom reductions, some patient(s) experience a shorter time frame for the slow down and some patients experience a longer control of symptoms with these medications (Ellison, 2021). In 2021, the first disease altering drug was Food and Drug Administration (FDA) approved, Aducanumab. This drug may reduce amyloid deposits in the brain but has yet to affect the progression of the disease (NIA, 2021). Therefore, these drugs can help provide the patient with some relief from symptoms of dementia but not alter the progression of the disease. The NIA states that, "Experts agree that medicines to treat these behavior problems should be used only after other strategies that don't use medicine have been tried" (2021, para. 15). Therefore, these medications tend to be a last resort in the treatment options for patients. For this reason, prevention strategies are necessary to research to provide a solution in place of the ineffective medication options society is offered.

Livingston and colleagues (2020) detail 12 risk factors for dementia and their life-course model that can prevent dementia. The 12 risk factors are diabetes, hypertension, head injury, smoking, air pollution, midlife obesity, infrequent exercise, depression, excessive alcohol intake, hearing impairment, social contact, and level of education (Livingston et al., 2020). These risk factors are listed in various stages of life of early-life, mid-life, and late-life factors. For example, education is considered an early-life factor while obesity and hypertension are mid-life factors (Livingston et al., 2020). The authors recommend targeted interventions for the population with these lifestyle risk factors to reduce the dementia risk (Livingston et al., 2020). The 12 risk

factors, if controlled, may reduce the onset of dementia in 40% of the cases these authors predict (Livingston et al., 2020). However, there are demographic considerations that could make targeted interventions more difficult to achieve. For example, people with a low education level and those in minority groups are less likely to trust medical advice or have access to this information. These groups are also less likely to have access to such interventions due to things like transportation barriers.

Another method of preventing the onset of dementia is computerized cognitive training, or otherwise known as brain games. The Advanced Training in Vital Elderly (ACTIVE) study tested three types of computerized cognitive training on 2,802 older adults (Tennstedt et al., 2010). This was a longitudinal study conducted over a decade. The results state, “Speed training may lower dementia risk by increasing brain reserve capacity through compensatory changes in function (e.g., enhanced capacity or efficiency of the brain) or via direct effects promoting viability of health tissue or decreasing the amount or effect of pathologic proteins and processes” (Edwards et al., 2017, para 29.) Out of the three types of brain games tested, speed training was shown to have a 29% reduction in risk of dementia after a decade when compared to the control group (Edwards et al., 2017). Brain games that involve speed training is one of the first to demonstrate risk reduction. Controlling for 12 risk factors is less accessible to most individuals compared to an individual playing brain games that are designed and prescribed in certain amounts to prevent ADRD. Especially since some of the risk factors are difficult to control on a personal level, such as air pollution. There is only so much control an individual has over their air pollution exposure. To further research computerized cognitive training clinical trials, like PACT, need to be successful in their recruitment and retention efforts to find results on prevention strategies for ADRD. The next chapter will review what the literature states about the

motivation to participate in ADRD research and if there is information about gender and sex differences.

CHAPTER 2: BACKGROUND AND LITERATURE REVIEW

Motivation + Participation in Clinical Trials

The Merriam-Webster definition of motivation is, “a motivating force, stimulus, or influence” (Merriam-Webster [MW], 2023). Essentially, motivation is the reason that drives an action to be executed. In this paper, the motivation a female or a male has towards participation in the PACT clinical trial is being analyzed. The computerized cognitive training (CCT) to be completed through PACT participation is considered a health behavior. CCT can also be referred to as brain games. Li and colleagues (2022) found in a meta-analysis that CCT was capable of improvement in cognitive function in those with mild cognitive impairment. However, due to the small sample sizes of the studies reviewed it makes the findings less generalizable and highlights the need for clinical trials like PACT to be successful to quantify the benefit of CCT (Li et al., 2022). In this chapter, the trends of participation in clinical trials are reviewed.

The discussion of the incentive of older populations to volunteer for clinical research has a common theme of their desire to contribute to society in a meaningful way (Bevan, Chee, McGee, & McInnes, 1993; Calamia, Berstein, & Keller, 2016; Jefferson, Lambe, Chaisson, Palmisano, Horvanth, & Karlawish, 2011; Warburton & Dyer, 2004). In 1993, Bevan and colleagues interviewed 197 patients and categorized them in two groups, group A were patients involved in trials and group C were out-patients who might volunteer for a trial. Both group A and C reported “to help other people” as their main driver or motivator to participate in a trial (Group A = 62%, Group C = 57%) (Bevan et. al., 1993). This desire to contribute to society

through research involvement is found to be the most frequent reported reasoning for clinical trial participation.

Warburton and Dyer (2004) found, "...it is clear that the most important motive is to make a contribution to society and research" (p. 377). They surveyed 260 individuals on a registry that were aged 50 years old or older (Warburton, & Dyer, 2004). A few years later Jefferson, et. al., (2011) writes, "...more participants attributed joining the registry to the societal benefit of advancing research about AD than endorsing any personal benefit as a motivator..." (p. 7). The study surveyed 280 participants from the Boston University Alzheimer's Disease Center (BU ADC) through postal mail (Jefferson et al., 2011). The motivation to advance research about ADRD was the most frequent reason the respondents selected to answer why they enrolled in a research registry for AD studies (Jefferson et al., 2011). That theme was referred to as "societal benefit," and the second most common answer was to benefit "family, friends, or future generations" which they labeled "personal benefit" at 21% of responses (Jefferson et al., 2011, p. 5). These findings suggest that motivation to participate is more than spare time, that motivation involves an aspiration to help others.

Additionally, two other studies with small sample sizes, have similar findings for motivations to join dementia research registries. In a 2013 study, 107 individuals were interviewed and 44% of respondents said they wanted to help others as their important factor for the decision to register for the registry (Avent, Curry, Gregory, Marquardt, Pae, Wilson, Ritchie, & Ritchie, 2013). In a similar study, Calamia and team (2016) found, "...individuals were more likely to enroll in research studies when they believed that their participation would help improve the health of others" (para. 18). Most older participants choose to enlist their services in university studies, clinical research, or dementia research registries due to their desire to help

others (Avent et al., 2013; Bevan et al., 1993; Calamia et al., 2016; Jefferson et al., 2011; Warburton & Dyer, 2004). All the examples listed in this section illustrate that participation in clinical trials is due to motivation from the opportunity to help society.

The difference between the studies reviewed and the proposed research of this paper is sample size and the gender difference emphasis in this analysis. The sample size of this paper will close to double (2,617) most of the literature cited. The above-mentioned research is beneficial to recruitment and retention strategies. These studies made no mention of gender differences. Given that females are more likely than males to participate in ADRD prevention research it is important to look further into what motivates males so that recruitment efforts can reflect those incentives that will help with the call to action of participation (Bibbins-Domingo & Helman, 2022). The age of a prospective participant may be a component of the motivation for partaking in research.

The older adult population may be retired, approaching retirement or unemployed. Scarmeas and colleagues (2001) reported that older adults spend seven hours on average on social leisure activities per day. These facts lead to the assumption that people aged 60 and older technically have more spare time to commit to their duties as a participant in a research study (Warburton & Crosier, 2001). However, the National Institutes of Health (NIH) reported data on participant ages within clinical trials. The report shows that adults older than 65 years of age represent only 19% of clinical research participants (Lauer, 2022). Where most participants were aged between 18 and 65 years old (58%) (Lauer, 2022). This highlights a contrast between the thought of the aging adults being more likely to volunteer due to additional spare time not truly being the case in the United States for clinical research. Through this example it is evident that the motivation to volunteer for clinical research is more complex than the perception of extra

spare time to commit to participation. The desire to help people through ADRD prevention research participation and the incentive to benefit from the prevention efforts are the frequent motivational components. With this information, the following section will review how gender and sex representation looks like in clinical trials.

Gender representation in clinical trials

According to the FDA, females are no longer underrepresented in clinical trials reports of 2022 on demographics of the participants. Most of the females who participate are white females, roughly 78% of females in clinical trials were reportedly white (FDA, 2019). The change in representation is noted in the NIH as well, they reported that in 2013 females represented 44.3% of the sample size and in 2018 that grew to 52.4% (Bibbins-Domingo & Helman, 2022). In the National Institute of Aging (NIA) specifically, females represented over 50% of the sample size in all clinical trials in the years of 2013, 2014, 2016 and 2018 (Bibbins-Domingo & Helman, 2022). Akyol and team (2020) reports that individuals that are older, male, and with lower education levels are priority groups that need guidance for preventive health behaviors for AD. The knowledge that females are more likely to participate in ADRD prevention research is important in the creation of recruitment and retention efforts for clinical trials. These findings highlight why it is important to better understand what motivates males to participate in ADRD prevention research. Equal representation of males and females will aid in the generalizability of the results.

Smith, Ali, & Ouach (2015) completed 1000 interviews about motivation and action of Australians for brain health and risk reduction of dementia. They found that the groups that intended to act in the next month were females (36.1%), people aged 60+ (41.8%) and those with a university level education (38%) (Smith, Ali, & Ouach, 2015). Another study surveyed 284

participants in Turkey and found that females had higher perceived severity, cues to action, and lower levels of perceived barriers than men (Akyol et al., 2020). In the Turkish study the findings included evidence that women were most likely to act on the health behavior because of the motivation to improve brain health (Akyol et al., 2020). It is possible to infer that the higher prevalence of AD in females along with the likelihood of caregiving to someone with ADRD could lead to an overall higher level of awareness.

The more awareness in combination with the rising education achievements of females result in greater attention to personal wellness (Akyol et al., 2020; Kutner, Greenburg, Jin & Paulsen, 2006; Smith et al., 2015). Literature suggests that the more awareness or knowledge of AD leads to more efforts or motivation to partake in preventive health behaviors for ADRD (Akyol et al., 2020; Werner et al., 2013; Yang et al., 2010). Confidence in one's ability to complete the required duties of a research participant plays a role in motivation to participate as well.

Jalili, and colleagues (2019) surveyed 333 participants on factors that influenced preventive health behaviors for ADRD, such as supplementation. They found a significant relationship between self-efficacy and gender, specifically female respondents. They concluded that knowledge was the highest predictor for omega-3 supplementation (Jalili et al., 2019).

These studies have the theme that knowledge itself is a motivator in ADRD prevention health behaviors. They show that there are some differences between the genders when it comes to the knowledge of ADRD risk. The studies included findings suggesting that females reported higher rates of perceived susceptibility, worry or fear when it came to their knowledge about ADRD (Jalili et al., 2019; Werner, 2013). These examples demonstrate that there are differences

in motivation between females and males, while both feel called to help others the awareness of risk that females have may be the ultimate motivation for participation.

Health Belief Model

In the review of the prior literature the component of helping others is a motivation for both genders with females having a higher concern about their own brain health (Aykol et al., 2020; Smith et al., 2015). Now these findings will be applied to the Health Belief Model (HBM). HBM is used often in research that seeks to explain why an individual partakes in a health-related behavior. HBM was derived from Rosenstock, Hochbaum, Kegeles & Leventhal. Rosenstock (1974) states that the model attempts to explain preventive health behaviors as well as predict them based on certain beliefs or constructs. The model states that accurate prediction of a preventive behavior is dependent on the motivation and/or- value of the outcome based on an individual's belief system (Rosenstock, 1990). There are various constructs within the HBM; perceived susceptibility, perceived severity, perceived benefits, perceived barriers are the four main constructs from the original model. As research has advanced recommendations to modify and add to the model have been suggested. Such recommendations include self-efficacy and cues to action. These additional constructs make up the Extended Health Belief Model (EHBM).

Self-efficacy contributes to the EHBM through reviewing the various degrees of confidence a person has in their ability to achieve a health-related behavior. Cues to action considers different emotion evoking scenarios that contribute to the motivation to start a preventive health behavior. Cues to action can be internal, such as concern about one's own health and it can also be external, such as being referred to encouraged to participate in a preventive health behavior. In general, HBM and EHBM are more descriptive in nature and not necessarily explanatory. This model does not offer strategies to get someone to adopt preventive

health-related behavior. This model is used to explain why a healthy behavior is most likely taken up by an individual or answer what might stop action from happening (Rosenstock, 1990).

Table 1 lists the constructs of the EHBM with the respective definitions.

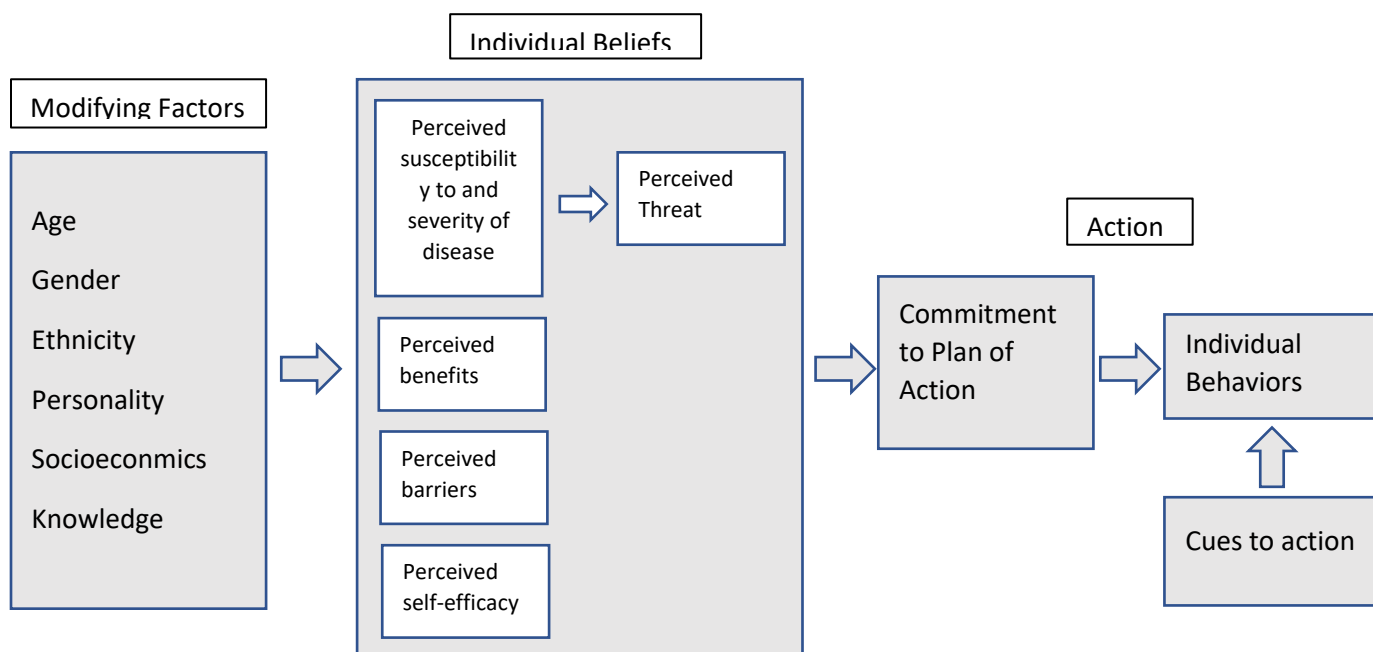
Table 1 *Definitions of EHBM Constructs:*

Construct	Definition
Perceived Susceptibility	The subjective perception of their individual risk in development of a disease or illness.
Perceived Severity	The subjective feelings about the severeness or seriousness of a disease or illness.
Perceived Benefits	The subjective perception of the capabilities of one or more health-related behaviors to reduce the threat of development.
Perceived Barriers	The subjective and objective reality of obstacles an individual faces to achieve preventive health-related behavior.
Cues to Action	The motivation that triggers an individual to decide to take on a preventive health-related behavior.
Self-Efficacy	The subjective amount of confidence a person feels they have the skills and/or resources necessary to perform a preventive health-related behavior.

A limitation of this model that is important to the current study is that this model assumes that everyone has the same amount of accessibility to information, specifically about ADRD. Kutner and colleagues (2006) stated that females have a higher rate of literacy and therefore likely higher rates of knowledge about the risk of ADRD. The EHBM is limited due to its inability to provide strategy to get someone to adopt a health behavior. The understanding of how a prospective participant filters their interest in taking on a healthy behavior is beneficial in the design of the recruitment strategies of a clinical trial. For example, if perceived barriers were

cited as the strongest influence on someone's motivation to participate, that would work as a starting point in study design. Figure one illustrates the diagram of filters that the theoretical framework proposes an individual goes through or considers before adopting a health behavior.

Figure 1 *Extended Health Belief Model (EHBM)*



In Figure one there are three categories: Modifying Factors, Individual Beliefs, and Action. Modifying factors are things that can influence individual beliefs that then shape the action towards the health behavior. In this paper, gender is the modifying factor that is being examined. From the literature review there is evidence to demonstrate that knowledge is a modifying factor towards ADRD prevention clinical trial participation. Now to review the individual beliefs and the impacts they have on motivation.

In a prevention for ADRD study where researchers surveyed individuals' beliefs on the health behavior of omega-3 supplementation they found a significant relationship between gender and self-efficacy (Jalili et al., 2019). They wrote that female scored mostly "good points"

on all HBM constructs in their measurements which is assumed to mean that females are influenced for several reasons but nonetheless influenced by awareness (Jalili et al., 2019). Lee & Jim (2022) reported similar findings in their cross-sectional study where they said that higher dementia knowledge, higher perceived benefit, and being female gender were all significantly factors towards engagement in an AD preventive health behavior, such as cognitive training. Overall, it can be generalized to say that females have a higher level of awareness of ADRD whether it be from the risk they have themselves in the risk to develop the disease or by likelihood that they are to take care of a loved one who has a form of dementia (Jalili et al., 2019; Lee & Jim, 2022).

Furthermore, two additional studies found that cues to action were a significant motivator for AD prevention clinical trial participation (Akyol et al., 2020; Werner, 2003). Few studies mentioned gender differences but one detailed that the female participants reported higher rates of cues to action as their motivation to volunteer (Akyol et al., 2020). In general, the literature about specific gender differences within the EHBM was scarce but all resulted in similar findings. Females are motivated for ADRD prevention healthy behaviors in part because of their knowledge of their own risk of the disease and the experience of care taking for someone with ADRD. As previously mentioned, knowledge is a modifying factor that leads to the next category of “perceived susceptibility and severity of the disease.” This drives motivation to engage in healthy behaviors to prevent the disease for oneself. While HBM and EHBM may not be a perfect theoretical fit it does provide a starting point to consider. The lack of gender differences noted in the literature illustrates that there is need to add to this body of research. This paper seeks to accomplish that through the analysis of the PACT clinical trial’s Motivational Questionnaire.

Theory of Reasoned Action | Theory of Planned Behavior

Another theoretical framework that should be considered is the Theory of Reasoned Action and the Theory of Planned Behavior (TPB). Researchers have long wondered what drives an individual to adopt healthy behavior. Theory of Reasoned Action (TRA) from Ajzen and Fishbein's (Fishbein & Ajzen, 1975) and the Theory of Planned Behavior (TPB). TPB is an extension or updated version of TRA (Ajzen, 1985; Ajzen & Driver, 1992) that considers what predicts the execution of a health behavior. TRA contends that intention is predicated by a person's attitude toward the behavior and the subjective norms around that behavior (Fishbein & Ajzen, 1975). If the attitude toward the behavior is relatively positive, it has been demonstrated to predict that the behavior will be adopted (Ajzen & Driver, 1992).

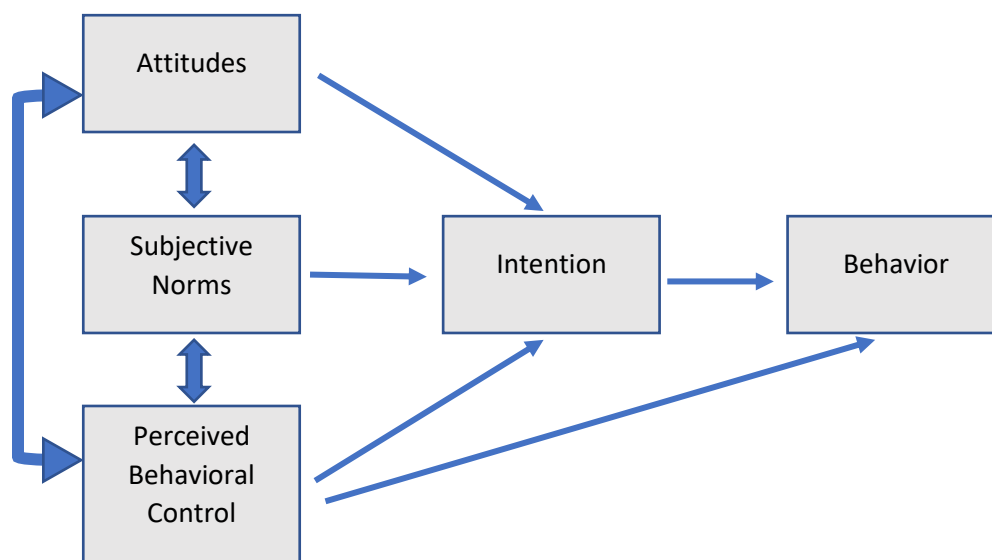
There has been much debate in the research regarding how much subjective norms influence an individual's intention towards the performance of a behavior (Ajzen & Driver, 1992; LaCaille, 2013; Murphy, Vernon, Diamond, & Tiro, 2014). Murphy and colleagues (2014) surveyed over two thousand females about mammography screenings and asked about benefits, barriers, and subjective norms found, "our analyses confirm intention as an important predictor of screening behavior, but it is not the only psychosocial factor with a direct effect" (p.127). This finding highlights that intention is a motivator for a person to perform a healthy behavior, such as getting a screening test done. However, they went on to conclude, "In our models, intention did not completely mediate the effect of barriers and subjective norm" (Murphy et. al., 2014 p.127). Overall, this study and others have illustrated that while typically TRA examines what leads to intention, intention does not always overrule the power of barriers and the social pressures individuals face (Ajzen & Driver, 1992; Murphy et. al., 2014).

Now, the TPB adds in a construct that has been shown to strengthen the predictive power of the original theory of TRA because it adds “perceived behavioral control” (PBC) (Ajzen, 1991; Armitage & Conner, 2001; Godin & Kok, 1996; LaCaille, 2013). As described by LaCaille (2013), perceived behavior control can be described as, “A person forms beliefs about the factors that may facilitate or be barriers to engaging in a specific behavior (e.g., “I have time before work, I have access to a gym, and I am physically able to exercise”) (para. 5). If someone perceives a barrier, then that in turn affects their motivation and intent to complete a behavior. Similarly, in Armitage & Conner’s (2001) meta-analysis & Murphy and colleagues (2014) study, a person may have all the motivation to complete a behavior but if there is an external barrier, such as transportation, then it may impede their performance of the behavior.

The PBC construct strengthens the accuracy of prediction of behavior through the TRA/TPB theories (Ajzen, 1991; Armitage & Conner, 2001; Godin & Kok, 1996; LaCaille, 2013). The combination of strong perceived behavior control and greater intent leads to a better chance the person will engage in the behavior (Armitage & Conner, 2001; Godin & Kok, 1996; LaCaille, 2013). In relation to PACT participation this would mean the participant believes that they have the time to commit to the CCT and that confidence leads to the likelihood that they decide to volunteer for the research study. Therefore, the TRA/TPB theoretical framework offers insight into subjective social norm influence as well as how personal beliefs about barrier control impact the motivation to enroll in an ADRD prevention clinical trial. Due to the Motivational Questionnaire of the current study being completed after the decision has been made to participate it gives a unique opportunity to learn which factor was a stronger motivator for a female versus a male.

Figure 2 offers a diagram of the theoretical framework for TPB. This diagram shows the order of considerations that impact the intention to go through with a health behavior or not.

Figure 2 Theory of Planned Behavior (TPB)



In this diagram the three constructs that influence intention and behavior outcomes are attitudes, subjective norms, and perceived behavioral control. The purpose of this study is to analyze if one of these constructs is more motivating for one gender compared to the other. The purpose of the addition of PBC is to include external and environmental factors that predict a person's intention (Ajzen, 1991). Whereas, in HBM and EHBM the external and environmental factors like ethnicity and socioeconomic status are considered modifying factors. In PBC these influences can be otherwise said as, "constraints on action, the mere formation of an intention was insufficient to predict behavior...and is held to explain why intentions do not always predict behavior" (Armitage & Conner, p. 472., 2001). The responses to the Motivational Questionnaire may reveal what control the participants believe they have over their barriers to participate and how that impacts their intention.

Recruitment and Retention within clinical trials

Recruitment and retention are important phases in construction and maintenance of a clinical trial study design. Several clinical trials take longer than originally predicted due to an increased participant recruitment time (Chaudhari et al., 2020). Other potential problems are the delay of the clinical study due to a drop in the retention rates. In a study conducted in the United States with over a thousand participants it was found that 60% of retention issues were caused by the length of time required for participation (Abshire et al., 2017). In that same survey, 43% of responses stated that their lack of belief in the effectiveness of the intervention lead to their drop out (Abshire et al., 2017). A delay or extension in the recruitment period of a clinical trial can lead to a study going over budget.

Recruitment can cost up to 25% of a total budget for a clinical trial and retention costs can eat up about 9% of the total budget (Sertkaya et al., 2014). If recruitment and retention efforts are not effective, a clinical trial can run into trouble when it comes to completion of the study. For this reason alone, it is imperative to best understand what motivates individuals to join into a study as well as how to help them remain in the study for the duration. Barriers exist for certain populations and the geriatric population which is of particular interest for this thesis and the PACT study has their own set of barriers. Barriers for recruitment of geriatric patients include travel to arrive to the clinical site. This could be availability of transportation in general, the time and cost of gas it takes to get there, and the complexity of the directions to locate the research site (Cassidy et. al., 2001). These barriers should be considered in the development stages of the budget allocation in a clinical trial but also in the overall study design.

While reducing barriers due to logistics for participants is a necessary step, retention efforts may need to be more focused on the interpersonal needs of the participant. In a study

about the recruitment and retention of elderly adults, Cassidy and others found three key retention strategies that dealt specifically with the relationship between the participant and the study. The first strategy they noted was a retention plan that had interpersonal sensitivity, the second strategy was that the participant needs a consistent contact person, and finally the third strategy was to design an investment of time between study personnel and the volunteer in the first stages of the trial at the start of involvement (Cassidy et. al., 2001). All three of these strategies can assist clinical trials with attrition. Based on budget estimates discussed previously, this is an advantageous step for the researchers.

Summary

The overall goal of this study is to better understand how to recruit and retain participants that reflect the general population as best as possible. Specifically, when it comes to participants for clinical trials related to ADRD prevention research. There is a need to find interventions that will provide prevention or delay of the onset of ADRD. The facts and figures report in 2021 from the AA states, “More than 6 million Americans of all ages have Alzheimer’s. Seventy-three percent are aged 75 or older. About 1 in 9 people aged 65 and older (10.7%) has Alzheimer’s” (para. 3). This rate of prevalence comes with a steep price tag as well, estimated to be \$2.8 trillion (about \$8,600 per person in the US) dollars by the year 2023 (WHO, 2022). It is time to invest in research for ADRD prevention research such as CCT. Brain games could be accessible to most if they are found to be beneficial to brain health and the delay of the onset of ADRD. To better understand if CCT helps to prevent ADRD a large sample size is needed to ensure generalizability to society.

The knowledge of what motivates a male versus a female to enroll in a clinical trial can aid in the development of messaging. Literature suggests females are already more aware of AD

and their own risk. This research study can assist with the recruitment of males in AD prevention trials and increase the rate of awareness of ADRD of the public. The previous literature reviewed in this chapter reported a common theme of knowledge about the disease and about opportunities to participate in healthy behaviors and the influence that had on the action of the behavior (Jalili et al., 2019; Lee & Jim, 2022). These studies considered the HBM in their analysis and found that females are more likely to be aware of the risk of ADRD and thus have a higher rate of “perceived susceptibility and severity of the disease” (Jalili et al., 2019; Lee & Jim, 2022).

Other literature reviewed in this analysis demonstrated that females are on average over 50% of the sample size of clinical trials which is increased from the 44% average in 2013 (Bibbins-Domingo & Helman, 2022). From this perspective it is important to note that women were not always allowed to participate in clinical trials. Women have the right by law to participate in clinical trials since 1993 through the Women and Minorities as Subjects in Clinical Research law. This law ensures that women and minorities are represented in all clinical trials. The history of women participation in clinical trials started off with low percentages of women represented to now making up 50% or more of the study (Bibbins-Domingo & Helman, 2022). Whereas men have been the only consistent study subject in history. This could aim to explain why a male may be more motivated by the subjective norms that is male participation in research. While also shedding light on the fact that now the barrier of entry to clinical research participation is more controllable by females than in previous history. Highlighting the PBC construct of the TPB theoretical framework, where when one perceives more control over their barrier to entrance, they are more likely to go through with the desired action (LaCaille, 2013).

However, most research papers on these topics have relatively small sample sizes, use closed-end surveys, and some even assess what a person “might do” if they were to enter in an

AD research registry. Therefore, this proposed study offers this body of research a new perspective. The Motivational Questionnaire of the PACT study is an open-ended questionnaire given to participants that are eligible and enrolled in the trial. This perspective focuses on the why someone went through with participation. This study aims to compare gender and sex differences in motivation to participate in the PACT clinical trial or ADRD prevention research.

The current study's main research question is: Are there any gender (male vs. female) differences in motivation to participate in AD prevention clinical trials.

Other research questions this study aims to answer are:

1. Will one gender be motivated by risk or concern at a higher rate?
2. Will the male gender be motivated by subjective social pressures at a higher rate than the female gender?

CHAPTER 3: METHODOLOGY

This study investigated what motivated two genders, female and male, to participate in the PACT clinical trial. This study analyzed 2,617 participant responses to the Motivational Questionnaire. This questionnaire was conducted as part of the protocol for the PACT clinical trial. The questionnaire has four open-ended questions that the participants complete after the participant has been screened for eligibility to enroll into the PACT study. For this study's purpose only questions one and two will be used in the analysis. The Motivational Questionnaire is an open-ended questionnaire completed during the first visit of the PACT study. Participants that complete this questionnaire have consented to being a PACT participant, have completed a version of the Montreal Cognitive Assessment (MoCA), and a Geriatric Depression Scale (GDS).

The study sample of 2,617 participants were comprised of 1,861 (71.1%) females, 756 (29.8%) males. Majority of the participants were not Latino/ Hispanic 2,459 (94.0%) and 157

(6.0%) participants reported Latino / Hispanic. White / Caucasian made up 2,305 (88.1%) of the sample, 211 (8.1%) African American, 20 (0.8%) Asian, 3 (0.1%) Native Hawaiian/Pacific Islander, 3 (0.1%) American Indian / Alaskan Native, 12 (0.5%) Biracial, and 29 (1.1%) Other. The study sample is well educated, with 689 (26.3%) of participants with a Bachelor of Arts or Bachelor of Science and with 835 (31.9%) of participants with a master's degree. Most of the participants were White/Caucasian and had a bachelor's degree or higher.

Below in Table 7 the demographic information of the study sample is listed for the 2,617 participants. This sample is titled: The General Sample. The results section will describe the findings from the analysis of question one with a written analysis and then a table will follow. The same order of results will follow for question two from the Motivational Questionnaire.

In Table 2 the demographic frequencies for the General Sample are displayed.

Table 2 *Demographic information for the General Sample*

Demographics	N=	%
Gender		
Female	1861	71.1%
Male	756	29.8%
Total	2617	
Ethnicity		
Hispanic / Latino	157	6.0%
Not Hispanic / Latino	2459	94.0%
Race		
White / Caucasian	2305	88.1%
African American	211	8.1%
Asian	20	0.8%
Native Hawaiian / Pacific Islander	3	0.1%
American Indian / Alaskan Native	3	0.1%
Biracial	12	0.5%
Other	29	1.1%
Missing / Refused	34	1.3%
Education		
8 th Grade	1	0.0%

9 th Grade	1	0.0%
10 th Grade	1	0.0%
12 th Grade		
13	117	4.5%
Some College	27	1.0%
Associates	299	11.4%
BA/BS	215	8.2%
Some school after Graduation	689	26.3%
Masters	158	6.0%
Doctorate	835	31.9%
	274	10.5%

As mentioned previously, much of the sample is White/Caucasian (88.1%) and well educated. In fact, 10.5% of the sample have a Doctorate degree. The motivational questionnaire is one part of the long-term study of the PACT clinical trial. PACT stands for Preventing Alzheimer's with Cognitive Training. The clinical trial is funded by the National Institute on Aging (NIA) and is operational at multiple sites such as University of South Florida (USF), University of North Florida (UNF), University of Florida (UF) with its two locations (Gainesville and Jacksonville, FL), Clemson University, and Duke University. The questionnaire is administered to participants after they complete a Geriatric Depression Scale. The participants of the PACT study are 65 years of age or older, they are cognitively healthy, and they have not had a stroke.

Figure 3 *The Motivational Questionnaire from the PACT Clinical Trial*

The Motivational Questionnaire:

1. What made you interested in participating in PACT?
2. What do you hope to get out of your participation in PACT?
3. What can you do if you get discouraged or frustrated during your training sessions?

4. What are three things that your trainer can do to motivate you if you get discouraged or frustrated during your training sessions, or if you find it difficult to complete your weekly sessions?

The questionnaire is administered on REDCap during visit one of the PACT studies. This visit includes a memory screener and a depression scale to determine eligibility to enroll in the PACT study. The participant completes both memory screener and the depression scaled prior to completion of the Motivational Questionnaire. The Motivational Questionnaire is only prompted to participants that score <5 on the Geriatric Depression Scale (GDS). Only participants that were eligible to participate in the PACT clinical trial are included in this sample. The Motivational Questionnaire responses were downloaded from the Redcap software into an excel document that was secure on the university's O-drive. From there the researchers coded within the same document until completion.

USF had a pilot version of this study with 50 participants from the USF location. USF allowed UNF to take over this pilot study for a manuscript and two thesis projects. From there the researchers accessed the data for 2,617 participants and began to create a qualitative codebook with themes and their definitions. Those themes were given number codes and used to code all of the responses from the sample. The pilot study's themes were used as a guide in the creation of the codebook for this study. Throughout the development of the codebook two researchers coded the scrubbed dataset in different saved files to ensure intercoder reliability throughout the code definitions to reach true saturation.

The purpose of this analysis is to review the responses to the first two questions of the Motivational Questionnaire. Specifically, to review if there are any differences between how two genders, male and female, respond when prompted about their motivation to participate in the

PACT clinical trial. This study aims to add to the literature about motivation to participate in a health-related behavior and how that may differ between people, specifically males and females.

The dataset was scrubbed of all identifiable information, including the gender of the person's response. Therefore, the gender of the person who left the response was unknown to the researchers coding the responses. The use of intercoder reliability strategies were implemented in the development of the codebook and used throughout the completion of the coding of the data to make sure there was minimally an 80% of agreement on the codes for each response. No specific intercoder reliability test was utilized, the researchers reviewed a certain number of codes and then calculated the percentage of codes that were agreed upon after review of individual coding efforts. In the next section the development of the codes is explained in detail.

Development of Codes

The code definitions for this study were developed by three researchers at UNF with the pilot study findings from USF and thematic analysis structure as the guide. As previously stated, researchers at USF started to code for themes for approximately 50 participants responses to the motivational questionnaire. The compiling stage of the thematic analysis was completed by the principal investigator of the PACT study when they provided motivational questionnaire data from across all sites for the current number of participants at the time to the primary investigator of the UNF location of the PACT study. The primary investigator shared the data through a high security folder on the O-Drive of the UNF VPN system. From there three researchers from UNF coded 50 responses at a time to refine the theme definitions.

After each researcher coded 50 responses independently, two of the researchers met to compare the codes. The goal was to reach saturation with our codes and their definitions. During the disassembling phase of the thematic analysis of the data, the researchers utilized the method of

coding. Coding is defined as, "...researchers identifying similarities and differences in the data (Castleberry & Nolen, 2018; Sutton & Austin, 2015). Therefore, each independent coding assignment of 50 responses and every meeting to clarify the definition of the found themes were a part of the disassembling phase. The meetings were with at least three UNF researchers and one of the coding meetings was met with the primary investigator of the UNF PACT study. During the meetings specific questions were shared with the group to title and define the themes. Throughout the process, the goal of the thematic analysis with multiple coders was to reach a satisfactory intercoder reliability due to the large sample size of this study.

The goal of the intercoder reliability is to establish 80% accuracy of codes between the three researchers. This is also considered the reassembling phase of the thematic analysis process when the themes found during the disassembling phase are categorized into an organized codebook. The first intercoder reliability check showed; For question one there was a 20% disagreement rate (10 out of 50 responses), question two was 22% disagreement rate (11 out of 50 responses), question three was 16% disagreement rate (8 out of 50 responses), and question four was 23% (28 out of 120 responses). The second and final intercoder reliability check was done on only the sections that did not meet the 80% accuracy goal; For question two there was a 16% disagreement rate (8 out of 50 responses), and question four was 17% disagreement rate (20 out of 120 responses). From there the researchers went on to code the sample. The sub themes were coded for as well.

For this thesis's purpose only questions one and two from the Motivational Questionnaire were analyzed. Future research should consider analyzing questions three and four of the Motivational Questionnaire. Those questions focus on retention initiatives that can help a participant stay in the study, which is important given the PACT trial is a three-year study. When

the researchers were coding the sample for questions one and two responses the qualitative themes were given number labels for the purpose of statistical analysis. The themes were numbered in no order one through five and one through six. Once all the responses were coded the dataset was uploaded to SPSS for further review.

Below is Table 4 that describes the themes and the subthemes from the codebook for question one from the Motivational Questionnaire.

Table 4 *Motivational Questionnaire question one theme definitions and subthemes.*

Question 1: “What made you interested in participating in PACT?”		
Theme Title	Definition	Subtheme(s)
Concern about Brain Health and Aging	Participants express their interest, worry or concern about preventing/maintaining/improving their memory or cognitive abilities. They may say something like preventing cognitive decline or improvement to their memory due to aging	N/A
General Personal Interest	Seeking further knowledge/understanding/enjoyment through their participation. Any type of understanding or grasp of information or seeking of learning towards Alzheimer’s, Dementia, personal cognitive abilities/personal health that is not specific to research. Participants mention that they are interested because they enjoy learning new things or find their participation to be an opportunity for learning. Not stating interest in research. Focused more on personal/intrinsic interest/curiosity/personal benefit/enjoyment.	N/A
Direct Experience with the disease	Participant responses state that they have had a form of direct experience or contact with people who had/have a history of dementia or Alzheimer’s, explaining that is the cause of their interest in their own participation. These responses will not mention who specifically.	1. Immediate Family 2. Extended Relationships
General Research Interest	Participants express their interest in general research, not necessarily specific to Alzheimer’s. They may state that their participation is overall interesting due to research and potentially helps	1. Dementia Research Interest

	others through research. Participants state explicitly that their interest is in research.	
Referred	Participants mention that their interest stems from someone in their life/social circle referring them to the study	<ol style="list-style-type: none"> 1. Spouse Referral 2. Family or friend(s) Referral 3. Professional Organization Referral
Altruism	Participants mention that they are wanting to “help others”. In this statement there is no mention of research, dementia research. This can be in combination with something that expresses their interest in the study in general or for personal reasons or it can be the only reason listed.	N/A

The definitions of these themes were reviewed by two other collaborators for feedback on clarity of interpretation. The multiple perspectives on the theme definitions curated thorough definitions that could be given to other researchers to help code all the 2,617 responses to two separate questions of the Motivational Questionnaire. By including examples of what is not included in the theme the coders were able to maintain 80% or better intercoder reliability. These efforts were put in place to ensure that saturation was reached and that there was ability to replicate this study. This method was used in effort to reach saturation with the themes for the responses received from the questionnaire.

Below is Table 5 where the themes are listed with examples from participant responses. The examples illustrate that sometimes there was more than one theme found in one response. The codebook rules explained that all themes in one answer were to be coded for representation for up to three codes within one response. The subthemes were required to be coded as well. T

Table 5 *Examples responses, selected at random.*

Question 1: “What made you interested in participating in PACT”		
Examples		
Themes		
Concern about Brain Health and Aging	“Concerns about getting dementia; witnessed someone living with dementia as a child; love a challenge.”	“Personal concerns about potential cognitive decline and scientific curiosity.”
General Personal Interest	“Always valued problem-solving skills and has noticed that with age, mental decline is inevitable and wants to delay/prevent that.”	“Always valued problem-solving skills and has noticed that with age, mental decline is inevitable and wants to delay/prevent that.”
Direct Experience with the Disease	“Mom has Alzheimer's Disease.”	“Mother afflicted with Alzheimer's; trying to continue to learn more about this disease.”
General Research Interest	“The hope of helping research better understand and possibly treat dementia.”	Interested in preventing and finding out things about Alzheimer's.”
Referred	“My wife.”	“Discussion with my wife and general interest in medicine and science.”
Altruism	“To see if I could be of help to others who might be experiencing a problem with this disorder.”	“Service to community.”

Within these examples of participant responses there are a couple responses that hold two themes within one response. For example, in the “Referred” theme examples one participant writes, “*Discussion with my wife and general interest in medicine and science.*” When the researchers were in the analysis process, they coded up to three codes per response as necessary. This example shows how two themes, both “Referred” and “General Personal Interest” are provided in this response.

The next table listed shows the definitions and names of the themes from the codebook for question two from the Motivational Questionnaire:

Table 6 *Motivational Questionnaire question one theme definitions and subthemes.*

Question 2: “What do you hope to get out of your participation in PACT?”		
Theme Title	Definition	Subtheme(s)
Prevent Dementia or Cognitive Decline	Participants mention that they hope to prevent cognitive decline for themselves or reduce their risk of getting dementia. Responses include hope for prevention and reduced risk of dementia / cognitive decline, in general and in their personal health. Responses are specific to Alzheimer’s disease, other related dementias, or general cognitive decline.	N/A
Personal Brain Health	Responses involve benefits related to general personal brain health and cognition. However, responses do NOT include elaboration about maintenance or improvement of personal brain health and cognition. Responses do not specifically name brain-related diseases like dementia or Alzheimer’s or cognitive decline	1. Maintain Brain Health 2. Improve Brain Health
General Personal Benefits	Responses involve personal benefit, exclusionary of maintenance / changes in brain health / cognition or prevention of dementia / cognitive decline. Responses include general interest / gaining understanding knowledge of general subject of brain health and Alzheimer’s disease or dementia or desire to determine one’s own current health. May also include general enjoyment in participation.	N/A
Benefit to Research and Others	Responses include providing benefits to general research and other people. Response excludes personal gain but focuses on contributions to society or the community.	N/A
Uncategorized	Participants express a hope for participation that does not fit into any of the other themes	N/A

Most definitions of the themes from question two responses did not contain subthemes. Only the theme “Personal Brain Health” contained two sub-themes; Maintain and Improve. When researchers were coding the data and clarifying the definitions, the two themes were identified of people reporting specifically the desire to maintain their brain health versus the

motivation to improve their brain health. Therefore, the two sub-themes were added to the main theme of “Personal Brain Health” due to the frequency they were reported in the responses.

Below is Table 6 where examples are listed for each theme from participant responses.

Table 7 *Example responses, selected at random.*

Question 2: “What made you interested in participating in PACT”		
Themes	Examples	
Prevent Dementia or Cognitive Decline	“The ability to delay mental decline, while contributing to a scientific data base.”	“Find ways to help prevent dementia/ Alzheimer's.”
Personal Brain Health	“Improve brain skills, wake up brain skills.”	“Wants to improve cognition in general.”
General Personal Benefit	“Experience something new and different.”	“Fun doing brain games. Otherwise knowing I am helping in the research.”
Uncategorized	“Yoga, deep breathing.”	“Same as #1 answer.”
Benefit to Research and Others	“Nothing. I hope to provide information useful for others to use.”	“The ability to volunteer and make a difference.”

In the table examples or the above example there are additional examples of responses that contain more than one theme within the one response. Such as, an example from “General Personal Benefit” was provided from the participant that stated, “*Fun doing brain games. Otherwise knowing I am helping in the research.*” In this example, the participant was coded for “General Personal Interest” and “Benefit to Research and Others.”

During the disassembling portion of the thematic analysis the researchers observed that many responses to one question had multiple themes present. Therefore, one response potentially could have two or more themes within their answer. The code that was used to factor this observation was an IF THEN sequence so that up to three themes could be accounted for within one answer. Therefore, no themes were left out or considered to have more “weight” than other

themes. The same analysis was run for the two genders and the demographic information. In the next chapter the results are described. The researchers utilized SPSS for the crosstabs feature to run a Chi-Square test of Independence on the General Sample. Both samples were utilized in this study due to the proportional difference in male representation in the General Sample. Chapter five, the discussion, compares the results of the analysis on both samples. To be sure of the frequencies identified in the General Sample were true it was necessary to create a sub-sample that allowed for equal gender and sex representation.

CHAPTER 4: RESULTS

This study aims to qualitatively review the Motivational Questionnaire responses from questions one and two and compare male and female, to see if there are any differences in the themes of their responses. The current study's main research question is: Are there any gender (male vs. female) differences in motivation to participate in AD prevention clinical trials.

Other research questions this study aims to answer are:

1. Will one gender be motivated by risk or concern at a higher rate?
2. Will the male gender be motivated by subjective social pressures at a higher rate than the female gender?

The General Sample of 2,617 participant responses were analyzed through a crosstabs IPSS function to perform the Chi-Square analysis. The General Sample Chi Square test of Independence resulted in observable differences between males and females when it comes to their interest in PACT. The review analyzed the number of females and that reported a theme for question one of the Motivational Questionnaire, "What made you interested in participating in PACT?" The comparison showed that there was a significant difference between the genders and the reported

themes. Females were more likely than men to report they had some form of “Direct Experience with the Disease” (χ^2 (df=1) = 20.217^a, $p < .001$).

Females are equally likely as males to list “Concern about Brain Health and Aging”, (χ^2 (df=1) = .727^a, $p < .210$). Both genders are interested in participation due to concern about their own brain health and aging. This result provides evidence that both genders feel a similar amount of risk or concern about their own potential development of Alzheimer’s disease or other related dementias.

The theme “General Personal Interest” had significant results, (χ^2 (df=1) = 8.491^a, $p < .002$). The proportion of males that are interested in participation for personal reasons like to learn more about Alzheimer’s disease is higher than that of the females in this sample. Along with health benefits that participants hope to receive because of participation there is also a desire to try brain games, learn more about dementia, or better operate a computer in male participants.

There is a significant relationship between the two variables. Females are more likely than males to list “Direct Experience with the Disease” (χ^2 (df=1), = 20.217^a, $p < .001$). This significant finding is concurrent with the data that states that females are more likely to be caretakers for others who have a form of dementia. This interaction with the disease is a motivator behind females' reason to participate in AD prevention research because they see in real time the degenerative nature of the disease.

The theme “General Research Interest” did not reach significance between genders (χ^2 (df=1) = .007^a, $p = .486$). Both genders are interested in participation within research itself and some more specifically with AD prevention research. As demonstrated in the Methodology

chapter, the sub-theme within the theme “General Research Interest” differentiates whether a participant mentioned AD research in their answer or did not specify the type of research.

There was not a significant relationship between the genders and their interest in the PACT study listed as a referral from another source such as their spouse, an advertisement, or an organization. The theme “Referred” was not significant between genders (χ^2 (df=1, = .073^a, p=.432). A prospective participant can learn about the opportunity through a family or friend, but the referral is ultimately not the reason they are interested in PACT participation.

A Chi-Square test of Independence was performed to assess the relationship between male and female likelihood to report altruistic reasons that lead them to their interest in participation for the PACT study. There was not a significant difference in the theme, “Altruism” (χ^2 (df=1),= 2.602^a, p=.062). Although volunteering in clinical trials naturally has an altruistic component it is not the motivator for both genders in this General Sample when it comes to their participation in the PACT clinical trial.

Below is Table 6 which displays the above written description in a list in the table below.

Table 8 *Question 1 Results Chi Square Analysis*

Question 1: “What made you interested in participating in PACT?”						
Themes	Male		Female		χ^2	P Value
	N	%	N	%		
Concern about Brain Health and Aging	234	27.8%	608	72.2%	.727 ^a	.210
General Personal Interest	195	25.8%	383	20.6%	8.491 ^a	.002
Direct Experience with the Disease	197	26.1%	654	35.1%	20.217 ^a	<.001

General Research Interest	199	26.3%	487	26.2%	.007 ^a	.486
Referred	47	6.2%	121	6.5%	.073 ^a	.432
Altruism	105	13.9%	216	11.6%	2.602 ^a	.062

^a The IPSS syntax was written to review up to three codes within one answer and these are the results of Chi Square of each gender against each theme.

These results indicate some differences between males and females within the General Sample, specifically the females of this sample have listed their “Direct Experience with the Disease” proportionally more than men. While males reported “General Personal Interest” more than females. These findings illustrate that the higher reports of women being the caretakers of those with the disease does impact their motivation to participate in activities that benefit their brain health. Next, the results will be reviewed for the General Sample responses to question two from the Motivational Questionnaire.

Table 8 demonstrates the Chi Square Analysis results for the General Sample of 2,617 participant responses to question two of the Motivational Questionnaire. A chi-square test of independence showed that there was no significant association between gender and the theme “Prevent Dementia or Cognitive Decline” (χ^2 (df = 1) = 1.476^a, p=.122). The proportions do not differ by gender, this result reveals that the males and females in this study both hope to prevent any cognitive decline through their participation.

The proportion of subjects who reported the hope to improve or maintain their personal brain health did differ by gender. Females are more likely than males to list “Personal Brain Health” (χ^2 (df=1) = 13.665^a, p=<.001). This result correlates with the result from the first

question most females reported that they were most interested in PACT due to their concern about their brain health and aging.

In this sample there is no significant difference between males and females in the theme of “General Personal Benefit” (χ^2 (df = 1) = 1.234^a, $p < .144$). This insignificant difference between genders shows that overall people hope to receive some form of general personal benefits from their participation in the PACT clinical trial. Recruitment materials should list the potential benefits of computerized cognitive training to maximize efforts because “General Personal Benefit” was the most frequent theme throughout the male sample (n=2,617, 30.8%) and the second more frequent theme in the female sample (n=2,617, 28.6%).

A chi-square test of independence showed that there was a significant association between gender and the theme “Benefit to Research and Others” (χ^2 (df=1) = 10.468^a, $p < .001$). This result illustrates that male participants hope to benefit research and others through their participation in the PACT clinical trial. This is reflective from the trend in the most common theme from question one, where more men than females listed that they were interested in the PACT study for altruistic reasons.

A chi-square test of independence showed that there was a significant association between gender and the theme “Uncategorized” χ^2 (df = 1) = 9.478^a, $p = .002$. This category was created because it appeared some participants did not wish to answer this question, or their answer was not represented in any of the other themes and there was not a high enough proportion of similar answers to justify additional themes. In this finding, males are more likely to not answer the question directly than females.

Table 8 Showcases the results of the General Sample from Question 2

Table 9 *Question 2 Results Chi Square Analysis*

Question 2: “What do you hope to get out of your participation in PACT?”						
Themes	Male		Female		χ^2	P Value
	N	%	N	%		
Prevent Dementia or Cognitive Decline	166	22%	450	24.2%	1.476 ^a	.122
Personal Brain Health	219	29%	680	36.5%	13.335 ^a	<.001
General Personal Benefits	233	30.8%	533	28.6%	1.234 ^a	.144
Benefit to Research and Others	253	33.5%	505	27.1%	10.468 ^a	<.001
Uncategorized	31	4.1%	37	2.0%	9.478 ^a	.002

^a The participants responded with 1 of 3 codes within their answer to the second question of the Motivational Questionnaire. The IPSS syntax was written to review up to three codes within one answer and these are the results of Chi Square of each gender against each theme.

These results indicate that there are some differences between males and females within the General Sample, specifically the females of this sample hope to receive benefit to their “Personal Brain Health” proportionally more than men from their PACT participation. While males reported “Benefit to Research and Others” more than females. These findings illustrate that the higher reports of women having increased risk of developing the disease does impact their motivation to participate in activities that benefit their brain health.

Next race and ethnicity of the samples are analyzed through a Chi-Square test of Independence. The goal of this next analysis is to review the proportional differences between race and ethnicity participation in clinical trials.

Race and ethnicity information is not within any of the proposed research questions of this study. However, it is necessary to look at the proportions of demographics amongst genders. As

the data reports, the entire sample is highly educated. However, the categories can make the difference between a matched case having or not having a graduate degree. For example, some of the educational categories combine educational levels, like anything under High School graduation is considered its own category. Another example, grades 16th & 17th are combined to make a category, which is a bachelor's degree (16th) and post-graduation training or grad school (17th) but not a master's degree. This reclassification of the educational level may have led to all significant findings from the analysis.

Based on the chi-square test amongst gender and demographic information there is significant difference in education (χ^2 (df=4) = 43.917^a, $p < .001$). Over 80% of the male sample has a bachelor's degree or higher compared to 72% of females has a bachelor's degree or higher within the General Sample. This result is significant given the much higher rate of female participation in this sample.

Table 10 Illustrates the General Sample Demographic Data

Table 10 *Demographic information Chi-Square analysis*

General Sample (N=2,617)		Female		Male		Total
Demographic Category	N	%	N	%		χ^2
Ethnicity						.304
Yes – Hispanic/Latinx	115	6.2%	42	5.6%		
No – Not Hispanic/Latinx	1745	93.8%	714	94.4%		
Race						.019
White/Caucasian	1623	88.3%	682	91.7%		
African American	171	9.3%	40	5.4%		
Asian	13	0.7%	7	0.9%		
Native Hawaiian/Pacific Islander	2	0.1%	1	0.1%		
American Indian/Alaskan Native	3	0.2%	0	0.0%		
Biracial	9	0.5%	3	0.4%		
Other	18	1.0%	11	1.5%		
Education						<.001
9 th -12 th	97	5.2%	22	2.9%		
13 th -15 th	425	22.8%	116	15.4%		

16 th -17 th	581	31.2%	266	35.2%
Master's	597	32.1%	238	31.5%
Doctorate	161	8.7%	113	15%

a This table includes the educational categories that were created to organize the data. Table

Based on the chi-square test amongst gender and demographic information there is significant difference in education (χ^2 (df=4) = 35.668^a, $p < .001$). Over 80% of the male sample has a bachelor's degree or higher compared less than 72% of females has a bachelor's degree or higher. Proportion of races amongst the genders have significant findings as well, χ^2 (df = 6) = 21.329^a, $p < .001$. There are significantly more African American females who participate in the PACT study than African American men.

These results demonstrate differences between females and males and how they report their motivation for participation in an AD prevention clinical trial. For question one responses there was evidence that male, and female report their motivation differently. Females listed their "Direct Experience with the Disease" more than males. And in the second question analysis males reported higher interest in benefiting research from their PACT participation. In the next chapter the findings are discussed at length.

CHAPTER 5: DISCUSSION

The goal of this research project is to explore potential differences and motivators between males and females to participate in the PACT clinical trial. This is an important question to explore due to the proportional difference in gender representation in ADRD prevention research. The sample size of the PACT study in this paper is example of the incredible gap between female (71%) participation compared to males (29%). This analysis seeks to better understand what the underlying motivators are for the participants in the PACT study and then

compare the findings by males and females to further understand best practices for recruitment and retention. Recruitment and retention were discussed in Chapter two regarding the difficulty most clinical trials have with attaining their target sample size on time and within budget (Chaudhari et al., 2020). This paper aims to explore motivational trends between males and females to help close the gap of demographic sample size goals. A better understanding of recruitment and retention strategies is important to the future of clinical trials in hopes that future studies can retain equal representation of the population and reach target sample sizes efficiently.

Also, to add to the growing body of literature regarding gender motivation is another goal of this research. Past literature contends that one of the top reasons individuals enroll in clinical trials is due to the help and benefit it provides others or society (Bevan et al., 1993; Calamia et al., 2016; Jefferson et al., 2011; Warburton & Dyer, 2004). While this was a popular response especially from males it was not the most frequent response for this sample.

Most sample sizes of the above-mentioned literature ranged from 197-1000 participants and this current research project has a total sample size of double that (2,617). Also, in the other studies some of the surveys and interviews were completed with adults of the age range of 50 years to 64, while this study's age range was 65 years of age or older. Therefore, this study provides a large sample size for analysis as well as the perspective of individuals who have consented and enrolled as a participant in an ADRD prevention clinical trial.

In general, the main research question of this study was answered; yes, there are differences between male and females when it comes to what motivates them to participate in the PACT trial. Females and males differed in whether their "Direct Experience with the Disease" or their "General Personal Interest" motivated them to participate in PACT. Ultimately, females' proximity to the disease was the second most frequent listed interest. While males had personal

interests such as the enjoyment of learning something new or a desire to learn more about the disease itself as the second most frequent response to why they were interested in participating in PACT. This result is comparable to the literature described in Chapter two where the more awareness of the disease led to action to participate in clinical trials like PACT (Mielke et al., 2014).

Prior research found similar results, Smith, and colleagues (2015) found in their 1000 interviews to Australians about doing brain health activities to prevent dementia that, “It was notable that moderate to high knowledge was the variable most consistently associated with action, in request to all risk-reduction behaviours investigated (mental activity, physical activity and dietary action) (p. 120). The sheer knowledge about the disease is a frequent motivator. Females reported higher rates of perceived susceptibility and worry about their knowledge about ADRD in two other studies which highlights the motivator behind the knowledge (Jalili et al., 2019; Werner, 2013). With knowledge comes fear and motivation to act to prevent ADRD.

It is important to note that males in this study reported their personal interest about learning more about the disease. This study provides another example of the high level of awareness females have about ADRD and how that cognizance leads to motivation to act on healthy behaviors to prevent. They know about the disease because of their high rates of personal interaction with it and that creates motivation to participate in opportunities that may help them avoid ADRD. This paper found similar results because majority of females stated that their interest in participation in PACT is from their worry about their own brain health and their direct familiarity with the disease. Therefore, the combination of previous literature and the current findings of this study highlight the importance of recruitment strategies that increase the representation of male participation. Males are reporting their motivating factor being the

opportunity to learn more about the disease. Recruitment efforts should consider more educational talks in the community to raise awareness and provide disease education for males.

In question two of the Motivational Questionnaire analysis the General Sample proved that there are differences between the males and females of this sample in the themes related to what they hope to get from PACT participation. Females most frequent reported theme was “Personal Brain Health,” and males most frequent theme was “Benefit to Research and Others.” This finding emphasizes the EHBM construct, perceived benefits and shows that while the actual benefit hoped to gain from clinical trial participation may differ, this construct is a motivator. This analysis provides evidence that the perceived benefit to gain can differ between the two genders.

Now that the main research question of this study has been addressed, two follow-up research questions will be proposed.

RQ1: Will one gender be motivated by risk or concern at a higher rate?

The analyses reveal no significant difference between males and females when reporting “Concern about Brain Health and Aging.” $p < .210$. Therefore, both genders are interested in PACT participation due to their concern about their brain health. The perceived severity and susceptibility of ADRD is a motivation for participation in opportunities that may provide the mitigation of personal risk for both genders. The proportional difference of women to men shows that those that are aware of their risk for ADRD are motivated to participate in clinical trials aimed at prevention. Therefore, more women are in the PACT study likely due to their higher rates of awareness of ADRD. However, when there is awareness of risk of ADRD, both male and female participants are motivated at the same rate to participate in ADRD prevention studies.

RQ2: Will male gender be motivated by subjective social pressures at a higher rate than the female gender?

In question two analysis the females reported the theme “Personal Brain Health” as what they hoped to get out of their PACT participation most. Mielke and others (2014) stated that females are more likely to be the caretaker and develop a form of dementia themselves. Males most frequent response for this question was theme “Benefit to Research and Others.”

Both genders hope to receive prevention of dementia and cognitive decline out of their participation reported at similar proportions and did not reach statistical significance. However, it does contribute to the research because this knowledge about how expressing participation benefits from computerized cognitive training is important when recruiting because it aids in motivation to participate.

In all findings there is an echo from previous research such as from Lee & Jim (2022) where they reported higher dementia knowledge, higher perceived benefit, and the female gender were significant factors in AD prevention behavior. Now this study not only supports similar findings in the literature but can further define and identify specific gender differences in AD prevention motivation behavior. Females from this sample are likely to be more aware of AD and they believe in the personal benefits of participation. The results of this study show that males are more motivated by the benefit to others and to learn more about the disease through their participation. Comparable findings were reported in in two different studies where males were significantly less likely to engage in help seeking behaviors such as the utilization of healthcare and males were more expected to abide by the gender role constraints or social constructs of society and beware of health-information and less likely to engage in help seeking behaviors like the utilization of healthcare (Ek, 2015; Juyrud, & Rennels, 2017).

Additional findings worth noting are the participants are highly educated, 74.7% of the sample have a bachelor's degree or higher. The most common level of education in this sample is a master's degree at 31%. Most of the sample was female participants at 71.1%.

In previous literature trends have been reported that females are more likely to report a feeling of susceptibility to the disease as their motivation to participate in clinical trial research (Rosentock et al., 1988; Verheggen FWS, Nieman F, Jonkers R., 1998). The screening process that a prospective participant goes through to get enrolled in PACT can be considered preventative screening. This health behavior is a result of the motivation to reduce the perceived susceptibility one feels about ADRD. Verheggen and colleagues (1998) stated, "...patients may want to stabilize feelings of threat by embracing the opportunity given by a trial" (p. 122). The potential benefits from PACT participation towards personal brain health can help people, as per females in this study, to neutralize their perceived threat of the disease. It is important to question if the rate of awareness and disease awareness was higher amongst males if there would be less significant differences between the genders when it comes to motivation to participate in the PACT study.

Men (14%) reported altruistic reasons for their motivation. Altruism is listed as the most frequent reason for motivation to participate in clinical trials or to sign up to be on dementia research registries (Avent et al., 2013; Bevan et al., 1993; Calamia et al., 2016; Jefferson et al., 2011; Warburton, & Dyer, 2004). Interestingly, in this study altruism was not found to be the most frequent theme for either gender. In fact, altruism related responses were not the second or third most common answers. This finding was unexpected given the literature review of how influential altruism was reported to be for motivation to participate in clinical trials. This result

suggests there is a need to recruit males, potentially increasing ADRD awareness may increase interest.

The conclusions from this study are that females are more aware of the risk of ADRD and that is their motivation to participate, and they hope to receive personal benefit from their participation, such as delay in the onset of dementia. In contrast, males are motivated by the desire to learn more about the disease in general and hope to benefit the society with their contributions to research. While both genders both reported “Concern about Brain Health and Aging” as their most frequent theme for interest in PACT participation, understanding the other variances in motivation as listed above can guide recruitment and retention strategies. A limitation of this study is the need to further analysis gender difference with consideration of race and ethnicity. As the EHBM reports, ethnicity is a modifying factor. These results do answer the research questions of this study. There are differences between females and males in motivation to participate in ADRD prevention research. Females are more likely to participate due to their concern about their health. Males are more likely to be motivated by subjective social norms compared to females.

Future research should consider reviewing questions three and four to complete the analysis of the Motivational Questionnaire. Recruitment is essential in a clinical trial and retention is imperative for a clinical trial. Questions three and four are aimed at understanding what the participant will do to keep their motivation as well as offering suggestions to the researchers for tactics to assist with the maintenance of motivation.

CHAPTER 6: CONCLUSION

This paper began with the prevalence statistics of ADRD in the US. Noting that the population with an increased risk of developing ADRD is becoming more and more dense as the

baby boom generation is approaching their 80s as of 2023 (AA, 2021). Females are two thirds of the diagnoses of ADRD (AA, 2017; Mielke, 2018). The assumptive reasonings for the higher rate of ADRD in females are the fact that women live longer, and have higher rates of depression (Mielke, 2018; Arias et al., 2021). As a larger population of our older society gets diagnosed with this disease, the cost of healthcare increases steadily (WHO, 2022). The medications on the market for ADRD are a last resort and none of them alter the disease (NIA, 2021). Preventative strategies such as controlling for 12 different risk factors and practicing CCT are all associated with a reduced risk of ADRD (Livingston et al., 2020; Edwards et al., 2017).

To improve the trajectory of 1 in 9 people developing a form of dementia it is necessary to run clinical trials on these promising preventative treatments. Understanding the motivation to participate from a gender perspective can aid in recruiting a sample size that achieves demographic and representation goals. The EHBM and TRA/TPB theoretical frameworks provide guidance as to what leads a person from thought to action on a health-related behavior. However, this current study analyzes the qualitative responses left by participants in the PACT study. Offering a unique perspective because the open-ended format of the questions does not constrain the participant's answer. From this analysis, researchers can focus their efforts on increasing awareness for recruiting potential male participants to expand representation in ADRD prevention research.

There are three key takeaways from this study. The first takeaway is an echo from one of the main findings; males have an underrepresentation in ADRD prevention research. In the sample of this study most male participants have a high level of education in the PACT study. This illustrates that males that have lower educational levels are almost absent from this study. Therefore, that group requires specific recruitment strategies in order to strengthen the

generalizability of the results of the research. Based on the results of the current study there are no recommendations for recruitment strategies. There are differences between the two genders in this study. Moving forward ADRD prevention clinical trials could aim to conduct targeted community outreach towards the lower educated male population. The result of this study offers information about how to approach targeted community outreach for males with lower levels of education. A discussion about the benefits to others that participation provides and educational opportunities to learn more about ADRD through participation. Through trial-and-error attempts with this takeaway in mind more research can be done to generate successful strategies in recruitment of a generalizable sample, on time.

The second takeaway from this study is that in general the results add to the body of literature of predictive health behavior differences amongst females and males. The literature reviewed illustrated that the majority of published research about this concept have sample sizes of less than 1000 participants. Prior research concluded that altruism was the driving motivator for the majority of participants. This study illustrated that altruism is a motivator for male participants, but female participants are motivated by their personal health benefits. This addition to the predictive health behavior theoretical frameworks is powerful given the 2,617 total participants in this sample size. This study provides insight that only meta-analyses of this topic have attempted to provide. There are gender differences in motivation and open-ended survey responses prompt themes that are not suggested by the researchers. Meaning, through qualitative analysis this study discovered the common themes amongst almost three thousand participants. From this study future investigations should include more open-ended questions about motivation and compare the gender differences.

The last key takeaway is the understanding that knowledge of the motivational differences amongst the genders can help with retention. It is important to know how to recruit participants and equally important to know how to keep the participants. For a longitudinal study it can be costly to have a high attrition rate. The utilization of an open-ended questionnaire like the Motivational Questionnaire from the PACT study can give the staff tools. For example, within the PACT study the purpose of the Motivational Questionnaire is to have feedback from the participant that staff can use in case the participant is wanting to withdraw from the study or feeling frustrated with their brain training. The staff can use the participants' own words about their motivation to help encourage the participant to adhere to the study requirements.

Overall, this current research project suggests that targeted community outreach towards males with lower education status can help increase the generalizability of the research. It also suggests that it is possible to predict a person's health related behavior and that there are gender differences. Finally, there are two areas where motivational knowledge can benefit clinical trials and that is in recruitment as well as retention.

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