

# REFINING DEMENTIA INTERVENTION: THE CAREGIVER-PATIENT DYAD AS THE UNIT OF CARE



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Unlike most other chronic diseases dementia, gradually destroys the very essence of relationships. Why? Beyond the sentinel impairment of memory present in the early stages of the commonest forms of dementia such as Alzheimer's disease, most prominent among the effects of dementia are the gradual inexorable destruction of insight and the patient's ability to communicate and reason. Over time, the loss of cognitive function leaves people with dementia unable to perform the roles of spouse, parent, and friend they had previously played,<sup>1,2</sup> and damages their capacity to participate fully in decisions regarding their own treatment planning, personal care, and day-to-day essential functions. The force of disease leaves the family caregiver, particularly the live-in caregiver, increasingly and inexorably abandoned.

The lost capacities must be compensated for, and this task falls predominantly to the family caregiver. Most dementia care in Canada occurs at home in the community.<sup>3</sup> While paid personal supportive care is common, financial and other considerations mean that it generally cannot substitute completely or even adequately for the 24-hour needs of the person with dementia. It is the patient's spouse or child who becomes the front-line care provider.<sup>4,5</sup> Ninety-seven percent of persons with dementia have at least one caregiver, the majority being female members of their families, 50% of whom are aged 65 years or older.<sup>6-11</sup>

Unlike other forms of caregiving in chronic disease, the caregiver of the person with dementia must engage in a role that transforms a longstanding familiar relationship of mutual decision making and collaboration into one characterized by unfamiliar and often painful or anxiety-provoking unilateral decision making: thinking and deciding for two, as caregivers often say. These decisions gradually involve and take over the very substance of the daily life of the patient, whose loss of insight frequently leads to a misunderstanding of and resistance to these essential, and previously independently made, decisions that now fall to the caregiver: when to

go to sleep, when to get up, what to eat, when to drink, when to bathe, how to dress, and, perhaps more profoundly, how to interpret withdrawal and apathy, suspicion and aggressiveness, or complaints and discomfort; when and how to give medications; when to interpret distress as serious illness and seek help; and when to go to the doctor or the emergency department. The family caregiver, confronted with these tasks relatively suddenly, without training, and sometimes without choice, often feels both alone and confused. Most often, caregivers readily accept and often express satisfaction with their caregiving role.<sup>12-14</sup> However, the toll on caregivers is intense and profound.

Of course, every experienced clinician recognizes the truth of this clinical description. However what is not as well recognized is the profound importance this has on the successful management of the dementia. It is known that family involvement is associated with better psychological and psychosocial well-being of the patient<sup>15</sup> and higher patient life satisfaction,<sup>16</sup> and the care families provide can allow those with dementia living in the community to age at home rather than in an institution.<sup>17-20</sup> While data are lacking, increased burden on the caregiver and challenges in providing care impair dementia management and may lead to earlier institutionalization.

Hence, dementia illnesses cannot be managed without taking into clinical account both partners in the caregiver-patient dyad. This factor is most relevant when assessing the live-in family caregiver, who is usually a spouse or adult child. It may be asserted with some confidence that *all treatment interventions fail in dementia unless the unit of dementia assessment and management is recognized to be the live-in family caregiver-patient dyad.*

This is more than just humane medicine: it is essential to effective practice. It is also key to the prevention of significant impairment in the caregiver component of the dyad. The shorthand terminology that has been used to describe caregiver vulnerability is "caregiver burden" (CB). This is a useful term, but it has limited

diagnostic utility and is hard for the clinician to evaluate in the office. However, because effective clinical management is impossible without caregivers, CB is a core factor in the assessment and treatment of dementia.

The causes of CB are diverse, but the most prominent correlate is the behavioural and psychological symptoms of dementia (BPSD) that almost inevitably emerge during the course of the disease. Many studies report that it is this array of behaviours that has the greatest impact on caregivers and contributes most to the development of CB. BPSD are involuntary manifestations of the disease process and can include apathy (the most common of the BPSD); depression and anxiety; sleep cycle disturbances; “resistance” to care; irritability, agitation, and physical aggression; personality change; psychotic symptoms including suspiciousness, paranoid ideation, delusions, and hallucinations; wandering, pacing, and exit seeking; repetitive activities (perseveration); screaming and inappropriate verbalizations; hoarding; inappropriate voiding or spitting; and inappropriate sexual behaviour.<sup>9,21–23</sup> BPSD are very difficult for any caregiver to cope with, and many caregivers are puzzled by their cause and management, especially when ordinary means of addressing puzzling behaviours in others, such as reasoning or asking for clarification, may no longer work when dealing with someone who has dementia.

Particular BPSD appear to have more impact and result in a greater degree of caregiver distress. Wandering, depression, verbal and physical abuse, sleep disturbances, and psychotic symptoms have been shown to often overwhelm caregivers and precipitate institutionalization.<sup>9,24,25</sup> It can be extremely difficult for family caregivers to maintain their role in the face of bizarre behaviours often unrepresentative of the person the caregiver used to know and love. When this happens, the relationship between caregiver and care recipient loses its intimacy and may rupture.<sup>26,27</sup> This breakdown, in turn, dramatically increases the caregiver’s feeling of burden, accompanied by loss and grief, and significantly impairs effective dementia management plans.

## What Is the Effect of CB on Caregivers?

Caregivers are at disproportionate risk, compared to non-caregiver peers, of acquiring physical and psychological impairments,<sup>21,28–40</sup> including the following:

- Higher prevalence of physical symptoms
- More visits to the doctor
- Higher rates of prescription drug use
- Poorer subjective ratings of health
- Compromised immune function as measured by inflammatory markers such as interleukins
- Exacerbation of pre-existing illnesses including diabetes, hypertension, and other cardiovascular diseases
- Higher rates of depression (10% meet *Diagnostic and Statistical Manual* criteria for depression, and over 40% have depressive symptoms)
- Increased use of psychotropic medications (7–31% of caregivers)
- Increased rates of relapse of pre-existing psychiatric illness
- Increased rates of overuse of substances such as alcohol or drugs, especially prescription medications
- Emotional vulnerability – anxiety, grief, guilt, shame, rage

**Table 1. Factors That Increase Caregiver Burden**

Less knowledge of dementia and its treatment
Belief that BPSD are volitional and within the care recipient’s control
Excessive demands exceeding the capacity of the care recipient
Excessive rigidity
Unpredictable or unreliable responses
“Immature” coping skills such as emotion-based coping
High levels of negative affect such as criticism and hostility
Pre-existing caregiver depression
History of prior poor caregiver health
Lack of social support
Strained past relationship with care recipient
Living with the care recipient

Sources: Dunkin and Anderson-Hanley,<sup>6</sup> Canadian Institute for Health Information,<sup>9</sup> International Psychogeriatric Association,<sup>25</sup> Vitaliano et al.,<sup>40</sup> Brodaty,<sup>44</sup> Donaldson et al.,<sup>45</sup> and Gilleard et al.<sup>46</sup>

## What Is the Effect of Caregiver Reactions on Dementia Management?

Most importantly, the response of the caregiver to the BPSD may intensify (or moderate) burden through direct and indirect (feedback) effects.<sup>25,41–43</sup> Caregivers who react with *hostility and criticism* elicit negative behaviours from the care recipient.<sup>25</sup> This, in turn, creates a negative feedback loop wherein a negative attitude prompts an increase in BPSD that, in turn, increase the negative attitude – and the cycle continues.<sup>23</sup>

## What Are the Apparent Causes of CB?

Burden is intensified among caregivers with *less knowledge* of dementia and its treatment, who may believe that BPSD are volitional and within the care recipient’s control rather than a manifestation of the disease.<sup>6,23</sup> Other caregiver reactions may increase burden by exacerbating the symptoms of the care recipient, including making demands that exceed the capacity of the care recipient and then criticizing failure, being excessively rigid, and being unpredictable or unreliable in responses or routines.<sup>25</sup> These and other factors predictive of burden are summarized in Table 1.

## Assessing the Live-In Family Caregiver–Patient Dyad Unit of Care

Basic clinical and diagnostic assessment protocols of the person with dementia have been fairly well established. While essential, clinical assessment and focal intervention with the person with dementia are not sufficient for effective management. It is clear that effective clinical management requires a broader diagnostic approach that incorporates the system of care and, most especially, the live-in family caregiver-patient dyad. This means using an expanded model of clinical dementia assessment and diagnosis. The model presented here is derived from the clinical models developed at the Cyril and Dorothy, Joel and Jill Reitman Centre for Alzheimer’s Support and Training in the Geriatric Psychiatry Program of Mount Sinai Hospital in Toronto. This centre is a clinical unit that, in collaboration with primary care physicians geriatricians, memory clinics and the like, delivers evidence-informed comprehensive assessment and interventions for caregivers dealing with dementia (<http://www.mountsinai.on.ca/care/reitman/alzheimer-support>). Figure 1 illustrates an integrated caregiver-patient dyad model of assessment.



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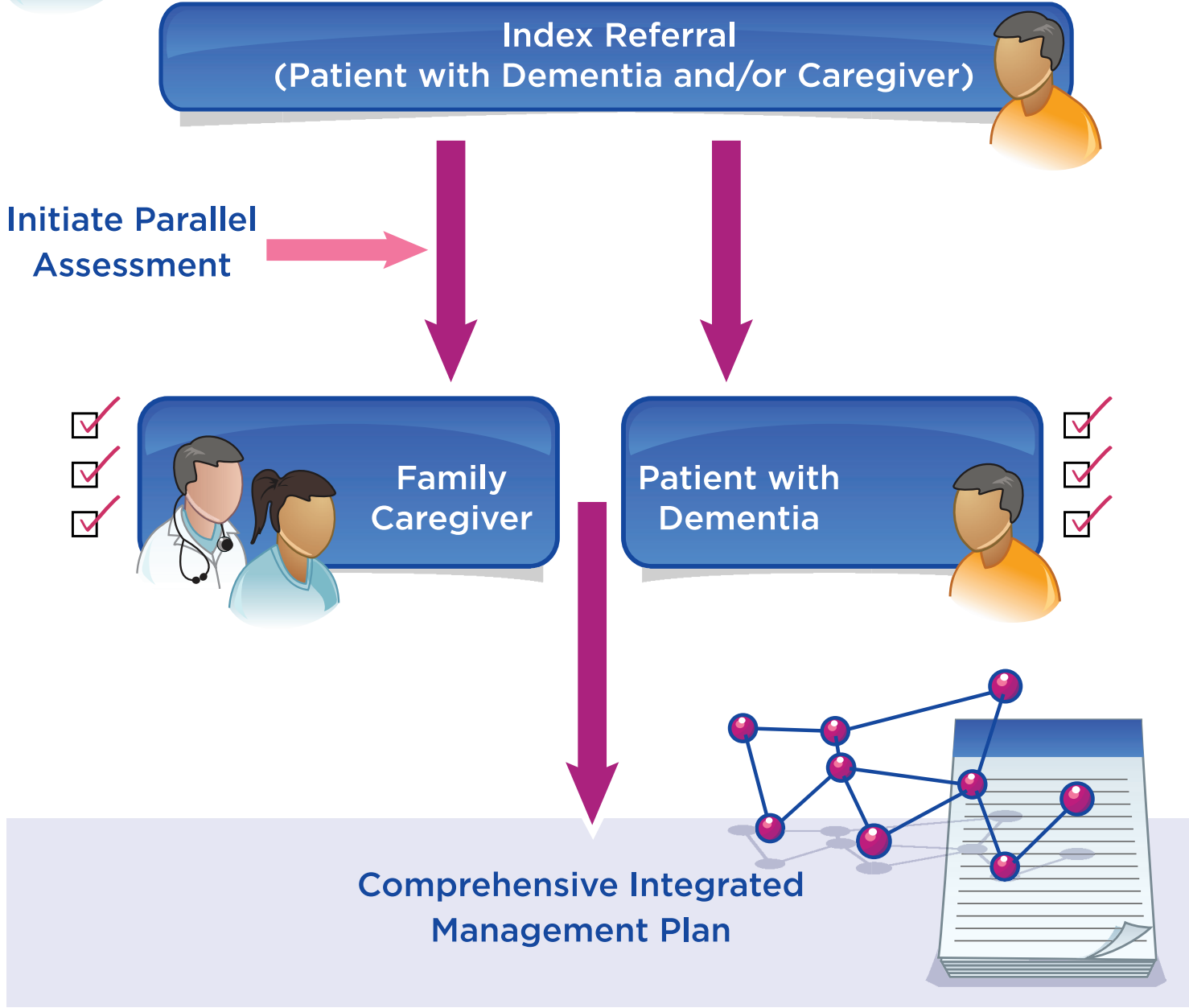


Figure 1. Integrated caregiver-patient dyad model of assessment.

## Caregiver Assessment

This section focuses on assessing and managing the caregiver component of the dyad, although it is obvious that both the patient and caregiver must be systematically evaluated and the data integrated into a comprehensive plan. Caregivers should be sensitively led to the understanding that both they and the person with dementia are part of a system, which means that their needs must and will be assessed as well. Their role in the assessment process goes far beyond simply providing collateral information about the person with dementia. For some caregivers, this may be the first time that they have been the direct focus of inquiry aimed at determining their specific challenges, needs, and concerns.

The domains of assessment important in evaluating caregiver burden, vulnerability, and resilience include the following:

- Medical: caregiver illness history, including medications
- Psychiatric: history, especially depression
- Current instrumental support structure: presence and adequacy of financial resources, environment, and personal support workers
- Professional support: psychological and medical
- Social support: confidants and family
- Knowledge and understanding of dementia, beliefs about and emotional reactions to the disease, especially BPSD; culturally determined attitudes including stigma
- Caregiver-patient relationship: current – including levels of patient’s demands and needs that exceed caregiver’s capacity; and past – including conflict
- Caregiver’s coping style: immature emotion-focused coping versus mature problem-focused coping

## Dementia Management: Caregiver Interventions

Just as the diagnostic and assessment stage is two pronged, so is the intervention stage. Because of the limited effectiveness of medications in addressing dementias, interpersonal and behavioural care remain the mainstays of management plans, and the family caregiver is most often at the centre of the planning and delivery of care.

Recent meta-analyses have evaluated interventions to enhance the capacity of family caregivers.<sup>47–49</sup> Interventions that targeted the caregiver were designed to relieve burden and depression and to improve knowledge, well-being, and coping skills. Intervention modalities included psycho-education, cognitive behavioural therapy, counselling, case management, telephone or Internet support, physical exercise, communications skills, and general support. However, no single intervention was sufficient to address caregiver needs and enhance their capacities; an integrated approach is most effective.

Based on empirical data and data derived from clinical experience, effective caregiver interventions are multi-faceted but may be broadly divided into three domains:

1. Instrumental and practical
2. Emotional
3. Skills training, knowledge acquisition, and problem solving

The progressive nature of the disease requires specific monitoring and

adaptation of the techniques in each domain as the disease evolves. Timely intervention, modified to the evolving clinical picture and pressures on the caregiver, sustains the system of care and delays premature institutionalization.

## Instrumental and Practical Interventions

Instrumental management of dementia in the community requires a wide array of resources that change in type, frequency, and accessibility as the disease progresses. Depending where in the country care is being accessed, there will be more or less centralization of resources and information for caregivers. However, it is important to keep in mind that, in the main, such instrumental care systems tend to be fragmented and poorly organized, and caregivers are bewildered by the array and, in some cases, unaware of options they may have to evaluate and choose from. It is widely recognized that giving caregivers appropriate “guidance” and hands-on help with the navigation of the system is of great value in reducing CB and in enhancing dementia management.

When evaluating instrumental needs of caregivers, the domains of inquiry and management are as follows:

- Respite resources (brief and longer term)
- Safety measures (management of wandering, protection of the caregiver from aggression)
- Legal issues (powers of attorney, capacity assessment)
- Financial issues
- Transportation
- Housing and long-term care (including retirement and nursing homes)

## Key Points

- *Ninety-seven percent of persons with dementia have at least one caregiver, the majority being female members of their families, 50% of whom are aged 65 years or older.*
- *While essential, clinical assessment and focal intervention focused only on the person with dementia are not sufficient for effective management.*
- *All treatment interventions in dementia fail unless the live-in family caregiver–patient dyad is managed as the unit of dementia assessment and management.*
- *CB causes caregivers to be at disproportionate risk, compared with non-caregiver peers, of acquiring physical and psychological impairments.*
- *Burden is intensified among caregivers with less knowledge of dementia and its treatment who may believe that BPSD are volitional and within the care recipient’s control rather than being a manifestation of the disease.*
- *Based on empirical data and data derived from clinical experience, caregiver intervention may be broadly divided into three domains: instrumental and practical; emotional; and skills, knowledge, and problem solving.*

- Social and recreational supports
- Medical and health care resources (including the availability of a family doctor, home visits, home nursing care, emergency care)

### **Emotional Interventions**

There is a wide range of emotional and psychiatric experiences associated with caregiving. A key factor in caregiving is the common feeling of isolation. Despite well-intended help of willing family and friends, caregivers often and accurately understand that those who do not live day to day with the experience of caregiving for dementia are unable to understand how overwhelming it is emotionally. Hence, both professional and peer support are essential factors in managing CB.

The following are key domains of emotional vulnerability of caregivers to be assessed and managed:

- **Major depressive disorder** requiring formal treatment, including antidepressant medication
- **Anxiety/worry** syndromes best managed by identifying and addressing core concerns with appropriate problem-solving therapeutic interventions
- Prolonged “disenfranchised” **grief and loss** of the relationship and future associated with dementia, best managed with supportive psychotherapy and modified grief counselling
- **Social dislocation**, damaged self-image, and withdrawal, often best managed with a program of systematic self-care
- **Anger**, resentment, and feelings of entrapment; these require psychotherapeutic intervention

### **Skills, Knowledge, and Problem Solving**

Caregivers are confronted with the same array of problems facing professional caregivers but lack the background knowledge of or training in dementia. In addition, they must learn and implement their skills in a complex emotional environment of anxiety, loss, fear, and entrapment with which professional caregivers do not have to contend.

There are many resources available for caregivers. Most readily available are the resources offered by the Alzheimer’s societies (e.g., the Alzheimer Society – Canada, <http://www.alzheimer.ca/>; Alzheimer’s Disease International, <http://www.alz.co.uk>). Caregivers are often very resourceful and seek out information about the disease online, in books, from organizations, and by attending organized workshops and support groups. However, it is the experience of the Reitman Centre that general knowledge and non-specific support are of limited value to the caregiver in implementing day-to-day interventions and dealing with complex BPSD. General rules and principles are of some value but are far from sufficient to meet caregivers’ needs. Hence, beyond education forums, caregivers require a specific tailored curriculum of training based on their own particular challenges, often involving other family members.<sup>18</sup> Unfortunately, these kind of integrated, comprehensive, individualized experiential hands-on interventions – which combine direct observation and coaching of caregivers responding to challenging situations, formal problem-solving techniques, and the exploration and understanding of caregivers’ emotional reactions and which appear to be most

effective – are just evolving and are not yet widely available.

### **Summary**

Caregiver-specific therapeutic support and skills training comprise an evolving field of expertise. Until comprehensive programs are more widely accessible, it will be up to clinicians to ensure that caregivers’ needs for education and training are addressed as effectively as possible using available resources.

### **Disclosure**

Joel Sadavoy has conducted antidepressant research for United Paragon Associates. Virginia Wesson has no conflicts of interest to declare.

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### **References**

1. Dempsey M, Baago S. Latent grief: the unique and hidden grief of carers of loved ones with dementia. *Am J Alzheimers Dis Other Demen* 1998;13(2):84–91.
2. Perel V. Psychosocial impact of Alzheimer disease. *JAMA* 1998;279:1038–9.
3. Keefe J. Supporting caregivers and caregiving in an aging Canada. Montreal (QC): Institute for Research on Public Policy, 2011; [www.irpp.org](http://www.irpp.org).
4. Hebert R, Dubuc N, Buteau J, et al. Resources and costs associated with disabilities of elderly people living at home and in institutions. *Can J Aging* 2001;20:1–22.
5. Lafreniere S, Carriere Y, Martel L, Belanger A. Dependent seniors at home: formal and informal help. *Health Rep* 2003;14:31–9.
6. Dunkin J, Anderson-Hanley C. Dementia caregiver burden. A review of the literature and guidelines for assessment and intervention. *Neurology* 1998;51 Suppl 1:S53–60.
7. Brodaty H, Green A, Koschera A. Meta-analysis of psychosocial interventions for carers of people with dementia. *J Am Geriatr Soc* 2003;51:657–64.
8. Statistics Canada. 2002 general social survey. Cycle 16: aging and social support. Ottawa (ON): Author; 2002.
9. Canadian Institute for Health Information. Caring for seniors with Alzheimer’s disease and other forms of dementia. Ottawa (ON): The Institute, 2010; <http://www.cihi.ca>.
10. Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Can Med Assoc J* 1994;150:899–913.
11. Statistics Canada. Census of Canada 2006. Ottawa (ON): Author, 2006; <http://www.12statcan.ca/english/census01/products/highlight/AgeSex.cfm>.
12. Kramer B. Gain in the caregiving experience: Where are we? What next? *Gerontologist* 1997;37:218–32.
13. Cohen C, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002;17:184–8.
14. Hollander M, Liu G, Chappell N. Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthc Q* 2009;12:38–47.

15. McCallion P, Toseland R, Lacey D, Banks S. Educating nursing assistants to communicate more effectively with nursing home residents with dementia. *Gerontologist* 1999;39:456–8.
16. Mitchell J, Kemp B. Quality of life in assisted living homes: a multidimensional analysis. *J Gerontol B Psychol Sci Soc Sci* 2000;55, P117–27.
17. Cranswick K, Dosman D. *Elder care: what we know today*. Ottawa (ON): Statistics Canada; 2008.
18. Mittelman M, Haley W, Clay O, Roth D. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology* 2006;67:1592–9.
19. Spurlock W. Spiritual well-being and caregiver burden in Alzheimer's caregivers. *Geriatr Nurs* 2005;26:154–61.
20. Stone R. Caregivers of the frail elderly: a national profile. *Gerontologist* 1987;27:618–26.
21. Schulz R, O'Brien A, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence correlates and cause. *Gerontologist* 1995;35:771–91.
22. Mega M, Cummings J, Fiorello T, Gornbein J. The spectrum of behavioral changes in Alzheimer's disease. *Neurology* 1996;46:130–5.
23. Donaldson C, Burns A. Burden of Alzheimer's disease: helping the patient and the carer. *J Geriatr Psychiatry Neurol* 1999;12, 21–8. doi: 10.1177/089198879901200106.
24. Haley W. The family caregiver's role in Alzheimer's disease. *Neurology* 1987;48 Suppl 6:S25–9.
25. International Psychogeriatric Association. Module 4: role of caregivers. In, International Psychogeriatric Association, Behavioural and Psychological Symptoms of Dementia (BPSD) Educational Pack. Northfield (IL): The Association; 2002.
26. Reis M, Gold D, Gauthier S. Personality traits as determinations of burden and health complaints in caregiving. *Int J Aging Hum Dev* 1994;39:257–71.
27. Williams R, Briggs R, Coleman P. Carer rated personality changes associated with senile dementia. *Int J Geriatr Psychiatry* 1995;10:231–6.
28. Akkerman R, Ostwald S. Reducing anxiety in Alzheimer's disease family caregivers: the effectiveness of a nine-week cognitive-behavioral intervention. *Am J Alzheimers Dis Other Demen* 2004;19:117–23.
29. Alspaugh M, Stephens M, Townsend A, et al. Longitudinal patterns of risk for depression in dementia caregivers: objective and subjective primary stress as predictors. *Psychol Aging* 1999;14:34–43.
30. Baumgarten M, Battista R, Infante-Rivard C, et al. The psychological and physical health of family members caring for an elderly person with dementia. *J Clin Epidemiol* 1992;45:61–70.
31. Brown P, Potter J, Foster B. Caregiver burden should be evaluated during geriatric assessment. *J Am Geriatr Soc* 1990;38:455–60.
32. Burns A, Rabins P. Carer burden and dementia. *Int J Geriatr Psychiatry* 2000;15:S9–13.
33. Coon D, Thompson L, Steffen A, et al. Anger and depression management: psychoeducational skill training interventions for women caregivers of a relative with dementia. *Gerontologist* 2003;43:678–89.
34. Dura J, Kiecolt-Glaser J. Sample bias in caregiving research. *J Gerontol* 1991;45:P200–4.
35. Hooker K, Monahan D, Shifre K, Hutchinson C. Mental and physical health of spouse caregivers: the role of personality. *Psychol Ageing* 1992;7:367–75.
36. Katon W, Kleinman A, Rosen G. Depression and somatization: a review. *Am J Med* 1982;72:241–7.
37. Kiecolt-Glaser J, Glaser R, Shuttleworth E, et al. Chronic stress and immunity in family caregivers of Alzheimer's disease victims. *Psychosom Med* 1987;48:181–9.
38. Pruchno R, Resch N. Aberrant behaviours in Alzheimer's disease: mental health effects on spouse carers. *J Gerontol* 1989;44:S177–82.
39. Saad K, Hartman J, Ballared C, et al. Coping by the carers of dementia suffers. *Age Aging* 1995;24:495–8.
40. Vitaliano P, Young H, Russo J, et al. Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer's disease? *J Gerontol* 1993;48:202–9.
41. Zarit S, Todd P, Zarit J. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist* 1986;26:260–6.
42. Brodaty H, Hadzi-Parlovic D. Psychosocial effects on carers of living with persons with dementia. *Aust N Z J Psychiatry* 1990;24:351–61.
43. Vitaliano P, Russo J, Young H, et al. The screen for caregiver burden. *Gerontologist* 1991;31:76–83.
44. Brodaty H. Caregivers and behavioral disturbances: effects and interventions. *Int Psychogeriatr* 1996;8 Suppl 3:455–8.
45. Donaldson C, Tarrier N, Burns A. Determinants of carer stress in Alzheimer's disease. *Int J Geriatr Psychiatry* 1998;13:248–56.
46. Gilleard C, Boyd W, Watt G. Problems in caring for the elderly mentally infirm at home. *Arch Gerontol Geriatr* 1982;1:151–8.
47. Pinquart M, Sorenson S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr* 2006;18:577–95.
48. Schoenmakers B, Buntinx F, Delepereire J. Factors determining impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas* 2010;66:191–200.
49. Sorensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist* 2002;42:356–72.