RESEARCH PAPER | Social Science | Volume : 4 | Issue : 5 | May 2014 | ISSN - 2249-555X

Psycho-Social Problems and Coping Mechanisms in Caregiver's Of Dementia Patients

KEYWORDS: Dementia, Caregivers, Care recipients.

G.S.Sangeeth
Research Scholar, Department of Social Work, Bishop Heber College, Trichy,

Dr.M.Daniel Solomon
Assistant Professor, Department of Social Work, Bishop Heber College, Trichy

ABSTRACT *Dementia is the major public health problem which is booming up globally and locally among elderly population. According to Elizabeth Hurlock (1953) old age starts from age 60 which is considered to be closing period of life span. The major purpose of this paper is to study on care, support and rehabilitation manifesting in varied states of psychosocial being and coping mechanisms among caregivers of elderly dementing population using secondary data. It pinpoints those caregivers of dementia must inculcate resilience for promoting emancipation of their own problems and assist the care recipient problems in the light of social work mediations. The articles deals with the reviews of psycho-social being, coping mechanisms of caregivers of dementia, inferences from the reviews and solution from social work perspective for public health problem which is projecting as the global problem.*

Introduction: Health is a major tool to enhance psycho-social wellbeing and coping mechanisms of dementia care givers. Dementia is not confine to elderly population but also have influence on other stages of life. According to ICD-10 (2004) "Dementia is a syndrome due to diseases of brain usually of a chronic or progressive nature in which there is disturbance of multiple cortical functions including memory, thinking orientation, comprehension, calculation, learning capacity, language and judgment". Consciousness is not clouded. Occasionally cognitive decline will be accompanied by deterioration in emotional control, social behavior or motivation. Due to gradual to severe cognitive decline and other co morbidities, caregivers are mandatory to assist them. Care giving refers to attending to other individual's health care needs. Caregivers often indulge in attending to others activities of daily living. The caregivers are paid and un paid caregivers in the families. As the severity and long period of exposure to care giving can lead to burden and psychological strain and distress. The care giving can be rendered by any individuals in the family. The primary caregivers undergo different deviant psychological social states with less coping states which has to be addressed and remedial measures has to be sought.

Magnitude of the problem: According to Dementia India Report (2010) prepared by Alzheimer's and Related Society of India (ARDSI) high lights that India will overtake the U.S with regard to increase in dementia client which will be posing greater challenge to Indian economy causing economic draining and frequent deaths. According to World Alzheimer Report (2012) prepared by Alzheimer's and Related Society of India (ARDSI) high lights that people with dementia India will touch 4.41 million by 2015. (Source: The Hindu, September 20, 2012, 12:56)

According to WHO (2012) Worldwide, 35.6 million people have dementia and there are 7.7 million new cases every year.(Source: www.ho.imt/mediacentre/factsheets/fs362/en)

Overview of Dementia
Dementia is an organic disease. Dementia's alarming symptoms are recent memory loss, difficulty in performing known –task, problem with language (use of terminologies), orientation loss (time, place), poor judgment, problem in abstract thing, misplacing things, changes in mind, personality changes, passive loss of initiative. The some of the types of dementia are as follows Alzheimer's disease where the chemistry and structure of the brain changes, vascular dementia is failing of oxygen supply to brain. Brain cells may die suddenly or following a stroke or small stroke, dementia with lewy bodies are presence of spherical structures that develop inside the nerve cells, fronto temporal dementia (picks disease) is damage mainly focus on the frontal part of brain where personality and behavior affects than memory, Creutfedlt – jackob disease will attack central nerves system, Korsakoff's syndrome is a brain disorder which is associated with heavy drinking. The rarer risky causes of dementia are Progressive supra nuclear palsy, Binswanger's diseases, Multiple sclerosis, Motor neuronal disease, Parkinson's disease According to Deheon and Reiseng (1999) stage -1- no dementia – no cognitive decline, stage -2- No dementia – very mild cognitive decline, stage -3- no dementia – mild cognitive decline, stage -4- early stage – moderately cognitive decline, stage -5- mid stage - moderately severe cognitive decline, stage -6- mid stage – severe cognitive decline, stage -7- late stage –very severe cognitive decline.

Dementia and caregiver's.
The care rendered to the normal old age is minimal where care to dementing patients is extensive. Role of care givers of dementia are to assist in activities of daily living such as household, shopping, cooking, helping in access to transportation, arrangement of appointments like hospital services, financial management, attending telephonic calls, checking mails and managing legal affairs, helping the person take medications correctly either remanding or through direct administration of medicine by physicians directions, helping the person to follow the directions of treatment prescribed for dementia care recipient, Helping the dementia recipients in activities of daily living like bathing, toileting, dressing etc, managing behavioral problems of the disease such as aggression, agitation, night time disturbance etc, finding and utilizing support system like day care center are some of the roles of caregivers with reference to dementia.

Some of the perceived obstacles to dementia care are:- lack of awareness, less health seeking behavior, lack of training and support, lack of funding dementia research, stigma, lack of policy initiatives for people with dementia, difficulty in providing overall management for dementing patients..

Impact of care giving has different levels. Individual level including:- fatigue, body pain, depression, mood fluctuation, cognitive problems, anxiety, stress, financial crisis, loss of time for self care, less quality of life. Family level includes conflict about care giving role, lack of support for caregivers,

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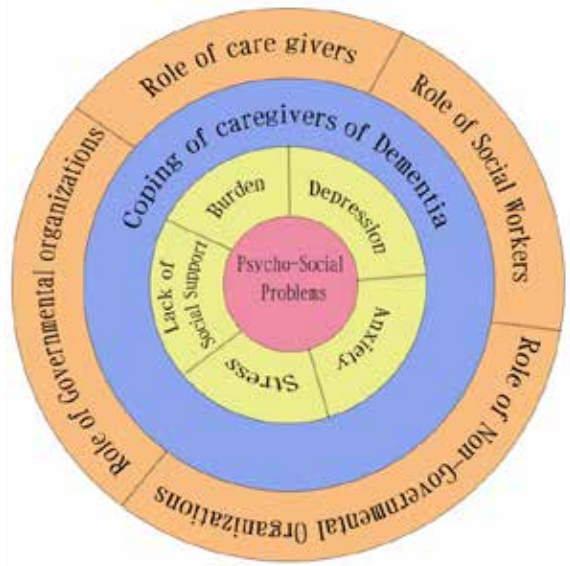
difficulty in balancing healthy and sick recipient, inter personal conflicts in family, less participation in ritual in family, lack of cohesion, tension in coordinating overall work. Community level includes: Lack of social networking, less social support, stigma.

Figure 1.1 Conceptual mapping on psychosocial problems and coping mechanism of caregivers of Dementia



This article firstly discuss about the in-depth insights on psychological problems which is operationally define as burden, anxiety, depression, stress. According to muthuramalingam (2014) Social support as a network of individuals who are able to provide information, resources, emotional and psychological support through either formal, professional or through less formal mutual involvements with in a family, friendships or social group is considered as operational definition for discussion. Lack of social support is key for social problem. So the psychosocial problems and coping will be elaborately discussed in the light of the literature.

Psychosocial problems of caregivers of Dementia:

Zhang Hong (2013)Studied on psychological distress, family functioning and social support in family caregivers for patients with dementia states that dementia clients have negative effect on family mental health reveals that defected family functioning and low level social support are evitable among family caregivers of dementia. Sayed Pahlavanz etal., (2010)study the effects of family education programme on the caregiver's burden of families of elderly with dementia caregivers and highlights that family caregivers are an essential in health care services. Through conducting psycho-educational programmes can reduce caregiver's burden. Developing and monitoring projects are also recommended. Stewart NJ et al.,(2014) conducted a studyon rural caregivers for a family members with dementia: models of burden and distress differ from women and men and inferred that women had more burden and severity of distress than men and spouses had more severity of distress than adults. Patient's functional decline was related to caregiver burden. Van der Lee (2014) had studied on Multivariate models of subjective caregiver burden in dementia: systematic review highlights that the personality of the caregiver's express neurotic traits have stronger influence on caregiver's burden. Feeling competent or enjoying higher self-efficacy will reduce burden and enhance mental health of caregivers. Adelman RD etal., (2014) conducted a clinical review on caregivers burden and portrays that based on individual circumstances and context in which burden occurs should be considered after assessment to tailor intervention for caregivers. D'Aoust RF et al., (2014)conducted a study on depression in informal caregivers of person with dementia inferred that caregivers affect and perceived burden are strongly related to depressive symptoms. Sutter M (2014)conducted a study on linking family dynamics are associated to stronger mental health. This study has progressed family empathy, flexibility and communication whereby better caregiver mental health was delivered and care for people with dementia was obtained. Pim cuiperset al., (2010)conducted a portrays that social support is significant means of rendering assistance to the dementing elderly and researcher found that better situation and coping gained through four forms of support like information, advice, coping strategies, moral and emotional support. Matindale-Adam j et al., (2013) had done an investigation on a trail of dementia caregiver telephone support found that telephone support group are efficient way to converse with the patients. It provides better support for caregivers of individuals with a worsening condition. Etters L et al (2008) conducted study on caregivers burden among patient caregivers review of literature and found that even thou interventions are directed towards ameliorating caregivers burden, suggests that individually planned multi-component intervention decreases burden, improve quality of life and enable care givers to provide at home care for longer period to institutionalization. Astri aldeitt et al., (2010) studied on awareness of carer distress in dementia and found out there is little amount of knowledge about carer distress even thou family members who have dementia and study depicts on awareness of carer distress through intervention. Robinson et al., (2005) studied on making sense of dementia and adjusting to loss: psychological reactions to diagnosis of dementia in couples found that spouses can make join construction by adjusting to the changes in their role and identity and manage loss in the early stages of dementia.

Findings from psychosocial status in caregivers of dementia:-

- Negative mental health care giving leads symptoms are defective family functioning and low level of social support.
- Psycho education programme can reduce caregiver's burden.
- Financial burden leads to caregiver's burden.
- Negative caregiver'swill lead to neurotic traits but feeling competent or enjoying higher efficacy will reduce burden.
- Individualized tailor made intervention should be planned after assessment based on circumstance and context of burden.
- Caregiver's perceived burden and affect are related to emotions.
- Family dynamics is associated with mental health and promotion of healthy care giving.
- Better situation and coping can gained through different forms of support.
- Telephonic conversations are good form of social support.
- Individual plan along with be multi-component intervention decreases burden, improves quality of life and longer care can be rendered by caregivers.
- In spouses the adjustments can be made among them through changes in role, identity and loss management in the early stage.

Coping among caregivers of Dementia

Secondly, coping is positive way of responding to the situation and to the problem of care giving in dementia through inner resilience, which can be discussed below in the light of literature:

Cooper c et al (2006) conducted a study on Coping and anxiety in caregivers of people with Alzheimer's disease and expresses that addressing anxiety reduction is through coping strategies through the intervention are essential. Cooper c et al (2008) studied on coping strategies, anxiety, and depression in caregivers of people with Alzheimer's disease

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emotional –focused strategies and problem-focused strategies was mediated in this intervention study. The researcher found in his study and suggested that a psychological intervention package must emphasize emotion-focused coping which may be rational approach to reduce anxiety in dementia caregivers. Zucchella C et al (2012) studied on caregivers burden and coping. The finding highlighted With regard to coping strategies, the dysfunction strategy was predictive as caregiver burden. Successful caregivers were based on problem-oriented strategies in early stage of disease when solution can be still sought. Romero-Moreno R (2011) studied on motives for care giving: relation The motives are Intrinsic and Extrinsic. The participants were divided into four motivational profiles namely HIHE = High Intrinsic Motives + High Extrinsic Motives, LILE = Low Intrinsic Motives + Low Extrinsic Motives; HILE = High Intrinsic Motives + Low Extrinsic Motives and LIHE = Low Intrinsic Motives + High Extrinsic Motives The researcher found there is no difference between group with respect to frequency of behavioral problems. When compared to variables like caregiver's resources (rumination, cognitive reappraisal) and outcome (depression, anxiety and anger) was found worst. Kneebone 11 et al (2003) protary's in his study that it is advantageous to have tendency towards problem solving and acceptance styles of coping which enhances care giving in dementia. Incorporating coping measure will influence practice. Chun M et al (2007) Differences in stress and coping model of emotional stress among Koreans, Koreans-American and white-American caregivers highlights instrumental support was need for Korean care givers, emotional support was the need of Korean Americans caregivers. This finding alarms us that stress and coping process in caregiver's differences in the effects of the client's problem and of social support. Kaye j et al (1994) studied on spirituality among caregivers and found that professional interventions with network in church may be useful. Prayer, forgiveness and spiritual reading material are some coping resources which may be helpful for some caregivers. Levine (1981) studied on coping with dementia revealed that through collaboration of skill training programme designed helps them to be employed to improve and expand coping skills.

Findings from dementia caregiver's coping

- Anxiety coping strategies must be incorporated in interventions.
- Psychological intervention package should have emotional coping strategies
- Successful caregiver can be through problem oriented strategies in the initial stage.
- Caregivers with different motives are compared and found that resources and outcome of caregivers are worst.
- Problem solving and acceptance styles are advantageous to promote coping in care giving.
- Stress and coping from different cultures depends on effect of the patients problem and social support
- Prayer, forgiving and spiritual reading along with professional mediations enhances coping for some caregivers
- Skill training can improve some caregivers to improve and expand coping skills.

Role of social worker in psychosocial problems and coping enhancement in primary caregivers of Dementia patients:
The following are remedies from social work perspectives for public health problem

- Awareness about dementia involving mass media through mediums like puppet show, role plays, modeling etc. Street plays can be displayed in communities.
- Psycho-education about dementia and about care giving to primary care givers.
- Crisis management for primary caregivers,
- Anger management for primary caregivers ,
- Professional counseling for primary caregiver
- Motivational enhancement of primary care giver
- Family enrichment programme for enhancing family dynamics
- Psychotherapy like cognitive –behavior therapy, family therapy by trained professionals.
- Create and conduct support group in associations of dementia care giver's.
- Promote literacy on government and institutional schemes in caregivers for patients.
- Referral services to shelter homes, day care, respite care.
- Tap funding agencies for research and involve in research as emacipatory in function
- Advocacy for policy making exclusively for care givers and care recipients.
- Skill building through capacity building programmes in care of caregivers for promotion of themselves and carerecipients.
- Prepare ICE (information communication and education) material in vernacular language.
- Design and promote certificate, Diploma courses for caregivers by collaborating with RCI.
- Promote health seeking behavior among elderly through caregivers.

Role of NGO's in promoting care givers of dementia:-

- More non-governmental organization must emerge for emerging public health problems with social work intervention approach.
- Creating awareness in the community on dementia by community based programmes.
- Conducting outreach programme at satellite centers for early identification, intervention and counseling.
- Establishment of day care cum rehabilitation centers, shelter home and respite care of dementia patients by appointing caregivers.
- Capacity building programme for dementia caregivers on vivid concepts of care giving with reference to dementia
- Potential Ngo's can extend funding to promote caregivers research specifically on Dementia.
- Can form SHG for dementia caregivers as an association through non-governmental organization for holistic development
- Implement care, support and rehabilitation programmes accompanied by monitoring and evaluation periodically for dementia clients and caregivers welfare.
- Promote multi-disciplinary approach can be adopted in the organizations working on Dementia.
- Conduct internships and in-service programme in the field of dementia and care giving for students who specializes in geriatric care..
- Conduct training programnes to professional/ paraprofessionals on dementia and care giving as continuous education programme

Role of government:

- Disability pension has to be ensured in moderate and severe dementia along with old age pension.
- Concept of care for elderly has to be incorporated in school and college curriculum as value based education.
- Geriatric social work has to be added as a new specialization which must be connected to rehabilitation council of India.
- Subsidies in accessing their needs can be allotted as 50%.
- In terms of deserted elderly with dementia, government can rescue the deserted elderly in shelter homes by giving residential care by paid care giving through government appointing them with decent remuneration.
- Recruit many geriatric social workers to enhance quality of life of caregivers and care recipients.
- Grants can be sanctioned for individuals and organization working for elderly with neuro psychiatric disorder and related disabilities.
- Care and protection bill can be passed for elderly with neuropsychiatric disorders and disabilities, further it can be enforced as an act.

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- ❖ Incorporate that state should have geriatric specialty wards in every government, private and corporate hospitals.

Conclusion: Primary care in the family is very resourceful for caring for their loved ones. It is family members and professional's responsibility to make old age individuals to experience healthy and active ageing. Every citizen's responsibility is to identify dementia in early stage and make them to access health care systems to combat greater public health problem. Dignity and security has to be ensured for every elderly person above 60 years of age. We have to collectively join hands and eradicate dementia through innovative measureslike polio, a public health problem. Caregiver's holistic healths have to be ensured by enhancing psychological well being strengthening social support system and through coping which are obligatory. When caregiver's are cared care giving may have positive influences on care recipient, disabilities can be prevented, caregiver's health especially mental health can be enhanced. For positive healthy care giving family dynamics have to be strengthened like problem solving, decision making, cohesion, social support, defined roles, healthy boundaries, observing rituals. Good family dynamics has to be strengthened for healthy family functioning in caregiver's families of dementia patients. Preventive and promotive measures have to be taken to eradicate dementia which enhances the development of country from economic drainage and disabilities in future and promotion of healthcare system by human resource development through skill development. Services have to be renovated in the community for drastic need which is forecasted locally and globally prevailing and in the days to come with reference to Dementia.

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