Knowledge of Alzheimer's Disease and its Relationship with Attitude towards Genetic Testing for the Disease: A Survey of the General Public in Bangladesh

By

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A thesis submitted to the School of Pharmacy in partial fulfillment of the requirements for
the degree of
Bachelor of Pharmacy (Hons)

School of Pharmacy
Brac University
April 2022

# Declaration

It is hereby declared that

1.  The thesis submitted is my/our own original work while completing degree at Brac University.

2.  The thesis does not contain material previously published or written by a third party, except where this is appropriately cited through full and accurate referencing.

3.  The thesis does not contain material which has been accepted, or submitted, for any other degree or diploma at a university or other institution.

4.  I/We have acknowledged all main sources of help.

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# Approval

The thesis/project titled "Knowledge of Alzheimer's disease and its relationship with attitude towards Genetic Testing for the disease: A Survey of the General Public in Bangladesh" submitted by Sariya Uzrat Chowdhury, ID: 18146050 of Summer, 2021 has been accepted as satisfactory in partial fulfillment of the requirement for the degree of Bachelor of Pharmacy on April 2022.

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# Ethics Statement

This study does not involve any kind of human and animal trial.

# Abstract

**Purpose:** Alzheimer's disease (AD) is a multifactorial neurodegenerative brain disorder that affects approximately 5.3 million people in the United States, including nearly half of the population aged 85 and up. It has become a devastating condition with a huge societal impact, both in terms of financial costs and the aging population. The objective of this study was to evaluate knowledge and attitude towards genetic testing of AD.

**Method:** A cross sectional survey was conducted by distributing a goggle form contacting pretested questions. The data was analyzed using Microsoft Excel and GraphPad prism software for calculating descriptive statistics.

**Result:** A total 209 responses were collected within 1.5 months' time period. Among the 209 responders 169 participants were below the age of thirty and 40 participants were above above the age of thirty, where highest number of participants were between ages 20 to 30. By doing T test using GraphPad prism we saw a significant difference in knowledge level between the below and above 30 age groups.

**Conclusion:** From this study we concluded that knowledge regarding AD and awareness of genetic screening of AD is still quite poor. Therefore, proper information and awareness regarding genetic testing of AD should be spread.

**Keywords:**     Alzheimer's disease; Genetic testing; Knowledge; Attitude

# Dedication

*Dedicated to my parents*

# Acknowledgement

At first, all the praises to Almighty Allah, Who gave me the opportunity to come this far and made this project happen.

I would like to show my heartfelt gratitude to my project supervisor, Namara Mariam Chowdhury, Lecturer and Program coordinator, School of Pharmacy, Brac University, without whom, the execution of this project would never be possible. I will be forever be immensely grateful to her for her guidance, encouragement, instructions and monitoring throughout my project work. I would also like to thank Easin Uddin Syed, Lecturer, School of Pharmacy, Brac University for his guidance and invaluable suggestions. Besides, I would also like to thank Professor Dr. Eva Rahman Kabir, Dean, School of Pharmacy, Brac University, who has always been an inspiration for me.

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# Table of Contents

# List of Tables

# List of Figures

## List of Acronyms

AD             Alzheimer's Disease

EOAD          Early Onset of Alzheimer's disease

LOAD          Late onset of Alzheimer's disease

# Chapter 1

# Introduction

## 1.1 What is Alzheimer's disease

Alzheimer's disease (AD) is the leading cause of dementia and one of the major medical challenges of our century. In total, 40 million individuals are expected to suffer from dementia throughout the world, with this figure expected to double every 20 years until about 2050. Alzheimer's disease (AD) is a neurodegenerative condition characterized by amyloid peptide (A) deposits and neurofibrillary tangles in the brain. It is a neurological ailment that is progressive and devastating, accounting for up to 80% of all dementia diagnoses globally. Over 35 million individuals worldwide suffer from dementia, and this figure is anticipated to more than treble by 2050, reaching 115 million. (Bruni et al., 2021) Two subtypes of Alzheimer's disease can be separated based on the age at which the illness manifests: late-onset AD (LOAD) and early-onset AD (EOAD).The most frequent kind of AD is LOAD, which is defined as AD that begins later than 65 years of age. EOAD is most commonly diagnosed in those under the age of 65, accounting for roughly 1–2% of all cases. Moreover, mutations in three genes have been discovered in autosomal dominant EOAD: the amyloid precursor protein (APP), presenilin 1 (PSEN1), and presenilin 2 (PSEN2) genes.(Dobricic et al., 2012) PSEN1 has around 200 variants, the majority of which are missense mutations, but there are also minor duplications and deletions, as well as bigger deletions. PSEN1 mutation carriers had a median age of onset of 43 years, with the vast majority of cases occurring before the age of 60. According to the AD and FTD Mutation Database, there are around 16 mutations in PSEN2.(Goldman & Van Deerlin, 2018) Genomic research, which is quickly advancing, has the potential to alter many aspects of health care, including illness prevention, diagnosis, and treatment. Several genes linked to Alzheimer's disease (AD) have recently been identified and

cloned; two commercial genetic tests are now available, and further tests are in the works.(Susceptibility, 2011) The study of Alzheimer's disease's (ADs) diverse genetics has progressed faster than that of any other prevalent disease. Not only have three rare autosomal dominant mutation locations been discovered, but globally inherited susceptibility polymorphisms linked to risk and age of onset distributions for familial and "sporadic" Alzheimer's disease have also been verified.(McConnell et al., 2018). Sporadic Alzheimer's disease has a major hereditary component as well. The apolipoprotein E gene (APOE) is linked to a significant increase in the risk of EOAD and LOAD. Alzheimer's disease (AD) has a high heredity rate, with late-onset AD having a heritability of 58–79% and early-onset AD having a heritability of over 90%. Genetic connection gives a solid foundation on which to develop our knowledge of the disease's genesis. Over 50 genes have now been linked to Alzheimer's disease, suggesting that it is a multi-component illness, as evidenced by pathway studies (immunity, endocytosis, cholesterol transport, ubiquitination, amyloid- and tau processing).(Sims et al., 2020) Prior to the COVID-19 pandemic, AD was the third highest cause of mortality in the United States, trailing only heart disease and cancer as a cause of death for the elderly. Most developed nations see AD as one of the most serious economic risks. According to research, the cost of Alzheimer's disease will be $7 billion in 2030 in the United States alone, including carers. The number of people afflicted is now larger in industrialized nations, which coincides with the proportion of elderly people. According to Alzheimer Disease International, about 44 million individuals worldwide suffer from Alzheimer's disease or an associated dementia, with the number of persons afflicted expected to rise to 65.7 million by 2030.

## 1.2 Current treatments and diagnosis

Because dementia mostly affects individuals over the age of 60, the expanding expansion of lifespan has resulted in a fast increasing number of patients with dementia, primarily Alzheimer's disease, prompting a surge in research focused on the illness's treatment. The evolution of Alzheimer's disease can be divided into three stages: preclinical, moderate cognitive impairment, and dementia, although a seven-stage model can be more precisely defined. Stages and levels of impairments include: 1. No impairment 2. Very mild cognitive decline 3. Mild cognitive decline 4. Moderate cognitive decline (early-stage dementia) 5. Moderately severe cognitive decline (early mid-stage dementia) 6. Severe cognitive decline (late mid-stage dementia) 7. Very severe cognitive decline (late-stage dementia)(Rasmussen & Langerman, 2019)

Despite all of the hard work that has gone into research, there are still no viable therapeutic options for the condition. The World Health Organization has designated ADRD as a public health priority, and has listed public education, prevention, and early identification as critical initiatives for reducing the disease's expanding impact. Given the progressive nature of ADRD and the lack of a cure, prevention, early identification, and appropriate therapy of early cognitive deficits are critical for both patients and caregivers to better manage the condition.(Elbejjani et al., 2021)

Aducanumab was authorized via the FDA's Accelerated Approval Program, which allows medications to be approved sooner for certain critical illnesses. This enables those living with the condition to receive therapy sooner. Acuranumab's approval was predicated on the drug's ability to decrease amyloid in the brain. Medicine firms are obligated to do further studies once a drug is authorized through the fast approval process to establish whether there is a clinical benefit.
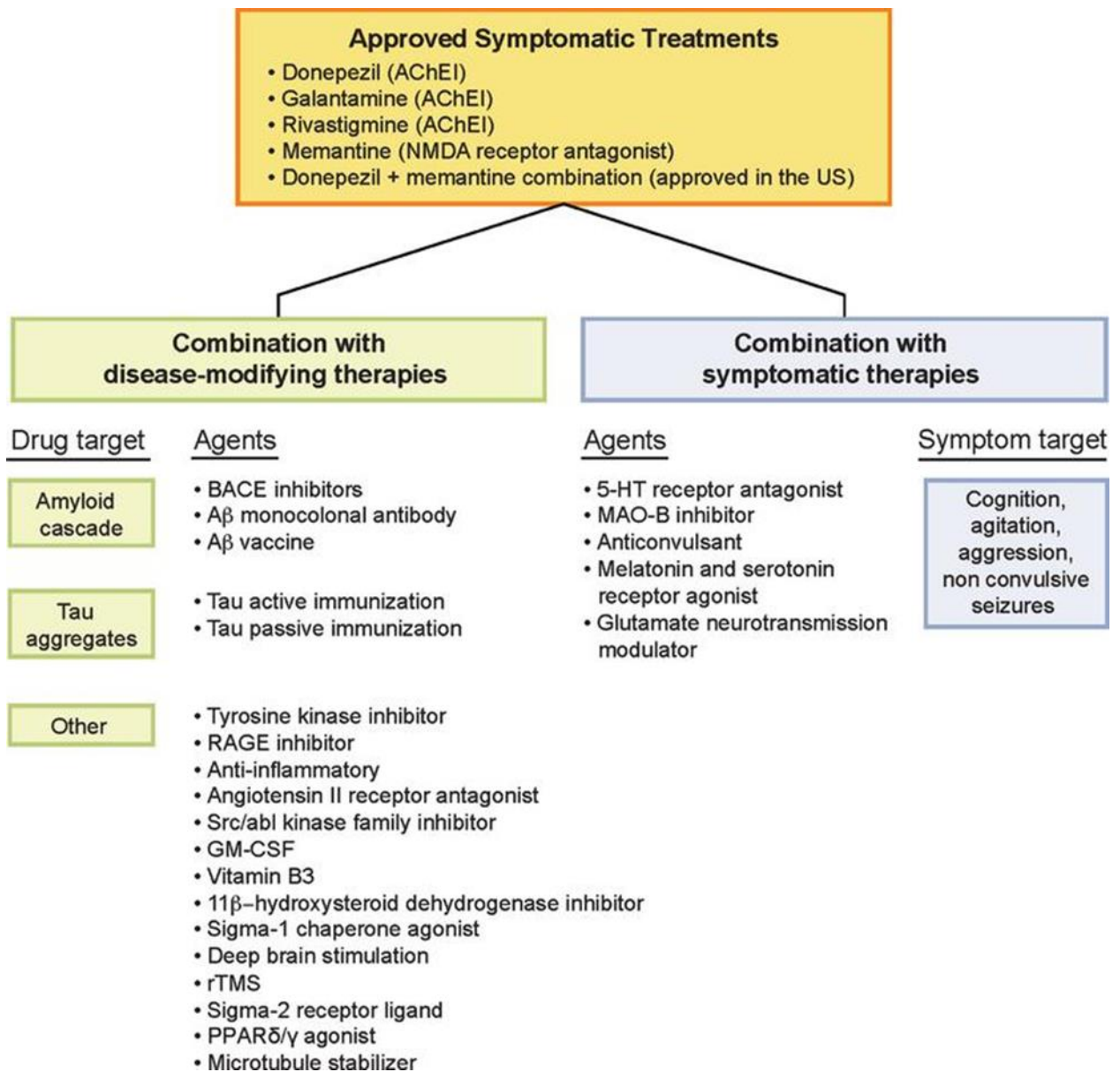
*Figure 1 Combination therapies in the AD drug development pipeline. 5-HT, 5-hydroxytryptamine (serotonin); Aβ, amyloid-β; AChE1, acetylcholinesterase inhibitor; AD, Alzheimer's disease; BACE, aspartyl protease β-site amyloid precursor protein cleaving enzyme; GM-CSF, granulocyte-macrophage colony-stimulating factor; MAO, monoamine oxidase; NMDA, N-methyl-D-aspartate; PPAR, peroxisome-proliferator activated receptor; RAGE, receptor for advanced glycation end-products; rTMS, repetitive transcranial magnetic stimulation.*

Nowadays, a multifactorial customized therapy of Alzheimer's disease is being explored, based on the following components:

o Open communication between the physician, caregiver, and patient: a real and successful exchange of information and sentiments between them will allow for timely symptom identification, accurate evaluation and diagnosis, and appropriate counseling.

- o Behavioral approaches

- Consistency and simplification of environment

- Established routines

- Communication tactics such as maintaining a calm demeanor, giving enjoyable activities, using basic language, and only expressing "no" when safety is at risk- Timely planning for legal and medical decisions and needs

- Cognitive behavioral therapy

- Exercise therapy, light therapy, music therapy

- o Caregiver support

- Short relaxation breaks for the caregiver are planned.

- Preparing for the impacts of dementia on cognition, function, and behaviors, expectancies, and avoiding circumstances that might aggravate symptoms or increase threats to safety and well-being are all part of psychoeducation.

- o Pharmacological interventions

For people with Alzheimer's disease, only two types of pharmacologic treatment are now available. Patients with mild, moderate, or severe Alzheimer's disease dementia, as well as Parkinson's disease dementia, should take the cholinesterase inhibitors donepezil, rivastigmine, and galantamine. Memantine is a non-competitive N-methyl-D-aspartate receptor antagonist and dopamine agonist that has been licensed for use in individuals with moderate-to-severe Alzheimer's disease (Weller & Budson, 2018). The only FDA-approved AD drugs are the AChEIs donepezil, galantamine, and rivastigmine, as well as the NMDA antagonist memantine. AChEIs work by preventing an enzyme called acetylcholinesterase from breaking down acetylcholine. This means there is a higher concentration of acetylcholine in the brain,

which leads to better communication between nerve cells. This may ease some symptoms of Alzheimer's disease for a while. As a result, AChEIs improve central cholinergic neurotransmission and, as a result, tend to slow cognitive loss, at least in the first year of therapy. Further deterioration happens, however even stopping these medications for a short time causes fast decrease and is linked to a higher probability of nursing home placement.(Yiannopoulou & Papageorgiou, 2020)

## 1.3 Situation of AD in Bangladesh

There are just a few statistics on the number of Alzheimer's patients in Bangladesh. In this country, there is no accurate epidemiological data on Alzheimer's disease. Here, awareness of Alzheimer's disease is at an early stage. As a result, the affected patient and their family members face a variety of issues on a regular basis. There is a certain amount of money available to pursue Alzheimer's research. Bangladesh, a low- and middle-income country, is yet unprepared to deal with Alzheimer's disease. The majority of the individuals in the country are now in their twenties. However, in 20–30 years, this country will have a sizable elderly population. As a result, now is the time to think about the condition and its care in a proactive manner and take the appropriate steps. Policymakers, health professionals, and other interested parties should work together to make Alzheimer's disease a national priority in Bangladesh.(Rahman et al., 2017)

## 1.4 Organizations working in favor of Alzheimer's disease

The Sir William Beveridge Foundation has a section called Dementia Bangladesh that focuses on Alzheimer's Associations in Australia and their expert instructors in Bangladesh offering dementia care training for essential workers. In 2014, they held their first International Dementia Conference in Dhaka, Bangladesh, to raise awareness about the Challenges of an Aging Population for a Developing Country, which revealed that over 35 million people

worldwide suffer from dementia, with that number expected to double by 2030 and triple by 2050 to 115 million. SAJIDA Home Care is providing home-based health care to 36 patients in Dhaka city, with 62 caregivers, 23 of whom have received Dementia Care Skills training from Mr. Md. Rashed Suhrawardy, who has extensive expertise in Dementia Care and a strong background in Home Care. Caregivers get diplomas from the Bangladesh Dementia Task Force after completing the program (BDTF). BDTF is a social media-based group that raises awareness about dementia concerns in Bangladesh. The Alzheimer's Society of Bangladesh (ASB) is a non-governmental, non-profit volunteer organization that was founded in 2006 to provide a platform for social workers, carers, and doctors to react to the needs of dementia patients with the goal of enhancing their quality of life. It's worth noting that ASB was the catalyst for the Dementia movement in Bangladesh for the first time. Since its founding, ASB has continuously pursued a wide range of activities aimed at increasing awareness, providing education and training, and providing dementia assistance and research. Alzheimer's disease International (ADI) granted full membership to the Alzheimer's Society of Bangladesh in 2009, recognizing its critical role and significant contribution to the area of dementia. Other groups that help with the elderly do not specifically address Alzheimer's disease or dementia. Since its inception in 1960, the Bangladesh Association for the Aged and Institute of Geriatric Medicine has been one of the most important non-governmental organizations in Bangladesh working for the care of the aged.  It is registered with the Department of Social Services and Social Welfare and is dedicated to the well-being of seniors over 55. This organization offers neurological assistance among its services. Help Age International Bangladesh (which works globally for the elderly), Resource Integration Centre, Dhaka Ahsania Mission, and Old Rehabilitation Centre are some of the other NGOs that deal with the elderly. With the tagline "A Care for the Generation," the Service Centre for Elderly People (SCEP) in Rajshahi began

working for the elderly in 1994. It offers health care and recreational opportunities to seniors aged 60 and up, ensuring their social and emotional well-being.(Roy et al., 2020)

## 1.5 What is genetic testing

Genetic tests are a form of screening tool used on symptomatic, asymptomatic, and healthy persons. They are utilized in clinics with decreasing prices. As a procedure, genetic testing use the definition of alterations in chromosomes, genes, or proteins. Thousands of genetic tests are now available for a variety of complicated chronic conditions, including cancer, diabetes, cardiovascular disease, and Alzheimer's disease, with more on the way. Interest in these tests is growing as a result of a variety of circumstances in both developed and developing nations. Interest in these tests is growing as a result of a variety of circumstances in both developed and developing nations. One of these variables is the likelihood of early diagnosis, which reduces morbidity and death. Furthermore, by altering the patient's lifestyle, negative (poor) test findings might lead to a more normal existence. This translates to decreased suffering and agony. Nonetheless, test findings do not guarantee that the individual will develop a chronic condition. These test results also raise serious concerns about genetic prejudice. Furthermore, the risk of inaccurate test findings leading to unneeded medical procedures is regarded as a significant barrier to genetic testing.(ALTAN & ÇAM, 2020) Advances in neurodegenerative disease genetic testing have enhanced the capacity to establish precise diagnoses, give family members with recurrence risk information, and (in certain circumstances) identify clinical trial eligibility. A variety of neurodegenerative diseases have a hereditary basis, and when inheritance is autosomal dominant, there is a 50% chance of recurrence. The diagnosis of a neurodegenerative disease can have ramifications not just for the person who has been diagnosed, but also for their families, who may be observing a loved one's deterioration while also considering their own chance of developing the disease.(Roberts et al., 2020). Alzheimer's disease is the most prevalent and well-studied kind of dementia. In persons with early onset

AD, genetic factors can be either monogenic (driven by a single gene) or polygenic (contributed by several genetic variations throughout the genome). In addition to environmental and behavioral risk factors, late-onset AD is largely polygenic, or caused by genetic risk factor variations. (Huq et al., 2021) The use of whole genome sequencing, which is becoming available, is anticipated to boost diagnostic yield even further. Many neurodegenerative diseases have yet to be linked to a genetic etiology. Even when genes are known to cause illness, today's technology cannot detect all harmful gene alterations, and the significance of a detected gene change may be unclear.(Roberts et al., 2020)

## 1.6 Current global scenarios of genetic testing of Alzheimer's

Alzheimer's disease is a widely recognized serious disease, and most industrialized nations have studies on the socioeconomic impact of the condition. By 2030, the number of Americans aged 65 and older with Alzheimer's disease might reach 13.8 million in the United States. This is a significant rise from the projected 5.8 million Americans aged 65 and older who now suffer from Alzheimer's disease. Alzheimer's disease claimed the lives of 1, 22,019 people in 2018, the most recent year for which data is available, making it the sixth highest cause of death in the United States and the fifth leading cause of death among those aged 65 and over Stroke, HIV, and heart disease deaths declined between 2000 and 2018, whereas reported deaths from Alzheimer's disease surged by 146.2 percent. In 2019, an estimated 18.6 billion hours of care were provided to patients with Alzheimer's disease or other dementias by over 16 million family members and other unpaid carers. Payments for health care, long-term care, and hospice services for those 65 and older with dementia are expected to total 305 billion dollars in 2020. The United States, like other industrialized countries in Europe, North America, Australia, and certain Asian countries, has online pages that give information on how to identify and prevent Alzheimer's disease. Age, sex, and socioeconomic and cultural backgrounds all have a role in the frequency of Alzheimer's disease across Asia's emerging and established countries. There

are alarming risk factors in the health sector as a result of Alzheimer's disease, and the illness's social-economic impact is also significant. Because of its impact on the elderly in some overpopulated nations, Alzheimer's disease has become a severe socioeconomic burden. In these nations, the function of caregiver management has also been emphasized for a long time. AD is also a worry in certain South Asian nations. For a long time, our neighbor India has been concerned about the impact of AD on social structure and economic growth. According to the Alzheimer's and Related Disorders Society of India's Dementia India Report 2010, India's dementia population is 3.7 million, with that figure expected to treble in the next 20 years. The National Institute of Ageing was formed by the Indian government, and the National Policy for Older included particular provisions for people with dementia. A lot of studies on the impact of Alzheimer's disease on the lives of ordinary people have been conducted in rural locations. Pakistan is also aware of the impact of Alzheimer's disease on society. Pakistan is also aware of the impact of Alzheimer's disease on social and economic difficulties, as evidenced by a number of research on the disease's course, symptoms, and practitioner advice. Nepal has conducted research into the protocols that doctors should use while dealing with Alzheimer's disease. Sri Lanka has policies in place, as well as a number of research on the prevalence of Alzheimer's disease and treatment options.(Roy et al., 2020)

## 1.7 23andMe Genetic test kit

Since 2006, 23andMe which is a direct-to-consumer (DTC) online genetic-testing service that provides a genetic ancestry report and a genetic health report, has collected biological samples, self-reported information, and consent documents for biobanking and research from over 1,000,000 individuals (90 percent participating in research). Consumers may now select whether or not they want to know if they contain specific genetic markers linked to late-onset Alzheimer's and Parkinson's disease in the newest edition of 23andMe. The FDA granted 23andMe permission to commercialize Late-Onset Alzheimer's Disease, Parkinson's Disease,

and Hereditary Thrombophilia genetic health risk assessments, among other findings, on April 6, 2017.

## 1.8 Rational of the study

Alzheimer's disease (AD) is a progressive dementia marked by a decline in cognitive function that eventually leads to impairment and death. For the most majority of patients, there are no viable treatment options, and the underlying causes of the condition are unclear, with the exception of a tiny percentage of family instances caused by genetic abnormalities. Therefore, this study is done to discover whether or not person with more knowledge would want to know if they have genetic predisposition to Alzheimer's disease and their view on genetic testing in general. It will also help us to understand the current scenario in Bangladeshi people and their knowledge level toward Alzheimer's disease and genetic testing.

# Chapter 2

# Aims and Objectives

The goal of this study is to analyze people's knowledge and opinions about Alzheimer's disease genetic testing in Bangladesh. We looked at whether knowledge and attitudes were linked, as well as if they were linked to demographic as well as prior experience with the disease in one's family or other factors. The other objectives are to aid in research and to develop interest on genetic testing of AD. The objective is to collect data and perform a survey also perform regression analysis to compare knowledge of participants with attitude.

# Chapter 3

## Methodology

This study was planned to develop a reflection of the knowledge of Alzheimer's disease and its relationship towards genetic testing of the disease. The survey was set up in a manner that it would be sufficiently powerful to concentrate information from participants with respect to the learning about recognize the field in Bangladesh. The questionnaire was developed by thinking relevant and distinct literary works to reach the goals of this study. The participants for this study was selected randomly from different schools, colleges and universities. Online consents were taken from the participants and were then asked to fill the validated, structured questionnaire delivered to them through email.

The responses were scored and all statistical data were performed through Microsoft excel and GraphPad Prism software. Descriptive statistics were used to summarize the data. T test and ANOVA test was used to investigate the relation between knowledge and attitude. We distributed a google doc with relevant questions and relative options to various people through social media. Total 209 responses were collected 1.5 months through social media. Data had been collected from 209 participants and were categorized in Microsoft excel.

# Chapter 4

# Result

## 4.1 Demographic summary

A total 209 responses were recorded within 1.5 months. Among the 209 responders 124 (59.1%) were female, 84 (40.4%) were male and 1 (0.5%) preferred not to reveal their gender. In addition to that the participants were divided by age groups of below and above thirty. 169 participants were below the age of thirty and 40 participants were above above the age of thirty, where highest number of participants were between age 20 to 30.

Turning to the next information which is about the academic background, it was found that highest level of education was bachelor's 110(52.6%) and second highest level was master's 57 (27.3%). Moving to participant's having any close one to them with Alzheimer's disease, majority of participants voted "No" and about 23.6% voted "Yes".
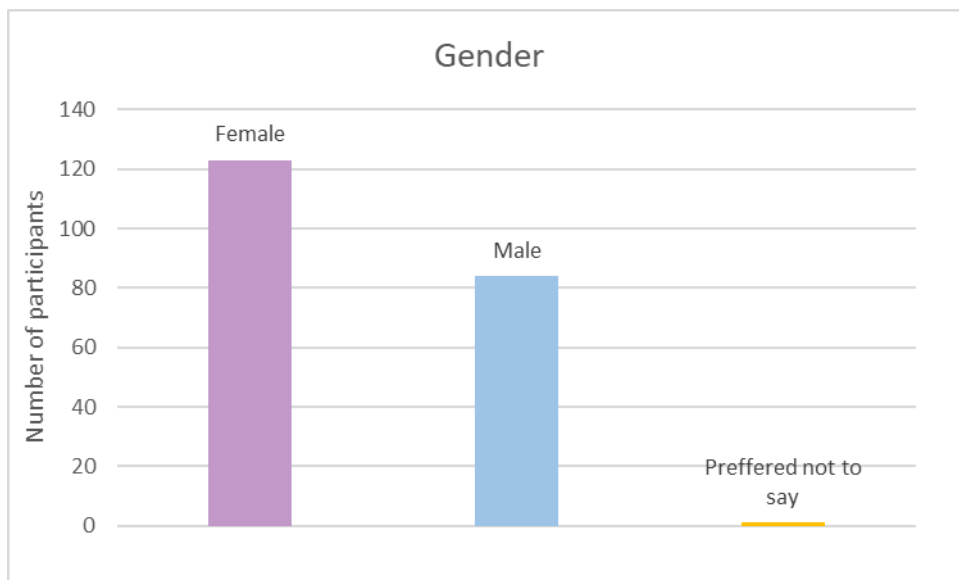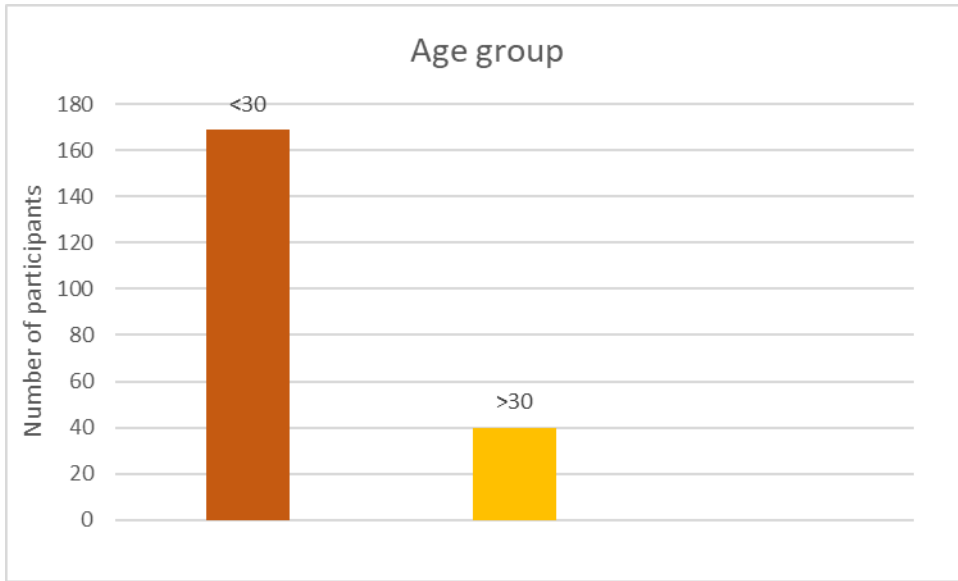


*Figure 2 Gender demographics*
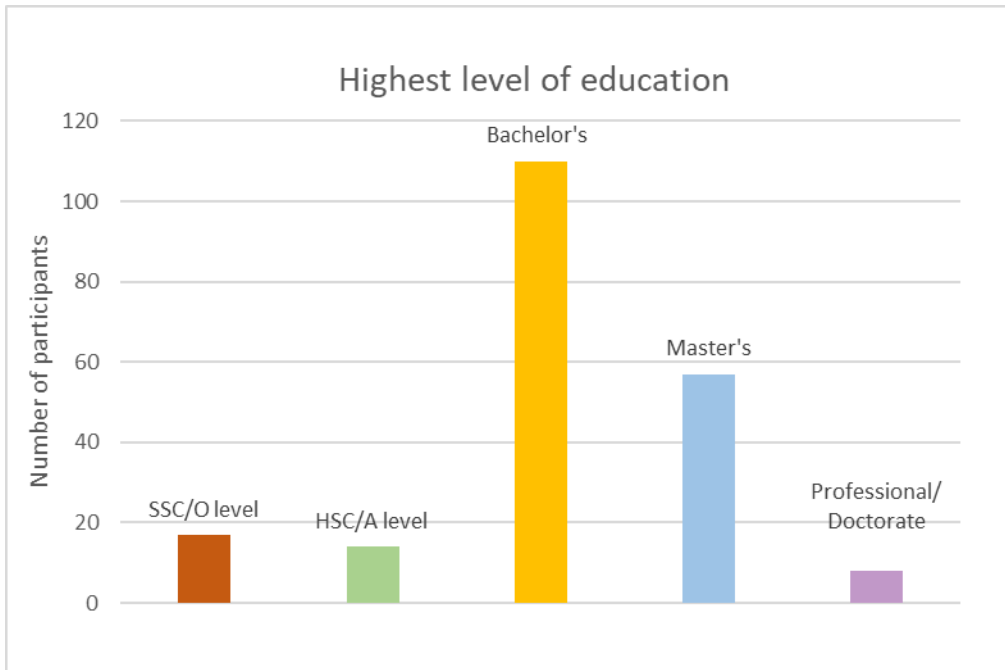
*Figure 3 Age demographics*



*Figure 4 Demographics on participant's highest education level*

*Table 1 Demographic information of the participants*

| Variables | Percentage |
|---|---|
| **Gender** | |
| Female | 59.1% |
| Male | 40.4% |
| Preferred not to say | 0.5% |
| **Age** | |
| <30 | 80.8% |
| >30 | 19.2% |
| **Education level** | |
| SSC/O level | 6.7% |
| HSC/A level | 8.1% |
| Bachelor's | 52.6% |
| Master's | 27.3% |
| Professional/Doctorate | 3.8% |
| **Having a close on with Alzheimer's disease** | |
| Yes | 73.7% |
| No | 26.3% |

## 4.2 Statistical analysis of knowledge of Alzheimer's

In case of measuring knowledge scores of Alzheimer's disease true/false and checkboxes were used to assess knowledge about Alzheimer's disease. The participants' were asked if Alzheimer's disease is a type of dementia and majority of participants 82.2% voted in favor of it. Moving to the question if Alzheimer's symptoms are reversible, the highest amount of votes were "True".

Now, comparing knowledge scores between below and above age 30, by doing T test on GraphPad prism software the p value was seen < 0.05 which indicates significant difference between the two variables. Moving to knowledge scores between gender male and female there was no significant difference as the p value was 0.4532. In case of highest level of education ANOVA test was done and there was also no significant difference. Whereas having a close person with AD and not having any close person with AD showed significant difference as the p value was <0.0001.

*Table 2 Assesment of participant's knowledge about AD*

| Variables | Mean | P Value | Significantly different |
|---|---|---|---|
| <30 Vs >30 | 10.97 / 14.84 | <0.0001**** | Yes |
| Female Vs Male | 11.15 / 10.83 | 0.4532 | No |
| SSC/O level vs HSC/A level vs Bachelor's vs Master's vs | 11.20 / 10.39 / 10.69 / 11.28 | 1.527 | No |

| | | | |
|---|---|---|---|
| Professional/Doctorate | 13.25 | | |
| Having close one with Alzheimer's disease vs Not having close one with Alzheimer's disease | 14.43 | <0.0001**** | Yes |
| | 10.83 | | |

## 4.3 Statistical analysis of attitude of genetic testing

Moving to measuring total attitude scores between below and above age 30, significant difference was seen as the o value was < 0.05. However, there was no significant difference between attitude score of male and female gender. Moving to highest level of education the p value was 0.0009 which indicates significant difference. However, among this only SSC/O vs Bachelor's and SSC/O level vs Professional/ Doctorate showed significant difference. Finally, there was no statistical significant difference between having a close one with AD vs not having close one with AD as he p value was 0.2470.

*Table 3 Assesment of participants attitude towards genetic testing of AD*

| Variables | Mean | P value | Significant difference |
|---|---|---|---|
| <30 vs >30 | 16.18 | 0.0338* | Yes |
| | 14.78 | | |
| Female | 15.76 | 0.9821 | No |

| | | | |
|---|---|---|---|
| vs <br><br> Male | 15.75 | | |
| SSC/O level <br><br> vs <br><br> HSC/A level <br><br> vs <br><br> Bachelor's <br><br> vs <br><br> Master's <br><br> vs <br><br> Professional/Doctorate | 13.40 <br><br> 14.83 <br> 16.52 <br><br> 15.47 <br> 17.63 | 0.0009*** | Yes |
| Having close one with Alzheimer's disease <br> Vs <br> Not having close one with Alzheimer's disease | 16.32 <br><br> 15.75 | 0.2470 | No |

## 4.4 Correlation analysis

Here, the correlation between below age 30 participants shows low association as the $R^2$ value is 0.0975.
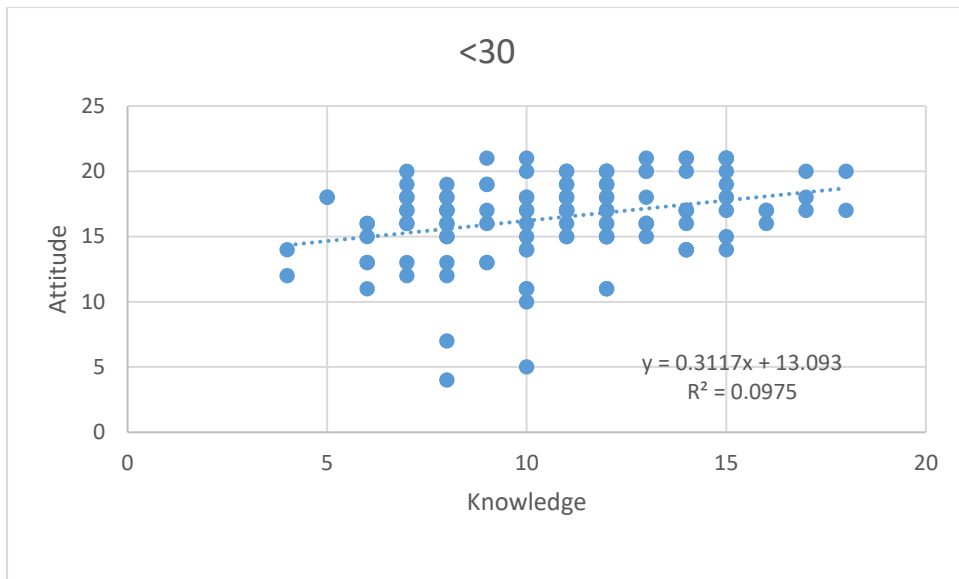
*Figure 5 <30  participant's knowledge vs attitude linear regression*

Similar  to  below 30 age responders the correlation between the total know and attitude of
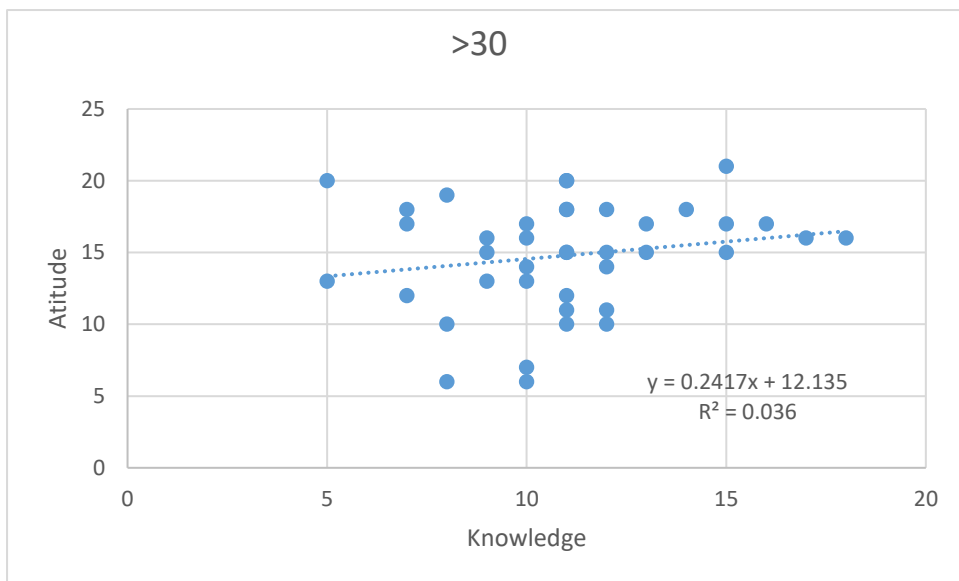
above 30 age participants has low  association.



*Figure 6 >30 participant's knowledge vs attitude linear regression*

Comparatively, the correlation between total knowledge and attitude of Male participants

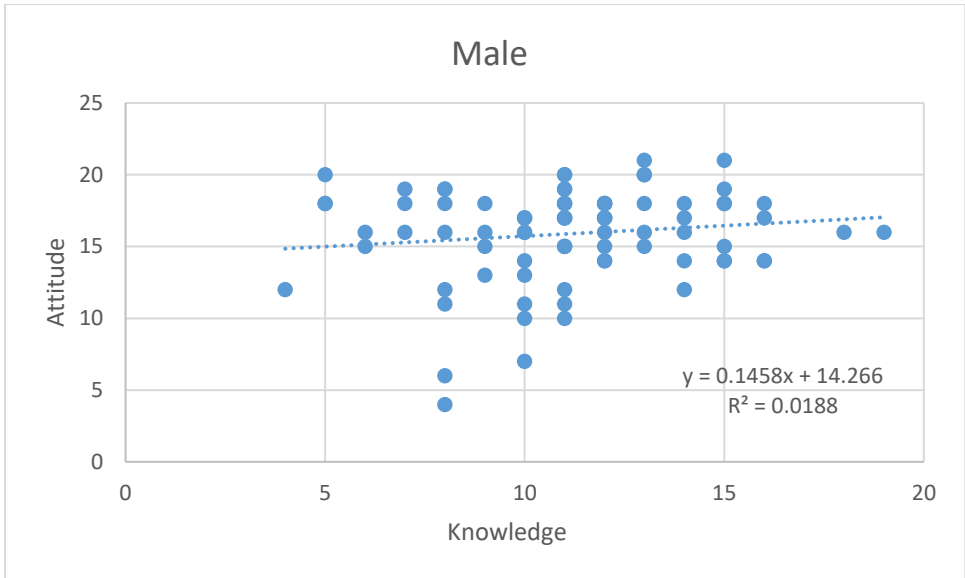shows weak association as well because the $R^2$ value is 0.0188.

*Figure 7 Male participant's knowledge vs attitude linear regression*

Lastly, the correlation between total knowledge and attitude of female participants has low association similar to the previous variables.
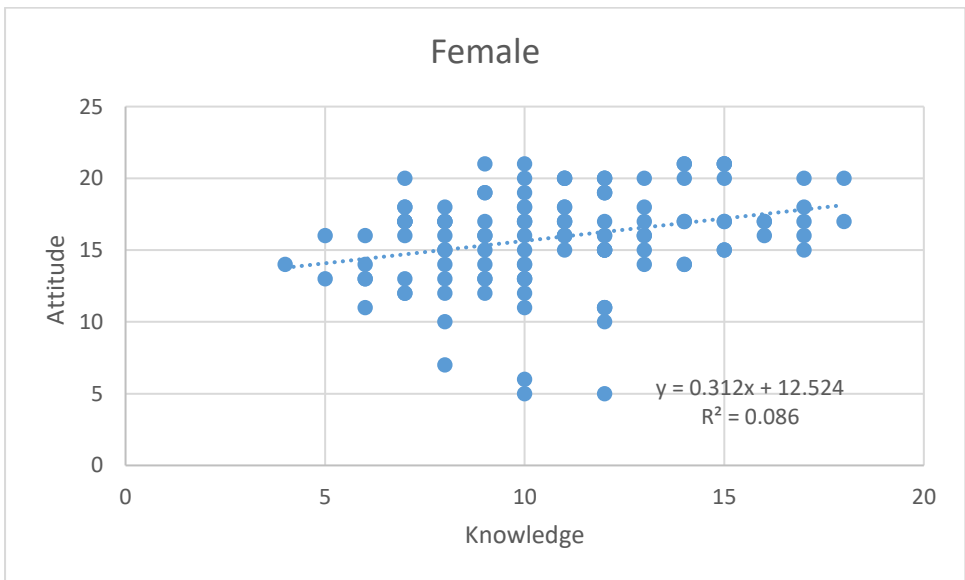


*Figure 8 Female participant's knowledge vs attitude linear regression*

# Chapter 5

## Discussion

The main aim of this study was to evaluate the attitudes and knowledge of Bangladeshi people toward Genetic testing of Alzheimer's disease. The results of the present study revealed that the majority of people have insufficient knowledge and lack of awareness about Alzheimer's disease. From this study, we saw that majority of the responder's are aware of the disease and has idea of some common symptoms of AD. Furthermore, we found that majority of the participants are aware that AD is one type of dementia and it's not curable. However, majority of participants don't know if the symptoms are reversible or irreversible and if there's any blood test to detect the disease.

Now, because the number of participants was quite low that is why to validate this result we needed a broader sample size. We saw significant difference of knowledge and atittude on AD between the two age groups however the number of participants below thirty is higher compared to participants above age thirty. That's why to get the accurate result we need more even numbered participants. Moreover, we also saw a significant difference between having any close one with AD and not having any close one with AD. Similar to the age groups the number of participants weren't even as majority of responders 72.2% do not have any close friend or family with AD.

Furthermore, significant difference between highest levels of education was seen but only SSC/O vs Bachelor's and SSC/O level vs Professional/ Doctorate showed difference. Moreover, number of participants between these groups were not even so the result cannot be considered accurate.

As the participant number was only 209 this limits the generalizability of our findings and suggests that more deficits in knowledge and poorer attitudes could be observed in more representative samples, highlighting the need for larger-scale national studies on knowledge of AD and attitudes towards genetic testing of AD. Additionally, the number of total participants was only 209 which might have caused the results to be inaccurate, so this study needs to be done on a broader scale. Also if we had more even number of participants among the groups e results would be more accurate. Also, majority of participants showed positive attitude about government investing more money for the development of genetic testing of AD.

In case of responder's attitude towards genetic testing we saw majority of participants (79.8%) showed positive attitude regarding doing genetic testing to detect early onset of AD. However, awareness regarding genetic test in general is poor as only 33.5% participants knows about it. Moving to number of participants who thought or discussed the possibility was also low (34.9%). Regarding at home test kit 23andMe, only 7.7% participants has heard or is aware about this testing method. Therefore, we concluded that concordant with efforts to educate the general public regarding AD and genetic testing of AD.

Now, from the regression analysis we saw at there's no relation between both the female and male participant's knowledge and attitude as the $R^2$ value was below 0.95. Additionally, there was also no relation between both below and above 30 age participant's knowledge and attitude. So, we can say there's no significant connection between the participant's knowledge of Alzheimer's disease with their attitude towards genetic testing of AD.

# Chapter 6

## Future prospects

In the last 15 years, significant progress has been made in understanding the genetics of Alzheimer's disease, but there is still more work to be done. The number of Alzheimer's patients is steadily increasing. The rising rate of life expectancy is linked to the high prevalence of Alzheimer's disease patients. AD is a disease that causes significant misery to patients and their families, as well as a major healthcare burden with financial and societal implications. In sum, then, the results of this study showed that the overwhelming majority 209 responders considered genetic screening procedures aiming to detect AD if this procedure is integrated as a standard procedure in Bangladesh.

Further research would be planned by a questionnaire survey in larger scale to find more accurate results.

# Chapter 7

# Conclusion

The study's findings suggest that the participants are lacking in genetic knowledge but have a favorable attitude toward genetic tests in general. Because the general education and intellectual level of the society is high in developed countries, individuals have detailed knowledge about the positive / negative aspects of genetic testing, however, in developing country like Bangladesh general knowledge regarding genetic screening is quite low. Therefore, it can be said that the positive attitude towards genetic testing (high / low education level) is not based on accurate reliable knowledge, but based on estimation. According to our research, there is a lot of curiosity among people who are taking part in the study in finding out if they are vulnerable to the disease. As a result of the lower prices of the tests and the approval of the official social security organization, the test is likely to be used more frequently. Validity, priority, applicability of Genetic Tests, faith in technology, and quality control should all be promoted in this regard. Apart from the importance and benefits of genetic testing, due to economic constraints and cultural factors in developing countries such as Bangladesh, complex chronic / for the inconvenience of the control and prevention priorities, such as smoking control, stress reduction, a healthy diet, proven effective, such as physical activity people the implementation. Furthermore, we may conclude that the participants' knowledge of Alzheimer's disease has no impact on their attitudes on genetic testing for the disease. Apart from the importance and benefits of genetic testing, due to economic constraints and cultural factors in developing countries like Bangladesh, frequent complex chronic / for the inconvenience of the control and prevention priorities, such as smoking control, stress reduction, a healthy diet, proven effective, such as physical activity people the implementation of health measures should also be given priority. Finally the more aware the people are about

the benefits of genetic screening of AD, the more they are likely to support this procedure. As other countries are improving their medical sectors, it is now high time to improve our medical system.

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## Annexure

## Questionnaire

<u>**Consent part**</u>

Questionnaire survey to assess the Knowledge and Attitude and regarding Genetic Testing for Alzheimer's Disease among the general population of Bangladesh.

We will ask you some questions about your knowledge and opinions regarding certain aspects of this disease.

Any personal information collected from this survey will not be disclosed in any publication and only the data collected from this survey will only be used for research (B. Pharm thesis) purpose and if further publications result from the study and the data will not be shared with any Third party.

If you agree to the terms and conditions stated above please select agree to move to the questionnaire section

- o Agree
- o Disagree

<u>**Demographic Data**</u>

Gender (for the purpose of demographic data)

- o Female
- o Male
- o Prefer not to say

Age

_____

Educational Level

- o   No formal education

- o   SSC/O level

- o   HSC/A level

- o   Bachelor's

- o   Master's

- o   Professional/Doctorate

Are there any people with Alzheimer's disease who are close to you?

- o   Yes

- o   No

## How Much Do You Know About Alzheimer's Disease?

1.  Are you aware of Alzheimer's Disease?

    - o   Yes

    - o   No

2.  Below are some statements about Alzheimer's disease. Please read each statement

    carefully and place check mark whether you think the statement is True or False. If

    you aren't sure of the right answer, make your best guess.

    - o   Alzheimer's disease is one type of dementia.

    - o   Dementia is an inevitable part of aging.

    - o   There is currently not a blood test for diagnosing Alzheimer's.

    - o   Alzheimer's disease cannot be cured.

    - o   Alzheimer's symptoms are reversible.

3. Which of the following do you think are signs and symptoms of the disease?

o   Memory loss

o   Repeating questions

o   Loss of spontaneity and sense of initiative

o   Difficulty completing familiar tasks

o   Challenges in planning or solving problems

o   Confusion with time or place

o   Problems with words in speaking or writing

o   Trouble understanding visual images and spatial relationships

o   Changes in mood and personality

## **What Do You Think About Genetic Testing?**

1.  How much do you know about genetic testing?

o   Almost Nothing

o   A lot

2.  Have you ever thought of or discussed the possibility of getting a genetic test?

o   Yes

o   No

3.  Have you ever heard of genetic testing to determine if a person is at greater risk of developing Alzheimer's disease?

o   Yes

o   No

4.  Do you know there's FDA approved at home genetic test named 23andMe for early detection of Alzheimer's disease?

o   Yes

o No

5. How likely would you use this genetic test if you had the opportunity?

   o Not likely

   o Highly likely

6. This genetic test should be available for those who want to use them

   o Strongly Disagree

   o Strongly Agree

7. More money should be available for the development of Alzheimer's genetic tests

   o Strongly Disagree

   o Strongly Agree

8. If this type of genetic screening is integrated as a standard procedure in Bangladesh

   will you support it?

   o Not likely

   o Highly likely