

REVIEW ARTICLE

“Double Patients”: Managing Psychological Symptoms in Caregivers of Patients with Dementia

¹Alka A Subramanyam, ²Shipra Singh

ABSTRACT

Caregivers of patients with dementia are a vulnerable population themselves. They go through various phases of roles, based on the stage of the illness. There is a phase of acquiring the caregiving role, defining the quantum of involvement, and also finally dealing with eventual loss and the re-defining the role once the loss is final. This put the caregivers through a lot of stress, and makes them vulnerable to a host of psychological concerns themselves.

Through a series of cases, this article attempts to understand caregiver issues, and find a way to help, as well as shown how a lot of hand-holding at each stage aids the caregiver from reaching burn out and at times depression.

Keywords: Burn out, Caregiver, Dementia, Role transition.

How to cite this article: Subramanyam AA, Singh S. “Double Patients”: Managing Psychological Symptoms in Caregivers of Patients with Dementia. *Ind J Priv Psychiatry* 2017;11(2):11-16.

Source of support: Nil

Conflict of interest: None

INTRODUCTION

The phenomenon of population aging is becoming a major concern all over the world. According to the United Nations report, the global share of the elderly aged 60 years and above has increased from 9.2% in 1990 to 11.7% in 2013 and will continue to grow as a proportion of the world population, reaching 21.1% by 2050. Presently, about two-thirds of the world’s elderly population is living in developing countries.¹ With this, there has been an expected rise of age-related illnesses like dementia and subsequently, their caregivers.

There were an estimated 46.8 million people with dementia worldwide in 2015 and this figure is likely to double every 20 years. The incidence of dementia increases

exponentially with increasing age. The incidence doubles with every 6.3 years increase in age, from 3.9 per 1,000 person-years at age 60 to 64 to 104.8 per 1,000 person-years at age 90+.^{2,3} More than 60% of people with dementia live in developing countries. People with dementia require high level of care in nearly all aspects of their lives, and, hence, caregivers have a pivotal role to maintain the quality-of-life of the care recipient. The majority of the dementia patients is living in the community and is looked after by the informal caregivers, who are mostly the family members.

WHAT DO CAREGIVERS DO?

Caregivers do “whatever it takes.” Their role may range from occasional assistance to full time care, including physical care, symptom management, emotional support, help with activities of daily living, and support while the care recipient is in a living facility. In relation to this, Archbold⁴ gave the concept of care providers and care managers. Care providers provide hands-on care including dressing, assisting with finances and other daily activities, whereas care managers arrange for others to provide care, e.g., a nurse for individual care or an accountant to maintain the finances. Spouses are generally seen as care providers, whereas adult children and other relatives act as care managers. Care providers tend to be more stressed than care managers. Flow Chart 1 illustrates the caregiving career of a dementia caregiver.

WHO ARE THE CAREGIVERS?

Caregivers for dementia patients are mostly informal, the family members. According to the 10/66 Dementia Research Group, spouses consist of the largest proportion of these caregivers, followed by children and children-in-law, mostly female, although now, the number of male caregivers is also on the rise.⁶

CORRELATES OF CAREGIVING STRESS

Being a dementia caregiver can be a highly stressful and challenging task. It often requires long hours of involvement and sometimes even physically taxing tasks. A carer has to find a balance between caregiving and other demands of the family, children, career, and social obligations. This poses them to an increased risk of perceiving

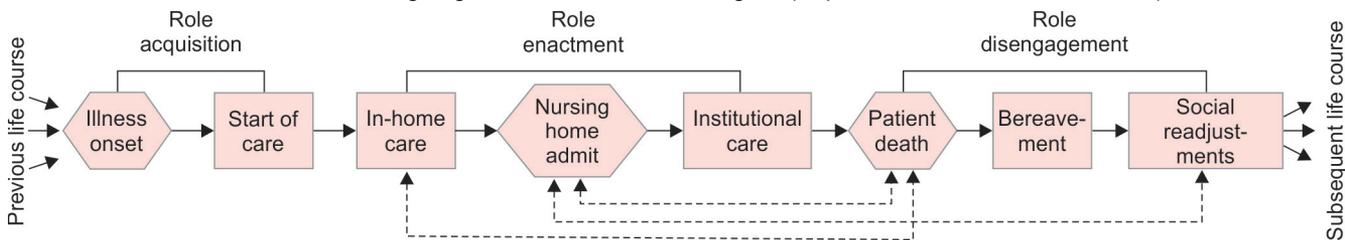
¹Associate Professor, ²Assistant Professor

¹Department of Psychiatry, Topiwala National Medical College & B. Y. L. Nair Ch. Hospital, Mumbai, Maharashtra, India

²Department of Psychiatry, Dr. Ram Manohar Lohia Hospital and Post Graduate Institute of Medical Education and Research New Delhi, India

Corresponding Author: Alka A Subramanyam, Associate Professor, Department of Psychiatry, Topiwala National Medical College & B. Y. L. Nair Ch. Hospital, Mumbai, Maharashtra, India e-mail: alka.subramanyam@gmail.com

Flow Chart 1: Caregiving career of a dementia caregiver (Reproduced from Aneshensel et al⁵)



burden, stress, and mental and physical ill health, which are found to be higher when compared with caregiving for patients of physical disability.⁷

Studies have found various predictors of high caregiver distress⁷⁻⁹:

Caregiver Factors

- Female gender
- Spouse
- Coinhabiting with care recipient
- Low socioeconomic status
- Care provider > care manager
- Inadequate knowledge about dementia

Disorder-related Factors

- Physical and cognitive decline
- Frontotemporal dementia (compared with other types due to more behavioral disturbances)
- Longer duration
- Behavioral and neuropsychiatric disturbances
- Impairment in activities of daily living

Relationship Factors

- Low self-confidence
- High neuroticism
- Expressed emotion
- Experience of “role captivity”
- Emotion-based coping strategies
- Confrontative coping strategies

CAREGIVING AND THE STRESS PROCESS

Stress is undoubtedly a common occurrence in caregivers, and it becomes even more significant in those who care for patients with dementia as compared with caregivers of patients with other chronic illnesses. Caring for a relative with dementia becomes entirely different due to its exceptional characteristics of having changes in the usual role patterns, the continuous mourning process of gradually losing a loved one, and the irreversible and uncontrollable nature of the illness.

In the forthcoming section, we will be discussing the problems faced by the caregivers, through a series of

cases, which may help understand different aspects of caregiving.

Case 1: Dr A, a 69-year-old pediatrician, and her 76-year-old surgeon husband have been following up for the last 5 years, in our geriatric psychiatry services. He was diagnosed with dementia. He has not really shown much change, but in the last 2 years, the decline has been more rapid.

Dr A comes into the clinic one day, stating that she is “fed up” and “wants to end her life.” She just cannot take it anymore, and the feeling of helplessness is overwhelming.

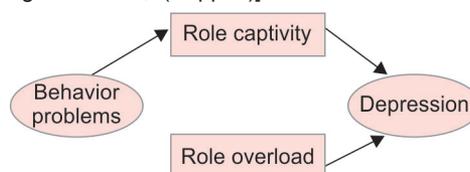
On enquiry, it is found that she is very upset particularly that her husband, who she says “often sits like a statue” and has no response, has suddenly started chasing women during their daily visit to the park, and even kissed one the other day. “That was the last straw.”

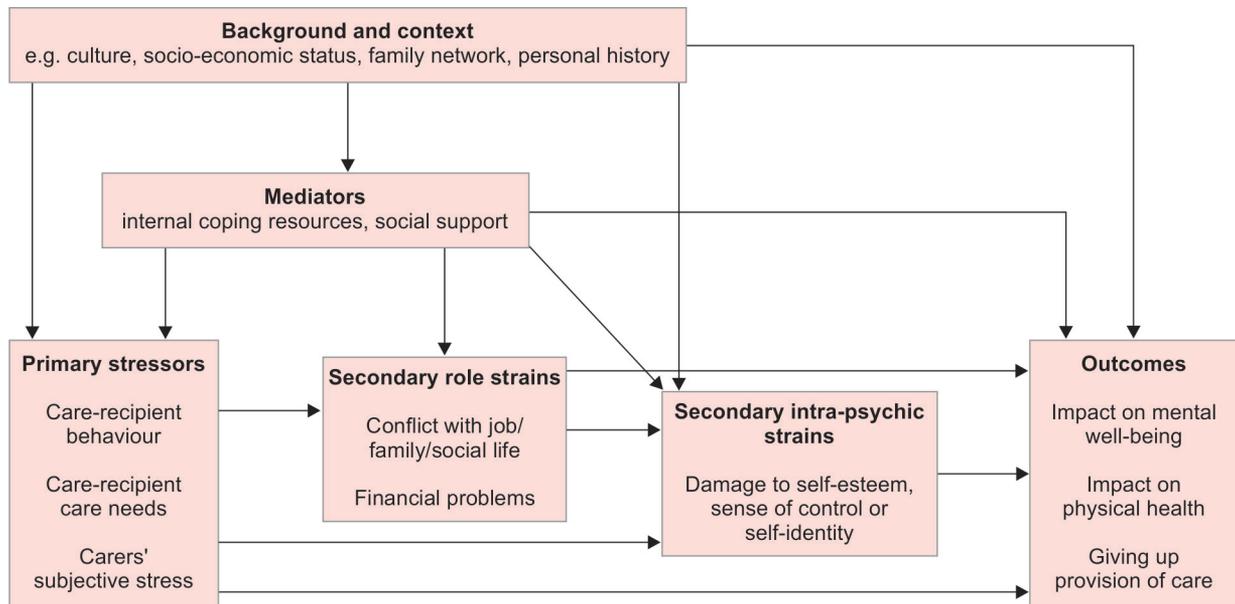
Why is Dr A so disturbed? What has happened to her?

Caregiving is a complex process and involves diverse effects on carer and includes multiple factors that are responsible for their perception and reaction as a result of their role. Dr A (the wife) was taking care of the husband since many years; however, recent appearance of behavioral symptoms increased the physical (of consistently supervising him) as well as emotional load (embarrassment and helplessness on her part to control it), which, in turn, arouses the feeling of exhaustion and depression.

This can be well-explained by Campbell, who suggested that sense of “role captivity” (carer’s feeling of being “trapped” in their role), caregiver overload (fatigue and burnout), adverse life events outside of the caregiving role, and relationship quality are strong predictors of caregiver burden (Flow Chart 2).¹⁰ Various other models have been developed to explain this process. Poulshock and Deimling¹¹ suggested that dependency of the patient

Flow Chart 2: Campbell’s model of caregiver strain [Reproduced from Behavioral Disturbances of Dementia and Caregiver Issues Int Psychogeriatr 1996;8(Suppl 3)]



Flow Chart 3: Pearlin et al model of caregiver strain (adapted from Pearlin et al¹²)

on caregiver and behavioral symptoms arising due to dementia lead to caregiver burden, affecting psychological, physical, financial, and social well-being of the patient.

Similarly, Pearlin et al¹² highlight areas that contribute to caregiver stress (Flow Chart 3). The background context includes the preexisting resources and support to the carer and other life events. Primary stressors are the hardships directly related to illness, i.e., level of assistance required by the patient, behavioral symptoms of dementia. Then, there are secondary stressors, which are classified as strains experienced in roles and activities apart from caregiving (family conflicts and social life), and the other is the intrapsychic strain, which involves the carer-related factors like diminishment of self-concepts, personality, and role captivity. A caregiver's stress appraisal is based on the perceived resources and can be intervened by appropriate coping and social support.

PROTECTIVE FACTORS FOR CAREGIVING STRESS

The factors making a caregiver vulnerable or contributing to his/her distress have been discussed earlier. Similarly, it has been found that there are elements that mitigate it. Foremost, is the knowledge about dementia *per se*, its management, and prognosis that would help the caregiver in early acceptance of the illness. Professional support becomes essential during the events of difficult behavior of the patient, and easy accessibility to such help develops a sense of confidence in caregiver to manage such events. Informal support from other family members, friends, and neighbors is of considerable importance. Participating in support groups provides the caregiver a platform to discuss the day-to-day issues,

gaining new insights about the same and an outlet to their emotions. In addition, individual's physical and psychological characteristics, like having good functional health, mature and problem solving coping strategies, sense of self-efficacy and mastery, and a close relationship with the person with dementia help in perceiving more positive caregiving experiences and alleviating the strain.¹³⁻¹⁵

IMPACT OF CAREGIVING ON CAREGIVER

Dementia caregivers are found to have increased risk of health problems as compared with the general population. They have compromised immune system and poor wound healing. Cardiovascular problems and other chronic conditions like diabetes mellitus, arthritis, and anemia are frequently present.^{16,17} In addition, they are less likely to engage in preventive health behaviors like exercise; instead, they have involvement in detrimental activities, such as smoking, drinking, etc.^{18,19}

They are vulnerable to develop psychological distress, and high rates of prevalence of depression and anxiety among them is evident in previous studies. In developing countries, rates of psychiatric morbidity range from 40 to 75%. Emotions of anger, resentment, and guilt are often felt and, sometimes, even lead to acts of abuse and violence toward the patient.^{7,8}

The long hours of care cause caregivers to curtail the other activities. They reduce social involvements, restrict their time with family and friends, and sometimes have to give up the employment as well. There is less time for leisure and hobbies. This leads to a contraction of the social network of the caregiver and, hence, isolation.^{20,21}

Further, the cost of managing a patient with dementia is quite high. Direct costs include medical consultations, investigations, pharmaceuticals, provision of personal and nursing care, and often, residential care in the later stages. Moreover, a dementia patient in a family setting leads to indirect costs including loss of earnings by patient himself and family caregivers as they miss or give up employment, hours of informal care, and mortality burden.^{7,22,23}

Although it seems that caring for a person with dementia only leads to burden of all sorts, a positive side of it has also been identified. Many caregivers do report a sense of satisfaction and gratification in caregiving and identify personal gains, uplifts, and enjoyment resulting from caregiver responsibilities. They perceive pride in the ability to meet challenges; an improved sense of self-worth; a sense of growing closer to the care recipient; and the experience of warmth, comfort, and pleasure in caregiving. Various models have been proposed to explain these experiences. The existential perspective suggests that the process of finding meaning through difficult life experiences is based upon the values one embraces and the choices one makes, as well as one's willingness to assume responsibility for right action and conduct.^{24,25}

CAREGIVER INTERVENTION

Well-being of the caregiver is equally important as that of the care recipient, as both are interconnected. Studies have shown that caregiver interventions are related to improved outcomes for caregivers in the form of increasing their knowledge, improving mood, reducing stress and depression levels, and delaying institutionalization of the patient.^{26,27}

Various strategies that have been implicated for helping the caregivers are²⁷⁻²⁹:

- *Psychoeducation*: It is generally delivered by trained professionals, and includes both educational and supportive strategies. It includes providing information about the disease process, disruptive behaviors, and caregiving skills in order to enhance the ability to manage the problematic behaviors of the care receiver. On the contrary, supportive activities are designed to maintain interaction among group members to enhance mutual support, increase networks among them, and normalize stressful experiences.²⁸
- *Counseling*: In counseling interventions, specific individual needs of the caregiver are identified. Counselors focus mainly on helping caregivers understand and resolve their reactions to the caregiving process. This can be delivered via group meetings or during individual/family sessions and were targeted to a caregiver's individual needs and problems.²⁸
- *Support groups*: Through participation in such groups, a caregiver can learn from the experiences of others who have faced the same challenges. It forms a social network that can help reduce feelings of isolation, fear, and hopelessness; and in identifying community resources.
- *Respite care*: It provides caregivers a temporary rest from caregiving, while the person with dementia continues to receive care in a safe environment, either at home or a residential facility. The care provider can be a friend, family member, or paid service.

Case 2: Mr B is a 79-year-old man, suffering from moderate dementia since the last 5 years, who for the past 1 year has been brought religiously by his daughter-in-law, who would take care of him, bring him for follow-ups, monitor his medication, etc. The daughter-in-law is 34 years old, and married since a year. However, she approached the counselor as she wishes to seek a divorce from her husband (who travels frequently), as she was not able to cope with taking care of her father-in-law. The social worker who was involved suggests that Mr B will need either a caretaker or a placement home soon, as per her assessment.

What happened to Mrs B (daughter-in-law) and what can be done?

Mrs B, being the sole caregiver, was experiencing the phenomenon of "role captivity," as has been explained earlier. She had limited time for self and a constricted social network, and, hence, was not able to cope with role overload.

- *Intervention*:
 - *Concept of "shared caregiving"*: relevant in nuclear families of recent times.
 - *"Time out" to the primary caregiver*: making use of the respite care.
- *Involvement in social activities*.
- *Cognitive skills*: e.g., distraction, imagery (including guided or vivid imagery), attention refocusing, dissociation.
- *Relaxation*: Relaxation technique like progressive or autogenic relaxation training.
- *Social skills training*: It involves role-play, modeling, rehearsal, assertiveness training, or training in verbal or nonverbal communication that could be used to teach coping with specific caregiving issues, e.g., role-playing, asking a relative for some assistance and support in looking after the care recipient, or using role-play to deal with behavioral problems of the care recipient.
- *Problem solving*: Very often, we might encounter caregivers, particularly daughters-in-law, in our social milieu, who are ushered into their role of caregiving,

without having a bond with the patient. This leads to a host of psychological problems and distress, and resentment toward the patient and family in general. Anticipating this distress, and preparing them for the path ahead, can prove to be very helpful.

Case 3: Mr C is a 72-year-old man who has been taking care of his 65-year-old wife for the past 5 years since the doctor diagnosed her with dementia. They stay with their son, daughter-in-law, and grandchildren, who are great support to him and share the caregiving with him. They also have a hired help for 6 hours of the day, who has been with them for 4 years. Unfortunately Mrs C has been progressing in her illness. Of late, she has started wandering out of the house at night and has even fallen down on a couple of occasions. Their psychiatrist attributes the increased wandering away to the recent shift in house, as they bought a bigger home and have shifted there. Mr C is very worried that his wife might inadvertently harm herself. He really does not know how to deal with this and is contemplating moving back to his old house (which they sold), but knows the support there will be limited.

In such situations, which involve dealing with the challenging behavior of the patient, problem-solving approach is of utmost importance. It includes following steps:

- *Determine the problem:* Patient behavior/caregiver reaction or concern
 - *Define/operationalize:* Frequency, duration, intensity, characteristics, antecedents, and consequences of behavior, e.g., in above situation, when, where, and how often does it happen?
 - Assess previous attempts to address
 - Establish priorities; set goals and realistic outcome
 - Treat or eliminate antecedents and triggers
 - Unmet physical needs (e.g., pain)
 - Unmet psychological needs (e.g., loneliness)
 - Environmental causes (e.g., stimulation, noise)
 - Psychiatric causes (e.g., depression)
 - Trying to make changes slowly and carefully
 - Develop plan
 - Brainstorm best practice and evidence guidelines strategies
 - Help caregiver select strategies based on type of problem and dyad's needs, abilities, and resources, e.g., adapt environment to reduce exit-seeking, identification/global positioning system, safe wandering paths
 - Write strategies down
 - Teach caregiver to use strategies, practice, and role models
 - Review and troubleshoot plan
 - Emotional coping strategies for the caregiver
- Taking a moment in the garden
 - Walking to the next room
 - Wishful thinking
 - Acceptance
 - Remembering good times the caregiver had with the patient
 - Managing guilt

Case 4: Mrs D takes care of her 84-year-old mother who stays with her in her married home since the last decade. She is a case of dementia and has been progressing slowly. Mrs D has so far been coping with the decline. However, of late, she is most perturbed because she says her mother even refuses to be bathed. She let it go once or twice, but for 3 to 4 days, she would be like that until she felt it would affect her general hygiene. Her mother gets upset, often howls loudly, and starts shouting saying "Leave me alone, leave me alone, do not you dare touch me" so much so that a scene is created in the entire locality. What should Mrs D do to help herself and her mother?

The best way to tackle a situation like this is by cognitive restructuring

- Identify the situation (e.g., my mother hates to take a bath)
- Identify current thoughts (e.g., it is a struggle every-day. If I was a better caregiver, I could do this)
- Recognize current emotions/feelings (e.g., frustrated, weary, dread, tired of doing this)
- Challenge/replace unhelpful thoughts (e.g., maybe she does not need a bath every day. Maybe a sponge bath is ok)
- Match milder feelings to milder thoughts (e.g., flexible, capable of doing it)

One of the most efficacious interventions until now in this aspect has been REACH (Resources for Enhancing Alzheimer's Caregiver Health).³⁰ It involved information provision, didactic instruction, role-playing, problem-solving, skills training, stress management techniques, and telephone support; and resulted in significantly lower depression, burden, and care recipient problem behaviors, and higher self-care and social support as compared with controls.³¹

CONCLUSION

Caregivers are an integral part of life of their demented relative. Their support is fundamental to continue care of people with dementia in the community. However, in the process of caregiving, high levels of burden, and physical and psychological ill health are seen. Interventions for caregivers can ameliorate these factors and would, thereby, lead to improved well-being of the dementia patients as well as the caregivers. Therefore, management of the dementia requires a comprehensive plan

that includes a partnership between doctors, health care workers, and families, and specifically the care of "hidden patients," the primary caregivers.

REFERENCES

1. United Nations, Department of Economic and Social Affairs, Population Division. World Population Ageing. New York: United Nations; 2013. pp. 1-2.
2. Prince, MJ.; Wimo, A.; Guerchet, M., et al. World Alzheimer Report 2015: the global economic impact of dementia. London: Alzheimer's Disease International; 2015. pp. 10-12.
3. Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, Hall K, Hasegawa K, Hendrie H, Huang Y, et al. Global prevalence of dementia: a Delphi consensus study. *lancet* 2006 Dec;366(9503):2112-2117.
4. Archbold PG. Impact of parent-caring on women. *Fam Relat* 1983 Jan;32(1):39-45.
5. Aneshensel, CS.; Pearlin, LI.; Mullan, JT., et al. Caregiving career and stress processes. In: Profiles in caregiving: the unexpected career. 1st ed. Waltham (MA): Academic Press; 1995. p. 24.
6. Prince M, The 10/66 Dementia Research Group. Care arrangements for people with dementia in developing countries. *Int J Geriatr Psychiatry* 2004 Feb;19(2):170-177.
7. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci* 2009 Jun;11(2):217-218.
8. Brodaty, H. Module 4—Role of family caregivers. In: Draper B, Brodaty H, Finkel SI, editor. The IPA complete guides to behavioural and psychological symptoms of dementia—specialists guide. Northfield (IL): International Psychogeriatric Association; 2015. pp. 4.2-4.12.
9. Schoenmakers B, Buntinx F, De Lepeleire J. Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas* 2010 Jun;66(2):191-200.
10. Campbell P, Wright J, Oyebode J, Job D, Crome P, Bentham P, Jones L, Lendon C. Determinants of burden in those who care for someone with dementia. *Int J Geriatr Psychiatry* 2008 Oct;23(10):1078-1085.
11. Poulshock SW, Deimling GT. Families caring for elders in residence: issues in the measurement of burden. *J Gerontol* 1984 Mar;39(2):230-239.
12. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990 Oct;30(5):583-594.
13. Goode KT, Haley WE, Roth DL, Ford GR. Predicting longitudinal changes in caregiver physical and mental health: a stress process model. *Health Psychol* 1998 Mar;17(2):190-198.
14. Gottlieb BH, Rooney JA. Coping effectiveness: determinants and relevance to the mental health and affect of family caregivers of persons with dementia. *Aging Ment Health* 2004 Jul;8:364-373.
15. Schoenmakers B, Buntinx F, De Lepeleire J. The relation between care giving and the mental health of caregivers of demented relatives: a cross-sectional study. *Eur J Gen Pract* 2009;15(2):99-106.
16. Vedhara K, Cox NK, Wilcock GK, Perks P, Hunt M, Anderson S, Lightman SL, Shanks NM. Chronic stress in elderly carers of dementia patients and antibody response to influenza vaccination. *Lancet* 1999 Feb;353(9153):627-631.
17. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003 Nov;129(6):946-972.
18. Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry* 2004 May-Jun;12(3):240-249.
19. Alzheimer's Association. Alzheimer's disease facts and figures. Chicago (IL): Alzheimer's Association; 2007.
20. Brodaty H, Hadzi-Pavlovic D. Psychosocial effects on carers of living with persons with dementia. *Aust N Z J Psychiatry* 1990 Sep;24(3):351-361.
21. Leong J, Madjar I, Fiveash B. Needs of family carers of elderly people with dementia living in the community. *Australas J Ageing* 2001 Sep;20(3):133-138.
22. Access Economics. The dementia epidemic: economic impact and positive solutions for Australia. Canberra: Alzheimer's Australia; 2003.
23. Brodaty, H.; Green, A.; Low, LF. Family carers for people with dementia. In: Burns A, O'Brien J, Ames D, editors. Dementia. 3rd ed. London: Hodder Arnold; 2005. pp. 117-135.
24. Boerner K, Schulz R, Horowitz A. Positive aspects of caregiving and adaptation to bereavement. *Psychol Aging* 2004 Dec;19(4):668-675.
25. Farran CJ. Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: stress/adaptation and existentialism. *Gerontologist* 1997 Apr;37(2):250-256.
26. Brodaty H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. *J Am Geriatr Soc* 2003 May;51(5):657-664.
27. Pinquart M, Sörensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr* 2006 Dec;18(4):577-595.
28. Acton GJ, Kang J. Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis. *Res Nurs Health* 2001 Oct;24(5):349-360.
29. Pinquart M, Sörensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr* 2006 Dec;18(4):577-595.
30. Schulz R, Burgio L, Burns R, Eisdorfer C, Gallagher-Thompson D, Gitlin LN, Mahoney DF. Resources for Enhancing Alzheimer's Caregiver Health (REACH): overview, site-specific outcomes, and future directions. *Gerontologist* 2003 Aug;43(4):514-520.
31. Cooke DD, McNally L, Mulligan KT, Harrison MJ, Newman SP. Psychosocial interventions for caregivers of people with dementia: a systematic review. *Aging Ment Health* 2001 May;5(2): 120-135.