

Effect of Educational Intervention on Caregiver Burden & Quality of Life in Dementia in an Egyptian Sample

Thesis

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List of Abbreviations

AChEIs: Acetyl cholinesterase inhibitors

AD: Alzheimer disease

ADI: Alzheimer Disease International

ADL: Activities of Daily Living

ADRQL: Alzheimer's Disease Related Quality of Life Instrument

BANSS: Bedford Alzheimer Nursing Severity Scale

Ben enlarg: Benign enlargement

BI: Burden Interview

BPSD: Behavioural & Psychological Symptoms in Dementia

CAMCOG: Cognitive Scale of the Cambridge Examination for Mental Disorders of the Elderly

CDR: Clinical Dementia Rating

CERAD/ BRSD: Consortium to Establish a Registry for Alzheimer Disease- Behavioral Rating Scale

CG: Control group

CSDD: Cornell Scale for Depression in Dementia

CST: Cognitive Stimulation Therapy

Dec: decreased

Diag: diagnosis

DISAD: Disability Assessment for Dementia

e.g.: example

Employ: employment

GHQ: General Health Questionnaire

GMS: Geriatric Mental State

HR QOL: Health Related Quality of Life

IADL: Instrumental Activities of Daily Living

Int: Intervention

MCI: Mild cognitive impairment

MI: Medical illness

MMSE: Mini Mental State Examination

MTS: Mental Test Score

MWU: Mann Whitney U Test

NPI: Neuro Psychiatric Inventory

OT: Occupational therapy

PWD: Person with dementia

QOL: Quality of Life

QOL AD: Quality of life in Alzheimer disease

rho: Spearman correlation coefficient

RMBC: Revised Memory and Behaviour Checklist

RO: Realty Orientation

RT: Reminiscence Therapy

SD: Standard deviation

SG: Study group

St: status

TAP: Tailored Activity Program

TIA: Transient ischemic attack

VT: Validation Therapy

WSR: Wilcoxon Signed Ranks Test

x²: Chi square Tests

Introduction

The increase in the number of people suffering from dementia is of increasing global concern (*Nomura et al., 2007*).

Since population aging has become a worldwide phenomenon, the burden of the age-related neurodegenerative diseases is expected to increase dramatically in both developed and developing nations (*Fratiglioni and Qiu, 2008*).

Dementia is a collective name for progressive degenerative brain syndromes which affect memory, thinking, behavior and emotion. Alzheimer disease is the most common cause of dementia. Eventually those affected are unable to care for themselves and need help with all aspects of daily life (*Alzheimer's Disease International, 2008*).

Alzheimer disease, and other dementias incur huge costs to society, to the families of those affected, and to the individuals themselves. Costs to society include both direct costs to health and social services and indirect economic costs in term of lost productivity, as carers are taken out of the workplace, and the economic costs to those families caring for or funding the care of their relative. Increasingly as treatments become available, these costs are targets for change, and are part of the cost-benefit analysis of new compounds, especially the largest single direct cost, that of the provision of nursing and other forms of continuing care. Apart from the financial costs to families there is the emotional impact resulting in distress and psychiatric morbidity (*Lovestone, 2003*).

It has been recently estimated that 24.2 million people live with dementia worldwide, with 4.6 million new cases annually. Most people with dementia live in low and middle income countries, 60 percent in 2001 rising to 71 percent by 2040. Numbers will double every twenty years to over 80 millions by 2040. Increases to 2040 will be much sharper in developing countries (300 percent) than developed regions (100 percent) (*World Population Prospects, 2002*).

An estimated one in ten persons over age 65 and nearly half of those 85 or older have Alzheimer disease. One to four family members act as caregivers for each individual with the disease. The national tab for caring for individuals with Alzheimer disease is estimated at 100 billion dollars in the United States (*Alzheimer's Foundation of America, 2008*).

Dementia impacts the patient's entire family and network. At the centre of this family are at least one caregiver and the patient. Caregivers are defined as those looking after someone with dementia. The standard of care for the patient with dementia must include care for the caregiver of that patient (*Alzheimer Society of Canada, 2008*).

Interventional studies, with the aim of reducing the burden of care through drug or non-drug therapies, have been scarce (*Ikeda, 2005*).

Care for the patients with severe dementia requires a global therapeutic strategy integrating pharmacological approach into the environmental dimensions, psychotherapeutics and rehabilitation. The objective is to maintain autonomy as long as possible, and to improve the quality of life by reducing the psychological suffering of patients and families. Education and support for caregivers are essential to develop better attitudes towards the patient, improve communication and optimize the quality of life (*Pancrazi and Metais, 2005*).

There is an urgent need, in the absence of any formal services, to develop interventions designed to improve the lot of people with dementia, and their families. Lack of awareness of dementia as a health condition, coupled with unresponsive local health services are two of the biggest problems facing those with dementia in the developing world (*Alzheimer's Disease International, 2008*).

The most basic rationale for early detection and intervention arises from the escalation of the patient's severity of symptoms. Increased severity of illness is potentially associated with greater suffering and greater risk of violence, derailment from psychosocial trajectories, and socially alienating, self stigmatizing behaviours.

Early intervention can potentially be delivered before such suffering and risks have occurred, thus providing a type of tertiary prevention. This potential is generally recognized in the psychiatric clinical and research communities, and, as a result, early detection and intervention programs are being organized with increasing frequency. Additionally, possible benefits of early detection and intervention are more hypothetical and have become the subjects of active current empirical investigation (*McGlashan & Woods, 2005*).

Justification of the Research

Intervention by education is a recent practice with positive results, needed to be tried in our culture. It has a special importance because of its central role on caregiver burden and quality of life of the person with dementia; in the absence of curative treatment for the illness.

The Premises

1. There is already a rising titer of aging population and care givers, with dementia in Egypt; who need more services and care.
2. Studies are scarce about caregiver burden and well being, educational intervention, quality of life, and behavioral and psychosocial factors influencing them; in dementia in Egypt.
3. No previous systematic studies have been done in Egypt to study the effect of educational intervention on quality of life and caregiver burden and well being in those patients.
4. Education as an intervention proved to diminish burden and improve QOL in other contexts in developing world.

Aim of the Work

The aim of this work is to study the effect of educational intervention directed towards caregivers on caregiver burden and well being, and quality of life of patients; and the factors affecting caregiver burden, well being and quality of life of patients of dementia in Egypt.

Hypotheses of the Work

1- Educational intervention directed to caregivers of demented patients has a positive influence on:

- Caregiver burden and well being.
- Quality of life of patients with dementia in Egypt.

2- There is a relationship between the following factors and caregiver burden and well being, and QOL of the person with dementia;

- Patients' symptomatology.
- Severity of dementia.
- Degree of cognitive impairment.
- Behavioral symptoms in demented patients.
- Functional disabilities in activities of daily living.

Subjects and Method

Subjects

I- Sample

The study included 100 patients with dementia, and their principle caregiver, selected from Institute of Psychiatry, Ain Shams University Hospitals, outpatient clinics and El-Abbaseya Hospital for Mental Health. Selection was done according to the following rules;

A- Inclusion criteria:

1. *Diagnosis:* dementia, diagnosed according to DSMIV- TR diagnostic criteria.
2. *Gender:* both males and females.
3. *Nationality:* Egyptian.

B- Exclusion criteria:

1. Patients with aphasia.
2. Patients with impaired conscious level, secondary to physical illness or side effect of medication.
3. Patients with organic brain syndrome other than dementia.

II- Selection of cases and site of the study

Cases were selected from; the Institute of Psychiatry, Ain Shams University Hospital, and El-Abbaseya Hospital for Mental Health outpatient clinics. Our random sample included all PWD and their caregivers who agreed to participate in the study. Selection, follow-up, and the study proper were done from November 2006 to February 2008.

A- The Institute of Psychiatry

It is located in Eastern Cairo, and serves both urban and rural areas, including areas around Greater Cairo as well. The Institute of Psychiatry, is subdivided into paid and non-paid sections. There are 58 paid beds and 26 non-paid beds, distributed in 4 inpatients units. The Institute of Psychiatry, has 3 outpatient clinics daily for 4 days per week, i.e. on Sunday there are 3 outpatient clinics working; Clinic 1,2, and 3. The same applies to Mondays, Wednesdays, and Thursdays. On the average 25-35 patients attend each of those 3 clinics daily. The Institute of Psychiatry, also has a specialist Geriatric and Memory Clinic, working on weekly basis, serving elder population.

B- El- Abbasseya Hospital for Mental Health

It was established in 1883. It is the major psychiatric facility in the country, with a total bed capacity of nearly 3600 beds, can be increased at pressure time to 4000 beds, currently holding near of 1700 bed capacity. The inpatient wards are *distributed as follows*:

- ❑ Admission wards
- ❑ Long term care wards
- ❑ Forensic wards
- ❑ Military wards

The hospital, also contains 2 full-cost paid buildings, of 200 beds capacity for males and females. The hospital, has a Geriatric inpatient ward for females, with a capacity of 60 beds. The hospital, also provides an outpatient services in the form of *outpatient clinics as follows*:

- ❑ One morning clinic daily from Saturday to Thursday (average patient flow: 120-150 patients / day).
- ❑ One afternoon clinic daily from Saturday to Thursday from 1 to 3 o'clock (average patient flow: 50-70 patient / day).

El-Abbasseyya Hospital outpatient clinic, also has an Old age Psychiatry outpatient clinic on 2-days weekly basis, Monday and Wednesday, providing care for elderly population, with average patient flow of 20 patients / day.

Method

A- Preparation of the tools:

Both the pilot study and the study proper were preceded by preparation of the tools, which were used in the study. This included translation, and assessing the reliability and validity of the translation of the 10/66 intervention modules, and of the scales which were not translated before in previous studies including; *Burden Interview*, *Mental Test Score*, *Revised Memory and Behavior Problems Checklist*, *Disability Assessment For Dementia*, *General Health Questionnaire*, *Clinical Dementia Rating*. This stage took two months, May and June 2006.

B- Pilot study:

The study proper was preceded by a pilot study for four months, from July to October 2006; and included 10 patients diagnosed with dementia, in the Institute of Psychiatry and El-Abbaseya Hospital for Mental Health.

Objectives of the pilot study:

1. To assess the reliability of the clinical diagnosis.
2. To assess the applicability of the used questionnaires.
3. To assess the reliability and validity of the used translated questionnaires against the *Geriatric Mental State Schedule*.

All patients and their caregivers who participated in the pilot study gave an informed consent, before being allowed to complete the scales used.

The pilot study revealed the following:

1. Each question has to be read to the subjects and explained to them by the researcher.
2. The researcher has to make sure that the subject answers in relation to the time period assigned to the scale.
3. According to the pilot study some scales were inapplicable; either due to cultural difference, or unavailability to occur in our sample, or to problems with translation which needs further study. These scales were omitted from the study. These included; *the Ten Word List learning Task (Ganguli et al., 1996)*, *Environmental Assessment*, and *Social Assessment (Kane, et al., 1994)*.
4. Dementia cases were diagnosed by specialists and referred to the examiner.

C- The study proper:

1- Informed consent:

It was taken from patients, caregivers and controls; after discussing with them the details of the study.

2- Comprehensive assessment:

- *History:* personal, present history, past psychiatric and medical history, family history, social and demographic data.
- *Diagnosis* according to DSM IV- TR.
- Physical examination.
- Interviewing the principle caregiver.

3- Tools applied in the study:

1. Geriatric Mental State, Arabic Version (*Ashour et al., 2003*).
2. Quality of Life, Brief Arabic Version (*Ashour et al., 2003*).
3. Burden Interview, Arabic Version (*Ashour et al., 2006*)
4. Mental Test Score, Arabic Version (*Ashour et al., 2006*)
5. Revised Memory and Behavior Problems Checklist, Arabic Version (*Ashour et al., 2006*)
6. Disability Assessment For Dementia, Arabic Version (*Ashour et al., 2006*)
7. General Health Questionnaire, Arabic Version (*Ashour et al., 2006*)
8. Clinical Dementia Rating, Arabic Version (*Ashour et al., 2006*)

1- The Geriatric Mental State Schedule, Arabic Version (*Ashour et al., 2003*)

The need for a semi-structured and reliable method for assessing and recording mental state in the elderly has been confirmed by the continued use of this interview. Since 1976, when it was first reported (*Copeland et al., 1976, Gurland et al., 1976*), work on refining the interview has progressed to the third edition. The network of epidemiologists, psychiatrists and medical staff using the GMS interview is truly international, with centres being established in Africa, Asia, North and South America and Europe (*University of Liverpool- GMS Resource Centre, 2008*).

It measures a wide range of psychopathology in elderly people both in institutionalized settings and in community settings. A comprehensive fully structured clinical interview covering symptoms of depression, psychosis, anxiety, in addition to dementia. It takes 20-40 minutes to complete, and mimics a through consultation with an experienced specialist doctor. Scoring is: 0= No (or normal), 1= Yes (or abnormal) but mild to moderate intensity, infrequent or fleeting, 2= Yes (or abnormal) and severe, frequent or persistent, 8= No reply elicited, Or question not understood, Or reply inaudible, inappropriate, or incoherent, Or rating uncertain, 9= Question not asked Or inapplicable.

2- Quality Of Life, *Brief Arabic Version (Ashour et al., 2003)*

Developed at *Quality of Life Research Unit*- University of Toronto-Canada. Nine specific areas of life that are an important part of the lives of all people are looked at. They are *Being* (Physical, Psychological, and Spiritual), *Belonging* (Physical, Social, and Community) and *Becoming* (Practical, Leisure, and Growth). The *Brief Version* of the Seniors' Quality of Life Profile contains 27 items selected from the 111 items of the *Full Version*; 3 for each of the 9 areas of life. Each of the 27 items is scored according to its importance, and level of satisfaction with it.

To obtain QOL Score for each of the nine areas of life:

- Total the Basic Scores within each of the nine areas;
- Divide each total by its valid *n*, (i.e., the number of values entered for that area);
- Enter the Basic Score for each of the nine areas of life.

To obtain an overall *Being Score*: add together the Physical, Psychological, and Spiritual Being Score, then divide by three. Calculate overall *Belonging* and *Becoming* Scores in a similar way. To arrive at the *Overall Quality of Life Score*, add the *Being*, *Belonging*, and *Becoming* scores and divide by 3.

3- Burden Interview, *Arabic Version (Ashour et al., 2006)*

Its main indication is assessment of feelings of burden of caregivers in caring for an older person with dementia. It takes nearly 25 minutes to administer. It is one of the most widely used tests of caregiving burden. It is simple to use and score. If a person receives a high score on the test, he may be at risk for the physical complications of caregiver stress. It consists of 22 items to answer. Scoring is 0= Never, 1= Rarely, 2= Sometimes, 3= Quite frequently, 4= Nearly always (*Zarit et al., 1980*).

4- Mental Test Score, Arabic Version (Ashour et al.,2006)

A Mental Test Score (MTS), consisting of 26 questions testing memory and orientation was developed from the *Blessed Dementia Scale*, and was used in large inpatient study of mental impairments of the elderly, under the auspices of the *Royal College of Physicians*. A score of 25 and above (out of 34) was within the normal range. Analysis shows that the questions varied considerably in their discriminatory value. Deletion of the less effective questions results in an abbreviated test of ten questions with similar discriminatory power to the full test. Shorter tests of this kind are recommended for further practical evaluation in geriatric departments (*Hodkinson, 1972*).

The MTS rapidly assess elderly patients for the possibility of dementia. It is widely used in clinical and research settings in Britain for detecting and monitoring cognitive impairment, and is easily administered and well tolerated by raters and subjects (*Holmes, 1996*).

5- Revised Memory and Behaviour Problems Checklist, Arabic Version (Ashour et al.,2006)

It is used for assessment of behavioural problems in patients with dementia. Items were gathered from the original Memory and Problems Checklist (*Zarit and Zarit, 1983*), plus additional items.

It consists of problems the patients sometimes have. The rater should indicate if any of these problems have occurred during the past week. It consists of 24 items to answer. Scoring is 0= never occurred, 1= not in the past week, 2= 1 to 2 times in the past week, 3= 3 to 6 times in the past week, 4= daily or more often, 9= don't know/ not applicable (*Teri et al., 1992*).

6- Disability Assessment For Dementia, Arabic Version (Ashour et al.,2006)

The literature as well as consultations with health care professionals and caregivers clearly indicates the need for a disability measure designed specifically for community-dwelling individuals with AD. Such an instrument is essential to help clinicians and caregivers make decisions regarding the choice of suitable interventions and to monitor disease progression. In addition, as a research tool, it could be used to describe the functional characteristics of populations with AD, the course of the disease, and also as an outcome variable in intervention studies and clinical trials. The DAD Scale was developed in an attempt to fulfill these needs.

The objectives of the DAD Scale are to quantitatively measure functional abilities in activities of daily living (ADL) in individuals with cognitive impairment such as dementia and to help delineate areas of cognitive deficits which may impair performance in ADL. Basic and instrumental ADL are examined in relation to executive skills to permit identification of the problematic areas. The primary aim is to have a standardized, valid, reliable and sensitive measure of functional disability in AD and other dementias. Another objective is to obtain a French and English instrument which is short and easy to administer.

The DAD Scale is intended specifically for the assessment of disability in community residing individuals with cognitive deficits such as AD and other dementias. It consists of 10 main items to answer Scoring is : yes = 1, No= 0, N/A= Not Applicable (*Gelinas et al., 1999*).

7- General Health Questionnaire, Arabic Version (Ashour et al.,2006)

The General Health Questionnaire (GHQ) is a screening device for identifying minor psychiatric disorder. It can be used for all ages from adolescent upwards. It can be used with general population, or with patients in any sort of non-psychiatric clinical, or primary care settings. It is used by researchers and clinicians. There are many versions which vary in number of

items. The GHQ-12, is a quick, reliable and sensitive short form, ideal for research studies, and is used in this study .

Scoring is done by *Likert Scale*: 0,1,2,3 from left to right. 12 items, 0 to 3 each item. Score range from 0 to 36. Scores vary by study population. Scores about 11-12 typical. Scores more than 15 is an evidence of distress. Scores more than 20 suggests severe problems and psychological distress (*Goldberg & Hillier, 1979*).

8- Clinical Dementia Rating, Arabic Version (Ashour et al.,2006)

The Clinical Dementia Rating (CDR), a global rating device, was developed for a prospective study of mild senile dementia - Alzheimer type. The CDR was found to distinguish unambiguously among older subjects with a wide range of cognitive functions, from healthy to severely impaired. It consists of 6 items. Scoring is: 0= None, 0.5= Questionable, 1= mild, 2= Moderate, 3= Severe. The total CDR rating is made from the sum of boxes which represents an aggregate score of each individual's area (*Huges et al., 1982*).

The CDR was developed to clinically denote the presence of dementia of Alzheimer type, and stage its severity. The clinical protocol incorporates semi-structured interviews with the patient and informant to obtain information necessary to rate the subjects' cognitive performance in six domains: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. The CDR has been standardized for multi-center use, and inter-rater reliability has been established. Criterion validity for both the global CDR and scores on individual domains has been demonstrated, and the CDR has also been validated neuro-pathologically, particularly for the presence or absence of dementia (*Morris, 1997*).

The 10/66 Intervention- Arabic Version (Ashour et al.,2006)

This consists of three simple, manualized modules, delivered over five half hour sessions at weekly intervals.

1- Assessment One session

- Dementia assessment
 - a. Confirm diagnosis
 - b. Cognitive and functional impairment
 - c. Behavioural symptoms
- Caregiver's knowledge and understanding of dementia.
- Caregiving arrangements
 - a. Who are the family members?
 - b. Who lives at home with the person with dementia?
 - c. In what ways do they help out the principle caregiver?
 - d. What behavioural problems are the family caregivers having to cope with?
 - e. How burdened do they feel by caring for the person with dementia?

2- Basic education Two sessions

- Dementia: A general introduction to the illness.
- Dementia: What can I expect.
- What causes dementia.
- Care and treatment for people with dementia.

3- *Specific training regarding problem behaviours* Two sessions

Problem behaviours identified in the initial assessment sessions are dealt with individually, as necessary.

- Personal hygiene
- Dressing
- Toileting and incontinence
- Repeated questioning
- Clinging
- Aggression
- Wandering
- Loss of interest and activity

(Alzheimer Disease International, 2006)

Procedures

- Initial assessment, using available tools, for all 100 patients and caregivers.
- Intervention modules were applied for 50 patients, according to *Alzheimer's Disease International (2006)*; and 50 patients were left as controls (with random allocation).
- Control patients had sessions without the specific intervention (follow up and usual psychiatric management).
- Evaluation of outcome was done after three months.

Ethical Consideration and Budget

Our research was done with consideration to the guidelines of the *American Psychiatric Association (2001)* Code of Ethics. The investigator was responsible for the budget of the study. No *conflict of interest* has been found.

Time Table for Research

- *Preparation of the tools*: May and June 2006.
- *Pilot study*: From July to October 2006.
- *Selection of the cases*: Selection, follow-up, and the study proper were done from November 2006 to February 2008.
- *Statistics, final writing, and revision*: From March 2008 to December 2008.

Statistical Analysis

The statistical analysis was done using an IBM compatible computer and the *Statistical Package for the Social Science (SPSS 10)*. Statistical analysis was done according to *Ingelfinger et al. (1994)* and *Knapp and Miller (1992)*.

Statistical tests

Descriptive statistics was presented as means \pm standard deviations, and number and percentage (frequency distributions). Analytical tests used included *Chi square test*, and *Cross tabs* for contingency table analysis, *Mann-Whitney U test* for two- independent samples, *Wilcoxon signed rank test* in two- related samples. Correlation analysis was also performed whenever appropriate using *Spearman correlation coefficient*, in Bivariate Correlation procedure.

Significance Level

Significance levels of 0.05 and 0.01 were used throughout all statistical tests within this study.

Tabulation and Graphical Presentation

Tabulation and graphical presentation was also done according to *Knapp and Miller (1992)*.

Working Definitions

Dementia is a type of chronic encephalopathy that can have many causes, including irreversible degenerative and potentially reversible non degenerative causes (*Caselli and Boeve, 1999*).

It is an acquired global impairment of intellect, memory and personality, but without impairment of consciousness (*Gelder et al., 2006*).

The term dementia describes a clinical syndrome of at least 6 months of chronic and progressive impairments in two or more domains of cognitive function such as memory and language in the absence of delirium or a psychiatric or medical illness that can cause cognitive dysfunction. In addition, the impairments must interfere with usual and everyday activities (*Cotter et al., 2004*).

It is also defined as a progressive impairment of cognitive functions occurring in clear consciousness. Dementia consists of a variety of symptoms that suggest chronic and widespread dysfunction. Global impairment of intellect is the essential feature, manifested as difficulty with memory, attention, thinking, and comprehension. Other mental functions can often be affected, including mood, personality, judgment, and social behaviour. Although specific diagnostic criteria are found for various dementias, such as Alzheimer disease or vascular dementia, all dementias have certain common elements that result in significant impairment in social or occupational functioning and cause a significant decline from a previous level of functioning (*Neugroschl et al., 2005*).

Alzheimer disease (AD) is the disease process that ultimately results in Alzheimer dementia. Early in the patient's course, Alzheimer disease may cause memory loss of insufficient severity to warrant the designation of dementia (*Caselli and Boeve, 1999*).

Dementia of the Alzheimer type is a progressive, neurodegenerative condition characterized by deterioration in cognition and memory, progressive impairment in the ability to carry out activities of daily living, and a number of neuropsychiatric symptoms (*Jalbert et al., 2008*).

Other patients with AD may follow an atypical course with progressive aphasia or progressive apraxia rather than a typical Alzheimer dementia. Most of the time, however, AD causes Alzheimer dementia (*Caselli and Boeve, 1999*).

AD is one disease among many, both degenerative and non degenerative, that can produce the categorical syndrome of a chronic progressive encephalopathy. *Reversible forms* of dementia are truly chronic encephalopathies and often produce one or several of the following:

- Hypersomnolence
- Acute or subacute deterioration
- Fluctuating severity
- Severe electroencephalographic abnormalities
- Visual hallucinations
- Tremulousness
- Unsteadiness

Or it may be accompanied by non neurological symptoms, within the context of another disease process, such as hypothyroidism, or immunosuppression.

Irreversible forms of dementia are generally:

- More slowly progressive (more than a year or two).
- Fluctuate much less.
- Do not occur within the context of another potentially causative disease.
- Have recognizable clinical and cognitive profiles.
- Not accompanied by many of the clues of a reversible chronic encephalopathy.

In mild to moderate stages, clinical cognitive patterns can be very helpful in distinguishing various dementing illnesses. In late stages, however, patients are more diffusely impaired both cognitively and somatically, making it difficult to differentiate one degenerative brain disease from another (*Katzman, 1992*).

Epidemiology

With the aging population, the prevalence of dementia is rising. The prevalence of moderate to severe dementia in different population groups is approximately 5 percent in the general population older than 65 years of age, 20 to 40 percent in the general population older than 85 years of age, 15 to 20 percent in outpatient general medical practices, and 50 percent in chronic care facilities (*Wancata et al., 2003*).

AD is the most common cause of dementia overall, accounting for more than half of all cases, and it increases in frequency with advancing age. Epidemiological age-specific estimates of incidence and prevalence vary by region and study due to differences in diagnostic criteria and population demographics (*Farrer and Cupples, 1994*).

There is an exponential increase in AD with advancing age at least through the ninth decade. The prevalence of severe dementia over the age of 60 is estimated at 5 percent, and over the age of 85, between 20 and 50 percent. The lifetime risk of developing AD is estimated to be between 12 and 17 percent (*Kokmen et al., 1996*).

Following age, apolipoprotein E (Apo E) status is second most important risk factor. In both familial late onset and sporadic cases, the Apo E ϵ -4 allele increases risk and the ϵ -2 allele decreases risk (*Saunders et al., 1993*), (*Corder et al., 1994*).

The life time risk of AD in people without a family history increases from 9 percent without an Apo E ϵ -4 allele to 29 percent with one copy of the Apo E ϵ -4 allele (*Seshadri et al., 1995*).

In limited populations, other genetic factors play a determining role including; Down syndrome (trisomy 21) (*Wisniewski et al., 1985*), familial early-onset Alzheimer Kindreds (chromosome 14) (*Sherrington et al., 1995*), and the Volga German Kindreds of familial early onset AD (chromosome 1) (*Levy- Lahad et al., 1995*).

Tab (1)

Tab (2)

Tab (3)

Results

I- Socio-Demographic Characteristics of the Sample

The study population included a hundred patients with dementia and their principle caregiver. Fifty patients were left as controls, and intervention modules were applied to fifty patients.

Tables (9-15) show comparison of the socio- demographic data of the study group and control group.

1- Sex groups:

The study included 53 males (53%) and 47 females (47%). (Table: 9)

Tab (9)

Fig (1)

2- Age groups:

The age of the studied sample ranged from 60 to more than 80 years of age; with a mean of 70.46, SD= 5.88. The peak incidence for males was from 70-74 years. The peak incidence for females was from 75-79 years. Table (10)

Tab (10)

Fig (2)

3- Work groups:

58 studied persons were retired (58%), and 42 housewives (42%). (Table: 11)

Tab (11)

Fig (3)

4- Marital status groups:

48 studied persons were married (48%), 48 widow/widower (48%), 3 single (3%), and 1 divorced (1%). (Table: 12)

Tab (12)

Fig (4)

5- Education groups:

62 persons were literate, and 38 were illiterate. (Table: 13)

Tab (13)

Fig (5)

6- Caregiver status groups

47 (47 %) of the PWD were cared for by son and family, 40 (40%) by the daughter, and 13 (13%) by wife, sister, and nephews. (Table: 14)

Tab (14)

Fig (6)

7- Caregiver marital status groups

80 of the caregivers, were married (80%), 1 (1%) widow, 19 (19%) single. (Table: 15)

Tab (15)

Fig (7)

II- Medical Data

1-Medical illness groups:

Peak incidence for medical illness was for osteoarthritis 19 (19%), renal dis 8 (8%), diabetes and hypertension 8 (8%), diabetes 7 (7%), hypertension 6 (6%), stroke/ TIA 6 (6%), and coronary heart disease, and other cardiac dis 6 (6%). (Table: 16)

Tab (16)

2- Medical illness dichotomized groups

76 had medical illness (76%), and 24 had not (24%). (Table: 17)

Tab (17)

Fig (8)

3- Primary diagnosis groups

a- Primary diagnosis

Dementia of the Alzheimer's type was found in 92 (92%) persons, vascular dementia 5 (5%), and dementia due to multiple etiologies 3 (3%). 61 (61%) was of mild severity, and 39 (39%) was of moderate severity. (Tables: 18 and 19)

Tab (18)

Fig (9)

b- Severity

Tab (19)

Fig (10)

4- Secondary diagnosis groups

a- Secondary diagnosis

59 (59%) of the studied persons had major depressive disorder, 10 (10%) had insomnia related to dementia , 4 (4%) had generalized anxiety disorder, and 3 (3%) had hypochondriasis as a secondary diagnosis. 75 (75%) was of mild severity, and 1 (1%) was of moderate severity. (Tables: 20-23)

Tab (20)

Fig (11)

b- Caseness

Tab (21)

c- Certainty

Tab (22)

d- Severity

Tab (23)

Fig (12)

Fig (13)

III- Correlation of Caregiver Burden with Study Variables

1- GMS Diagnosis

There was a positive correlation between the *severity* of the primary diagnosis (dementia) and burden; which was statistically significant ($P < 0.01$). (Table: 24)

Tab (24)

2- Psychiatric Diagnosis according to GMS

No statistically significant difference was found between psychiatric disorders and burden. (Table: 25)

Tab (25)

3- Medical Illness

No statistically significant difference was found between medical illness and burden. (Table: 26)

Tab (26)

IV- Correlation of Quality of Life with Study Variables

1- GMS Diagnosis

There was a negative correlation between *primary diagnosis* of dementia and its *severity* and QOL; which was statistically significant ($P < 0.01$). (Table: 27)

Tab (27)

2- Psychiatric Diagnosis according to GMS

No statistically significant difference was found between psychiatric diagnosis and QOL. (Table: 28)

Tab (28)

3- Medical Illness

No statistically significant difference was found between medical illness and QOL. (Table: 29)

Tab (29)

V- Comparison of Study Scores Before and After Intervention

A statistically significant difference ($P < 0.001$) was found between each of the study group and control group mean scores in comparison separately on all study scores, before intervention and after three months; in favor of study group mean scores. (Tables: 30-40)

1- Mental test score before intervention and after 3 months

Mean MTS scores of SG were 16.3 before intervention compared to 14.54 after 3 months. Scores for CG were 14.88 before intervention compared to 13.18 after 3 months. Significant deterioration was noticed in both groups. (Table: 30)

Tab (30)

2- Revised Memory and Behaviour Check List before intervention and after 3 months

Mean RMBC scores of SG were 51.68 before intervention, compared to 45.9 after 3 months. Scores for CG were 57.6 before intervention compared to 60.8 after 3 months. Results were statistically significant in favor of SG. (Table: 31)

Tab (31)

3- Burden Interview before and after 3 months

Mean BI scores of SG were 46.7 before intervention compared to 41.2 after 3 months. Scores for CG were 51.52 before intervention, compared to 55.1 after 3 months. Results were statistically significant in favor of SG. (Table: 32)

Tab (32)

4- General Health Questionnaire before and after 3 months

Mean GHQ scores of SG were 19.72 before intervention compared to 16.24 after 3 months. Scores for CG were 20 before intervention compared to 22.12 after 3 months. Results were statistically significant in favor of SG. (Table: 33)

Tab (33)

5- Clinical Dementia Rating before and after 3 months

Mean CDR scores of SG were 6.96 before intervention compared to 8.32 after 3 months. Mean scores for CG were 7.34 before intervention compared to 8.86 after 3 months. There was a significant deterioration in both groups. (Table: 34)

Tab (34)

6- Disability assessment for Dementia before and after 3 months

Mean DISAD scores of SG were 18.06 before intervention compared to 27.66 after 3 months. Mean CG scores were 15.3 before intervention compared to 9.24 after 3 months. Results were statistically significant in favor of SG. (Table: 35)

Tab (35)

7- Disability assessment for Dementia sub-domains before intervention and after 3 months, Study Group

Peak incidence for means of DISAD sub-domains scores of SG before intervention was 3.2 for hygiene, 2.2 for dressing, telephoning, going on an outing, finance and correspondence and leisure and housework. Peak incidence after 3 months was 4.2 for hygiene, 3.2 for dressing, telephoning, going on an outing, finance and correspondence, and leisure and housework. Difference was statistically significant. (Table: 36)

Tab (36)

8- Disability assessment for Dementia sub-domains before intervention and after 3 months, Control Group

Peak incidence for means of DISAD sub-domains scores of CG before intervention was 2.92 for hygiene, 1.9 for dressing, telephoning, going on an outing, finance and correspondence. Peak incidence after 3 months was 1.92 for hygiene, 1.06 for leisure and housework, and 1.04 for dressing, going on an outing, and finance and correspondence. Results showed significant deterioration. (Table: 37)

Tab (37)

9- Quality of Life before and after 3 months

Mean QOL scores of SG were 4.16 before intervention, compared to 4.85 after 3 months. Mean scores for CG were 3.73 before intervention compared to 3.29 after 3 months. There was modest improvement in favor of SG, which was statistically significant. (Table: 38)

Tab (38)

10- Quality of life sub-domains before intervention and after 3 months, Study Group

Mean QOL sub-domains scores of SG before intervention were 4.5 for being, 4.31 for belonging, and 3.67 for becoming. Mean scores after 3 months were 5.13 for being, 4.99 for belonging, and 4.36 for becoming. There was modest improvement, which was statistically significant. (Table: 39)

Tab (39)

11- Quality of life sub-domains before intervention and after 3 months, Control Group

Mean QOL sub-domains scores of CG before intervention were 4.1 for being, 3.81 for belonging, and 3.26 for becoming. Mean scores after 3 months were 3.62 for being, 3.35 for belonging, and 2.9 for becoming. There was modest deterioration, which was statistically significant. (Table: 40)

Tab (40)

VI- Correlation of Total Study Scores

There was a *positive correlation* between *Burden interview* and Revised Memory & Behaviour Checklist, General Health Questionnaire, and Clinical Dementia Rating. A *negative correlation* with; Mental Test Score, Disability Assessment for Dementia and Quality of Life, which was statistically significant ($P < 0.001$). (Table: 41)

There was a *positive correlation* between *Quality of Life* and Mental Test Score, and Disability Assessment for Dementia. A *negative correlation* with Revised Memory & Behaviour Checklist, Burden interview, General Health Questionnaire, and Clinical Dementia Rating, which was statistically significant ($P < 0.001$). (Table: 42)

No statistically significant difference was found between diabetes, hypertension, osteoarthritis, or Coronary Heart Disease with *MTS*. (Table: 43)

1- Burden interview

Burden Interview was *positively correlated* with RMBC, GHQ, CDR; and *negatively correlated* with MTS, DISAD, and QOL. Results were statistically significant. (Table: 41)

Tab (41)

2- Quality of Life

Quality of Life was *positively correlated* with MTS, DISAD; and *negatively correlated* with RMBC, BI, GHQ, and CDR. Results were statistically significant. (Table: 42)

Tab (42)

3- Medical illness

No statistically significant difference was found between diabetes, hypertension, osteoarthritis, or Coronary heart disease with *MTS*. (Table: 43)

Tab (43)

To sum up the previous essay;

1- Social and educational intervention may have an effect in ameliorating caregiver burden, improving QOL of the person with dementia.

2- A *positive correlation* was found between *Burden Interview* and Revised Memory & Behaviour Checklist, General Health Questionnaire, and Clinical Dementia Rating; and a *negative correlation* with; Mental Test Score, Disability Assessment for Dementia and Quality of Life.

3- A *positive correlation* was found between *Quality of Life* and Mental Test Score, Disability Assessment for Dementia; and a *negative correlation* with Revised Memory & Behaviour Checklist , Burden Interview, General Health Questionnaire, and Clinical Dementia Rating.

Discussion

Discussion will go through the following items:

- 1- Testing the study hypotheses.
- 2- Speculations about some special findings in the study.
- 3- Generalizability of the results.
- 4- Co-validation of the results in relation to other studies.
- 5- Summing up about the importance of the collected data.

Each issue will be tackled in a comprehensive module.

Results of Hypotheses Testing

Our results showed that educational intervention have an effect in alleviating caregiver burden, and improving quality of life; of persons with dementia of different aetiologies, within the mild to moderate severity category, of populations with characteristics similar to ours.

Correlation of Caregiver Burden with Study Variables

GMS diagnosis

There was a positive correlation between the *severity* of the primary diagnosis (dementia) and burden; which was statistically significant ($P < 0.01$). (Table: 24)

Psychiatric diagnosis according to GMS

No statistically significant difference was found between psychiatric disorders and burden. (Table: 25)

Medical illness

No statistically significant difference was found between medical illness and burden. (Table: 26)

Correlation of Quality of Life with Study Variables

GMS diagnosis

There was a negative correlation between *primary diagnosis* of dementia and its *severity* and QOL; which was statistically significant ($P < 0.01$). (Table: 27)

Psychiatric diagnosis according to GMS

No statistically significant difference was found between psychiatric diagnosis and QOL. (Table: 28)

Medical Illness

No statistically significant difference was found between medical illness and QOL. (Table: 29)

Comparison of study scores before & after intervention

A statistically significant difference ($P < 0.001$) was found between each of the study group and control group mean scores, in comparison separately on all study scores, before intervention and after three months; in favor of study group mean scores. (Tables: 30-40)

Correlation of Total Study Scores

There was a *positive correlation* between *Burden interview* and Revised Memory & Behaviour Checklist, General Health Questionnaire, and Clinical Dementia Rating. A *negative correlation* with; Mental Test Score, Disability Assessment for Dementia and Quality of Life, which was statistically significant ($P < 0.001$). (Table: 41)

There was a *positive correlation* between *Quality of Life* and Mental Test Score, and Disability Assessment for Dementia. A *negative correlation* with Revised Memory & Behaviour Checklist, Burden interview, General Health Questionnaire, and Clinical Dementia Rating, which was statistically significant ($P < 0.001$). (Table: 42)

No statistically significant difference was found between diabetes, hypertension, osteoarthritis, or Coronary Heart Disease with *MTS*. (Table: 43)

Abido et al. (2006), found significant relationship between GMS diagnosis of dementia, depression, and schizophrenia; with QOL.

Hewedi et al. (2003), found significant relationship between ICD 10 symptom checklist diagnosis of psychotic features and QOL; but not for sleep disorders, and behavioural changes.

Abido et al. (2006), found no significant difference between medical illness and QOL.

Missotten et al. (2008), in a study in Belgium found that gender, age and place of residence had no significant influence on ADRQL scores. In contrast, ADRQL scores correlated significantly with MMSE, CAMCOG, IADL, ADL, CERAD/BRSD, and CDR-M.

Generalizability of the Results

Our results can apply to populations of socio-demographic profile, number of the sample, and methodology similar to ours.

Socio-Demographic Variables

Our study included 100 persons with dementia; 53 *males* (53 %), and 47 *females* (47 %).

Female gender is implicated as a risk factor for Alzheimer (*Neugroschl et al., 2005*).

The *age* of the studied sample ranged from 60 to more than 80 years of age; with a mean of 70.46 and SD= 5.88. The peak incidence for *males* was from 70-74 years. The peak incidence for *females* was from 75- 79 years.

Increasing age is the greatest risk factor for developing Alzheimer (*Neugroschl et al., 2005*).

In the *Canadian Study of Health and Aging (1994)*, a larger a large representative sample of adults 65 years of age or older residing in the community and in institutions , the prevalence of dementia was estimated to be 8 percent.

Although there do not appear to be gender differences in the incidence of dementia, women tend to have a higher incidence of Alzheimer disease in old age, whereas men tend to have a higher incidence of vascular dementia at younger ages (*Hybels & Blazer, 2003*).

58 (58%) were *retired* and 42 (42%) were *housewives*. 48(48%) were *married*, 48 (48%) were *widow/widower*, 3 (3%) were *single*, and 1 (1%) was *divorced*. 62 (62%) were *literate*, and 38 (38%) were *illiterate*.

Epidemiological studies have suggested that people with less education are at increased risk of developing Alzheimer (*Neugroschl et al., 2005*).

Peak incidence for *medical illness* was for osteoarthritis 19 (19%), renal dis 8 (8%), diabetes and hypertension 8 (8%), diabetes 7 (7%), hypertension 6 (6%), stroke/ TIA 6 (6%), and coronary heart disease, and other cardiac dis 6 (6%).

Correlation between *diabetes, hypertension, osteoarthritis, and coronary heart disease* with MTS did not reach statistically significant level. (Table: 42)

Recent research suggests that diabetes mellitus and hypertension are *modest* risk factors for Alzheimer disease and vascular dementia (**Takeda, 2008**), (**Luchsinger et al., 2001, 2007**), (**Hassing et al., 2002**).

47 (47 %) of the study population were cared for by *son and family*, 40 (40%) by the *daughter*, and 13 (13%) by *wife, sister and nephews*. 80 of the caregivers, were married (80%), 1 (1%) widow, 19 (19%) single.

Dementia of the *Alzheimer's* type was found in 92 (92%) persons, *vascular dementia* 5 (5%), and dementia due to *multiple etiologies* 3 (3%). 61 (61%) was of mild severity, and 39 (39%) was of moderate severity according to CDR.

In the *Canadian Study of Health and Aging (1994)*, the prevalence of Alzheimer disease was 5.1 percent, whereas the prevalence of vascular dementia 1.5 percent.

59 (59%) of the studied persons had *major depressive disorder*, 10 (10%) had *insomnia related to dementia*, 4 (4%) had *generalized anxiety disorder*, and 3 (3%) had *hypochondriasis* as a secondary diagnosis. 75 (75%) was of mild severity, and 1 (1%) was of moderate severity according to DSMIV-TR.

Studies have demonstrated depression as a risk factor for Alzheimer (**Small, 2005**). Depression is a risk factor for the disease, may be confused with it, or occur as part of the syndrome. Major depression occurs in about 10 percent of cases, with less marked episodes and symptoms occurring in over 50 percent (**Jacoby and Oppenheimer, 2002**).

Our Findings Co-validate with Recent Studies in Intervention;

Kazui et al. (2008), found that the quality of life of demented people was better at institutions with staff members having more professional knowledge, indicating the importance of education of staff members and the possibility that such education improves the quality of life of the demented people.

Gitlin et al. (2008), found that tailoring activities to the capabilities of dementia patients and training families in activity use resulted in clinically relevant benefits for patients and caregivers. Treatment minimized trigger behaviors for nursing home placement and reduced objective caregiver burden. Noteworthy is that depressed caregivers effectively engaged in and benefited from the intervention.

Kuroda et al. (2007), found that the care managers' support to caregivers who provide continuing home care is important for caregivers' HRQOL.

Graff et al. (2006), found that ten sessions of community occupational therapy over five weeks improved the daily functioning of patients with dementia, despite their limited learning abilities, and reduced the burden on their informal caregivers. The effect sizes of all primary outcomes were higher than those found in trials of drugs or other psychosocial intervention, and these effects were still present at three months.

(Gitlin et al., 2005), found that an in-home skills training program helps sustain caregiver affect for those enrolled for more than 1 year. More frequent professional contact and ongoing skills training may be necessary to maintain other clinically important outcomes such as reduced upset with behaviors.

Livingston et al. (2005), in a systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia, found that behavioural management techniques centered on individual patients' behaviour are generally successful reduction of neuropsychiatric symptoms, and the effects of these interventions last for months, despite qualitative disparity.

Psycho-education intended to change caregivers' behaviour is effective, especially if it is provided in individual rather than group settings, and improvement in neuropsychiatric symptoms associated with these interventions are sustained for months. They recommended these types of interventions. Specific types of staff education lead to reductions in behavioural symptoms and use of restraints and to improved affective states.

The diversity and variability in caregiver problems suggest that multi-component interventions that provide a range of services designed to improve family support and to provide group support to alleviate the burden of caregiving for relatives with dementia can have a greater impact on caregiver well-being than narrowly focused interventions. Those that provide counseling and support over long periods of time seem to be the most effective (*Sorensen et al., 2002*).

In the *New York University Spouse- Caregiver Intervention Study* (*Mittelman et al., 1995*), female caregivers entered the study with an average of three more symptoms of depression than male caregivers (as measured by scores on the Geriatric Depression Scale), a significant difference ($t= 3.5$, $p< 0.001$). In fact, 50 percent of the female caregivers had depression scores of 11 or higher (indicative of possible clinical depression), compared to 30 percent of male caregivers.

As time went on caregivers in the control group became more depressed, whereas those in the treatment group did not, suggesting that the intervention, rather than reducing depression, acted as preventive treatment. The difference between the treatment group and the control groups grew over time and became statistically significant by the end of the first year. The intervention had no greater impact on female caregivers than on male caregivers.

The study demonstrated that counseling and support enabled caregivers to postpone or to avoid placing their relatives with dementia in nursing homes. Analysis of the data showed that the difference between caregivers in the two groups in depressive symptoms and appraisal of the behaviour of the person with Alzheimer disease accounted for a large part of the effect on their ability to keep their relatives at home (*Mittelman et al., 2004*).

Teri et al. (2003), in a study of 153 community dwelling patients of Alzheimer disease found that an integrated treatment program designed to train dementia patients and their caregivers in exercise and behavioural management techniques was successfully implemented in a community setting. Caregivers were able to learn how to encourage and supervise exercise participation, and patients participating in this program achieved increased levels of physical activity, decreased rates of depression, and improved physical health and function. Post-test physical function improvements were maintained at 24- month follow-up and, for those patients entering with higher levels of initial depression, improvements in depression were maintained after 24 months.

Gitlin et al. (2001), determined short-term effects of a home environmental intervention on self-efficacy and upset in caregivers and daily function of dementia patients. The environmental program appears to have a modest effect on dementia patients' IADL dependence. Also, among certain subgroups of caregivers the program improved self-efficacy and reduced upset in specific areas of caregiving.

Hepburn et al (2001), tested role-training intervention as a way to help family caregivers appreciate and assume a more clinical belief set about caregiving and thereby ameliorate the adverse outcomes associated with caregiving. They found that a caregiver training intervention focused on the work of caregiving and targeted at knowledge, skills, and beliefs benefits caregivers in important outcome dimensions. The results suggest the benefits of providing information, linkage, and role coaching to dementia family caregivers.

In Summary,

Well designed epidemiological research can generate awareness, inform policy, and encourage service development. However, such evidence is lacking in many world regions, and patchy in others, with few studies and widely varying estimates (*Ferry et al., 2005*).

The *10/66 Dementia Research group*; MidEast correspondent *Prof/ Abdel Moneim Ashour*, have attempted to redress the research imbalance through south-south and south-north research collaborations (*Prince et al., 2007*).

Studies are scarce regarding profile, caregiver burden and QOL of persons with dementia in Egypt. There is evidence that education in early cases as an intervention proved to diminish burden and improve QOL in other contexts in developing world in 10/66 population- based research programme. This goes well with the notion that dementia is not just a biological disorder but a social, economic, and epidemiological event in wider context.

It is important to start intervention as early as possible after diagnosing dementia, to help patients and caregivers cooperate and adapt; and reduce incidence of behavioural problems and institutionalization. Social and educational intervention can be offered to caregivers through educating them the nature of the illness and how to manage symptoms, and deal with dementia. A positive therapeutic alliance should be done. Many media of education can be used (cards, drawings, pamphlets, electronic devices, discussions, group work and mass media, among others) (*Ashour, 2007*).

An action research program stands or falls on its ability to inform and encourage policy development on the basis of the evidence accumulated through its activities. Our challenge is to use our findings to raise public awareness, stimulate local clinical training and practice, and influence social welfare and health care policy making at the national and international level.

In these respects our relationship with *Alzheimer Disease International* (ADI) is crucial. ADI is affiliated to the *World Health Organization*. The needs of people with dementia in developing countries is now a major priority for ADI, and our findings are disseminated on its website, at its

conferences, and in its regular newsletters and World Alzheimer Day Bulletins, distributed to its 76 member associations worldwide; including *Alzheimer's Egypt- Prof/ Abd El Moneim Ashour*. In term, the National Alzheimer's Associations are able to use our materials for local publicity, and to influence national policy makers at governmental level.

Dementia is one of many health conditions in the developing world characterized by lack of awareness, stigma, limited help seeking, few services, and much unmet need. The evidence provided by research, can be a powerful argument for change (*Prince et al., 2007*).

Finally,

- 1- There is statistical evidence that educational intervention is effective for PWD within the mild to moderate severity category.
- 2- Educational intervention directed towards the caregiver may have a role in decreasing caregiver burden, and improving quality of life of PWD.
- 3- Most benefit occurs within the first 3 months of treatment.
- 4- Sessions take from 20 to 30 minutes each, for five sessions, which needs to be tailored to time available and individual load at outpatient clinics.
- 5- The lack of sufficient formal services for PWD in developing counties, made it necessary to make use of informal services, hence, the 10/66 intervention directed towards informal caregiver.
- 6- Informal services are most available in developing countries, including India, where the 10/66 intervention started and were effectively used in rural communities.
- 7- Our efforts included translation of the intervention modules, and the scales used in the study, to Arabic language, after Spanish and Indian, and applying it in our population.

Limitations of the study

- 1- The longitudinal follow up should have been done on longer periods.
- 2- The study should have included other groups, like resident homes, and long term facilities persons.
- 3- The study should have included other research groups from other cities in Egypt, to have larger effect.
- 4- Formal services could have been included in the study.

Critique to the thesis:

- 1- References should be written completely.
- 2- Details of the scoring and the data of the used scales should be included. Unused scales should be mentioned.
- 3- Too many scales were included. Basic scales enough.
- 4- Cross validation of the new scales against the GMS could be done in separate study.
- 5- Appendix should contain all used scales.

Conclusion

Our results showed that educational intervention directed towards caregivers have an effect in alleviating caregiver burden, and improving quality of life; of persons with dementia of different aetiologies, within the mild to moderate severity category.

In the lack of sufficient formal services and economic barriers; informal services, in the form of education of the caregiver of person with dementia towards specific intervention, appears to have the most benefit in this group in developing countries.

Summary

Capitalizing on the available tools, we studied the effect of educational intervention on quality of life and caregiver burden in dementia in an Egyptian sample.

The aim of this work was to study the effect of educational intervention directed towards caregivers on caregiver burden and well being, and quality of life of patients; and the factors affecting caregiver burden, well being and quality of life of patients of dementia in Egypt.

The study included 100 patients with dementia, and their principle caregiver, collected from Institute of Psychiatry, Ain Shams University Hospitals, outpatient clinics, and El- Abbasseya Hospital for Mental Health.

The study was preceded by preparation of the tools, which were used in the study. This included translation, and assessing the validity of the translation of the 10/66 intervention modules, and of the scales which were not translated before in previous studies. This stage took two months, May and June 2006.

The study proper was preceded by a pilot study for four months, from July to October 2006; and included 10 patients diagnosed with dementia, in the Institute of Psychiatry and El-Abbasseyia Hospital for Mental Health.

The study proper included the following:

1- Informed consent:

It was taken from patients, caregivers and controls; after discussing with them the details of the study.

2- Comprehensive assessment:

- *History:* personal, present history, past psychiatric and medical history, family history, social and demographic data.
- *Diagnosis* according to DSMIV- TR .
- Physical examination.
- Interviewing relatives as carers.

3- Tools applied in the study:

1. Geriatric Mental State, *Arabic Version (Ashour et al., 2003)*
2. Quality of Life, *Brief Arabic Version (Ashour et al., 2003)*
3. Burden Interview, *Arabic Version (Ashour et al., 2006)*
4. Mental Test Score, *Arabic Version (Ashour et al., 2006)*
5. Revised Memory and Behavior Problems Checklist, *Arabic Version (Ashour et al., 2006)*
6. Disability Assessment For Dementia, *Arabic Version (Ashour et al., 2006)*
7. General Health Questionnaire, *Arabic Version (Ashour et al., 2006)*
8. Clinical Dementia Rating, *Arabic Version (Ashour et al., 2006)*

4- Procedures:

- Initial assessment, using available tools, for all 100 patients and caregivers.
- Intervention modules were applied for 50 patients, according to *Alzheimer's Disease International (2006)*; and 50 patients were left as controls (with random allocation).
- Control patients had sessions without the specific intervention (follow up and usual management).
- Evaluation of outcome was done after three months.

Our results showed;

I – Socio-Demographic Variables

Our study included 100 persons with dementia; 53 males (53 %), and 47 females (47 %). The age of the studied sample ranged from 60 to more than 80 years of age; with a mean of 70.46 and SD= 5.88. The peak incidence for males was from 70-74 years. The peak incidence for females was from 75-79 years.

58 (58%) were retired and 42 (42%) were housewives. 48(48%) were married, 48 (48%) were widow/widower, 3 (3%) were single, and 1 (1%) were divorced. 62 were literate and 38 were illiterate.

47 (47 %) of the study population were cared for by son and family, 40 (40%) by the daughter, and 13 (13%) by wife, sister and nephews. Of the caregivers, 80 were married (80%), 1 (1%) widow, 19 (19%) single.

II- Medical Data

Peak incidence for medical illness was for osteoarthritis 19 (19%), renal dis 8 (8%), diabetes and hypertension 8 (8%), diabetes 7 (7%), hypertension 6 (6%), stroke/ TIA 6 (6%), and coronary heart disease, and other cardiac dis 6 (6%). No significant difference was found between diabetes and hypertension with MTS.

Dementia of the Alzheimer's type was found in 92 (92%) persons, vascular dementia 5 (5%), and dementia due to multiple etiologies 3 (3%). 61 (61%) was of mild severity, and 39 (39%) was of moderate severity.

59 (59%) of the studied persons had major depressive disorder, 10 (10%) had insomnia related to dementia, 4 (4%) had generalized anxiety disorder, and 3 (3%) had hypochondriasis as a secondary diagnosis. 75 (75%) was of mild severity, and 1 (1%) was of moderate severity.

III- Correlation of Caregiver Burden with Study Variables

There was a positive correlation between the *severity* of the primary diagnosis (dementia) and burden

No statistically significant difference was found between psychiatric disorders or medical illness and burden

IV- Correlation of Quality of Life with Study Variables

There was a negative correlation between *primary diagnosis* of dementia and its *severity* and QOL

No statistically significant difference was found between psychiatric diagnosis or medical illness and QOL.

V- Comparison of study scores before & after intervention

A statistically significant difference ($P < 0.001$) was found between each of the study group and control group mean scores, in comparison separately on all study scores, before intervention and after three months; in favor of study group mean scores.

VI- Correlation of Total Study Scores

There was a *positive correlation* between *Burden interview* and Revised Memory & Behaviour Checklist, General Health Questionnaire, and Clinical Dementia Rating. A *negative correlation* with; Mental Test Score, Disability Assessment for Dementia and Quality of Life, which was statistically significant ($P < 0.001$).

There was a *positive correlation* between *Quality of Life* and Mental Test Score, and Disability Assessment for Dementia. A *negative correlation* with Revised Memory & Behaviour Checklist, Burden interview, General Health Questionnaire, and Clinical Dementia Rating, which was statistically significant ($P < 0.001$).

No statistically significant difference was found between diabetes, hypertension, osteoarthritis, or Coronary heart disease with *Mental Test Score*.

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المقدمة

الفشل العقلى (عته الشيخوخة), هو اسم جامع لمتلازمات عقلية عضوية تؤثر بصورة متدرجة على الذاكرة و التفكير و السلوك و المشاعر؛ تؤدى فى النهاية إلى عدم قدرة الشخص المصاب على الاعتناء بالنفس و إلى احتياج المساعدة فى جميع نواحي الحياة اليومية.

يشكل الفشل العقلى كلفة باهظة للمجتمع و لأسر الأشخاص المصابين و للمصابين أنفسهم. و تشمل الكلفة للمجتمع تكلفة مباشرة للخدمات الصحية و الاجتماعية, و تكلفة غير مباشرة من خسارة الإنتاجية لمقدم الرعاية و الكلفة الاقتصادية للعائلات الراعية لأقاربهم المرضى. و بجانب الأعباء المالية للعائلات؛ يوجد الأثر النفسى المؤدى إلى المعاناة و المرض.

و يؤثر الفشل العقلى على عائلة المريض و شبكته الاجتماعية. و فى كل أسرة يوجد على الأقل مقدم رعاية واحد يعنى بالمريض. و يجب أن يشمل معيار الرعاية للشخص المصاب بالفشل العقلى الاهتمام بمقدم الرعاية للمريض.

و تعتبر الدراسات التدخلية التى تهدف إلى تقليل المعاناة لدى مقدم الرعاية قليلة. و توجد حاجة ملحة إلى تطوير تدخلات معدة من أجل مرضى الفشل العقلى و عائلتهم. و أثبت التدخل التعليمى فى حالات الفشل العقلى فعاليته فى تقليل المعاناة لدى مقدم الرعاية و تحسين نوعية الحياة للمريض.

و تحتاج رعاية مرضى الفشل العقلى خطة علاجية شاملة, تدمج العلاج الدوائى مع النواحي البيئية و العلاجات النفسية و التأهيل. و الهدف منها هو المحافظة على الاستقلالية بقدر الإمكان و تحسين نوعية الحياة عن طريق تقليل المعاناة النفسية للمرضى و عائلتهم.

و يعتبر التوجيه الإرشادى و المساندة لمقدم الرعاية من الأشياء المهمة لتكوين اتجاهات أفضل تجاه الأشخاص المصابين بالمرض و تحسين طريقة التعامل معهم, من أجل نوعية حياة أفضل للمرضى و تقليل معاناة مقدمو الرعاية.

إن نقص فهم الفشل العقلى كحالة صحية, إضافة إلى عدم كفاية الخدمات المقدمة؛ يعتبران من أهم المشاكل التى تواجه الأشخاص المصابين بالفشل العقلى فى البلاد النامية.

المبررات البحثية

- يوجد زيادة مطردة فى أعداد المسنين المصابين بالفشل العقلى فى مصر, الذين يحتاجون إلى مزيد من الخدمات و الرعاية.
- مازالت الدراسات قليلة عن معاناة مقدم الرعاية و التدخل التعليمى و العوامل المؤثرة عليهم؛ فى حالات الفشل العقلى فى مصر.
- أثبت التدخل التعليمى كفاءته فى تقليل معاناة مقدم الرعاية و تحسين نوعية الحياة للأشخاص المصابين بالفشل العقلى فى البلاد النامية الأخرى.
- باستخدام الأدوات المتاحة سنقوم بدراسة تأثير التدخل التعليمى على نوعية الحياة و معاناة مقدم الرعاية فى مرض الفشل العلى فى عينة مصرية.

الهدف من البحث

الهدف من هذا البحث هو دراسة تأثير التدخل التعليمى الموجه لمقدم الرعاية؛ على إحساسه بالعبء فى التعامل مع المريض، و تأثير ذلك على صحته النفسية، و نوعية الحياة للأشخاص المصابين، و كذلك العوامل المؤثرة فيهم، فى مرضى الفشل العقلى فى مصر.

الفروض البحثية

- التدخل التعليمى الموجه لمقدم الرعاية للأشخاص المصابين بالفشل العقلى، له تأثير ايجابى على معاناة مقدم الرعاية و نوعية الحياة للمرضى فى مصر.
- يوجد علاقة طردية بين الأعراض المرضية و درجة حدة المرض و درجة التدهور المعرفى و الأعراض السلوكية و العجز فى نشاطات الحياة اليومية فى الأشخاص المصابين بالفشل العقلى؛ و بين معاناة مقدم الرعاية فى مصر.

الطرق و الأدوات المستخدمة

المرضى المشتركون فى البحث:

أشتمل البحث على مائة مريض و مقدمو الرعاية الرعاية الأساسيين لهم, من الأشخاص المصابين بالفشل العقلى المترددين على عيادة الأمراض النفسية الخاصة بأمراض الذاكرة, بمركز الطب النفسى جامعة عين شمس و العيادة الخارجية بمستشفى العباسية للصحة النفسية.

الطرق المستخدمة فى البحث:

التقييم الاكلينيكي:

- التاريخ تقييم شامل لحالة المسن؛ و يشمل: أخذ التاريخ المرضى , متضمناً التاريخ الشخصى و تاريخ المرض و الحالة الصحية السابقة له و التاريخ العائلى , مع استيفاء المعلومات الاجتماعية و السكانية الخاصة به و تقييم قدرته على أداء النشاطات اليومية.
- التشخيص طبقاً للدليل التشخيصى و الاحصائى الأمريكى – الطبعة الرابعة المعدلة.
- الفحص الجسدى له.
- إجراء مقابلة مع أفراد أسرته و مقدم الرعاية.

الأدوات المستخدمة فى البحث:

- 1- معيار التقييم العقلى للمسنين, النسخة العربية.
- 2- قياس نوعية الحياة, النسخة العربية المختصرة.
- 3- معيار العبء لمقدم الرعاية.
- 4- حاصل الاختبار العقلى.
- 5- قائمة مشكلات الذاكرة و السلوك المعدلة.
- 6- معيار العجز لمرضى الفشل العقلى.
- 7- استبيان الصحة العامة.
- 8- مقياس الفشل العقلى السريرى.

الإجراءات المستخدمة في البحث:

- تم تقييم المرضى و مقدمو الرعاية مبدئياً باستخدام الأدوات المتاحة.
- التدخلات التعليمية تمت لخمسون مريضاً طبقاً لبرنامج جمعية مرض ألزهايمر العالمية، و خمسون بقوا بلا تدخلات كعينة ضابطة؛ و التي تعرضت لجلسات متابعة كالمعتاد مع مثل هؤلاء المرضى , و تم توزيع المرضى عشوائياً على المجموعتين.
- تم تقييم النتائج بعد ثلاثة أشهر.

النتائج

الدراسات السكانية الاجتماعية

أشتملت الدراسة على مائة شخص مصابين بالفشل العقلي؛ 53 رجل (53%)، و 47 امرأة (47%)؛ تراوح سنهم ما بين 60 إلى أكثر من 80 سنة، بمتوسط عمر 70,46 و إنحراف معيارى = 5,88 . قمة الحدوث للرجال كانت ما بين 70 – 74 سنة، و للنساء ما بين 75 – 79 سنة.

58 شخصاً (58%) كانوا متقاعدین و 42 (42%) كانوا ربات منزل. 48 شخصاً (48%) كانوا متزوجين، 48 (48%) أرامل، 3 (3%) غير متزوجين و 1 (1%) مطلقين. 62 كانوا متعلمين و 38 كانوا غير متعلمين.

47 شخصاً من عينة الفحص (47%) كان يتم رعايتهم بواسطة عائلة الابن، 40 بواسطة الابنة (40%)، و 13 بواسطة الزوجة و الأخت و أبناء الأخوة (13%). 80 من مقدمى الرعاية كانوا متزوجين (80%)، 1 كانوا أرامل (1%)، و 19 غير متزوجين (19%).

قمة الحدوث للأمراض العضوية كانت لالتهاب المفاصل 19 شخصاً (19%)، أمراض الكلى 8 (8%)، السكر و الضغط 8 (8%)، السكر 7 (7%)، الضغط 6 (6%)، و أمراض القلب و الشرايين 6 (6%)، أمراض الأوعية الدماغية 6 (6%).

مرض ألزهايمر كان متواجداً فى 92 شخصاً (92%)، الفشل العقلى الوعائى فى 5 (5%)، و الفشل العقلى لأسباب متعددة فى 3 (3%). 61 (61%) من الأشخاص كان لديهم درجة عسر بسيطة، و 39 (39%) درجة عسر متوسطة.

مرض الاكتئاب النفسى كان متواجداً فى 59 (59%)، و عدم النوم الثانوى للفشل العقلى فى 10 (10%)، و القلق النفسى فى 4 (4%)، و التوهم المرضى فى 3 (3%). 75 (75%) من الأشخاص المصابين كان لديهم درجة عسر بسيطة، و 1 (1%) كان لديه درجة عسر متوسطة.

معامل الارتباط لمعيار العبء لمقدم الرعاية مع متغيرات الدراسة

كانت هناك علاقة إيجابية بين درجة عسر التشخيص الأولى (الفشل العقلى) و معيار العبء لمقدم الرعاية.

لم توجد علاقة إحصائية ذات دلالة بين الأمراض النفسية، أو الأمراض العضوية (السكر و الضغط)؛ و معيار العبء.

معامل الارتباط لقياس نوعية الحياة مع متغيرات الدراسة

كانت هناك علاقة سلبية بين التشخيص الأولى للفشل العقلى و درجة عسره؛ و قياس نوعية الحياة.

لم توجد علاقة إحصائية ذات دلالة بين الأمراض النفسية، أو الأمراض العضوية (السكر و الضغط)؛ و قياس نوعية الحياة.

مقارنة بين ناتج الدراسة قبل و بعد التدخل

وجد إختلاف إحصائى ذو دلالة بين كل من مجموعة الفحص و مجموعة الضبط، قبل التدخل و بعد ثلاث أشهر فى صالح متوسط حاصل مجموعة الفحص.

معامل الارتباط للناتج الكلى للدراسة

كانت هناك علاقة إيجابية بين معيار العبء لمقدم الرعاية و قائمة مشكلات الذاكرة و السلوك المعدلة و استبيان الصحة العامة و مقياس الفشل العقلى السريرى. و كان هناك علاقة سلبية مع حاصل الاختبار العقلى، و معيار العجز لمرضى الفشل العقلى ، و قياس نوعية الحياة؛ و الفارق كان ذو دلالة إحصائية.

و كانت هناك علاقة إيجابية بين قياس نوعية الحياة و حاصل الاختبار العقلى، و معيار العجز لمرضى الفشل العقلى. و كانت هناك علاقة سلبية مع قائمة مشكلات

الذاكرة و السلوك المعدلة، و معيار العبء لمقدم الرعاية، و استبيان الصحة العامة، و مقياس الفشل العقلي السريري؛ و الفارق كان ذو دلالة إحصائية.

لم توجد علاقة دالة إحصائية بين السكر و الضغط و حاصل الاختبار العقلي.

في الخلاصة؛

أثبتت الدراسة أن التدخل التعليمي الموجه نحو مقدمي الرعاية لمرضى الفشل العقلي؛ له تأثير إيجابي في تخفيف معاناة مقدمي الرعاية، و تحسين نوعية الحياة لمرضى الفشل العقلي، ذو درجة عسر خفيفة إلى متوسطة، و الناتج عن أسباب مختلفة.

Caregiver Burden in Dementia

Dementia is a disease that impacts the patient's entire family and social network. At the center of this family are at least one caregiver and the patient.

Caregivers are defined as those looking after someone with dementia. These can be formal, paid caregivers or informal caregivers such as family members or friends. The standard of care for the patient with dementia must include care for the caregiver of that patient (*Alzheimer Society of Canada, 2008*).

The term caregiver refers to anyone who provides assistance to someone else who is in some degree incapacitated and needs help.

Informal caregiver:

Is an individual, such as family member, friend, or neighbor, who provides unpaid care. Such a person can be providing care full - time or part-time and can live with the person being cared for or can live separately.

Formal caregiver:

Is a volunteer or a paid care provider associated with a service system.

The cost of caring of people with dementia is enormous, both monetary and psychological. Partners, relatives and friends who take care of patients experience emotional, physical and financial stress, and care giving demands are central to decisions on patients institutionalization (*Papastavrou et al., 2007*).

Informal caregivers are a major resource in the health care system for the elderly. Approximately two-thirds (64%) of older persons living in the community who need long-term care depend on family and friends as their only source of help. Whereas an additional 28 % receive a combination of informal and formal care; only 8 % used formal care or paid help only. Increasing numbers of elderly people are receiving a combination of formal

and informal caregiving, according to the 2000 survey by the *Federal interagency forum on Aging-related statistics*.

The crucial role of family members in maintaining the elderly in the community is made clear by the fact that 50% of the elderly with long-term care needs who have no family are in nursing homes compared to only 7 % of those who have family caregivers. Data from a national representative survey to identify caregivers conducted in 1996 led to estimates that more than 5 million households provide care for someone with Alzheimer disease or other dementias in the United States. Unless a cure is found, the number of people who provide care for elderly relatives with dementia can only increase as the population ages (*Mittelman et al., 2002*).

Caring for someone with dementia can stretch to limit the resources of any individual and is held to cause a greater emotional burden than caring for a physically disabled older person. This is partly because of inevitable changes in the relationship with the dementia sufferer, but also having to cope with the behavioural changes associated with the illness.

Usually the responsibility for care falls on one person, with a cascade effect in which each member of the family will take responsibility in turn, but not collectively. Often the carer copes with circumstances that otherwise might be thought to be intolerable, but there is much that can be provided by way of support (*Gilhooly, 1986*).

A caregiver occupies at least four roles:

- Knowledgeable informant about disease progression and response to therapies.
- Decision-maker for the patient.
- Caretaker for the patient.
- Second patient; with emotional, social, and financial burden.

If caregivers are to properly fulfill these roles, they need core knowledge and skills, including information about diagnosis, prognosis, and treatment, and support for emotional and financial burden. Randomized trials demonstrated providing information and support to caregivers may postpone the need for 24-hour nursing care.

Caregiver Burden

The term describes the emotional, social, medical, and financial impact of care-giving on a person. Manifestations include depression, isolation, stress-related illnesses, and poverty.

Caregiver burden is significant for at least three reasons:

1. Research shows that a caregiver's ability to accurately assess a patient is influenced by the caregiver's mood and burden.
2. Research shows that patients and caregivers benefit when caregivers receive interventions to relieve burden.
3. The caregiver is a person, not an instrument, who deserves the dignity and respect accorded to all persons.

(Cotter et al., 2004)

Epidemiology

Researchers in the *Canadian Study of Health and Aging (1994)*, interviewed more than 1000 caregivers in 36 cities across Canada.

Results showed:

- 50% of people with dementia live in the community.
- 97% of these people have a caregiver.
- 2.4% have no caregiver.
- 29% live alone.
- 8% have only one caregiver.
- 30% of informal caregivers in the community are employed.
- Over 70% of informal caregivers are women, most often wives or adult daughters.
- Half of the informal caregivers are over age 60, 36% are over age 70.
- Spouse-caregivers are less likely to have back-up support than others, and yet are more likely to be caring for a person with severe dementia.
- People with dementia who have severe functional disability receive far more services than those with mild to moderate disability.
- At each level of disability, caregivers of people with dementia use fewer services than caregivers of people without dementia.

(Alzheimer Society of Canada, 2008)

Behavioural changes in the person with dementia

Many of the studies that have investigated the impact of caring have been influenced by the work of *Grad and Sainsbury (1965)*, which evaluated the burden placed on carers caused by transferring elderly psychiatric patients back into the community. They introduced the distinction between objective and subjective burden in this context.

Objective burden: refers to the behavioural changes of a dementia sufferer and some of the practical problems that follow; for example the need to constantly supervise someone who is at risk of leaving the house and becoming lost.

Subjective burden: refers to the emotional reaction of the carer, such as a lowering of morale and a build up of stress or strain.

Gilleard (1984), has introduced the term '*daily hassles*' to refer to the day to day stressors that impinge on the carer. *Poulshock and Deimling (1984)*, have used the term '*caregiving impact*' to describe the social effect on the caregiver's daily life, such as changes in family employment and health.

The major behavioural problems experienced by carers have been elicited from carers using various forms of checklists. The main behavioural changes can be characterized as disinhibition and deficit. The loss of the capacity to inhibit behavioural reactions in a proportions of sufferers may result in aggression. It is estimated that 18% of dementia sufferers become either verbally or physically aggressive, adding to the stresses and strain experienced by the carer (*Burns et al., 1990*).

Neuropsychological deficits such as dyspraxia lead to problems with self-care skills, including dressing and feeding, which increases the physical burden of nursing care whilst memory and learning problems result in an inability to adapt to new circumstances and remain orientated (*Oppenheimer and Jaccoby, 1991*).

It has been noted that personality changes can be the most distressing to close relatives, with the worst of these being loss of social skills or social control, and a tendency to be apathetic or egocentric in relation to the needs of other people (*Gilleard, 1984*).

These problems tend to occur at the more severe stages of dementia, but even then the majority of sufferers continue to live in the community. Early on in the course of dementia the problems may be much less severe and more easily tolerated by supporters (*Eagles et al., 1987*).

Sanford (1975), required carers to list all the problems they encountered at home and then state which problems would have to be dealt with to make life tolerable. The main problems were nocturnal wandering and incontinence, an inability to dress or wash or feed unaided, immobility and dangerous behaviour, such as dealing with the gas cooker or heating appliances.

Other later studies have confirmed these findings, using problem checklists. *Greene et al. (1982)*, factor analysed the data from their study, deriving three problem dimensions that they termed 'apathy/withdrawal', 'behavioural disturbance' and 'mood disturbance'.

Similarly, *Gilleard et al. (1982)*, derived five factors labeled *dependency, disturbance, disability, demand* and *wandering*. *Gilleard (1984)*, also required carers to rate the severity of elicited problems. The most frequent severe problems are listed in table (4).

Having to be constantly with the dementia sufferer is a particular problem because it severely restricts the other activities of the carer, including recreation and social contact (*George and Gwyther, 1986*).

Another major problem is when the dementia sufferer becomes restless and agitated and starts to wander within the home. The carer has to be constantly on the alert for what may be happening in a different room. These and other problems can literally wear down the carer, with a progressive adverse effect on emotional wellbeing and physical health (*Pruchno and Resch, 1989*).

Tab (4)

Tab (5)

The psychological wellbeing of carers

The psychological wellbeing of carers has been investigated in some detail. Many studies report a higher level of depression compared with what would be expected from a community sample. *Morris et al. (1988)*, found that 14% of their sample of carers reported clinically significant levels of depressive symptoms as measured by the *Beck Depression Inventory*. This result is consistent with a range of other studies indicating a moderately increased incidence of depression in carers (*Pruchno and Resch, 1989*), (*Moritz et al., 1989*).

Even higher level of depression have been found by *Pagel et al. (1985)*, with 40% of their sample currently depressed according to the *Research and diagnostic criteria (Spitzer, 1978)*, and a further 41% having been depressed at some stage in caregiving.

Another major index of emotional disorder is the prevalence of probable caseness of psychiatric disorder measured by global ratings. *Bergmann and Jaccoby (1983)*, estimated that 33% of their sample of carers had what could be considered psychiatric disorder according to the *General Health Questionnaire (GHQ)*. *Gilleard et al. (1984)*, estimated that 68% of their sample exceeded the threshold value for caseness on the GHQ.

A study by *Anthony- Bergstone et al. (1988)*, compared the scores of carers with normative data on different features of psychiatric symptomatology using the *Brief Symptom Inventory*. The largest amount of symptomatology was seen in elderly women carers.

Some studies have reported very little change in emotional wellbeing in carers. *Gilhooly (1986)*, reported that her mixed sample of mainly spouse and sibling carers were in good mental health. *Eagles et al. (1987)*, found no difference in GHQ scores between co-resident carers of dementia sufferers and the relatives of non-dementing elderly. One reason for the discrepancy is that some carers are well adjusted to their situation, particularly if they live in a supportive environment and if the dementia sufferer is in early stage of the illness.

Health of carers

The level of objective burden is reflected in the health of carers. *Haley et al.(1987)*, found that their sample of 44 primary carers of dementia sufferers rated their health as poorer overall than a control group of non-carer subjects. Carers also had more chronic illness, assessed using the *Health Status Questionnaire*, and reported a greater number of recent visits to physicians and greater use of prescribed medicine.

Pruchno and Resch (1989), found that carers reported higher levels of chronic conditions. Ill-health was attributed both to the stress of caring and also to the physically demanding task of nursing. Commonly, the most vulnerable carer is looking after a dementia sufferer who requires a high level of nursing care as well as being frail and elderly him or herself.

Effects of caregiving on Physical health

There is conflicting evidence about the negative consequences of caregiving to physical health outcomes, with at least one study showing that there are effects of caregiving on physical health. However, several studies showed that caregivers of older adults with Alzheimer disease or other dementing illnesses are likely to reduce self-care behaviours, which may result in poorer physical health. Spouse-caregivers may be particularly vulnerable.

There are complex relationships between physical and mental health outcomes of caregiving. On the one hand, poor physical health has been identified as a risk factor for depression in caregivers. On the other hand, caregivers who are depressed may be less likely to attend to protective health behaviours (*Schulz et al., 1995*).

Mental health consequences of care giving

Caregivers are at risk for poorer mental health than non-caregivers of the same age. Although the elevated risk for depression among caregivers of people with dementia has been more widely studied than the risk of other

psychological disorders, there is also some evidence that caregivers are at risk for anxiety, anger, and hostility. The chronic strains of caregiving itself can be responsible for the onset of depressive disorders or anxiety disorders, or both, in adults with no prior evidence of vulnerability.

More than one-half of all people with dementia are cared for at home by their spouses. Spouse caregivers are affected not only by inevitable cognitive and functional deterioration caused by the illness of their husbands and wives, but also by the lack of family support, family conflict, changes in lifestyle due to the added responsibilities of the caregiving role, isolation, and constriction of social activities. Most spouse-caregivers are elderly themselves, and many experiences the illnesses that accompany advanced age. Nevertheless, spouse-caregivers often shoulder the entire burden of caring for their husbands and wives alone (*Zarit et al., 1985*)

Tab (6)

Stress related to caregiver burden

The last 50 years have witnessed an increase in research dedicated to psychological stress. One of the principle areas of development has been the conceptualization of stress as a process, and the resulting distinction between stressors, psychosocial mediators, and the stress response (*Vedhara et al., 2000*).

Assessment of status of family caregivers of persons with dementia living at home seems to be gaining considerable importance (*Andren and Elmstahl, 2008*).

Family members, often at great personal cost, provide much of the care for older adults with Alzheimer disease and other dementias in the community. Family caregivers of relatives with Alzheimer disease are at high risk for psychological distress, with rates of clinical depression and depressive symptoms far in excess of those for age-matched comparison subjects. This risk persists over the many years of caregiving and even after caregiving ends (*Mittelman et al., 2004*).

In recent years, a new realm of dementia research has emerged that focuses on the effects of caring for a family member with dementia. The emotional and physical stress of care-giving appears to increase susceptibility to disease. Caregivers have a higher prevalence of physical symptoms and poorer self rating of health than non-caregivers. While most research has focused on the wife as caregiver, new research on the effects on husbands and the impact of culture and ethnicity is emerging.

Some positive aspects of caring for patients with Alzheimer disease have also emerged with the finding that sibling and parent-child relationships are strengthened. In addition, new strategies of intervention to reduce caregivers stress and reduce early institutionalization are being developed (*Perel, 1998*).

In a study in Sweden, the family caregivers to 130 persons with dementia answered a questionnaire including a Caregiver Burden Scale, the Nottingham Health Profile Scale, Sense of Coherence Scale and the Euroqol instrument. The family caregivers experienced moderate burden,

and strong associations were noted between burden, especially isolation, disappointment and emotional involvement with perceived health and sense of coherence, adjusted for age and relationship. Caregivers with lower burden reported significantly better perceived health and higher mean score of Sense of Coherence than caregivers with higher burden (*Andren and Elmstahl, 2008*).

In a study in Japan of caregiver burden for stroke and dementia patients, total of 916 Japanese home caregivers answered the Zarit Caregiver Burden Interview. Higher scores were statistically significant for non-stroke patients with dementia and for stroke patients with dementia, but not for stroke patients without dementia. Prevalent stroke and, more strongly, dementia were associated with increased family caregiver burden. Among patients with dementia, the presence of stroke did not enhance caregiver burden further (*Muraki et al, 2008*).

Wilz and Fink-Heitz (2008) found that assisted vacations can have both immediate and longer lasting positive effects on participants' health. Assisted vacations can therefore be a way of diminishing the risk of stress disorders for caregiving spouses. Making assisted vacations available to people with dementia and their caregivers is a worthwhile goal for community support facilities working to reduce caregiver burden.

A study was done in Cyprus, to investigate the burden experienced by families giving care to a relative with dementia, the consequences of care for the mental health of the primary caregiver, and the strategies families use to cope with the care giving stressors. 172 caregiver/ care recipient dyads, participated in the study. All patients were suffering from probable Alzheimer's type dementia.

The results showed that 68.02 % of caregivers were highly burdened and 65 % exhibited depressive symptoms. There was no statistically significant difference in level of burden or depression when patients lived in the community or in institutions. High scores in the Burden Scale were associated with use of emotional-focused coping strategies, while less burdened relatives used more problem-solving approaches to care giving demands. The study showed that caregivers, especially women, need individualized, specific training in how to understand and

manage the behaviour of relatives with dementia and how to cope with their own feelings (*Papastavrou et al., 2007*).

A study in the United States, examined inter-relationships between family functioning, caregiver burden, and patient characteristics. Participants were 72 family caregivers of patients with mild to moderate dementia. Results showed that higher levels of caregiver burden were associated with increased caregiver depression and anxiety, greater frequency of memory and behavioral problems in the dementia patient, and poorer family functioning (*Tremont, et al., 2006*).

A study on caregiver burden in Japan found that in dementia patients, inability finding the way home, inability of managing money and fecal incontinence were the most difficult symptoms to cope with. An analysis of the factors related to caregiver burden found that the severity of dementia and the physical pain of the caregivers were directly related to burden. The study showed that the caregiver's burden is not only affected by the illness of the care recipients but also by the caregivers' background and the care environment (*Onishi et al., 2005*).

A study in Germany, evaluated the course and severity of dementia-related symptoms and their relationship to caregivers' subjective burden and depression over time. 45 patients with dementia and their caregivers were followed up for 2 years. The study showed that the stage of dementia, functional deficits, and behavioral disturbances are important factors when evaluating the relationship between patient's symptoms and caregiver's wellbeing (*Berger et al., 2005*).

A study in the United States examined predictors of types of strain experienced by caregivers of patients with dementia enrolled in primary care program. Data were collected from 150 patient-caregiver dyads who were enrolled in the program. Factor analysis of the caregiver strain index revealed three dimensions of strain (role, personal, and emotional) related to caregiving. Patient problem behaviors predicted all types of caregiver strain. Perceived lack of support from the health care team predicted personal and emotional strain, whereas higher income predicted role strain. Patient functional limitations predicted personal and role strain (*Diwan et al., 2004*).

In Italy, the family constitutes the major caregiving response to the needs of the elderly who are no longer self sufficient. They are often wives or daughters who have chosen to keep the patient at home with them. On average, three quarters of the caregiver's day is devoted to the patient. A study was done in Italy to describe a group of Italian caregivers of patients with a diagnosis of dementia to assess their levels of stress. Then caregivers were correlated with a number of socio-demographic variables and the patients' degree of cognitive impairment. The study was done on 236 caregivers of patients with Alzheimer disease.

The results showed that the average Italian caregiver of Alzheimer disease patient is a woman, approximately 60 years old. The majority are spouses followed by children. In general, these caregivers work at home, are housewives or retired, and are personally involved in caring for the patients. The greater the level of a patient's cognitive impairment and the less independent they are, the greater amount of care and supervision they require, leaving less free time for the caregiver; leading to higher levels of anxiety related to caregiving .

Towards the final stages of the disease, patient care tasks take up nearly all of the caregiver's free time, leaving them only about two hours per week for themselves. The increase of cognitive disorders and the resulting reduction of independence in daily life, together with the onset of behavioral symptoms, heighten the caregiver's distress, anxiety, and depression. Establishing a net work of community services able to alleviate the burden on families is therefore a priority (*Aguglia et al., 2004*).

A study was done in Canada to assess the overall QOL of 243 caregivers of dementia care receivers. Primary stressors were care receiver cognitive status, physical function, and behavioral problems. Results showed that well-being was directly affected by four variables: perceived social support, burden, self-esteem, and hours of informal care. Burden was affected directly by behavioral problems, frequency of getting a break, self esteem, and informal hours of care (*Chappell and Reid, 2002*).

A study in Canada on 29 male caregivers affiliated with Alzheimer organizations in Canada showed that, on average, physical health symptoms increased by one-third when comparing pre- and post-caregiving data. Caregiver health was related to perceptions of stress surrounding the provision of activities of daily living assistance, the frequency of behavioral problems, perceptions of stress associated with the patient's dysfunctional behaviors, and satisfaction with leisure opportunities (*Shanks-McElroy and Strobino, 2001*).

A study in Poland found that factors predicting caregiver stress include; presence of patient behavioral problems, the nature of the caregivers' social support, and ability to cope with difficult situations (*Ras and Opala, 2001*).

A study in Spain analyzed the factors affecting burden in 234 carers of patients with dementia. The study showed that non-cognitive symptoms, functional disability, poor perception of quality of life, and hours of attention to the patient predict caregiver burden (*Garre-Olmo et al., 2000*).

A study in England found that factors that cause caregiver burden include; gender, availability of support systems, relation -ship to the patient, the way the caregiver perceive the patient's symptoms, and his attitude and behavior to the patient (*Donaldson and Burns, 1999*).

Factors influencing stress and strain

The level of stress or strain is not necessarily related to the degree of behavioural disturbance in the dementia sufferer. It is clear that there are marked individual differences in the manner in which carers cope with their situation. For example, a sibling carer who occasionally has to provide help for a parent with mild dementia and is well supported by other siblings and friends may experience minimal levels of strain. In contrast, an elderly co-resident carer who is looking after someone with severe dementia and is isolated from other people is likely to be under severe strain (*Morris et al., 1988*).

a- Relationship factors

The degree of distance in the blood / role relationship has been confirmed as influencing the mental health of the carer. Generally, the greater the familial distance the less strain experienced by the carer (*George and Gwyther, 1986*).

This is partly because spouses tend to be co-resident with dementia sufferers and thus more likely to play a greater part in day to day caregiving. Despite this, it has been found that spouse carers are less likely to consider long-term institutional care for their relative, with the result they remain carers for a longer period (*Gilhooly, 1986*).

Another factor influencing strain is the quality of the relationship between the carer and the dementia sufferer. It has been suggested that the closer the emotional bond within the relationship, the less the strain for the carer. The quality of the past relationship has been found to correlate with the mental health of carers of dementia sufferers (*Horowitz and Shindelman, 1983*).

b- Gender differences

There is substantial evidence that female carers experience more strain than male carers, with increased levels of depression and lowered morale.

This imbalance is over and above the higher level of emotional disturbance found in women in community studies (*Morris et al., 1991*).

One major cause is thought to derive from the different life experiences and socialization patterns that men and women experience, with female carers expected to take on the traditional role as carer (*Finch and Groves, 1983*).

c- Coping strategies and attributional style

The manner in which carers respond to their experience varies enormously. One of the difficulties in coming to terms with caring for someone with dementia is the insidious onset of the illness and the continual change that occurs. Generally, carers appear to cope in a more adaptive fashion if they concentrate their energies on solving management and financial problems (*Barusch and Spaid, 1989*).

More broadly, the attributional style of carers has been related to level of depression. A sample of spouse carers were asked to rate their perception of control and causal attributions for changes in the behaviour of the dementia sufferer, and their perceived control over the sufferer's current behaviour. Results showed that perceived loss of control was associated with a higher level of depression among carers (*Pagel et al., 1985*).

Mitigating factors for psychological wellbeing were found to be if strain and stress is thought to be short lasting, and if the behaviour of the dementia sufferer affects only limited aspects of the carer's life. The ability of the carer to cope depends in part on what attitudes are adopted, and whether the carer can gain a sense of control of the situation. These interpersonal factors play their part, but equally important is the degree to which informal carers are supported by other people, including informal support and formal services (*Morris et al., 1989*).

d- Family and social support

The level of informal support is frequently considered by professionals working with carers. A negative aspect of caregiving is the degree of restriction from social activities and resulting increase in social isolation.

This problem can be offset to some extent if the carer is well supported by other family members or their community (*Niederehe and Fruge, 1984*).

Studies of the role of social support in ameliorating careburden indicate that it is the quality of support not the quantity that is important (*Gilleard et al., 1984*).

Morris et al. (1989), administered a measure of social support derived from the *Californian Human Population Laboratory Questionnaire (Berkman, 1983)*. This measure looks in some detail at the emotional, instrumental and financial help received, and the web of social relationships that surround the carer. Carers who tended to respond positively to these questions were less depressed and felt less strain overall.

Quality of Life in Dementia

Quality of life (QOL) is a general term applied to the totality of physical, psychological, and social functioning (*Fitzpatrick et al., 1992*).

The *World Health Organization (WHO) (1996)*, regards health as a state of complete physical, mental, and social well being, and not merely the absence of disease.

The criteria for QOL determination are cultural, societal, highly individualistic, and dependent on time of the assessment (*LaPointe, 1996*).

QOL is a factor which takes into account all the different aspects of life which makes a person feel that life is worth living.

These aspects include:

- Physical health
- Functional status
- Psychological and cognitive sphere
- Social health

There are two types of instruments for evaluating these aspects:

- *Firstly*: general ones which measure the QOL independently of illness.
- *Secondly*: those which are specific to the illness concerned.

(Pascual- Millan, 1998).

QOL, in simple terms, means: "How good is your life for you". The answer to this question is a measure of a person's QOL. Every person's life is different, and thus the way in which each person experiences a QOL is unique. Individuals lead complex lives that have many dimensions. A QOL approach recognizes that there are many different aspects of living that may contribute to quality. QOL consists of the relative importance or meaning attached to each particular dimension of QOL and the extent of the person's enjoyment with respect to each dimension. In this way, QOL is adapted to the lives of all humans, at any time, and from their individual perspectives.

QOL needs to include the quality of the environment in which the person lives. To address this, a *quality environment* is one which:

- Provides for basic needs to be met (food, shelter, safety, social contact).
- Provides for a range of opportunities within the individual's potential.
- Provides for control and choice within that environment.

(Quality of Life Research Unit, 2008).

Assessment of Quality of Life in Persons with Dementia

The concept and emphasis on QOL in dementia has appeared in the last decade. Given that there is no treatment for the disease, the main objective is to preserve the patients' QOL (*Lucas Carrasco, 2007*).

Although QOL is an important indicator to assess multiple facets of life, the QOL of AD subjects with impaired cognitive ability due to dementia has not yet been fully investigated (*Matusi et al., 2006*).

Dementia-specific QOL is the multidimensional evolution of the person-environment system of the individual, in terms of adaptation to the perceived consequences of the dementia. Adaptation is a major outcome in studies investigating interventions aimed at improving QOL in chronic conditions. It is argued that adaptation is an important indication of QOL in people with chronic diseases and therefore also in dementia (*Ettema, 2005*).

There is a growing consensus that QOL is an important outcome for assessing the effectiveness of intervention for dementia (*Naglie, 2007*).

QOL assessment provides a format for patients and caregivers to express whether an intervention has made an important difference to the patient's life. Improvement of QOL in dementia should have high priority in care, treatment, and research (*Scholzel - Dorenbos et al., 2006*).

Most authors agreed that patients with mild to moderate dementia themselves can validly and reliably estimate their QOL (*Roick et al., 2007*).

There are numerous methods available for assessing patients with AD, or other forms of dementia. QOL assessment is unique among these methods, because the QOL concept itself includes a subjective component that is fundamental to its measurement. It could be argued that measuring QOL is just as important as measuring; disease severity, disease progression, symptom response, cognition, behavioural disturbance, and activities of daily living, when assessing the impact of disease and intervention in dementia. The subjective nature of QOL provides health care professionals

with the opportunity of incorporating the value systems of patients and their carers into their assessment (*Walker et al., 1998*).

In dementia, QOL covers the same traditional areas:

- ❑ Cognitive competence
- ❑ Capacity to carry out every day activities
- ❑ Social conduct
- ❑ The balance between positive and negative emotions

However, evaluation of QOL in dementia has its own specific difficulties, since it is often impossible to determine such a fundamental factor as the subjective well being of the patient; in which case the opinion of the person looking after the patient is essential. QOL in dementia has specific features including; external social and objective dimensions such as; behavioural competence, the opinion of the carer and the quality of the patient environment, in addition to the subjective aspects related to the patient (*Pascual- Millan, 1998*).

QOL in dementing illness comprises the same areas as in people in general. *Domains* of QOL in patients with AD include:

- ❑ Competent cognitive functioning.
- ❑ The ability to perform activities of daily living.
- ❑ Engage in meaningful time use and social behaviour.
- ❑ Favorable balance between positive emotion and absence of negative emotion.

Dementing illness can strip the person of normal indicators of personhood. Formal assessment of such QOL indicators can counteract the tendency to view QOL as irrelevant to dementing illness (*Lawton, 1994*).

Even at the later stages of AD, patients show varying rates of decline. Improved knowledge about the characteristics and progression of the disease reveals that moderately severe and severe patients cannot be regarded as beyond help and have the potential to experience varying and even high levels of QOL (*Livingston et al., 2006*).

In a study in Japan, the quality of life of 91 demented people staying at 12 care institutions was evaluated with the Quality of Life Questionnaire for Dementia (QOL-D). A positive significant correlation was observed between the QOL-D score and the professional knowledge of institution. This result indicated that the quality of life of demented people was better at institutions with staff members having more professional knowledge, indicating the importance of education of staff members and the possibility that such education improves the quality of life of the demented people (*Kazui et al., 2008*).

A study was done in Belgium to assess the sensitivity of the Alzheimer's Disease Related Quality of Life instrument (ADRQL) applied to 357 Belgian people with dementia, 36 with mild cognitive impairment (MCI), and 72 controls. Each subject was evaluated with the ADRQL, the Mini Mental State Examination (MMSE), the Cognitive Scale of the Cambridge Examination for Mental Disorders of the Elderly (CAMCOG), the Katz's ADL classification (ADL), the Instrumental Activities of Daily Living (IADL), the Behavior Rating Scale for Dementia (CERAD/BRSD), and the Clinical Dementia Rating/Modified (CDR-M). Results showed that QOL of people with dementia is inferior to that of people with MCI and controls.

A study was done in Belgium, to examine the evolution of QOL in demented subjects at base-line, one, and two years later to determine clinical variables associated with QOL. Results showed no significant modification of QOL over 2 years period, whereas results from clinical instruments showed a significant deterioration. Results suggests that QOL is determined by other variables relating to the physical and social environment of the patients (*Missotten et al., 2007*).

A study of patient and informant reported QOL, was done in Denmark. 48 patients with early AD were included, and QOL assessed with *QOL AD*. Results showed that patients with early AD generally reported higher QOL than their informants. Self reported QOL did not correlate with the MMSE score. Behavioural changes and depressive symptoms were associated with low QOL (*Vogel et al., 2006*).

A study of 198 residents of assisted living facilities in the United States, found that despite cognitive impairment, residents in assisted living were rated as having a high QOL.

Correlates of QOL were:

- ❑ Non-mood neuropsychiatric symptoms, were the strongest correlates of QOL.
- ❑ Depressive symptoms.
- ❑ Functional dependence.
- ❑ Marital status.
- ❑ Cognition.

The study suggested that because of the strong association of neuropsychiatric symptoms with QOL, special attention should be given to their recognition and amelioration (*Samus et al., 2006*).

QOL as an outcome measure was used in study in Italy, to assess the effect of deinstitutionalization policies. Participants included 1492 subjects living in 174 residential facilities randomly sampled in 15 Italian regions. Assessment included the *WHO- QOL* scale, the *Global Assessment of Functioning*, and the *Physical Health Index*. The WHO- QOL scores of residents were compared with healthy subjects (N= 65), and outpatients of schizophrenia (N= 162). Mean WHO- QOL scores of residents were similar to those of outpatients with schizophrenia, and substantially lower than those of healthy controls.

Lower scores on WHO- QOL domains were associated with:

- ❑ Schizophrenia.
- ❑ Non-affective psychosis
- ❑ Unipolar depression
- ❑ Anxiety
- ❑ Somatoform disorder
- ❑ Shorter duration of illness
- ❑ Mood symptoms
- ❑ Lower *Global Assessment of Functioning* scores
- ❑ No participation in internal activities
- ❑ Physical Health Index score

The study highlighted a marked difference between patients in residential facilities and health controls in social domain. This suggests the need of well-designed rehabilitation plans; tailored to the patients needs, to foster the development of their independence, and ultimately improve their QOL (*Picardi et al., 2006*).

A study was done in United Kingdom, to compare the views of residents with dementia with the views of staff as to their QOL, and to look at factors associated with these ratings. The QOL- AD scale was used to rate residents' and staff 's perception of QOL, of 238 residents of 24 residential homes in the United Kingdom. Results showed that, for the residents, high QOL- AD scores strongly correlated with lower scores for depression and anxiety. In contrast, better QOL as rated by staff correlated most strongly with increased dependency and behavioural problems. Staff should be aware that mood rather than level of dependency has a greater impact on residents' QOL (*Hoe et al., 2006*).

A study was done in Japan to assess if the presence of neuropsychiatric symptoms may determine the characteristics and determinants of both the patients' and caregivers' QOL. The study included 140 persons with mild to moderate AD, and was administered the Japanese Version of QOL-AD, and Neuro- Psychiatric Inventory (NPI).

The score for the 'mood factor' (apathy, depression/dysphoria) in NPI predicted the overall QOL score as determined from both the patients' and the caregivers' responses for subjects with mild to moderate AD. The score for the 'psychosis factor' (delusions, hallucinations, anxiety, agitation, disinhibition, irritability, aberrant motor activity) in NPI predicted the total QOL score as determined by the patients and the caregivers among subjects with moderate AD only (*Matusi et al., 2006*).

A study in the United States, examined the impact of neuropsychiatric symptoms in AD patients' and care givers' QOL, and assessed the relationship of caregiver distress to neuropsychiatric symptoms and caregiver QOL. 62 patients with probable or possible AD and their caregivers were assessed with the Neuropsychiatric Inventory, QOL using the *QOL- AD* scale.

Results showed that caregiver QOL was negatively correlated with distress related to agitation, aggression, anxiety, disinhibition, irritability, and total Neuropsychiatric Inventory score. Patient QOL was negatively correlated with depression. Patient reported QOL- AD ratings at different

levels of cognitive functioning were not correlated with care giver reported ratings. Authors concluded that neuropsychiatric symptoms of AD patients adversely affect both patient and caregiver QOL. These results suggest that identifying and treating neuropsychiatric symptoms in AD may improve both patient and caregiver QOL (*Shin et al., 2005*).

A study of 193 persons with mild to moderate AD, was done in the United States to find how AD patients assess their overall QOL and determine the characteristics associated with this assessment. 181 of 193 patients (94%) able to complete a single-item QOL self -rating, had less severe dementia than patients not able to complete, but some had MMSE scores as low as zero.

Most patients rated their QOL as good (35%), or very good (36%). Latino patients, patients with less education, and depressed patients were more likely to rate their QOL lower. The study showed that a single-item global rating of patient QOL, could prove useful in assessing QOL of most mild to severe stage AD patients. Affective impairment more than cognitive or functional impairment, affected more patients' QOL. Screening for and addressing depressive symptoms could improve AD patients' QOL (*James et al., 2005*).

A study was done in Japan, to investigate QOL of patients with dementia, from the patients' viewpoint, and the role of an acceptance of dementia in maintaining important and distinctive elements of QOL. The subjects of the study were 18 patients, 21 family members, and 8 members of staff at a day-care facility in Japan. Patients with dementia hoped to maintain an 'ordinary' way of life. Living peacefully, living together, living healthily, and helping each other ; were considered by patients with dementia to be the important elements of their QOL. Living happily in the present is important, but hopes and expectations for the maintenance of human values in their future lives are of greater importance in their estimation of QOL.

Through recognizing these needs, a culture and understanding of 'living with dementia' can be nurtured. A dynamic process involving the mutual acceptance of dementia in the relationships between patients with dementia, their families, and care professionals enabled elderly people to surmount their initial troubles, and to recoup and activate their former humane attitudes. Positive thinking reappeared, and new forms of relationships

emerged. The patients, their families, and the care professionals came to understand each other better, and gained the sense of 'living together'.

The process began with 'confronting' the situation, and progressed to the final stage of 'acceptance'. The patient with dementia was confronted with the dementia itself, the family was confronted with the elderly person as a human being, the care professionals was confronted with her or himself. At first the care professionals had felt a sense of social responsibility for delivering justice, but they had gradually noticed that they were themselves relieved of the strains resulting from these attitudes. Acceptance of dementia by the care professionals was important in carrying forward this dynamic process, which helps to ensure the desired QOL for the patient with dementia (*Fukushima et al., 2005*).

Social Intervention in Dementia

Over the last three decades, interest has grown in the use of psychosocial interventions for people with dementia. Empirical studies, and systematic reviews have been undertaken on a range of such interventions to examine their effectiveness (*Bates et al., 2004*).

The limited efficacy of drug therapy and the plasticity of the human central nervous system are the two main reasons that explain this growing interest in rehabilitation. Different approaches have been developed. Two main approaches are:

- *Multistrategy Approaches* (Reality Orientatation and Validation Therapy, and Reminiscence Therapy)
- *Cognitive methods*

(*Cotelli et al., 2006*)

The evidence for clinical effectiveness of cognitive rehabilitation in patients with AD is debated. Therefore, it is important to collect more evidence about the outcome of non- pharmacological therapy of dementia (*Raggi et al., 2007*).

During the last 20 years there has been an important change in thinking about dependency in elderly people and dementia sufferers in particular. This has mainly taken place in day centers or residential care, where there is a move towards assessing the needs of dementia sufferers and designing interventions that will increase independent functioning.

The approaches that have been developed have also been applied more recently in the community, where the immediate caregivers are now beginning to be offered training in specific procedures for dementia sufferers (*Miller and Morris, 1993*).

Psychological approaches tend to be presented as therapies or treatments, but in lay terms they can be seen as appropriate methods for overcoming the

disabilities of a dementia sufferer and minimizing behavioural problems that are associated with the more severe stages of the illness (*Woods, 1987*).

Attitudes to care are crucial in terms of the outcome of caregiving procedures. It has been argued strongly that dementia sufferers are not always able to make the choices that they would if they did not have dementia, but that attitudes to care should always promote the person's individuality as an adult, providing dignity and self-respect (*Holden and Woods, 1987*).

The implications of this approach is as follows:

- 1– Dementia sufferers should be accorded full respect and dignity as people with human worth and rights.
- 2– Dementia sufferers should be treated appropriately for their actual age.
- 3– Dementia sufferers should be helped to participate in good social relationships in the ordinary community (*Woods, 1987*).

Attempts to achieve these goals present a major challenge to caregiving staff and carers alike. They imply an appropriate knowledge of dementia and psychological approaches that are individual-centered. This is a challenging area, given the range of disabilities of dementia sufferers and issues that arise, from deciding whether a person should continue to drive, to attempting to increase the activity levels of a severely demented person in residential care (*Jenkins et al., 1977*).

Care of the person with dementia

A- Individual care planning

This approach has enabled carers to address the needs of dementia sufferers more specifically. Each dementia sufferer is assessed in the broadest sense, identifying their resources and abilities. A care plan is then drawn up, indicating specific goals or targets to be achieved by a person. For example, the goal for a disoriented dementia sufferer might be to find the way to the day room independently, or to ask to be taken to the toilet. This approach has been evaluated in dementia sufferers and found to be successful in terms of showing improvements in areas tackled directly by the caregiving programme (*Woods,1987*).

This approach was illustrated by *Barrowclough and Fleming (1986)*, who evaluated the training of formal carers of dementia sufferers in “goal planning”. They site the case of a dementia sufferer who was no longer having a bath since she lived alone and there was no one to remind her to do so. The goal was for her to have a bath and dry herself twice a week at the day center with verbal prompting only. This was broken down into four specific stages to achieve the goal. There was a 30 % success rate in goal plans after long-term follow up, with success more likely if the stages were designed to be congruent with the amount of time available for working with the dementia sufferer.

B- Behavioural approaches

A feature of all psychological interventions is the assumption that a person can acquire new information and learn new skills. This is precisely the area in which dementia sufferers are most impaired, so it is not surprising that this has led to a therapeutic nihilism in some (*Woods, 1987*).

a- Preserved learning abilities

Skill learning

It is the ability to learn a specific set of procedures brought to bear on a particular task. Skill memory has been investigated in AD using the *Pursuit Rotor Task*, in which the subject has to maintain a stylus in contact with a small metal target on a rotating disc. Evidence for learning is that the subject improves after several attempts at the task. Although the baseline ability to keep the stylus on the target was lower in AD, the rate of learning was the same as with normal subjects (*Eslinger & Damasio, 1986*).

Verbal learning

It is frequently tested by giving the patient a series of word pairs (e.g. School, groceries), followed by the first word of each pair. The person is required to produce the second word of the pair. By repeating the test several times using the same items, the efficiency of verbal learning can be determined.

Patients with dementia have been found to do extremely poor on this test, taking many trials to learn an association. However, if the word pairs are semantically related their performance is much improved. It was found that learning of semantically related word pairs remains relatively preserved over time, contrasting with a deterioration in the learning of unrelated word pairs (*Little et al., 1987*).

b- Self care

A feature of most institutions that care for dementia sufferers is that they aim to maximize self care. This is sometimes difficult to achieve because of

the often quoted problem of it appearing to take longer to encourage a person to do a task than for the carer to do it themselves. Institutions can be structured not so much to teach new skills but to facilitate the use of old ones (*Baltes et al., 1983*).

Melin and Gotesdam (1981), reported a hospital; regime in which the dementia sufferers were given unlimited time to feed themselves with a large choice of food and accompaniments. This clearly led to an improvement in eating skills, compared to the old regime of limited choice and staff feeding the dementia sufferers if they took more than an allotted time.

In an earlier study, a more active form of intervention was described by *Rinke et al. (1978)*, who targeted 'bathing' as a skill, breaking it down into five components; undressing, soaping, rinsing, drying and dressing. Each component was prompted verbally (a reminder) or physically (demonstrating what to do, or handling the resident an item such as soap). The dementia sufferers were also given praise and a wall chart for visual feedback of progress as a reward for appropriate responses to a certain level. This programme was sufficient to bring about a significant improvement in each component, in comparison to dementia sufferers who were not given the same regime.

Urinary incontinence is a condition with numerous psychological and medical and medical implications for dementia sufferer. Estimates for prevalence range from 38 to 82 % in long- term care setting, depending on the degree of functional disability displayed by patients. The goal of incontinence programmes has been to establish independent toileting behaviour. The main technique has been to check regularly for dryness and then to prompt the patient to go to the toilet when necessary. Gradually the prompts are faded until the person responds appropriately by visiting and using the toilet (*Burgio et al., 1990*).

Independent toileting may be too high a goal in the case of dementia patients whose cognitive and physical disabilities are too severe. A complex set of skills is required, such as dressing / undressing, finding the toilet, mobility and planning ahead. For this reason, many programmes have concentrated on either teaching patients request assistance from staff when the need to void exists or training staff to regularly toilet patients (*Schnelle et al., 1988*).

Schnelle et al. (1983) used an hourly prompting technique that involved checking the patient's clothing and body to determine whether they were wet or dry and cueing the patient to request assistance to use the toilet. Social approval, such as praising the patient in an adult manner, was given for dry checks or appropriate requests for assistance. Conversely, social disapproval, such as indicating disappointment, was given for wet checks. This increased the frequency of correct toileting by approximately 45 % in a group of 11 dementia sufferers.

A critical aspect of establishing continence, however, is the degree to which staff members will assist patients in toileting. *Schnelle et al. (1988)* found that the care staff in the homes they studied assisted their patients an average of 0.49 times per day.

A modification of this procedure has been reported by *Burgio et al. (1988)* who argued that toileting more than every 2 hours is not practical and that even 2- hourly toileting may only be practical as an intervening measure. Accordingly, over a period of 4 months they gradually increased the intervals between prompts up to 4 hours, proceeding if the dementia sufferer improved. By 'thinning out' the schedule they were still able to increase dryness from 30 % of clothes checks during a baseline period to 62 % during the training phase.

c- Activity

Low levels of purposeful activity can be a feature of institutional care in the elderly, particularly for patients with dementia. The emphasis on physical care and activities of daily living is not always easy to match with alternative recreational or social activities. Increases in the level of interaction in old people's home can be obtained by providing regular recreational sessions. During these sessions the residents are given the opportunity to use various extra recreational materials (*Rothwell et al., 1983*).

In an earlier study, *Melin and Gotesdam (1981)* trained staff to use group activity sessions to encourage dementia sufferers to use recreational materials. They found, through direct observation of their behaviour, that the level of activity increased in the week following the sessions without further encouragement.

d- Behavioural problems

Troublesome and disruptive behaviours are a very frequent component of dementia, concurrent with the intellectual impairments. These include:

- Physical and verbal aggression
- Paranoid thoughts
- Disordered sleep
- Wandering
- Purposeless and repetitive activity

(Swearer et al., 1988)

Hussian and Brown (1987) has used stimulus control and operant to modify problem behaviours such as wandering and self stimulatory behaviours. This involves identifying the environmental cues for the behaviour and providing a system of rewards for appropriate behaviour, mostly in the form of social reinforcement.

Greene et al. (1982) taught carers to ignore their partner suspicious and accusatory verbalizations while reinforcing through praise and touch, their appropriate verbalizations. In addition, the partner was trained to ask questions in order to encourage appropriate behaviour and then reinforce responses through touching, praising and smiling. These relatively simple procedures, when structured in this fashion, were able to change significantly the aversive behaviour of the dementia sufferer from a baseline level. This approach relies on careful targeting of specific behaviours, tailored to the individual.

Tab (7)

C- Memory management

Memory rehabilitation

One of the main approaches used in neuropsychological rehabilitation is *memory management* or *memory retraining*. This approach, which consists of the systematic use of diary keeping or mnemonics has been found to be useful in patients with mild degrees of brain injury. The same techniques can be used with dementia sufferers at the early stages of their illness, when the degree of cognitive impairment is mild. For example, a dementia sufferer can be encouraged to use a diary to record daily events, telephone calls or appointments that someone without a memory disorder would not need to record (*Wilson, 1987*).

Hill et al. (1987), reported the use of imagery mnemonic training with a patient suffering from AD. This consisted of the repeated presentation of yearbook photographs paired with the corresponding name. A mnemonic was used, which involved identifying a prominent facial feature and creating a visual association with the name. The patient was able to learn this mnemonic technique to improve memory performance. The technique works particularly well if the person is encouraged to draw the association.

More impaired dementia sufferers cannot master these techniques or strategies, and would not remember when to use them. Hence the majority of rehabilitation approaches with dementia sufferers are pitched at a more basic level of cognitive functioning. Instead of training the person in a technique, either the environment is structured to decrease memory requirements, or the approach is directed to teaching information or changing the person's behaviour (*Wilson, 1987*).

Reality orientation

Reality Orientation (RO), originated in North America in the 1950s. it has been defined as an approach which may decrease confusion and dysfunctional behaviour patterns in people with dementia (*Patton, 2006*).

It began as a programme of activity for elderly patients at the *Veterans Administration Hospital* in Topeka, Kansas. It was developed as a means of orientating a person to their environment by means of continuous stimulation. In addition, an explanation of the therapy was given, as a means of stimulating unused neurological pathways and compensating for organic brain damage. Those who use the programme tend to support it on the base that it improves the quality of life for dementia patients, and has provided a coherent treatment package for caregiving staff (*Holden and Woods, 1987*).

It is generally agreed that RO may be delivered in two ways:

- *Firstly*: through constantly orientating patients to time, place and person. (24- hours Reality Orientation)
- *Secondly*: through orientating patients to reality within a group setting.

(Patton, 2006)

a- Classroom Reality Orientation:

It involves three to five patients meeting for at least two sessions a week. Usually the sessions last for half an hour, depending on the abilities of the dementia sufferers. At a basic level, the group concentrates on learning each other's names through the use of verbal prompts and name badges. The group leader prompts the participants to provide basic information about the day, date and weather, tactfully giving the correct information when necessary. With more able dementia sufferers, the approach is extended to include personal information about group members and complete features of the past and present; for example a common theme is changes in prices. Comparisons of the prices of food can be used to orientate the participants to current costs.

Similarly, newspapers, slides, or a short films can all be used to stimulate discussion about the present. In more advanced groups, the group determines the activities, where possible, with basic orientation information extended towards awareness of world news and the local community. These groups operate at a much higher level and include cooking, shopping, outings and music. They are only recommended for dementia sufferers who are functioning fairly independently in the community (*Holden and Woods, 1987*).

b- 24- Hour Reality Orientation:

In contrast, 24- hour reality orientation is designed as a means of communicating with the dementia sufferer, used throughout the person's waking hours. The approach is two-fold, firstly to restructure the environment of a person to improve orientation, and secondly to enhance orientation by communicating directly with the dementia sufferer. In every day conversation, the person is reminded of their name, where they are, the time of day, and current events in their surrounding. The aim is also to correct confused speech and actions and to prompt or encourage appropriate behaviours.

The approach is supplemented with changes in the physical environment to improve orientation, such as clocks, calendars, signs and pictures. For example, the staff ensure that there are signs that indicate where the dining rooms and toilets are, as well as a prominently placed information board. There is evidence that some patients may sometimes perceive symbols better than words, which suggests that both types of cues should be used (*Hanley, 1984*).

c- Ward Orientation Therapy:

Some have used a variation of 24-Hour Reality Orientation, termed Ward Orientation Training. This is a systematic attempt to combine the interpersonal and environmental approaches. In essence, the dementia sufferer is trained to use the environmental cues in a more active fashion. For example, large pictorial signposts may be placed round the ward which clearly label particular areas. The staff then accompany a dementia sufferer round the ward and train the patient to observe the signs (*Hanley et al., 1981*).

Hanley (1986) described the case of an 85- year old female patient who was incontinent, despite the introduction of a 2- hourly toileting regime in which she was taken to the toilet. A programme was established in which the two ward toilets were clearly sign- posted with large symbol and word signs. The dementia sufferer was prompted hourly to use the toilet by asking her if she would like to use it, with minimal assistance given to help her find the toilet on her own. She was cued when necessary with helping instructions. The programme substantially reduced the frequency of incontinence and could be reduced to 2-hourly toileting reminders.

Lam & Woods (1986) identified eight target locations thought to be important for an 80- year old female patient on a ward including her bedroom, bathroom, toilet, dayroom, dining room and ward-orientation board. A simple training procedure was implemented in which the patient was required to move to the locations from a fixed starting point. Verbal prompts and physical prompts (showing the person where the location was) were given only if the dementia sufferer failed, but otherwise social reinforcement was given when the target was found. The success of the training programme was interesting that when the dementia sufferer was relocated to a home, the staff were encouraged to implement a similar programme.

A study in Ireland was done to see how psychiatric nurses use RO and perceive its effectiveness in older person mental health care. The study included six psychiatric nurses practicing in an older person mental health care inpatient unit, who took part in indepth semi-structured interviews. These six nurses all practiced upon the same older person care unit, in psychiatric hospitals in Dublin, Ireland. *Upon analysis, interview data yielded the following:*

1. RO means interacting with patients about the patient's current environment, and issues in their situation.
2. The sampled nurses use RO frequently in their nursing work, with RO being most often used in the mornings and evenings.
3. RO is implemented through interacting with the patients. It may also be implemented as part of other approaches, such as occupational therapy.

4. Improvements in the areas of orientation and behaviour functioning may be possible through the use of RO.
5. Participants talked of the need for psychiatric nurses practicing in older person settings to become more aware of what RO entails as an approach.

Psychiatric nurses practicing in older person care environments often have to provide care to persons having difficulty comprehending reality. Participants in this study identified RO as an approach which can help older persons experiencing mental health problems such as AD, to cope with not being able to comprehend and recognize their surroundings. RO also facilitated a greater level of orientation, for older persons with mental health problems (*Patton, 2006*).

A study in Italy, reported data concerning the rehabilitation of 50 patients with probable AD, admitted during a 17- month period in a specialized unit. Participants were affected by dementia rating from mild to severe. The patients were treated with RO therapy, integrated, when needed, with individualized cognitive approaches. The results concerned the cognitive status evaluated by *Mini- Mental State Examination* (MMSE), the functional status, evaluated with the *Activity of Daily Living scale* (ADL), and the assessment of psychological and behavioural disorders, measured with the *Neuropsychiatry Inventory* (NPI). The cognitive, functional, and psychological assessments were administered at admission and discharge.

Results showed that the mean MMSE scores at admission and discharge were respectively 16.06 and 17.54 ($P= 0.005$). The mean ADL scores were 4.86 at admission and 5.02 at discharge ($P= 0.011$). Mean NPI scores were respectively 21.46 and 12.26 ($P< 0.001$). This survey of the 17- months experience suggests that a comprehensive treatment program may have beneficial effects on cognitive, functional, and in particular neuropsychiatric outcomes (*Raggi et al., 2007*).

D- Reminiscence

Increasingly, reminiscence therapy is being used as an alternative to reality orientation for dementia sufferers. Reminiscence is believed to be effective in improving the cognition and mood of demented people (*Wang, 2007*).

The approach was originally developed by *Butler (1963)* for elderly people without dementia and thought to provide opportunity to review and organize events in their life. It is usually conducted in a structured group setting and used to prompt memories from the past. This approach has some intuitive appeal with dementia sufferers because it focuses on the person strengths; which are their ability to use their remote memories as a way of communicating with other people. The approach is clearly popular amongst occupational therapists who work with dementia sufferers. Part of this may be because it concentrates on the individual as a person and attempts to capitalize on preserved functioning.

Robert Butler and others have noted the universal tendency of the aging person to reflect on, and reminisce about, the past. Reminiscence is characterized by the progressive return of memories of past experiences, especially those that were meaningful and conflictual. To varying degrees, elderly patients in therapy reminisce about the past, search for meaning in their lives, and strive for some resolution of past interpersonal and intrapsychic conflicts. *Life review therapy* systematically enhances this reminiscing process and makes it more conscious and deliberate.

The therapist may guide the process by encouraging the patient to write or tape a biography with review of special events and turning points. Techniques include reunions with family and good friends and looking through memorabilia, such as scrapbooks or picture albums. This technique has reported to resolve old problems, increase tolerance of conflict, relieve guilt and fears, and enhance self-esteem, generosity and acceptance of the present (*Jarvik and Small, 2005*).

Specific procedures have been designed to elicit memories such as the *Recall* package, which consists of six sets of slides with accompanying commentaries (*Help the Aged, 1981*).

Baines et al., (1987), has used the *Recall* package with dementia sufferers, in conjunction with old photographs of local scenes, personal photographs, books, magazines, newspapers, and domestic articles. This material was used to encourage the dementia sufferers to think and talk about past experiences.

Head et al. (1990) used a similar approach, in which three group leaders would use pictures of specific relevance to the members in order to cue memories from the past. They also used a technique called 'enactment' in which the person had to act out their past experiences, such as being a waiter/ waitress or using a washboard. This technique was used to encourage enthusiasm and interest and minimized some of the difficulties associated with hearing problems and concentration difficulties. Another approach used in their study was to use memorable objects, such as old kitchen equipment and articles of clothing to provoke responses and discussion.

In a similar study, *McKiernan and Bender (1990)* decided on a theme for each session and focusing for 15 minutes on a variety of illustrative materials, including music, objects, pictures and slides. They broke up the group into subgroups on occasions to increase the dementia sufferers' opportunity to speak to each other.

A study compared reality orientation with reminiscence therapy including three groups of dementia sufferers. One received no therapy, another received reminiscence first and the final group received reality orientation first. The group with reality orientation followed by reminiscence showed a significant improvement on a range of behavioral and cognitive measures including the *Holden Communication Scale* and the *Clifton Assessment Battery for the Elderly*. The other intervention group showed no such improvement on long term follow up, after an initial improvement during the reality orientation.

The difference was interpreted as indicating that skills learned during reality orientation, such as talking about current events and comparing the good and bad aspects of the past and present, enabled the dementia sufferers

to benefit from the subsequent reminiscence therapy. It helped them to focus on positive past memories, avoiding potentially upsetting memories.

This result suggests that, to benefit from reminiscence therapy, patients and staff need to be given prior training or 'induction' into the procedures used. It was notable that whilst reality orientation tended to decrease the life satisfaction of the dementia sufferers, reminiscence tended to lead to an increase. The contrast can be drawn between confronting dementia sufferers with unfavorable life situation and enabling them to enjoy memories concerning past experiences (*Baines et al., 1987*).

A study was done in Hong Kong, to find whether a specific reminiscence program leads to higher levels of psycho-social well being in nursing home residents with dementia. The study included 101 subjects; the intervention group (n= 30) adopted a life-story approach, while the comparison group (n= 35) provided friendly discussions to control for any changes in outcome as a result of social contacts and attention, and a control group (n= 30). The *Social Engagement Scale* and *Well being / Ill being Scale* were the outcome measure used. The outcomes of the groups were examined with reference to the baseline, immediately after intervention, and six weeks after intervention.

Using multivariate analysis with repeated measures, no significant differences in outcome were found between groups after intervention. Significant differences were observed in the intervention group, in the *Well being / Ill being scale* score measured immediately after intervention, but not for other groups. Results showed that although the intervention did not lead to significant differences between the three groups overtime, there was a significant improvement in psychosocial wellbeing for the intervention group (*Lai et al., 2004*).

A study was done in Taiwan to test the hypothesis that structured group RT can prevent the progress of cognitive impairment and enhance affective function in the cognitively impaired elderly. The study included 102 subjects; 51 in the experimental group, and 51 in a control group. The experimental subjects underwent eight group sessions, once per week. Measurements were done using MMSE and *Cornell Scale for Depression in Dementia* (CSDD).

Results indicated that intervention affected cognitive function and affective function as measured by MMSE and CSDD ($p= 0.015$ and 0.026) respectively; indicating improvement in cognitive function and decrease in depressive symptoms. The study showed that participation in reminiscence activities can be a positive and valuable experience for demented elderly persons (*Wang, 2007*).

In summary, reminiscence therapy can be seen as an appropriate approach for dementia sufferers and has been shown to have beneficial effects. As with reality orientation, there is the tension for care staff, between spending more time talking to residents and doing domestic activities and taking care of the physical needs of residents. Nevertheless, reminiscence does seem to have the added advantage that many people, including care staff, perceive it as an enjoyable activity with a personal focus (*Head et al., 1990*).

E- Cognitive stimulation therapy

Cognitive stimulation therapy (CST) is a brief treatment for people with mild to moderate dementia. It is based on the theoretical concepts of reality orientation and cognitive stimulation. It involves 14 sessions of themed activities, which usually runs twice a week over a 7 weeks period (*Spector & Orrell, 2006*).

Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment, and the social benefits of a group. CST treatment can be administered by any one working with people with dementia, such as care-workers, occupational therapists, or nurses. CST groups can take place in settings including residential homes, hospitals, or day centers (*Spector, 2007*).

A multi-center randomized controlled trial in the United Kingdom, of 201 older people with dementia, showed that CST when compared to no treatment, led to significant benefits in cognition and QOL (*Spector et al, 2003*).

CST is also cost-effective, and benefits in cognition are comparable to those gained through medication (*Spector & Orrell, 2006*).

F- Validation therapy

Validation Therapy (VT), is one of the best known psycho- social treatment for elderly affected by dementia. Notwithstanding its wide use, its efficacy is still a controversial issue, especially in comparison with other approaches (*Deponete and Missan, 2007*).

Validation therapy arose out of a reaction to the insensitive use of reality orientation. The inventor *Naomi Feil* grew up in a residential home for the elderly in Cleveland Ohio, where her parents worked and where she saw some negative consequences of reality orientation such as dementia sufferers being confronted with the reality of their illness and situation. In response she developed an alternative approach that involves listening with empathy to whatever dementia sufferers are trying to communicate about their current feelings.

The aim is to ‘validate’ what is said, rather than correcting factual errors, in order to establish a dialogue with the dementia sufferer. For example, if an elderly dementia sufferer says that someone is coming soon, then the response is not to correct the person but to empathize with their feelings of loss and insecurity (*Feil, 1982*).

Validation therapy has been widely used both as a way of communicating with dementia sufferers and more formally within a group setting. The aim is to make the members feel as comfortable as possible. In a weekly group the members are welcomed, followed by a group song and then discussion on a topic. The group finishes with a ritual thanking of members, a closing song and refreshments. Such roles as song-leader, welcomer, and host are encouraged within the group. The topics covered include those reflecting universal feelings such as anger, separation and loss, with the aim of allowing members to verbalize unresolved feelings and conflicts about their families or loss of role, home and faculties (*Bleathman & Morton, 1988*).

A pilot study explored the amount of verbal interaction between five dementia sufferers who attended group Validation Therapy over a period of 20 weeks. Compared to baseline level there was no overall increase in the degree of interaction between participants during Validation Therapy. However, it was noted that there was variability in the data, such that two showed a marked increase, and another two showed a marked decrease (*Morton & Bleathman, 1991*).

A study in Italy, of 30 elderly subjects in a nursing home compared the effects of VT, reminiscence, and no treatment on cognitive, functional, and affective status of the participants. The results indicated an improvement in the global functioning of the two treatment groups, compared to the control group, but the differences did not reach statistical significance.

Reminiscence was the most effective in improving cognitive, affective, and behavioural status; the VT group showed a reduction of the behavioural disturbance; the participants at the control group demonstrated a slight deterioration at all the three levels. Considerations are made about the implications of VT for the caregivers, as possible mediator of its effect on the elderly (*Deponte & Missan, 2007*).

VT has been applied since 2001 in Bologna, Italy, in a public trust, housing over 500 not self-sufficient elderly people. Around 75% of these

subjects suffer from cognitive impairment, associated to behavioural and psychological symptoms of dementia (BPSD) in over 35%. To assess the effectiveness of VT, a study was carried out involving 50 subjects divided in two groups; of cases and controls, made up by 27 and 23 patients, respectively. In both groups Neuropsychiatry Inventory (NPI) and the Bedford Alzheimer Nursing Severity Scale (BANSS), were used before the start and after the end of the study; where the case group underwent both individual and group VT.

The results showed a marked decrease of the average NPI symptom score in the case group (from 22.0 to 9.5) vs. a rise in the control group (from 21.7 to 24.1). agitation, apathy, irritability, and night time behaviours were the most improved NPI items among the subjects who underwent the VT. In these patients cases group, the NPI distress score turned out reduced, vs. a small increase in the control group. In the case group an improvement occurred with the BANSS too, even if much slighter changes were registered vs. the control group. The study suggested that VT is able to reduce the severity and frequency of BPSD, thus improving the relationship with and the management of patients having diagnosis of dementia without any side effects (*Tondi et al., 2007*).

In summary;

The different psychological approaches to the management of dementia sufferers have been reviewed above. The different forms of management described apply mainly to dementia sufferers in institutional care or day centers or hospitals, but there is no reason why they should not be adapted by informal carers in the community (*Morris, 1991*).

Pinkston and Linsk (1984), described how behavioural approaches have been applied in family settings, with training given by professionals.

The studies showed that the behaviour of dementia sufferers can alter in a positive fashion in response to the correct type of intervention. However, an underlying theme is that changes, such as increased activity, orientation and self-care skills will only be maintained with a continued input from carers. Sometimes it take extra effort to prevent problems developing later on. Thus the same amount of input, in terms of caregiving, if strategically placed can be used to produce a more desirable outcome (*Morris, 1991*).

Another underlying theme is that approaches must be tailored to individual dementia sufferers who may or may not benefit from a particular approach. For example, Reality orientation may make one person distressed, but be seen as pleasurable by another person. The same applies to Reminiscence therapy, which might consistently stir up unpleasant memories, or alternatively provide a relaxing activity which adds to the dignity of a person. To this extent a goal planning approach will help to ensure that each dementia sufferer is treated as an individual (*Barrowclough & Fleming, 1986*).

G- Educational and support groups

An increasingly popular way of supporting carers is to bring them together for a series of meetings, either educational or support groups. The meetings can be professionally or peer lead and can be time limited or continuous with members joining and leaving the group over time. The focus of these meetings varies substantially, providing education about dementia, training carers in how to manage the sufferer's disturbed behaviour and providing an opportunity for carers to be mutually supportive. It provides a vehicle for carers to express their hopes, fears, disappointments, worries and problems, and to share alternative methods of coping. In common with all successful groups, the meetings aim towards cohesiveness and should instill a sense of hope and common purpose in which the carers can learn from their experiences (*Yalom, 1975*).

a- Information

Information about dementia can be provided by professionals or experienced carers and supplemented by providing simplified literature about dementia. Areas that should be covered include the causes of illness, the effect of the illness the sufferer's behaviour, and the types of help available from community resources. Information groups are found in some centers, in which different professionals speak to the group in turn, each concentrating on their sphere of knowledge. These include a social worker, a community psychiatric nurse, a psychiatrist, a psychologist and a full-time worker from a voluntary organization that supports carers (*Morris et al., 1992*).

Information about the nature of dementia is particularly important because it enables carers to make sense of the disturbing behaviour of the dementia sufferer. Carers also need to gain confidence in coping with problems, and in this sense professionals can affirm positive ways of managing and tactfully suggest alternative methods where necessary. Information about community resources can also be imparted by professionals, but often the experience of informal carers is equally useful, being the consumers of services. In this regard, it can help to have carers at the different stages of the caregiving process included in group meetings (*Morris, 1986*).

b- Enhancing coping strategies

Carers often express the need to feel that their role is recognized by other people and that their experiences are validated. A way of facilitating this in a group is to encourage the passing on of management skills between the members of the group. The problem-solving approach provides a useful framework in which together, carers can explore solutions to the problems that they are facing.

This approach has been adapted specifically for carers of dementia sufferers by (*Zarit & Zarit, 1982*), (*Zarit et al, 1985*). The basis for this approach is drawn from the work of *D’Zurilla & Goldfried (1971)*, and involves enabling the carers to identify and describe specific problems, generate and evaluate a plan of intervention, and then implement and evaluate the plan. In a group setting, the participants can pool their knowledge and resources to provide ways of tackling problems, thus providing support for each other (*Toseland et al., 1989*).

A specific course incorporating the problem-solving model is outlined in table (8). A feature of the course is to apply problem-solving methods to specific aspects of caregiving, starting with identifying and managing problem behaviour, and proceeding to stress management techniques and ways of exploring the need for informal or formal support. The ideal size for groups of this type is approximately seven, allowing each member enough time to explore their own problems with the group as a whole. Specific problem-solving techniques are used by the facilitator, such as getting the group to list the ‘pros’ and ‘cons’ of a particular plan of action and encouraging members to try out solutions at home, reporting back at the next session.

Each group member is debriefed individually by a course facilitator, in order to provide practical information that has been overlooked in the group. It also enable the facilitator to monitor levels of emotional strain and the development of coping strategies, as a way of evaluating the efficacy of the group. In practice, these types of groups appear to encourage carers to adopt new approaches and learn from the experiences of other participants (*Morris et al., 1992*).

Tab (8)

A more intensive approach has been to use a highly structured 10- day residential programme for dementia sufferers together with their carers. Up to four dementia sufferers and their respective carers are admitted into hospital at any one time. The dementia sufferers receive memory retraining whilst the carers are given intensive education, group therapy, training in management skills and extended family therapy sessions that involve other members of the dementia sufferer's social network.

This programme has been noted to produce long-lasting increases in psychological wellbeing in the carers, over and above the waiting-list controls, and to reduce the level of admission of dementia sufferers into residential care. Such approaches may be costly in the short term, requiring more resources than running support groups, but in the long term they are justified by reducing the need for institutionalization (*Brodaty & Gresham, 1989*).

c-Psychotherapeutic orientation

One of the criticisms of groups that focus on management skills or coping strategies is that they ignore the emotional needs of carers. The main emotional adjustment stems from the losses associated with the onset of dementia, both in terms of loss of a relationship and loss of hitherto enjoyable and pleasurable activities.

This loss can result in feelings of anger, frustration and guilt, as well as despair concerning the future. In addition, carers are often challenged with the need to redefine their role and adjust their own priorities, in order that caregiving be a time for personal growth. Carers may need an emotionally

supportive environment where they can share their feelings openly with other people (*Toseland & Smith, 1990*).

Psychotherapeutically orientated groups have had mixed results, partly because carers within the group may be at different stages of adjustment (*Wasow, 1985*).

The sharing of emotions and subsequent perceptions of support was felt to be beneficial overall. However, individual expressions of anger and grief could have a negative effect on other group members, leading them to feel more depressed and less able to cope. Strong negative feelings that are expressed but not understood can overwhelm and threaten to destroy the cohesiveness of a group. To balance the increasing awareness or sense of despair created by the person's illness, groups which explore emotions should focus on curative factors such as support, education and inspiration of group members (*Schmidt & Keyes, 1985*).

d- Evaluation of groups

Formal evaluations of groups have tended to indicate positive results, both in terms of changes in carer emotional wellbeing and in high levels of consumer satisfaction. Carers reported an increased sense of control over their situation and felt that the group had helped them cope with specific problems. Carers showed an increase in knowledge concerning dementia, and a decrease in either burden or improvements in levels of psychological wellbeing. These studies encompass a variety of approaches including support, provision, and a skills training focus (*Zarit et al., 1987*), (*Whitlatch et al., 1991*).

There was reported improvements in personal coping, in addition to other psychological changes. These included greater balance between caregiving and other family responsibilities (*Toseland et al., 1989*).

However, the improvements found in one study for groups or individual counseling were no greater than for the waiting list controls. These carers in the waiting list reported the same improvement in managing the dementia sufferer's behaviour and increased assistance in home help and use of day care. It may be that the decision to seek help, combined with the initial

interview by those conducting the study, was sufficient to produce the change observed in carers who attended the groups (*Zarit et al., 1985*).

Studies that did not report positive changes in psychological wellbeing nevertheless found high levels of satisfaction with the groups. Typical of aspects they found helpful were :

- Learning that the problems were not unique.
- Having the chance to meet people with similar problems.
- Finding out how others are dealing with problems.
- Learning about available community resources.
- Gaining information about medical aspects of dementia.

High levels of consumer satisfaction, in the absence of objective change in behaviour, may reflect the perceived usefulness of the groups, but low impact in relation to other potent influences in the carers lives (*Haley, 1989*).

H- Educational Intervention in Dementia

The term *psychosocial* refers to social and environmental elements in an individual's life that interact with his or her intrapsychic processes. Such elements may be conceptualized at two levels;

- *The Intermediate Level* of factors arising within the immediate environments of the patient (e.g., friendship and family relations).
- *The Macro Level* of society and cultural norms (i.e., societal attitudes, culture and ethnicity).

The intermediate-level elements are more amenable to therapeutic interventions, whereas the macro-elements are less changeable but must be recognized and understood during therapy.

The *intermediate-level factors* include;

- Relationships
- Role changes
- Economics
- Environment
- Finances
- Spiritual matters
- Societal attitudes
- Ethno-cultural factors

(Sadavoy et al., 2004)

Family intervention with older adults

It is the process of bringing two or more family members together (often from multiple generations) to address problems encountered in the later stages of the family cycle. At the simplest level, family intervention provides education about the unique medical, psychological, and social challenges of aging as they affect the older adult and family. Family intervention also may facilitate communication among family members regarding age-related concerns, but it does not involve intentionally changing the way the family function. During the initial sessions, the therapist evaluates the family's unique strengths and vulnerabilities, including;

- *Life cycle transitions* faced by the family and by individual family members, e.g., onset of chronic degenerative illness.
 - *Individual roles* assumed by family members.
 - *Family relational processes*; that is, quality of attachment, caregiving bonds, communications, and problem solving.
 - *Ethnic or cultural factors*, including spiritual beliefs and practices.
- (McDaniel et al., 2001)*

Levels of Intervention

The family assessment should determine whether the intervention will most appropriately be psycho-educational, with a focus on sharing of information relevant to a late-life problem or illness; or therapeutic, with a goal of changing the family's structure and quality of relational functioning (*Shields et al., 1995*).

i- Psychoeducational intervention and community referral

Families who exhibit solid attachment bonds, open communication, and good problem-solving skills congruent with their stage of life cycle development do not require ongoing therapy but benefit from brief education and consultation regarding a specific late-life problem. E.g., when older adults develop Alzheimer, families benefit from information specific to the disorder and its management as well as referral to community agencies and support groups.

Usually, these families then can organize themselves for effective problem solving regarding the care and support for older adult. In the case of chronic, deteriorating illnesses, the family may benefit from brief, intermittent contact with the therapist at those transition points when the disease worsens. As pleasant and rewarding as these families are to work with, the therapist must recognize that typically they do not need regular, ongoing professional support.

ii- Restoring effective problem solving

Often, families have solid, positive bonds of attachment with good communication skills and a history of effective problem solving, yet they temporarily are overwhelmed by the intensity and unfamiliarity of a late-life problem, such as severe illness and functional decline.

Effective problem solving may be temporarily hindered because of sudden disequilibrium in the previously stable family structure. The family may need to reorganize lines of authority and decision making to bring them into accord with the demands of a later life transition.

iii- Improving patterns of communication

Some families who care deeply about each other and have solid bonds of attachment communicate little about serious problems. Others have been able to function with little overt communication in earlier stages of the life cycle, because they were not confronted with major loss, medical illness, or cognitive decline.

When faced with the challenges of aging, they have difficulty developing a common understanding of the problem and thus cannot work collaboratively to find and carry out solutions.

Families at these level benefit from active modeling of open communication, as well as firm structuring of negative or critical communication. Basic communication techniques, such as active listening, can greatly benefit these families, as can clear and consistent modeling of how to talk openly but respectfully about the problems of aging.

iv- Improving bonds of attachment and caregiving

Families with negative, weak, or ambivalent bonds of attachment typically have a history of conflict, marginal functioning, or insufficient nurturance between family members. These families may require referral to professional caregivers or long-term care facilities. The technique of family

life review can be used to induce empathy for the elder's position, thereby decreasing negativity.

Family life review is the process of bringing multiple generations together to invent a coherent intergenerational family story. Typically, this process is facilitated by constructing a *family genogram*, which is a graphic, multigenerational picture (family tree) that encapsulates family history, structure, and relationships overtime.

Indications

Most serious health problems of older adults are more successfully addressed when family members are involved in treatment. Although caution and clinical judgment must be exercised as to the type and timing of family interventions, substantial evidence indicates that psychiatric problems worsen or resolve less completely when conflictual or chaotic family environments are not addressed in treatment.

A range of interventions is focused specifically on caregivers of older adults with dementia. These include;

- 1- *Psychoeducational interventions* (focused on provision of information about late-life diseases, as well as training caregivers to manage problem behaviours).
- 2- The provision of *respite care*.
- 3- Professionally and peer-led *family support groups*.
- 4- *Cognitive behaviour psychotherapies* focused on the reduction of caregiver distress and burden.

The latter, may teach caregivers to monitor and challenge negative thought pattern, facilitate caregivers' problem solving abilities, and help caregivers reengage in pleasant activities. Research indicates that these interventions and therapies have positive effects on a variety of caregiver outcome variables and are associated with delayed nursing home placements of older adults with progressive cognitive disorders (*Carter & McGoldrick, 1999*).

The typical goal of these interventions is to improve a spouse's general ability to cope with the illness, or to help families find a balance between focusing on the illness and focusing on other family needs. There is some evidence that these interventions improve physical and mental health outcomes, but more research is needed to confirm these findings.

A meta-analysis of the results of studies of these interventions showed that they were able to produce statistically significant improvement in caregiver knowledge of the illness and ability to provide care and to alleviate depression and burden. Although there was a great deal of variability in effectiveness within each category the *psycho-educational* and *psycho-therapeutic* were the most consistently effective.

These interventions tended to focus on emotions, isolation, difficulties managing patient behaviour, and reducing the physical burden of care. Psycho-educational interventions also can potentially alter caregivers' appraisals of their ill relative's behaviour by improving knowledge, beliefs and skills related to caregiving.

Individual interventions are more effective than group interventions, probably because they are more able to adapt to the specific needs of the people that they are designed to help. Adult child-caregivers generally benefit more than spouse-caregivers. This may be partly because they become involved in caregiving with less information and experience than spouse-caregivers and are able to profit more immediately from the educational aspects of the interventions (*Kennet et al., 2000*).

Professional knowledge about dementia and care methods is necessary for the appropriate care of demented people (*Kazui et al., 2008*).

A range of psychosocial approaches can be offered, primarily targeted at the family. Although the evidence on interventions to support families is mixed, the conclusion from major studies is that a combination of family meetings and peer support is effective in reducing care-giver strain and delaying institutionalization, and that the best outcomes are achieved by multidimensional interventions individually tailored to carer needs (*Woods et al., 2003*).

Gitlin et al. (2008), studied whether a *Tailored Activity Program (TAP)* reduces dementia-related neuropsychiatric behaviors, promotes activity engagement, and enhances caregiver well-being. Two-group (treatment, wait-list control), randomized, controlled pilot study with 4 months as main trial endpoint. At 4 months, controls received the TAP intervention and were reassessed 4 months later. Sixty dementia patients and family caregivers were enrolled. Eight-session occupational therapy intervention involved neuropsychological and functional testing, selection, and customization of activities to match capabilities identified in testing, and instruction to caregivers in use of activities were given.

At 4 months, compared with controls, intervention caregivers reported reduced frequency of problem behaviors, and specifically for shadowing and repetitive questioning, and greater activity engagement including the ability to keep busy. Fewer intervention caregivers reported agitation or argumentation. Caregiver benefits included fewer hours doing things and being on duty, greater mastery, self-efficacy, and skill enhancement. Wait-list control participants following intervention showed similar benefits for reductions in behavioral frequency and caregiver hours doing things for the patient and mastery. Caregivers with depressed symptoms derived treatment benefits similar to non-depressed caregivers.

Project ACT is a randomized controlled trial designed to test the effectiveness of a non-pharmacological home-based intervention to reduce Behavioral and Psychological Symptoms of Dementia (BPSD) and caregiver distress. The study targets 272 stressed racially diverse family caregivers providing in-home care to persons with moderate stage dementia with one or more behavioral disturbances. All participants are interviewed at baseline, 4-months (main trial endpoint), and 6-months (maintenance). The four-month intervention involves up to 13 visits from an occupational therapist who works with families to problem-solve potential triggers (communication style, environmental clutter) contributing to behaviors, and instruct in strategies to reduce caregiver stress and manage targeted behaviors (*Gitlin et al., 2007*).

A study was done in US, to examine whether treatment effects found at 6 months following active treatment were sustained at 12 months for 127 family caregivers who participated in an occupational therapy intervention tested as part of the *National Institutes of Health Resources for Enhancing*

Alzheimer's Caregiver Health (REACH) initiative; at three assessment points: baseline, 6 months, and 12 months. Caregivers were randomly assigned to a usual care control group or intervention that consisted of six occupational therapy sessions to help families modify the environment to support daily function of the person with dementia and reduce caregiver burden. Following 6-month active treatment, a maintenance phase consisted of one home and three brief telephone sessions to reinforce strategy use and obtain closure.

For the sample of 127 at 6 months, caregivers in intervention reported improved skills, less need for help providing assistance, and fewer behavioral occurrences compared to caregivers in control. At 12 months, caregiver affect improved, and there was a trend for maintenance of skills and reduced behavioral occurrences, but not for other outcome measures. An in-home skills training program helps sustain caregiver affect for those enrolled for more than 1 year. More frequent professional contact and ongoing skills training may be necessary to maintain other clinically important outcomes such as reduced upset with behaviors (*Gitlin et al., 2005*).

Steultjens et al. (2004), in a systematic review of six intervention categories of OT, found that, comprehensive occupational therapy and specific OT interventions including training of skills and the instruction of assistive devices in later years result in positive outcomes on functional ability, social participation, and quality of life for community dwelling elderly people. OT can be effective in decreasing falls in elderly at high risk of falling.

Teri et al. (2003), in a study of 153 community dwelling patients of Alzheimer disease found that an integrated treatment program designed to train dementia patients and their caregivers in exercise and behavioural management techniques was successfully implemented in a community setting. Caregivers were able to learn how to encourage and supervise exercise participation, and patients participating in this program achieved increased levels of physical activity, decreased rates of depression, and improved physical health and function. Post test physical function improvements were maintained at 24-month follow-up and, for those patients entering with higher levels of initial depression, improvements in depression were maintained after 24 months.

Gitlin et al. (2001), determined short-term effects of a home environmental intervention on self-efficacy and upset in caregivers and daily function of dementia patients. They also determined if treatment effect varied by caregiver gender, race, and relationship to patient. 171 families of dementia patients were randomized to intervention or usual care control group. The intervention involved 5, 90-min home visits by occupational therapists who provided education and physical and social environmental modifications.

Compared with controls, intervention caregivers reported fewer declines in patients' instrumental activities of daily living and less decline in self-care and fewer behavior problems in patients at 3 months post-test. Also, intervention spouses reported reduced upset, women reported enhanced self-efficacy in managing behaviors; and women and minorities reported enhanced self-efficacy in managing functional dependency. The environmental program appears to have a modest effect on dementia patients' IADL dependence. Also, among certain subgroups of caregivers the program improved self-efficacy and reduced upset in specific areas of caregiving.

Hepburn et al (2001), tested role-training intervention as a way to help family caregivers appreciate and assume a more clinical belief set about caregiving and thereby ameliorate the adverse outcomes associated with caregiving. A community -based 14-hour training program was provided in seven weekly 2-hour sessions. Data were gathered from 94 participating family caregiver/ care-receiver dyads at entry to the study and 5 months later.

Significant improvements in burden and depression occurred with treatment group caregivers on measures of beliefs about caregiving and reaction to behavior. A caregiver training intervention focused on the work of caregiving and targeted at knowledge, skills, and beliefs benefits caregivers in important outcome dimensions. The results suggest the benefits of providing information, linkage, and role coaching to dementia family caregivers.

Evidence from several studies that have reported clinically significant results suggest that an important aspect of effective interventions is that they be designed to respond to the specific needs of each caregiver. An

intervention developed by *Henry Brodaty* in Australia in the late 1980s included an intensive 10- day training program, as well as periodic sessions and access to the services of a counselor. Although the main focus of the intervention was to teach caregivers problem-solving and coping skills, the possibility of calling a counselor after the formal training period was completed made the intervention responsive to individual needs.

This study, in which caregivers were followed for many years, demonstrated the potential long-term effects of such an intervention. Not only did the intervention reduce caregiver stress, but also, 8 years after entering the study, those who received the intervention were able to keep patients at home significantly longer than those who did not (*Brodaty and Gresham, 1989*).

10/66 Dementia Research Group

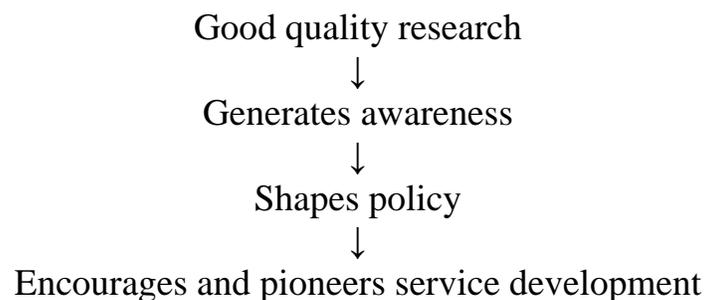
Less than one tenth of all population-based research into dementia has been directed towards the two-thirds or more of all people with dementia, who live in developing parts of the world. Hence, “10/66” (*Alzheimer’s Disease International, 2006*).

10/66 is a group of researchers who have linked together to try to redress this imbalance, encouraging active collaboration between research groups in different developing countries. The 10/66 Group is part of *Alzheimer’s Disease International* (ADI), and is co-ordinated through prof. *Martin Prince*, from the *Institute of Psychiatry*, King’s College, London.

The first meeting of the 10/66 Group was at the annual conference of ADI, held in 1998 at *Kerala*, India. This was the first dementia meeting ever to have been held in a developing country. India and other developing regions were particularly well represented. Since then, the 10/66 Group has held symposia at every annual ADI conference. Their representative in Egypt is prof. *Abd El Moneim Ashour*.

10/66 Dementia Research Group aims:

- To estimate the numbers of persons with dementia in those countries and regions that have not been studied.
- To use these studies to learn more about the causes of dementia.
- To describe care arrangements for people with dementia.
- To quantify the impact of providing care on caregivers.
- To encourage the development of support services, and to test how effective they are.



The dementia diagnosis pilot studies have been used to establish a method for diagnosing dementia in populations with very little formal education. These pilot studies have been completed in 25 centers worldwide allowing fair comparisons between rates of dementia in very different countries and cultures to be made.

The 10/66 research program has also made a preliminary study of the care arrangements for people with dementia in the developing world, the impact upon their caregivers, and the common behaviour problems that they encounter. Several other centers including Egypt are planning to carry out the pilot study.

The 10/66 intervention, *Arabic Version* **(*Ashour et al., 2006*)**

The 10/66 group has been working on an intervention designed to educate and train caregivers to better manage people with dementia in the community. Their intention is to offer this intervention to those they identify in their population-based studies, and to use this opportunity to evaluate its effectiveness.

Any intervention needs to take account of the following prevailing conditions:

1- Dementia is a hidden problem in most developing countries, with very few cases coming to the attention of secondary care services.

- There are very low levels of awareness regarding dementia at every level of society, including among health and social care professionals.
- Dementia is not seen as a medical condition, and consequently few families seek medical attention.

2- Health care services are not orientated to meet the needs of people with dementia.

- Services are hospital or clinic based with no domiciliary assessment or care.
- Such care as is provided, tends to be acute or short term, with no capacity for continuing care.

Thus:

1. There needs first to be some mechanism for the identification of cases in the community.
2. The intervention needs to be capable of being delivered in the home setting using existing resources.
3. In developing the intervention, consideration must be given to the resources available to deliver it.

The content and level of the intervention must be tailored to this, as well as to the cultural context.

The role of the caregiver:

The 10/66 intervention targets the person with dementia's main caregiver, and also includes members of the immediate and extended family. The aim is to provide some basic education regarding dementia and AD, and some more specific training regarding management of problem behaviours.

The intervention:

This consists of three simple manualised modules, delivered over five half hour sessions, at weekly intervals, consisting of:

- Assessment
- Basic education
- Specific training regarding problem behaviours
(Alzheimer's Disease International, 2006)

Their details described in material and methods, and appendix.