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Psycho-education Programme for Alzheimer's Caregivers and its Validation

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Abstract:
Alzheimer's disease was identified a century ago and is a progressive, degenerative disease affecting the geriatric population. But evidence of research in history of disease related to pre-pathogenic or pathogenic phase is subtle. In this advanced technological world, the cognitive function of a person if impaired affects not only an individual himself/herself but also the family members by creating enormous strain and burden for family caregivers which include in all dimensions of health like social, psychological, physical or economic aspects. The rate of progression is different and unique in each patient and it stumbles the caregiver's empowerment and the patient thereby becomes a victim / a recipient of poor care giving because of incapability to handle the issues. In this backdrop, the authors of the paper present the development of psycho-education programme with an emphasis on theoretical issues about Alzheimer's disease and capacity building to handle the patient. The content validity of the above programme is discussed.

Keywords: *Alzheimer's Disease (AD), Caregivers, Psychoeducation, Psychoeducation Programme*

1. Background

Historically, a century ago this mind robber degenerative disease was first studied, presented and published by German psychiatrist Alois Alzheimer's (1864-1915) and it was named after him. In 1910, Emil Kraepelin, German psychiatrist coined and published in the eighth edition of his Textbook of Psychiatry the term "Alzheimer's disease".

Alzheimer's disease (AD) is a chronic, progressive, fatal, degenerative disease of the brain that ultimately results in dementia. Alzheimer's is the important feature and commonest cause of dementia in the elderly of age over 65 years.

Under Clinical Classification of the degenerative diseases of the nervous system, Alzheimer's is one of the three terrible Central Nervous System degenerative diseases i.e., Alzheimer's, Parkinson's and Huntington's as per the International Classification of Diseases ICD-10th edition (WHO). The ICD-10 classification of Mental and behavioral Disorders: Clinical descriptions and diagnostic guidelines coded F00.0 Dementia in Alzheimer's disease with early onset (Pre-Senile type 2), F00.1 senile dementia type 1(Late onset) and F00.2 as senile dementias type 1 (mixed Alzheimer's) (Sartorius, N).

Clinically, Alzheimer's disease is pathologically characterized by the formation of abnormal structures in the brain, or beta-amyloid protein deposits, called 'plaques'. Memory dysfunction is a hallmark of Alzheimer's disease. Alzheimer's disease is observed with loss of cognitive function. Alzheimer's disease is manifested by loss of recent memory for events, persons and places.

According to American Psychiatric Association, Alzheimer's disease is characterized by the impaired ability to learn new information or recall previously learned information and one or more additional cognitive disturbances in language (aphasia), function (apraxia), perception (agnosia), or executive function.

Over time, they get increasingly confused and disoriented; also results in restriction of daily activities i.e. physical deterioration and in most cases, leads to the need of long term care till death occurs. This implies distress for patients and families, and economic loss in the form of cost entailed in the long term care. The catastrophic, confabulation, perseveration, sun downing, rummaging etc are some characteristics common behavioral problems described and manifested in the patients.

Alzheimer's disease course is divided into four stages, with progressive patterns of cognitive and functional impairments. They are pre-dementia, early (mild), moderate and advanced/severe (last) stage of Alzheimer's disease. In the last stage the patient is totally dependent upon caregivers. A definite diagnosis is usually made once cognitive impairment compromises Activities of Daily Living (ADL) but still the patient lives independently. The symptoms progress from mild cognitive and non-cognitive problems such as memory loss to total elimination of possibility of independent living. As the disease progresses, all the symptoms become apparent. (http://en. wikipedia.org /wiki /Alzheimer %27s-disease). The rate of progression from mild to late is highly variable from individual to individual and ranges from 3 to 20 years (Lewis, S & et.al, 2007).

The causes of dementia are varied. Depending on the cause some forms of dementia are treatable and reversible but Alzheimer's disease (AD) causing dementia is irreversible (http://www.wikio.com/article/74017358). Significant advances in research identified Alzheimer's disease is caused by reduced synthesis of the neurotransmitter acetylcholine. Genetic, lifestyle, and environmental factors are risk factors of Alzheimer's, an insidious disease. (http://en.wikipedia.org/wiki/ Alzheimer%27s-disease). Age is the primary risk factor for the Alzheimer's.

1.1. Caregivers

Alzheimer's disease is a weary disease of modern times because of its catastrophic consequences and progressing sequel for patient, family and caregivers. Alzheimer's disease patients cannot manage their personal life without the support and care of someone who is close to them called caregivers. A Caregiver is broadly defined as one who provides informal care to a family member -including basic Activities of Daily Living (ADL) such as bathing and dressing or Instrumental Activities of Daily Living (IADLs) such as cooking and housework (http:/wwwannalsoflongtermcare.com/article/4000). Caregivers may be primary or secondary, full time or part time and can live with the person being cared for or live separately. The people who interact most with Alzheimer's disease patients are their primary caregivers and/or the patients spouse (Howe, 2008). Caregivers can be thrust into the care-giving role abruptly (Kerr, & Smith, 2001). "Sometimes the role comes on suddenly" (Family caregiver support Workgroup report- Oct 2005). On an average, caregivers spend 20.4 hours per week providing care, 13 percent spend more than 40 hours per week. (Alzheimer's Reading Room Year 2009). Alzheimer's disease-care giving has significant social and financial costs (Gutterman, *et al.* 1999., Leon, & Neumann, 1998., and Small, *et al*, 1997).

1.2. Psycho-education

Historically, psycho-education came into the field of psychiatry after the onset of "Mental Hygiene Movement" of early 20th century through emergence of "Expressed emotion" and "Family Burden concept" in connection to severe and chronic psychiatric disorder like schizophrenia. The article "Psychotherapy and re-education" which was published in The Journal of Abnormal Psychology in 1911 was written by John E. Donley. In 1941 "The Psychoeducation Clinic" book was written by Brain E. Tomlinson and published by MacMillan Co. In 1991 Anderson CM published Family psychoeducation, social skills training, and maintenance chemotherapy in the aftercare treatment of schizophrenia: II. Two year effects of a controlled study on relapse and adjustment.

Psycho-education is termed the combination of "the empowerment of the affected' with "scientifically-founded treatment expertise" in as efficient manner as possible (Bauml, Frobose, Kraemer, Rentrop, &Pitschel-Walz,2006/2004). Bauml J, Frobose T, Kraemer S, Rentrop M, Pitschel-Walz G. Barker RL, Aubrey JM defined psycho-education as the "process of teaching clients with mental illness and their family members about the nature of the illness including its aetiology, progression, consequences, prognosis, treatment and alternatives.

Psycho-education comprises systemic, didactic psychotherapeutic interventions, which are adequate for informing patients and their relatives about the illness and its treatment, facilitating both an understanding and personally responsible handling of the illness and supporting those afflicted in coping with the disorder" (Bauml J, Pitschel-walz G 2006). Systematic, structured, didactic information on the illness and its treatment, and includes integrating emotional aspects in order to enable patients as well as family members-to cope with the illness.

The psycho-educational efforts are usually directed under four goals. They are 1. Information transfer: patient or families or careers learn about signs, symptoms and treatment. 2. Emotional Discharge: Patient or family ventilate frustration or exchange their similar experiences. 3. Support: cooperation increases in the therapeutic relationship which promotes adherence, compliance and minimize default.4. Assistance towards Self-Help: training to recognize the crises and take remedial steps.

The main principle of psycho-education is that everyone has the right to receive information about the illness and treatment in order to take more active role in relation to illness instead of being a passive recipient of care (Cross, & Kirby, 2001; Deegan, 1996; McGorry, & Edwards, 1997; and Muesar, *et al*., 2002). The most common being educational programme (face-to-face, on-line, software or published guidelines), frequent monitoring phone calls, self-help group's seminars, and support groups. The formats of Psycho education can be (peer) group-based, family based, caregivers based and parent based or individually implemented. If caregivers are educated they feel relaxed and in control of their condition, if they have greater understanding.

Donker Tara *et al.'s* (2009) meta-analysis focused on two types of psycho-educational interventions like active and passive and showed that brief passive psycho-educational intervention for depression and psychological distress reduces symptoms for mental disorders. The passive psycho-education is one which provides information, education materials or feedback/advice. Examples include leaflets, posters, audio-visual aids, lectures, internet materials or software. The active psycho-education includes materials such as books which describe and teach CBT (Cognitive Behavior Therapy). Brief passive psychoeducational interventions are easy to implement and can be applied immediately as they are not expensive. Beynon *et al.'s*. (2008) systematic review and meta-analysis of controlled trials showed group psycho-education to be effective for relapse prevention.

Psycho-education can be delivered through the post, email, via fact-to-face lectures or through information published on the web. Various methods and ways of intervention have been used in psycho-education for caregivers like novel web-based (Simpson, *et. al* 2009), Video-series (Steffen, 2000), Workshops (Coon, 2003), Telephone –based psycho educational interventions, (Davis, 2004). Houts, (1996) established a prescriptive problem-solving model. Thompson, & Spillsbury, (2000) "hi-tech" computer technology.

Many models of psycho-education have been developed. Information model, the skill training model, the supportive model, the comprehensive model, The Multiple Group Family Therapy model (The MGFT Model), The Behavioural Family Management Model, Family Focused Treatment (FFT), Peer-to-Peer Psycho Education Approach.

The effectiveness of patients' psycho-education has only rarely been studied among forensic schizophrenia patients (Aho-Mustonen, *et al.,* 2008; and Jennings, *et al*., 2002). Landsverk, & Kane, (1998) postulated that the processes that result in an effective outcome in psycho-education are still unknown.

Perry, Tarrier, Morris, McCartthy, &Limb, (1999) found there was decrease in number of manic episodes over 18 months. Cohom (2011) results of a randomnised controlled trial on the efficacy of a structured group psycho education intervention involving bipolar patients the recurrence was fewer to the group at five- year in comparison to the group who had non psycho education. Psycho education has helped in other conditions like Bipolar disorders, major depressive disorder, anorexia nervosa and post-traumatic stress disorders (PTSD) Hayes et al, (2013)

1.3. Psycho Education as an Intervention in Alzheimer's Condition

Psycho-education approach gives a clear understanding of their condition and self-knowledge about their individual strengths, family resources, and coping skills. Clients are relaxed and better equipped to deal with their problems which contribute to their emotional well being (Reyes, 2010). Psycho-education has a role in emotional and behavioral change. It broadens the perception and interpretation of the problems thereby it influences the person's emotions and behaviors, which in turn enhance the sense of self-efficacy. Self efficacy leads to self-control because the patients or the family members or caregivers feel helpless and out of control while caring with serious physical or psychological problems (Reyes, 2010).

Sanders, & Morano, (2008) provides an overview of psychosocial intervention of Alzheimer's disease and related dementia. Signe, & Elmstani, (2008), demonstrate that psychosocial intervention with the aim to give information to family caregivers of people with dementia had positive effects on caregivers' burden and satisfaction. Bootea, *et al* (2006) recognised psycho-social interventions as important treatments for people with dementia. Carmen, & Marina, (2002) observed psycho educational model for Hispanic Alzheimers' Disease Caregivers significant improvement on the caregiver's knowledge survey. Buckwalter, (1996) observes the interventions for family caregivers of patients with Alzheimer's disease in community-based settings.

2. Development and Description of the Psycho-education Programme

Psycho education programme was developed by the present authors which has two parts. Part I: Theoretical issues about the disease – for first 4 days followed by Summary and reflection on the 5th day. Part II: Capacity building of the caregiver to handle the patient - for 4 days and conclude with Summary and reflection on the last day. Put together this is a programme meant for 10 days.

Day's	Session topic
Part 1: Theory	
Day 1	Introduction to Alzheimer's disease
Day 2	The problems of Alzheimer's disease
Day 3	Needs of Alzheimer's disease patient
Day 4	Do's and Don'ts for Alzheimer's disease patient
Day 5	Summary and reflection
Part 2: Practical Tips to handle	
Day 6	Accepting inevitabilities
Day 7	Coping up with stress
Day 8	Consequence of good/bad care giving
Day 9	Tips to be realistic and happy in life
Day 10	Summary and reflection

Table 1: Description of the Day Wise Programme

The description of the day wise programme is described as follows.

- Day -1: Alzheimer: An introduction

2.1. Brain Tour

Keeping non technical person in mind, it covered the structure of the brain, (Fore brain (Front side), Midbrain (Middle side), and Hind brain (Back side). It also covered four lobes, Frontal lobe, Parietal lobe, Temporal lobe and Occipital lobe. It also covered the functions of the brain.

2.2. Memory and its Process

Meaning, processes, and types of memory covering episodic memory, sensory memory, Short term memory, long term memory, Semantic memory, Procedural memory, visual memory, echoic memory, replacement memory and motor memory.

2.3. Alzheimer's Condition

A progressive failure of organization of the higher mental functions of the brain and gradually destroying a person's ability is called Alzheimer's Condition. Some of the abilities that get affected are

- Knowing, perceiving, sensing or conceiving an act distinct from emotion and volition (power of willing).
- Memory and ability to learn
- Reason
- Judgments
- Communication
- Attention span, concentration,
- Orientation
- Perception
- Problem solving
- Reaction time
- Psychomotor activity (Carry out daily activities such as eating, bathing) etc.

They show changes in personality and behavior as follows

- Exhibit mood swings
- Express distrust in others
- Show increased stubbornness
- Withdraw socially
- Become anxious or aggressive
- Behave inappropriately

2.4. Causes of Alzheimer's Disease

- Age
- Genes and biological (oxidation theory)
- Environmental factors- (exposure to aluminum and accumulation of aluminum in the brain)
- Disturbance in immune system
- Head injury
- Beta amyloid plague

2.5. Changes in Brain by Nature: Characteristic Change in Brain

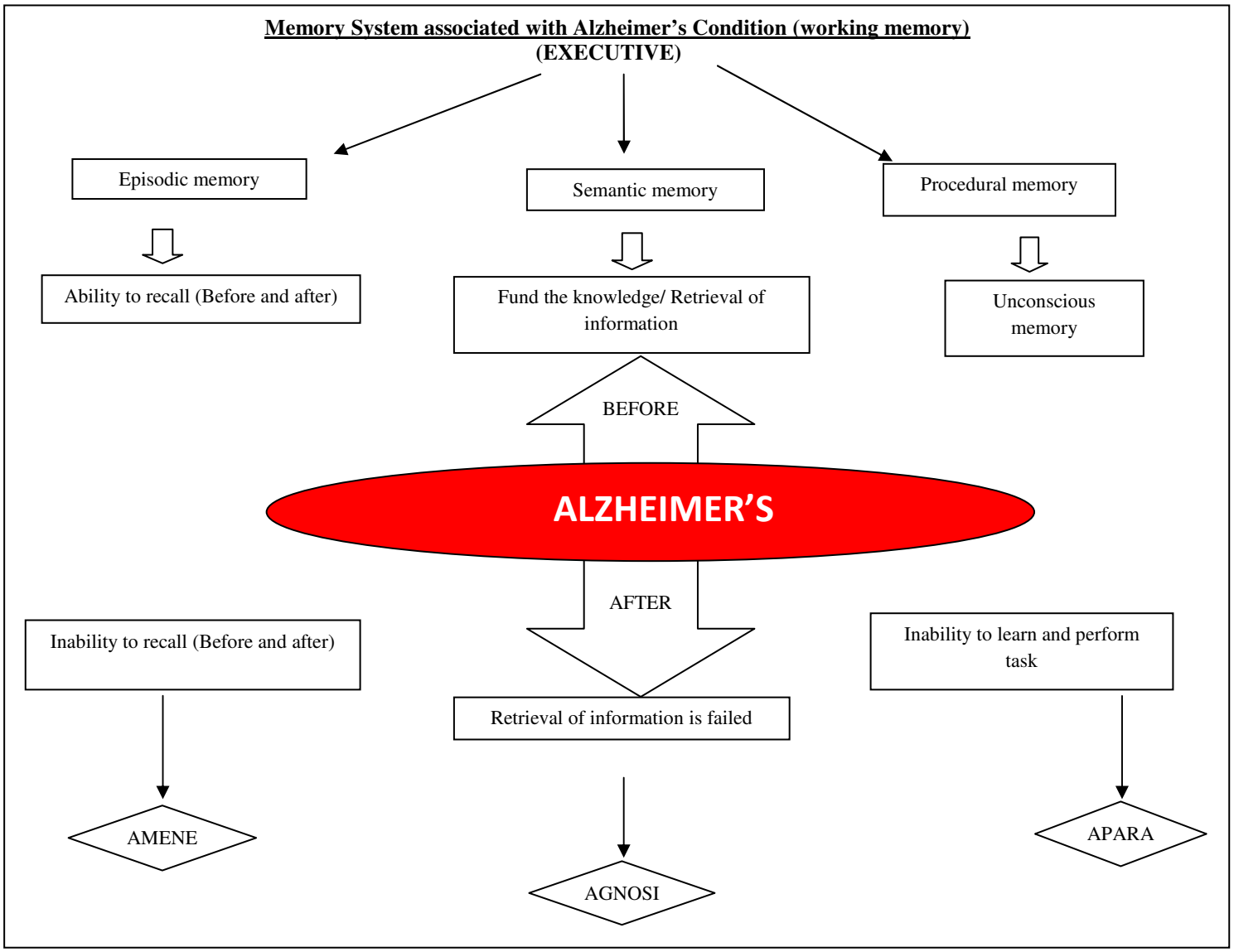

Figure 1: Memory system before and after Alzheimer's diseases

2.6. Physical Symptoms of Alzheimer's Condition

1 stage (Mild)	**2 stage (Moderate)**	**3 (final) stage (Severe)**
➢ Memory- Gradual and progressive memory loss	➢ Forgetting recent events or conversations	➢ Overall decline of mental functions memory loss ➢ **(Amnesia)** ➢ Absence of awareness **(Agnosia)**
➢ Disorientation -Time, place and person	➢ Confused in reality	➢ Loss of personality
➢ Behavior-Restlessness and anxiety, wandering, sleep	➢ Blunting of emotions and flat mood) **(Apathy)**	➢ Lacks personal control
➢ Impaired- judgments, reasoning, concentration, and orientation	➢ Psychotic syndrome-experiences or feeling things which do not exist (seeing, hearing, smelling, tasting, feeling and touching) (Hallucination) and exhibits false beliefs about different things (delusion) ➢ Difficulty in solving problems	➢ loss of ability to care for one's self ➢ Loss of awareness of oneself

➢ Difficulty -in following directions and performing routine tasks ➢ Loss of social skills ➢ Loss of interest on which they enjoyed	➢ confusion and restlessness personality changes ➢ difficulty in doing tasks like preparing food and Takes longer time to perform difficult task ➢ Withdrawal from social contact	➢ Forgetting events in one own history ➢ Inability to carryout motor activity despite motor function **(Aparaxia)** ➢ Fail to recognize family members
➢ Problems in Speech/language - trouble in finding the name of familiar objects, things **(Dysnomia)** ➢ problem in feeding ➢ problems in elimination ➢ problems in walking **(Asterixis)** ➢ Disordered reasoning	➢ Dysphasia (difficulty and Confused, using wrong words, mispronouncing words, speaking meaningless sentences, sparse and repetitive ➢ Difficulty in reading and writing**(Dysgraphia)** ➢ Neurological signs, hemi paresis with extensor planter response, ➢ **Akinesia** (absence of and increased muscle tone, Abnormal movements- either over active or less active(lethargy)	➢ Cannot understand the language ➢ difficulty in swallowing ➢ Bed wetting (Incontinence) ➢ Absence of speech**(Aphasia)** due to difficulty to recall words, stops communication ➢ Failure to recognize or identify objects despite intact sensory function**(Agnosia)**

Table 2

➢ Day 2: The Problems associated with Alzheimer's

SI. No	Problem Areas	Early	Middle	Late
1	Difficulty with familiar places and objects: Inside the home E.g.: toilet room, bedroom, bathroom, kitchen, dining hall	Difficulty Is less	Difficulty Is more pronounced	Difficulty Is too much
2	Difficulty with familiar places and objects: Outside the home E.g.: bus-stand, railway station, Bank, markets, post office, streets, etc.	Difficulty Is less	Confusion and less clarity to recognize and return home	Lost from home, and community
3.	Loss of Memory	Vague memory, can remember few things	Difficulty to remember on and off	Totally forgets the events and names /Unable to cook, clean, Shop
4	Difficulty in speech	No difficulty	-Difficulty in speech, skip or miss words, -struggles for sentence formation -Can converse if initiated	-Stops conversation -Absence of speech
5	Difficulty in walking	No difficulty	-Confused to walk -jumps, runs, hops, wants to sit in place of standing e.g. sits in the middle of the street	Aimless movements to Confining to bed
6	Difficulty in elimination related to bowel & bladder control Difficulty in eating and swallowing	No difficulty Can carry out without instructions	-Less difficulty and confused -can carry out with instructions	Much difficulty –bed wetting, Failure to recall e.g. uses kitchen as toilet Prefers liquid diet than solid diet
7	Loss of interest in hobbies and activities	No difficulty	Struggles to execute the routine hobbies	stops to execute and the caregiver recognizes it when not performing

8	Loss of Motivation	No difficulty	-With stimulations gets motivated and can respond	Difficulty dull, no interest, refuses, and hesitates
9	Difficulty in making decisions	No difficulty	Difficulty Is less, frequent	Difficulty Is too much. E.g. unable to calculate
10	Changes in behavior	No change in behavior	Shows behavior deviation from normal level of functioning to Depression, anxiety, irritability, repetitive behaviors anger, confusions Agitation, sleep Hallucinations	sleep changes, physical and verbal outbursts, wandering
11	Disorientation to time, place and person -Difficulty to recall the part of the day, month, year interval, period, schedule, calendar, season environment/Relationships E.g. Repeatedly ask questions /information about familiar events	Can Recognize friends, relatives	Reduced recognition of friends, relatives Problems of wandering	No Recognition of friends, relatives
12	Understanding and Interpretation of events like birth, death, marriages, festivals (Diwali), abortions, etc.	No Difficulty in understanding and interpreting	Difficulty to understand and interpret	Too difficult to understand and interpret
13	Difficulty in coping	Coping is satisfactory and unnoticed. Able to follow some of the daily routines	-lacks initiation about the task that are routine -Partially able to follow the daily routine with instructions	Not able to follow the daily routine

Table 3

- Day -3: Caregivers role in Alzheimer's condition

Sl. No	Problems	Needs of Alzheimer's patient	CAREGIVER'S ROLE
1	**AMENESIA Loss of memory** In terms of a. calculations b. daily medications c. plan of events	✓ Keeping appointments ✓ Remembering words or names ✓ Recall familiar places or people ✓ Managing money ✓ Keeping track of medications ✓ Doing familiar tasks ✓ Simple plan and organizing	• Check the ability for calculations like single digit addition, subtraction, multiplication and division etc • check for daily compliance for the medications and schedule like exercise, diet to be taken regularly in case of diabetic, hypertension etc • Make arrangement to facilitate the patient to take medicines as prescribed by doctors by labeling • keep voice recorder alarms turn on before food or after food to help in reminding different activities • Use monthly calendars that help the patient to recognize the Date, week, days, month and year to plan activity.
2	**Difficulty in language**	They need assistance in Communication because there is	• Name the objects frequently to strengthen and develop confidence in speech • Use signs and symbols to make the patient understand easily • Use simple words and common names

	Loss of ability to find words ⇩ **Expression of thoughts suppress** ⇩ **Conversation is not understood, can't follow conversations –becomes difficult and stopped**	✓ Difficulty to find words ✓ Difficulty to understand ✓ Difficulty in attention	• Talk one topic at a time • Use short conversation • Don't use alternative terms in any conversation that will lead to confusion • Reinforce the sentence to allow time to process the massage • Restate the message if not understood • Use yes-no answers when the patient fail to communicate • Recognize the trouble in finding the right words and Supply missing words • Encourage positive chain of thoughts during communication • Revert to native language • Use non verbal communication also • Speak slowly and clearly • Use gentle tone • Distract the patient if he repeats the same things.
Sl. No	**Problems**	**Needs of Alzheimer's patient**	**Caregiver's role**
3	Loss of orientation with a) time b) place c)person,	Needs reality orientation with ✓ Time ✓ Place ✓ Person to reduce confusion	• Label the rooms in the house to help the patient locate correctly the areas • Read daily newspapers for the patient to get oriented with the reality • Use calendar to make the patient recognize the year, month, days, weeks, dates, events like festivals etc prominently • Use the clock to make the patient recognize the day, time, hour, and minutes. • Label the room clearly with sign boards to avoid confusions and thereby help to use properly the purpose of rooms e.g. dining hall to eat • Use white boards to list the work of the day to be completed • Follow "**SAFE"** principle **S**-same environment **A-**Arrange the room furniture to the needs of the patient and safely **F**- frequently orient the patient about the area, things to be used with instruction so they do independently **E-** Easy access to self care

Table 4

- Day -4: Do's and Don'ts for Alzheimer's Patient

2.7. Area of Care: Physical Care

Sloe	**DO'S (to ease care giving)**	**DON'TS (to avoid stressors)**
	1: Communication	
	• Choose simple words • Choose short sentence • Repeat the sentence • Summarize what is said • Speak slowly and quietly to gain attention and concentration • Use short sentence • Call by nick name • Explain the care before doing	• Don't interrupt • Don't give negative instructions E.g.: you will fall; instead give positive commands like hold my hand • Don't distract • Don't ask many questions to avoid frustrations • Don't ask open ended question • Avoid seeking logical explanations • Avoid wordings like don't

	• Be gentle calm tone of voice • Supply words for communication when they struggle • Wait for answer • Break down the message into steps or parts • Give non verbal clues along with verbal instruction • Use picture to help to focus on conversation • Offer guess words to the forgotten words • Ask specific question at a time with yes or no options E.g. Do you like to wear red or blue color dress	• Avoid giving correction • Don't ask "don't you remember:……." • Don't ask repeated questions • Don't ask questions you require facts to be answered
2: Behavior		
	• understand the mal behavior and be with patient • Remove the objects which trouble the patient • Hallucination • Make and do everything to make the patient feel secure in your company • Give reality orientation with clocks, calendars, alarm • Distract the patient from self directed thinking	• Don't irritate • Don't hurry • Don't invalid the feeling • Don't fail to explain • Don't leave the patient alone • Don't produce unwanted noise, • Avoid strange surrounding • Avoid changes in routine • Avoid crowds • Avoid entrusting with unfamiliar persons • Don't put the patient in the darkness • Don't beat or punish • Don't lose cool
3: Hygiene		
	• Change the diapers promptly • Plan the bath (Sponge or bathroom) • Schedule the toilet timings every 2-3 hours • Limit the oral fluids at night times • Protect safety in the bathroom	• Don't leave unattended • Don't be rigid in routines • Don't argue • Don't make fun • Don't ignore hygiene needs of the patient
4: Nutrition		
	• Fir the denture properly • Provide calm atmosphere to focus on the meals • Provide Oral care • Check the temperature of the food items and beverages • Limit food choices at the meal • Give plenty of fluids and fibers during the day • Offer spoon, finger foods at frequent intervals	• Avoid distractions • Don't provide food that cause choking • Don't give coffee and tea at nights
5: Environment *"S"*		
	• Structure things in the same place • Simplify the place with few furniture in the rooms and same arrangement to avoid confusion and prevent fall • Safety: remove the potential hazards • Security • Create calm environment	• Don't distract • Don't create noise • Don't keep hazardous things near by

Table 5

2.8. Area of care: Psychological Care

Sl. No	DO'S (To Ease Care Giving)	DON'TS (to Avoid Stressors)
	1: Attend	
1.	• Keep every day routine consistent and simple • E.g. eating, bathing etc • By touch and eye contact during care • Be flexible • Give break in the schedule • Redirect the person's attention • Acknowledge request • Respond quickly • Use familiar objects and things more	• Alter the routine of daily care • Don't unnecessarily touch the patient • Don't expect his effort • Don't arguing about facts • Don't bring confrontations • Don't leave unattended
	2: Observe	
2.	• Make eye contact • Make sure he responds to you before caring like e.g. Says yes, ha-hoo etc • Look for reasons behind each behavior	• Don't distract
	3: Involve	
3.	• Be open in concern • Allow to do one by one • Be Gentle and respectful • Give only one task at a time as they cannot comprehend two or more task at the same time. • Involve patient also in family functions and traditions: In case of large gathering place where rest is possible	• • Don't be impatient • Don't entrust too many tasks at a time • Don't shy way accepting your patient
	4: Empathize	
4.	• Discuss the topics of particular interest e.g. A hobby, a favorite grandchild, a special event. • Show a caring attitude towards the patient • Express concern • Anticipate unpleasant situations and stay along	• Don't think care giving is a curse: It is a service to god • Don't miss- understand the patient: they are not intentional and purposive
	5: Encourage	
5.	• Continuous praise • Use positive comments always	• Don't irritate by new activity • Don't scold or abuse • Don't use negative comments
	6: Clarity	
6.	• Allow time to respond • Introduce oneself if they are new and address the person with name • Select the activity based on their functional ability	• Don't talk fast • Don't cause confusions
Sl. No	**DO'S (To ease care giving)**	**DON'TS (to avoid stressors)**
	7: Explain	
7.	• Give short explanation before taking an action	• Avoid lengthy reasoning
	8: Provide	
8.	• Barrier free environment • Safe and familiar environment • Assistive devices like side rails	• Don't place items like cleaning products, poisonous substances, razor blades, medication • Avoid swimming pools • Don't fallow patient to cook or use electric equipments like hot water kettle etc
	9: Listen	
9.	• Understand the felt- need when they • Verbalize e.g. Tea is too hot	• Don't be inpatient to listen

Table 6

- Day -5 Summary & Reflection

Includes the activity of clarifying doubts of all the 4 days.

3. PART –II

- Day -6: Accepting inevitabilities

Dear Caregivers,

Since, Alzheimer's is unique and Progressive with stages. The person affected with Alzheimer's is sure / certain to land up with failure in execution of these higher functions of the brain like Memory, Thinking, Behavior and Emotions.

Therefore, you need to understand about Alzheimer's and accept Alzheimer's condition and provide help/care to your best.

You need to be ready to

1.	• Accept Alzheimer's as a reality • Accept changes as they occur • Accept the patient as he/she is and not to have much expectations from them
2.	➢ Plan for the future ➢ Attempt to develop more clarity about Alzheimer's ➢ Participate with involvement for new role changes E.g. Going to the market to get things Going to the bank
3.	• Alzheimer's patient doesn't intend to hurt you or disrupt things but behaves in ways e.g. Strike which are not purposeful or intentional. It is because their felt need is unmet and could not communicate in the way they want it to make you understand. So fitting into their shoes, see in their eyes and caring for them is essential • Their negative emotions and reactions are signs of agitation and anger. • As Alzheimer's progresses, you will have new challenges. You are the best one to deal with them. Be courageous and you can do it.

Table 7

- Day -7: Coping up with Stress

3.1. Context of Stress and Needed Care

Sl.no	Context of care	What patient might do?	What caregiver might do?	What caregiver (√) Should do?	What caregiver (x) Should not do?
1	Hygiene	-Refuse to have bath -Refuse to change the dress -Refuse to groom - Fail to understand the need	Force or compel to do so	-Leave for a while as per their wish -convince them smoothly -do with their cooperation -understand they not intentional	-Not to force -Not to get irritated - Don't lose your health in the name of care
2	Feeding	-Refuses to have food because of dislike, loss of appetite -Spills the food -Throw/waste the food -Eating too much -Eating too less	-Compel to have the food - abuse for not having -Disappointed by the behavior	-Develop skill to organize in preparation and feeding -Manage with balanced diet	Don't skip the meals
3	Environment	-Fail to recognize the unpleasant situations like death of a close family member, friend or loved pet -Confused and react abnormally to new place -fail to use safety precautions -bad odo	Face Grief Embarrassed Stressed Neglects about safety and security	-Expect the unexpected to happen -follow safe principle -orient with familiar place	-Don't entrust with unknown people and place -Avoid new and strange environment

4	Money	Fail to calculate Fail to receive or give correct exchanges	Feels guilty	Know the limits	-Don't provide care without knowing the limits
5.	Social interaction	-Fail to recognize the event like marriage -Fail to remember the friends, distant relatives in social gatherings	-ignore in making the patient to attend such occasions -Worry about social stigma -Feel shy and shameful to seek help from others -Fail to accomplish and accompany the patient	-Nurture your relationship by living in reality and enjoy the moments -Think of ways to complete tasks as a team rather than being alone - Be open and not to worry about social stigma	-Don't get locked up with care giving alone - Don't think your troubling others -Be generous
6.	Cope	-Denial to cooperate with routines -Difficulty to understand with routines	Being rigid to implement the daily routine	-Educate yourself about Alzheimer's -Realize what you are - Remember that you're so important for the patient -have dignity	-Be flexible
7.	Communication	-Asking repeated questions -Use few words with non verbal communication -Stops communication	-Lose patience to answer the stereo-typed questions -make fun	-Answer patiently to the questions -Distract the thoughts	-Don't tease or make fun -Don't behave abnormally
8.	Task performance	-Lack of attention -Not able to follow what is told -not able to perform in sequence	-disappointed with the poor performance	-Encourage to continue the patient to live as independent as possible	-Don't blame yourself
9.	Mobility and exercise	Lack of interest in exercise	Stressed Force and compel	-Encourage to do as much as possible only as needed	-Don't compel -Don't irritate
10.	Sleep	-Does not sleep at regular time -Bed wetting -wandering -excess sleep	Stressed because of watching them constantly	-Follow bed time routine -Limit fluids to drink -keep the doors secured and locked -Sphincter muscle is weak	-Don't provide excess naps
11.	Medications	-Does not cooperate to take medications Skips, throws, noncompliance and complications to ill heath	-default case -complications -unnecessary visit to health system	-Make arrangement to facilitate to take drugs -check the follow of schedule	-Don't keep extra drugs accessible
12.	Schedules	-Does not follow the schedules of the day -disoriented with time	-Fatigue because of care giving -Time consuming and tedious efforts	-Remembers there will be good days and bad days -Allot time for yourself to do hobbies, spend time with others	-Don't think all days are same - Not to be burdened Don't become too much exhausted

Table 8

3.2. Suggestive Schedule-(Time Plan/Structure the Day-24 HRS)

Week/Day/Time	Activity of/for caregiver	Activity of/for patient	Did	Did not do it (Reasons)
5.30 am	Make a clean and neat Bed	sleep		
5.45	Prayer	sleep		
6.00-6.15	Oral care	Oral care		
6.15-6.30	Prepare tea and drink tea, coffee, milk			
6.30- 7.30	Prepare breakfast	Read newspaper		
7.30-8.00	Bath /shower/cut nails, clean foot, ears etc.	Bath/shower		
8.00-8.30	Breakfast, medication	Breakfast, medication		
8.30 -9.00	Wash utensils, clothes and keep the house clean	Listen to music's		
9.00-10.30	Hobby	Hobby		
10.30- 11.00	Prepare mid-morning tea, snacks and drink tea	Drink tea		
1100- 12.30 p.m.	Prepare lunch	Watch TV		
12.30-1.00	Have lunch /medications	Have lunch/medications		
1.00-4.00	Daily nap	Daily nap		
4.00-4.30	Prepare mid-evening tea, snacks and drink tea	Drink tea		
4.30-5.00	Go to temple/shop/visit friends house/walk	Go to temple/shop/walk		
5.00-6.00	Exercise/gardening	Exercise/gardening		
6.00-7.00	Watch TV /Communicate the	Watch Television		
7.00-8. 30p.m	Prepare night dinner/have dinner/medication /sleep routines-warm milk	Dinner		
8.30-5.30	sleep	sleep		

Table 9

3.3. Tips to Handle

Sl.no	Context of Care (Physical and Psychological)	Tips to Handle
1 **Physical**	Hygiene	Don't force Don't compel Don't irritate Make it enjoyable
	Feeding	Feed as per his likes and dislikes Provide soft, easily digestible recipes Avoid irritable food items Don't ignore feedings
	Environment	Don't change the order of arrangement Create conducive environment for caring with safety
2 **Psychological**	Behavior	Respond to emotions Don't ignore his needs Fulfill the unmet needs Respect the patient Treat normally Be flexible Be generous Don't ill-treat or tease

Table 10

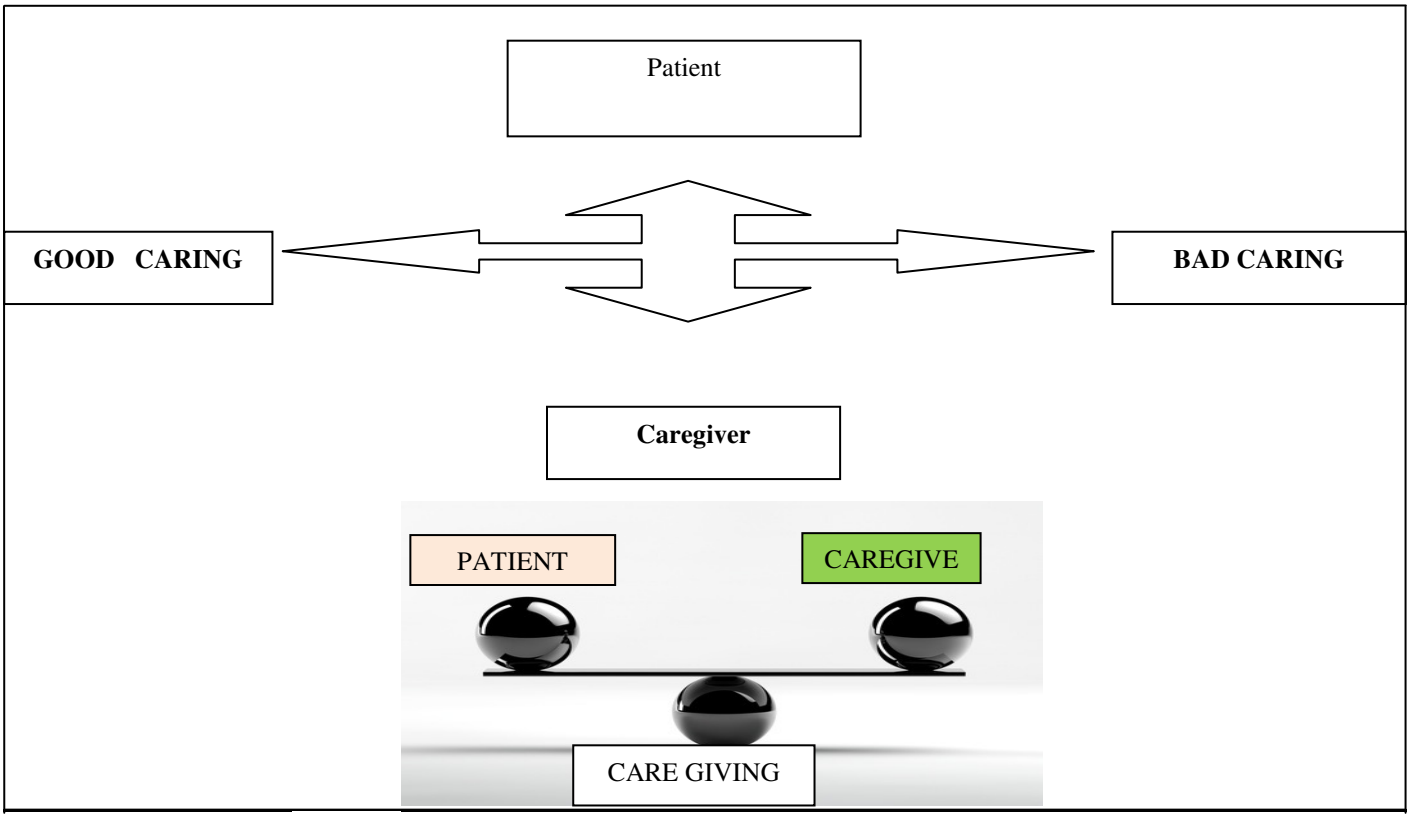

Figure 2: Balance between (Care giver) and (Patient) in Care giving is essential

- Day -8: Consequence of good/bad Care giving

Caregiver/ Patient	Dimensions of health	Consequence of Good Caring (positive effects)	Consequence of Bad Caring (negative effects)
Patient (Quality of care) **Caregiver** (Quality of life)	**Physical**	Good Quality of care is delivered	Poor quality of care is delivered
		Well Groomed	Not Well Groomed
		Trimmed	Poorly Trimmed
		Neat in appearance	Not Neat in appearance
		Pleasant and tolerant	Unpleasant and intolerable smell
Patient (Quality of care) **Caregiver** (Quality of life)	**Psychological**	Satisfaction is high	**No satisfaction in caregiving. Reflected in the ways of Guilt** –because of inability to carry on the role with efficiency, quality, satisfaction, confidence
			Anger-towards self, patient, circumstances like change of roles, increase in responsibilities and work load
			Embarrassment- improper plan, lack of knowledge to care
		Care giving is at ease	Care giving is difficult
		Stress is reduced in care giving	Care giving is stressful

Table 11: Consequence of good/bad Care giving

- Day -9: Tips to be Realistic and Happy

- ❖ Follow the best practice which are simple

Caregiver/ Patient	Dimensions health	Consequence of Good Caring (positive effects)	Consequence of Bad Caring (negative effects)
Patient (Quality of care) **Caregiver** (Quality of life)	**Moral**	Successful execution of role is in family and society	Unsuccessful execution of role is in family and society
		Care giving and execution of roles leads to peace *and happiness*	Not happy and Not peaceful because of failure to execute the work and role
	Social	Effective social networking with friends, relatives and family members	Ineffective social networking with friends, relatives and family members
		No Loneliness i.e. feeling involved and participate for activities related to socialism instead of being confined with patient in their homes	Thereby there is vacuum and Loneliness i.e. feeling withdrawn from society and confined with patient in their homes
	Economic	Good plan and progress of action can save time, money and energy	Waste of time, money and energy leads to fatigue, debt and poor time management there by not able to meet the goals

Table 12

- → Involve other family members in the care
- → Welcome tips for care giving
- → Balancing the routines of care and the caregiver
- → Mingle in community program like marriage, family by adjusting time with other members of the family
- → Be good manager of routine to both (self and patient)

- ➢ Day -10: Summary & Reflection

It covers the summary and reflections of all the last four days.

4. Content Validity

The content validity of the psycho education programme was established by getting the programme rated by experts. The authors of the present paper approached 15 experts including 5 Neuro physicians, 7 Clinical psychologists and 3 Nursing personnel specialized in Mental Health Nursing experts for validation. The experts were requested to check for relevance, appropriateness, sequence, language, and significance. The summary of rating by 15 experts of the entire psycho education programme is as follows:

	Extremely Appropriate	Appropriate	Just OK	Inappropriate	Extremely Inappropriate	Total (Max)
Experts	6	9	-	-	-	15
%	40%	60%	-	-	-	100%

Table 13: Rating of the experts on the Psycho education programme

An analysis of the above table indicates that all the experts have rated the programme as appropriate. Among them, 40% of them have rated it as extremely appropriate, while the remaining 60% of them have rated it as appropriate. Therefore, it can be concluded that the above psycho-education programme is appropriate for informing and influencing the care givers of Alzheimers patients. It further means that the above programme is capable of informing and influencing the care givers of Alzheimer's patients. Both the Part I consisting of theoretical issues as well as the Part II consisting of practical guidance are effective and useful. It is capable of developing the capacities among the care givers of Alzheimer patients. Therefore, the above Psycho-education programme could be used by professionals on Alzheimer's care givers.

5. References

i. Banerjee, S. and Roy, K. (2012). Approach to geriatric neuropsychiatric problems. New Delhi: Jaypee publishers.
ii. Bhaskararaj , D.E.(2011). Textbook of mental health nursing. (pp.515). New Delhi: Jay Pee Medical Publishers (P). Ltd.
iii. Bhatia, M.S. (2013). Essentials of psychiatry. New Delhi: CBS publishers.
iv. Carson,V.B. (2000). Mental health nursing: The nurse patient journey. Philadelphia: Saunders.
v. Daniels, R.N. and Laura, N.L. (2007). Contemporary medical surgical nursing. Thomson publication.
vi. Dipanjan B, et al.(2011). Psycho-education: A measure to strengthen Psychiatric Treatment. Delhi Psychiatry Journal. 14. No.1, 33-39.
vii. Dunphy. M (2007). Primary care: The art of science of advanced practices in nursing. F.A. Davis Company
viii. Fortinash ,M.(2004). Psychiatric mental health nursing. New Delhi. Elsevier publication.

ix. Gallagher –Thompson, D, Lovett, S., Rose, J, et al. (2000). Impact of psycho educational intervention on distressed family caregivers. J Clinical Geropsychol, 6:91-110.
x. Ginsberg, L.(2005). Neurology. India: Blackwell publishing.
xi. Grossberg .T.G. and Kamat.M.S.(2011). Alzheimer's the latest assessment and treatment strategies. America: Jones and Barlett publishers.
xii. Jones, S. and Roberts, K. (2010). Key topics in psychiatry. India: Elseveir.
xiii. Kapoor, B. (2013). Textbook of psychiatric nursing (Vol.1) New Delhi: Kumar Publishing House.
xiv. Mary, T.C. (2012). Psychiatric mental health nursing. New Delhi: Jay Pee Brother Publishers.
xv. Namboodiri, V. M. D. (2009).Concise textbook of psychiatry. New Delhi:Elseveir
xvi. Neeb, K.(2008). Fundamentals of mental health nursing. New Delhi: Jay Pee Brother Medical Publishers (P) LTD.
xvii. Neeraja, K.P,(2009). Essentials of mental health nursing. (pp.548). New Delhi. Jay Pee Brothers Medical Publishers (P) Ltd.
xviii. Park, K. (2009). Park's textbook of preventive and social medicine. (pp. 43). India: Banarsidas Bhanot Publishers.
xix. Primer, A. (1981). Disorders of the nervous system. India: Year book Medical Publishers.
xx. Raju, S. M. and Raju, B. (2010). Psychiatry and mental health nursing. New Delhi: Jay Pee Brothers Medical Publishers (P)Ltd.
xxi. Sadock, B., Sadock, J., and Virgina, A. (2013). Kaplan and Sadocks synopsis of psychiatry. New Delhi: Wolters Kluwer Lippicott Williams Wilkins.
xxii. Sartorius,N. The ICD-10 classification of Mental and Behavioral Disorders: Clinical Descriptions and Diagnostic guidelines, WHO, A.I.T.B.S Publishers & Distributors, Delhi.
xxiii. Savitz,I. and Bonthal, M.(2009). Neurology review for psychiatrist. (pp.55).America: Lippincott Williams, Wolter and Kluwerpublishers
xxiv. Shives,louise rebaeca.(2012).Basic concepts of psychiatric mental health Nursing (pp.457, 464). Wolter Kluwer, Lippincott wiliams and Wilkins.
xxv. Smeltzer, S. C., & Bare, B. G. (2004). Brunner & Suddarth's Textbook of Medical Surgical Nursing. (pp. 205, 210, 1987-88). Philadelphia: Lippincott Williams & Wilkins A Wolters Klumer Company.
xxvi. Stuart,G. W. (2013). Principles and practices of psychiatric nursing. New Delhi: Elseveir.
xxvii. Suzanne C.S., and Brenda.G.B., Janice.L.H.,Kerry.H (2010). Textbook of medical surgical nursing. Wolter and Kluwer Publications.Vol 2 .pp.1993.
xxviii. Thresia, M.T. (2012). Psychiatric and mental health nursing. New Delhi: CBS publishers.
xxix. Townsend.C.M.(2012).Psychiatric mental health nursing.Jaypeebrothers medical publishers .pp.390-393
xxx. Workman, I. (2010). Medical surgical nursing patient centered collaborative care. Elseveir Publication.
xxxi. Katherine.M.F and Patrica A.H.W. H. (2012). Psychiatric mental health nursing. Elseveir publications. (pp.38-41).
xxxii. Richard,J.G.(2007).Practical Guide to the care of the Psychiaatric Patient .(pp.64- 84).Philadelphia:Mosby.
xxxiii. Subrata,B.K.(2012).Approach to Geriatric Neuropsychiatric Problems.(pp.80,91).NewDelhi:Jaypee
xxxiv. Nambi,s.(2012).Psychiatry for nurses.(pp.109-110). New Delhi: Jaypee
xxxv. Sujatha,s.(2008).Textbook of Psychiatry.(pp.38-41).NewDelhi:Elsevier.
xxxvi. Fortinash,H.W.(2012),Psychiatric Mental Health Nursing.(pp.365). NewDelhi:Elsevier.
xxxvii. Edwad,C.C and Thomas,W.M. and Jonathan,M.S.(2007).Guide to Neuropsychiatric therapeutics.(pp.82-87).Philadelphia: Lippincott wiliams and Wilkins.
xxxviii. Benjamin,J.S and Virginia,A.S.(2007).Synopsis of Psychiatry.(pp.330-331). Philadelphia: Lippincott wiliams and Wilkins.
xxxix. Gail,W.S(2013).Principles and Practice of Psychiatric Nursing.(pp.406-411).Haryana:Elsevier.
xl. Joyce, M.B. and Jane, H.H. (2007). Medical Surgical Nursing Clinical Management for Positive Outcomes. (pp.2161-2171).St. Louis, Missouri: Eisevier.
xli. Louise, R.S. (2008). Basic Concepts of Psychiatric Mental Health Nursing. (pp.499-500). Philadelphia: Wolter Kulwer Lippincott wiliams and Wilkins
xlii. Noreen, C. F and Lawrence, E.F. (2007). Psychiatric Mental Health Nursing. (pp.238,616) The Thomson Corporation.
xliii. Sheena and Kate,R.(2007).Key Topics in Psychiatry.(pp.257)Churchill Livingstone.
xliv. Sheila,L.V(2006).Psychiatric Mental Health Nursing.(pp.482-494). Philadelphia: Lippincott wiliams and Wilkins.
xlv. Vyas,J.N and Niraj,A.(2008).Textbook of Postgraduate Psychiatry.(pp.57-61,481,641,703).NewDelhi:Jaypee Brothers Medical Publishers(P)Ltd.
xlvi. Verna, B.C. (2000).Mental Health Nursing: The nurse patient Journery. (pp936-942).Philadelphia:Saunders
xlvii. Mary,C.T(2007).Psychiatric Mental Health Nursing:Concepts of Care in Evidenced Based Practice.
xlviii. Alzhemier's Disease Education & Referral Center. Caregiver Guide. Retrieved on November, 11, 2010, from http://www.nia.nih.gov /alzhemiers/Publications/caregiverguide.htm
xlix. Alzhemier's Disease-Wikipedia, the free encyclopedia(2011). Retrieved June 1, 2011, from http://en.wikipedia.org/wiki/ Alzhemier's %27s_disease.
l. Australia Institute of Professional Counselors. (2014). Psycho education: Definition, goals and methods for clients. Retrieved 16 Feb 2016 fromwww.mentalhealthacademy.com.au.

li. Caregiver-Wikipedia, the free encyclopedia. Retrieved Jan 6, 2011 & Oct 29, 2010.
lii. Caregiving and Alzheimer's disease (2004)-Free Online Library. National women's Health Report. Retrieved from http://www.thefreelibrary.com/Caregiving%26+Alzheimer's+disease-a014781292.
liii. Caregiving in America Fact Sheet. Alzhemier's Reading Room (Dec 9, 2009) retrieved from http://ping. fm/pkSq0
liv. Martin, W. (2008). What does psycho-education refer to? Retrieved 15 Nov, 2010 from http://web4health.info /en/ answers/psy-therapy-education.htm
lv. NAMI (2003) |Family Psycho-education Retrieved 15 Nov 2010 from http://www.nami.org/template.cfm? section=About_Treatments_and_Supporta&template.
lvi. Psycho-education-Virtual Medical Centre (2010) Retrieved 15 Nov, 2010 from http://www.virtualmedicalcentre.com/treatments.asp?sid=140
lvii. Psycho-education-Wikipedia (2010) Retrieved 15 Nov, 2010 from http://en.wikipedia.org /wiki/
lviii. Psycho-education-Wikipedia (2015) Retrieved 25 Jul, 2015 from http://en.wikipedia.org/wiki/
lix. Psycho education Retrieved from http://www.thefreelibrary.com/ Caregiving%26+Alzheimer's+ diseasea014781292.
lx. Spector,J, AB, & Tampi,R, (2005).Caregiver Depression/Annals of Long Term Care.ISSN:1524-7929, Vol: 13.Retrieved November 22, 2010, from http://www.annalsoflongtermcare.com/article/4000