Methodology

Chapter 3

METHODOLOGY:

In the previous chapters, the theoretical concepts underlying the research findings have been unfolded and the statuses of the presently available studies in the area have been delineated. Impairments of autobiographical memory both for personal incident memory (memory for personally experienced incidents) and personal semantic memory (memory for facts about oneself), have been documented by several researchers even though there methodologies have varied (Addis & Tippett, 2004; Addis et al., 2007; 2008; Addis & Schacter, 2008; Addis et al., 2009; Baddeley & Wilson, 1986). Since autobiographical memory serves as the basis of an individual's identity and interactive processes in society, the apparently subtle changes also account for much of affective and functional disturbance, and thus ultimately relate to the quality of life. The individual's sense of wellness in life also depends on the way one can express one's identity and viewpoints in a coherent manner. While, medical technology is providing us with longevity, the issue of quality of life in dementia is also becoming a major concern.

The aim of our present study was to determine the (1) differences of Autobiographical memory impairment and wellness among patients with Alzheimer's disease (AD), vascular dementia (VaD), Parkinson's disease with dementia and with normal control (PDD), (2) the sex differences, if any, in impairment of autobiographical memory and wellness among patients suffering from the above diseases, as well as normal control and (3) whether impairment in autobiographical memory in the four groups is associated with subjective feeling of wellness.
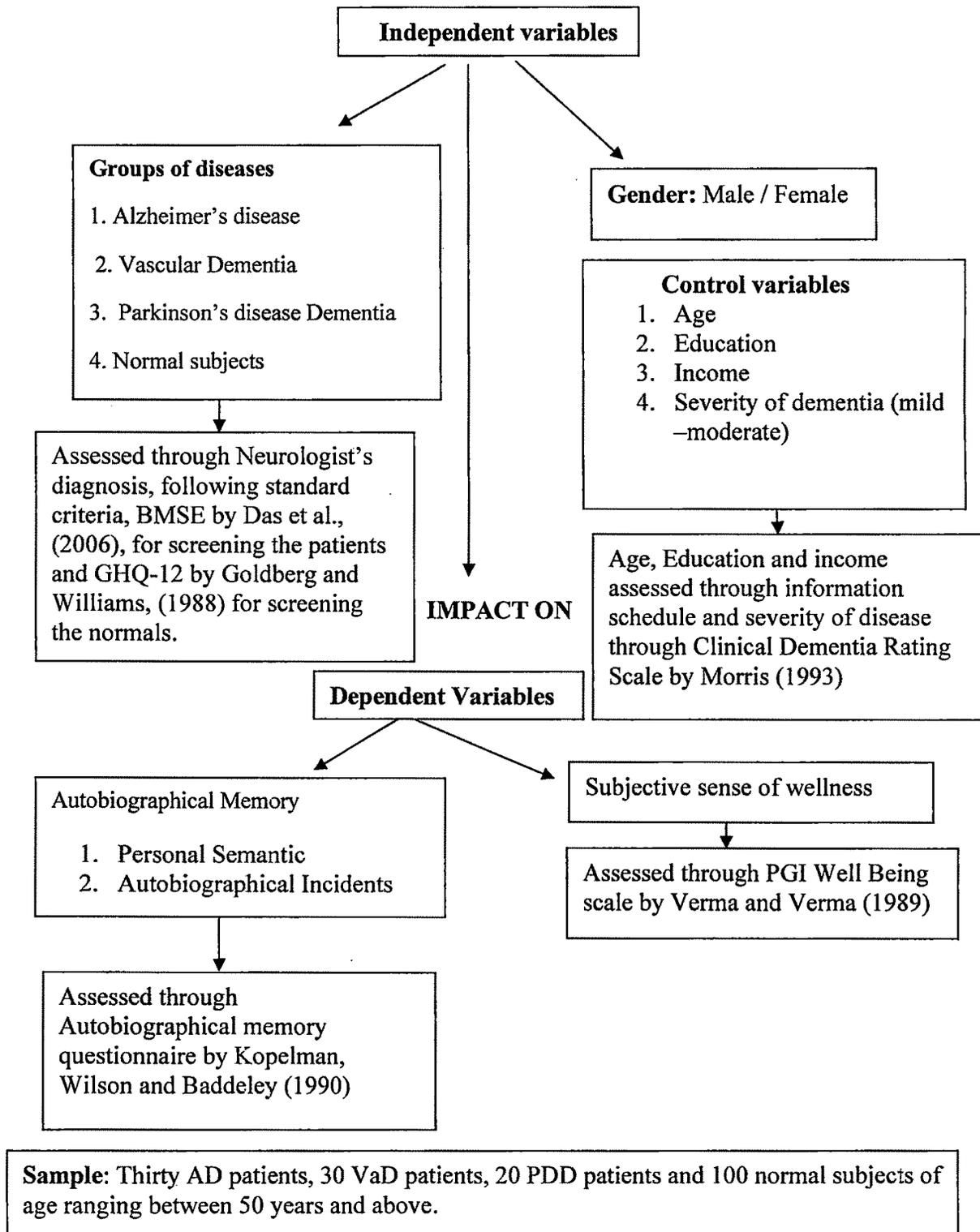
In the present chapter the methodology for the study has been detailed. The specific research hypotheses have been formulated; the variables of the study have been described and justified.

Their operational definitions have been specified. The selections of the sample and the measures used have also been elaborated. The procedures of data collection and the techniques for analysis employed have been narrated.

3.1 RESEARCH HYPOTHESES:

1. There will be significant difference between the different groups of patients with AD, VaD and PDD and the control group in terms of degree and nature of impairment in autobiographical memory.

2. There will be significant difference between the different groups of patients with AD, VaD and PDD and the control group in terms of subjectively experienced wellness.

3. There will be significant effect of gender on the degree and nature of impairment in autobiographical memory.

4. There will be significant effect of gender on subjectively experienced wellness.

5. There will be significant association between impairment in autobiographical memory and subjectively experienced wellness among different groups.

3.2 Schematic Representation of Research Design:

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                    ┌─────────────────────────────┐
                    │   Independent variables     │
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Groups of diseases

1. Alzheimer's disease

2. Vascular Dementia

3. Parkinson's disease Dementia

4. Normal subjects

Gender: Male / Female

Control variables
1. Age
2. Education
3. Income
4. Severity of dementia (mild –moderate)

Assessed through Neurologist's diagnosis, following standard criteria, BMSE by Das et al., (2006), for screening the patients and GHQ-12 by Goldberg and Williams, (1988) for screening the normals.

IMPACT ON

Age, Education and income assessed through information schedule and severity of disease through Clinical Dementia Rating Scale by Morris (1993)

Dependent Variables

Autobiographical Memory

1. Personal Semantic
2. Autobiographical Incidents

Subjective sense of wellness

Assessed through PGI Well Being scale by Verma and Verma (1989)

Assessed through Autobiographical memory questionnaire by Kopelman, Wilson and Baddeley (1990)

Sample: Thirty AD patients, 30 VaD patients, 20 PDD patients and 100 normal subjects of age ranging between 50 years and above.

3.2 SELECTION OF THE VARIABLES:

A variable is a symbol to which numerals or values are assigned (Kerlinger, 1995). It is defined as an event or condition, which can have different values- ideally, in experiments, an event or condition, which can be measured (Morgan et al., 1993). Variables are essentially categorized as dependent, independent and control variables (Snodgrass et al., 1985). In the perspective of the present study, these three kinds of variables have been defined and reported in the following section.

3.3 THE DEPENDENT VARIABLES:

The dependent variable is the attribute or performance being measured to determine the effect of manipulating an independent variable. The dependent variable may be characterized as behavioral, psychological or social depending on the nature of the work. A researcher in general tries to select the most sensitive, reliable and unobtrusive dependent variable possible.

In Chapter 1, the broad nature of the dependent variables has been illustrated. There were two broad categories of variables: one, the autobiographical memory impairment in aged persons having dementia, and two, their subjective sense of wellness.

The reason for selecting variables particularly in dementia has been amply delineated in Chapter 1.

3.4 THE INDEPENDENT VARIABLES AND THE RATIONALE FOR THEIR SELECTION:

An independent variable is a factor that can be varied or manipulated by an experimenter and its effects on the dependent variable are measured. In this study, the independent variables are three groups of diseases and gender of the patients.

Alzheimer disease (AD) is the most common neurodegenerative disease in adulthood and the most common disease that affects the episodic memory system. The hippocampus and other medial temporal lobe structures are damaged by AD first, and to a greater extent than other brain areas.

Baddeley and Wilson (1986) had noted that VaD patients with widespread diffuse changes in frontal lobe can access lifetime period and general events, but cannot recall specific and detailed autobiographical memories. Additionally, these individuals may produce confabulatory memories. They termed it as a "clouding" of autobiographical memory. A number of neuroimaging studies have focused on the role of frontal regions in the retrieval of AM's (Conway et al., 2000).

Remote memory impairment in PD with dementia, have been well documented (Freedman, Rivoira, Butters, Sax, & Feldman, 1984; Huber, Shuttleworth & Paulson, 1986). Remote autobiographical memory was substantially impaired due to impairment in one or more cortical areas including the lateral temporal and frontal lobes (Bayley et al., 2005).

Bengali Mental State Examination (BMSE) (Das et al., 2006) was used to detect and track the progression of dementia associated with AD, VaD and PDD.

Healthy older adults displayed a significant reduction of episodic details of autobiographical memories of past events than younger adults as documented from several studies (Levine et al., 2002; Addis et al., 2008). Older adults recalled fewer episodic autobiographical details and more semantic details that were not connected to any particular time or place than did younger adults (Levine et al., 2002). General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1988) was used to measure the mental health status of the normal controls.

Gender differences are well documented in the autobiographical literature (Bloise & Johnson, 2007; Pohl et al., 2005). Studies have noted that women perform better than men on episodic memory tasks that require verbal processing, whereas men outperform women on visuospatial processing (Herlitz & Rehnman, 2008; Lewin et al., 2001). Gender differences in cerebral functions have also been observed in functional brain imaging studies (Maguire et al., 1999).

3.5 ENUMERATING THE CONTROL VARIABLES:

To evade contamination in the effect of independent variables as far as practicable, it was imperative to identify at least the most important relevant variables and control them to maximize the effect of independent variable on dependent variable. All the groups are comparable in terms of control variable and the rationales for their selection are given below:

Age:

In the present study age of the patients ranged from 50 years and above. Most of the AD, VaD, PDD patients in Cognitive Clinic of Bangur Institute of Neurology, Kolkata were in the age range of 50 years and above. Similarly, for the normal groups similar age range was taken.

Education:

The educational levels of the patients and normal were at least primary education. This level was selected to attain the homogeneity.

Income:

In the present study, only those belonging to the middle class families and middle income status have been chosen as subjects. The orientation is towards the middle class family because such family is almost a model type of family (Lantz & Snyder, 1969). Kuppuswamy's (2012) socioeconomic scale has been used to measure socioeconomic status of families in urban communities. The income of the subjects was within the stated range of income.

Severity of the dementia:

At early to moderate stages of the disease, patients likely to recall their personal memories which tend to disappear as dementia progresses.

3.6 SELECTION OF SAMPLING TECHNIQUES:

Various techniques have been devised for obtaining a sample, which will be representative of its population. The adequacy of a sample (i.e it's lack of bias) depends upon the method used in collecting the sample (Garrett, 1966). Commonly used sampling methods are as follows:

(1) **Random Sampling:** Random sampling is the selection of cases from the population in such a manner that every individual in the population has an equal chance of being chosen. In addition, the selection of any one individual is in no relevant way tied to the selection of any other. Selections are independent of one another. A random sample is fairly representative of the population (Guilford & Fruchter, 1973).

(2) Biased Sampling: Biased sample has a systematic error. Certain types of cases have advantage over others in being selected. The likelihood of individual being chosen thus differs from one to another.

(3) Stratification in Sampling: This method is also known as quota or controlled sampling. It is a technique designed to ensure representativeness and avoid bias by use of a modified random sampling method. Stratification is a step in the direction of experimental control. It operates with sub-groups of the population are considered with respect to any variable that is suspected of correlating appreciably with the variables being studied. Random selections of cases are done within the defined subpopulations in appropriate numbers. The total sampling procedure thus known as stratified random sampling is likely to be more representative of a total population than a purely random sample (Guilford & Fruchter, 1973).

(4) Purposive Sampling: A purposive sample is one arbitrarily selected because there is good evidence that it is very representative of the total population. This is a convenient procedure, but it has the disadvantage that much prior information must have been obtained. There is also a risk that conditions may change to the extent that the particular segment does not represent the total population.

(5) Incidental Sampling: The term incidental sample is applied to those samples, which are taken because they are the most available. Results, thus obtained, can be generalized beyond such groups with some risk.

Among the various sampling techniques mentioned above, the **purposive incidental sampling technique** was selected for the present study. The relevant aspects considered for purposive

incidental sample selection are detailed below: as only those patients who came to the hospital and fulfilled the criteria were taken.

3.7 SAMPLING CRITERIA:

The present study was conducted with Bengali speaking middle class background. The sampling criteria were as follows:

Group I: Alzheimer's dementia (AD):

The AD patients were included after the consensus diagnosis by the neurologist and psychiatrist at the Cognitive Clinic, Bangur Institute of Neurology, Kolkata, following the NINCDS-ADRDA criteria (Mc Khann et al., 1984) and neuropsychological testing. The patients were included, after following the inclusion and exclusion criterion.

Inclusion criteria for Alzheimer's dementia patients:

i) Diagnosed by a neurologist as suffering from AD, fulfilling the NINCDS-ADRDA criteria for AD.

ii) Age range of 50 years and above.

iii) With a minimum of Class VI education.

iv) Socio-economic background- Middle class.

v) Able to read and write Bengali

vi) Clinical dementia rating scale range-0.5 to 2

vii) BMSE Score ≤ 26

Exclusion criteria for Alzheimer's dementia patients:

Patients were excluded for the following criteria:

i) AD due to any cerebral insult.

ii) With a history of co-morbid psychiatric and/or neurological disorder.

iii) History of head injury or central nervous system infection.

iv) History of alcohol or other substance abuse.

v) Presenting with medical conditions such as hepatic, renal and pulmonary disease, systemic infection or metabolic encephalopathy.

vi) With significant language and hearing problem

Group II: Vascular dementia (VaD):

The VaD patients were included after the consensus diagnosis by the neurologist and psychiatrist at the Cognitive Clinic, Bangur Institute of Neurology, Kolkata, following the NINDS-AIREN criteria (Román et al., 1994), along with neuroimaging report and neuropsychological testing. The patients were included, after following the inclusion and exclusion criterion.

Inclusion criteria for vascular dementia patients (VaD):

i) Diagnosed by a neurologist as suffering from VaD fulfilling the NINCDS-AIREN criteria for VaD.

ii) Age range of 50 years and above.

iii) With a minimum of Class VI education.

iv) Socio-economic background- Middle class.

v) Clinical dementia rating scale range-0.5 to 2

vi) Able to read and write Bengali

vii) BMSE Score ≤26

Exclusion criteria for vascular dementia patients:

Patients were excluded for the following criteria:

i) VaD due to any cerebral insult.

ii) With a history of comorbid psychiatric and/or neurological disorder.

iii) History of head injury or central nervous system infection.

iv) History of alcohol or other substance abuse.

v) Presenting with medical conditions such as hepatic, renal and pulmonary disease, systemic infection or metabolic encephalopathy.

vi) With significant language and hearing problem

Group III: Parkinson's disease dementia (PDD):

The PDD patients were included in the study after being diagnosed by the neurologist at the Cognitive clinic, Bangur Institute of Neurology, Kolkata. The PDD patients were referred to cognitive clinic and were included following the Movement Disorder Society (MDS) Task Force criteria along with neuropsychological testing.

The patients were included, after following the inclusion and exclusion criterion.

Inclusion criteria for Parkinson's disease dementia patients (PDD):

i) Diagnosed by a neurologist as suffering from PDD fulfilling the Movement Disorder Society (MDS) Task Force criteria (Emre et al., 2007).

ii) Within the age range of 50 years and above.

iii) With a minimum of Class VI education.

iv) Socio-economic background- Middle class.

v) Clinical dementia rating scale range-0.5 to 2

vi) Able to read and write Bengali

vii) BMSE Score $\leq$26

Exclusion Criteria for Parkinson's disease dementia patients:

Patients were excluded for the following criteria:

i) With a history of vascular insult to the brain leading to Parkinsonian features.

ii) Those suffering from Parkinson's Plus Syndrome.

iii) With comorbid psychiatric and/or other neurological disorder.

iv) With significant language and hearing problem.

v) With a history of alcohol or other substance abuse.

vi) Having significant medical conditions such as hepatic, renal and pulmonary disease, systemic infection or metabolic encephalopathy.

Group IV: Normal Group:

Only those individuals were included in the study as healthy normal subjects who fulfilled the following selection criteria.

Inclusion criteria for normal healthy subjects:

i) Absence of neurological signs on neurological examination.

ii) Within the age range of 50 years and above.

iii) Socio-economic background- Middle class.

iv) With minimum of class VI education.

v) Able to read and write Bengali

vi) Individuals with BMSE score >26 and above.

Exclusion Criteria for normal healthy subjects:

i) Individuals scoring above the cut-off point of 2 on the General Health Questionnaire (GHQ).

ii) Individuals with a previous history of psychiatric and neurological disorders.

iii) Individuals with a history of intake of drugs that are known to affect the functions of central nervous system.

iv) With significant language and hearing problem.

51

Measures of Control variables:

1. Information Schedule and Medical History taking format prepared for collecting personal and familial information.

2. Clinical dementia rating scale (CDR) by Morris, (1993) was used to assess the severity of the disease among dementia group.

Measures of Independent variables:

1. General Health Questionnaire (GHQ-12) by Goldberg and Williams, (1988) was used to measure the mental health status of the normal subjects.

2. Bengali validated Mini Mental State Examination (BMSE) by Das et al, (2006) was used to detect and track the progression of dementia associated with AD, VaD and PDD.

Measures of Dependent variables:

1. Autobiographical Memory Interview Scale by Kopelman, Wilson and Baddeley, (1990) was used to assess subject's Personal semantic and Autobiographical incident memory.

2. PGI General Well Being Scale by Verma and Verma, (1989) was used to assess the psychological well-being of an individual.

3.8 MATERIALS USED:

(I). Information Schedule and Medical History Format: (Appendix B1)

In the Information Schedule format, information were asked regarding the age of the subjects, education, address, income, occupation, marital status, history of present illness, family history, addiction (if any), history of diseases and neuroimaging reports.

(II). Clinical Dementia Rating Scale (CDR) (Morris, 1993): (Appendix B2)

The CDR was developed at Washington University School of Medicine and first published in 1982. It was last revised in 1993 for the evaluation of staging severity of dementia. It comprises six domains: memory; orientation; judgement and problem-solving; community affairs; home and hobbies; and personal care.

Administration:

It employs a semi-structured interview with both the patient and a reliable informant (usually spouse or adult children) to rate performance in six domains: Memory, Orientation, Judgment and Problem solving, Community Affairs, Home and Hobbies, and Personal Care. In rating each of these domains, the assessment should be on the patient's cognitive ability to function in these areas. The CDR structured interview collects information in a standard way from both the collateral source and from the subject relative to memory, orientation and so forth.

Scoring:

The Clinical Dementia Rating is a five-point scale in which CDR-0 connotes no cognitive impairment, and then the remaining four points are for various stages of dementia: 0.5 = possible dementia; 1 = mild dementia; 2 = moderate dementia; 3 = severe dementia.

Specificity & Sensitivity:

The sensitivity and specificity of the AMI have been reported to be 76% and 94% respectively (Morris, 1993).

In the present study, CDR was administered to patient groups as a screening tool for staging the severity of dementia.

(III). General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1988): (Appendix B3)

The General Health Questionnaire (GHQ-12) by Goldberg and Williams, (1988), a self-administering screening questionnaire consists of 12 items. It is widely used internationally to measure the mental health status of the individual.

Administration:

GHQ-12 consists of 12 items for assessing the severity of a mental problem over the past few weeks using a 4 point Likert type scale (from 0 to 3). It is a self-administering screening test. There is no time limit to complete it.

Scoring:

For each item, there are four response possibilities (0 - not at all, 1 - no more than usual, 2 - rather more than usual, 3 - much more than usual). Scoring was done by Likert type scale method [0 – 0 – 1 - 1]. Total score ranging from 0 to 36. The positive items were corrected from 0 (always) to 3 (never) and the negative ones from 3 (always) to 0 (never). A score of below 2 signifies a non-psychiatric case.

Specificity & Sensitivity:

GHQ-12 was found to have 1% sensitivity and 0.88% specificity respectively (Basu & Dasgupta, 1996). There was no difficulty in its applicability in Bengali culture. It is quite easy to administer and the scoring procedure is also very simple.

(IV). Bengali Validated Mini Mental State Examination (BMSE) (Das et al., 2006): (Appendix B4)

The Bengali Mental State Examination (BMSE) has contributed to detecting early cognitive impairment particularly those with dementia. The validated BMSE consists of 19 items assessing

orientation, attention, immediate and short-term recall, naming, repetition, praxis, reading, writing and visuoconstructional ability.

Administration:

The subject is required to respond to the investigator's questions verbally, or to produce it on paper (2 items). It requires about 10 - 12 minutes administering the test.

Scoring:

Each correct item is given a score of 1. A maximum score of 30 can be achieved on the BMSE with a cutoff score of ≤26.

Reliability:

Using a cutoff score of ≤26, the inter rater reliability of the BMSE have been reported to be 0.85 to 1.00 and intra rater was 0.76 to 0.98 respectively for detecting delirium or dementia (Das et al., 2006).

In the present study, BMSE was administered to both patient and control groups as a screening tool for dementia.

(V). Autobiographical Memory Interview Scale (AMI) (Kopelman, Wilson & Baddeley, 1990) (Appendix B5)

Autobiographical memory is described as a type of episodic memory that contains both personal incident memory (memory for personally experienced incidents) and personal semantic memory (memory for facts about oneself). Due to aging and other factors such as dementia, one's ability to form and maintain autobiographical memories is often altered.

The semi structured autobiographical questionnaire that assessed each participant's ability to recall both general information (semantic component) and detailed specific events situated in time and space (episodic component) from between three time periods.

In the personal semantic schedule, subjects were asked to recall facts from their past life, relating to childhood, early adult life and more recent facts.

In the autobiographical incident schedule, the participants were asked to recall autobiographical memories from same three time periods which were relevant to their personal lives (Childhood [referred to as Section A], Early adult life [Section B], Recent life [Section C]). As the study was conducted in Bengali speaking population, The Autobiographical Memory Interview Scale which was used in this study, differed from the original one in one particular domain, which was the information related to the last Christmas or Thanksgiving. We have replaced the original question regarding information related to the last Christmas or Thanksgiving with questions on Durga puja or Bijoya greetings in the recent life section of Personal semantic.

Administration:

A rapport was established with the subjects and was asked to sit comfortably in a quiet room. At the outset of interview, it was mentioned, "this is an interview in which some questions about your earlier life will be asked. The questions will concern your school days, early adult life and more recent times." Participants were given precise instructions, available during the task, to recall "a personal event which occurred only once, at a particular place and date, and lasted several minutes or hours but less than a day." They had to locate it in time and space and give as many details as they could. If the participant could not spontaneously recollect an event, cues and/or encouragement were provided to elaborate on any information that they have already provided during the course of their recall. In the case of a failure to produce any memories, the

participants were prompted with many general clues about each theme relative to a period without a time constraint. Thereafter, the test switched to another theme or question regardless of the nature of the recall.

Scoring:

Scoring should be undertaken subsequent to the interview. Personal semantic schedule involve a maximum of 2 points for perfect recall, with 1 point being scored for partial recall. On the autobiographical schedule, 3 points are given for an episodic memory, specific in time and place; 2 points for a specific personal memory, in which time and place are not recalled, or for a less specific event in which time and place are recalled; 1 point for a vague personal memory; and no points in the absence of a response or for a response based purely on general knowledge (semantic memory).

Verification could be done by: Spouses help the patients to verify the answers on the autobiographical questions through shared life experience; or noting inconsistencies in the subject's response.

Specificity & Sensitivity:

Using a cutoff score of 0.48, the sensitivity and specificity of the AMI (Kopelman et al., 1990) have been reported to be 76% and 94% respectively (Murphy et al, 2008).

In the present study, AMI was administered to both patient groups and control group as a screening tool for autobiographical memory impairment.

(VI). <u>PGI General Well Being Scale</u> (Verma & Verma, 1989) (Appendix B6)

It has been designed by Verma & Verma (1989), to assess the psychological well-being of an individual. The scale consists of 20 statements and higher scores indicate higher levels of well-being.

Administration:

It is a 20 item scale and the subjects are required to tick the items applicable to them as they feel 'these days and in the past one month'. The total number of items ticked by the participants makes the total number of well-being score. Thus, the range of score on the scale is 0 to 20. There is no time limit.

Scoring: The higher scores indicate higher levels of well-being.

Reliability:

The split half reliability index by using Kuder Richardson formula is reported to be 0.98 and test retest reliability index is reported to be 0.91.

3.9 <u>PROCEDURE</u>:

Ethical clearance for the study was obtained from the institutional ethics committee

The dementia patients on whom the present study was conducted were selected on the basis of above mentioned criteria and consensus diagnosis by neurologist and psychiatrist at the Cognitive Clinic, Bangur Institute of Neurology, Kolkata.

After this selection, an informed written consent was collected from all the patients [Appendix A].

Controls, as described in the above criteria were individuals who volunteered to act as controls and some participants were selected from the old age home of Kolkata. To ensure optimal comparability, spouses of the patients were also asked to participate as controls.

A total of 80 patients comprising of 30 patients with Alzheimer's dementia (AD), 30 patients with vascular dementia (VaD), 20 patients with Idiopathic Parkinson's disease dementia (PDD) and 100 normal subjects participated in the study.

The demographic characteristics of the patients and normal subjects will be presented in the result section.

Parkinson's disease patients with dementia are less in numbers as approximately 40 percent of Parkinson's patients develop dementia after ten to fifteen years following the PD diagnosis (Dodel, 2004).

Clinical Dementia Rating Scale (CDR) was used for screening the severity of dementia among patient groups. Similarly, General Health Questionnaire (GHQ-12) was used for screening the normal subjects with any psychiatric problems. Thereafter, Bengali mental status examination (BMSE) was used to detect the progression of dementia among patient groups.

Autobiographical memory questionnaire and PGI General Well Being Scale were used for assessment of autobiographical memory and general wellness and scoring was done according to the standardized procedures.

The duration for screening of the patients for AM questionnaire was approximately 2 to 3 hours. The time limit for overall assessment lasted for approximately two to three hours.

Scoring of all the scales were done according to the manuals. The Information Schedule was coded and a profile of the sample was drawn from it. Then the statistical treatment of the scores was attempted. The table below depicts the final sample of Study.

59

Table 3.1 showing the number of participants in the study.

	AD	VaD	PDD	Normals	Total
N	30	30	20	100	180

3.10 STATISTICAL ANALYSIS:

The statistical tools were selected in accordance with the objectives of the study. Two types of statistical technique were used:

Descriptive statistics: Means and Standard deviations of all the variables were calculated for the total sample.

Inferential statistics: Analysis of Variance (ANOVA) was conducted to determine the effect of Autobiographical Memory and wellness among four groups and effect of gender on Autobiographical Memory and wellness. Sheffe's post hoc test, t test and Correlation were tested for both main effects as well as for correlation effects.

The results of the analyses are delineated in detail in the next chapter.