

Living with Dementia: Caregiver Burden Reduction

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Prevalence

- There are 44.4 million dementia patients worldwide and 7.7 million patients being diagnosed each year
- Expected to rise to:
 - 75.6 million in 2030
 - 135.5 million in 2050

The annual worldwide economic burden of dementia is 604 billion dollars



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Causes/Treatment

- Alzheimer's disease is responsible for 60-70% of dementia cases
- There is no treatment to heal Alzheimer's disease
- Goal should be to improve and support the quality of life in patients, their families, and caregivers.
 - ▣ Can reduce burden through education on proper care and protecting caregivers social life and psychological health



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Major Factors effecting stress of caregivers

- Loneliness
- Depressive mood
- Being exposed to behaviors not expected from patient
- Insufficient knowledge about the disease
 - ▣ When provided with places/people that give support the negative effect of patient symptoms on caregiver decreased and quality of life of caregiver improved.



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Early Stage

- Vital for patient to receive more effective support, care, and treatment
- Treatment to prevent advancement should be started rather than a “wait and see” approach
- Patients’ families can cause diagnosis to be delayed up to 4 years



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Early Stage Continued

- Forgetfulness and losing the concept of time
 - Asking the same questions repeatedly or retelling stories
- Studies show BPSD are more destructive in caregiver depression than the cognitive disorder.
 - Some behavioral and psychological symptoms are: anxiety, delusions, depressive moods, aggression, skepticism, wandering,...



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Middle Stage

- Symptoms become more prominent and restrictive at this stage
 - ▣ Awkwardness when eating, struggle dressing, time orientation becomes impaired
- This stage increases depression symptoms two-fold in caregivers.
- With more awareness, decision-making abilities, and knowledge of patients families increase while negligent behaviors decrease



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Advanced Stage

- Patient is unable to perform self care
 - ▣ Eating, bathing, and dressing all performed with complete dependence
- As patient dependence increase, morality and morbidity increase in caregivers
- Caregivers report to doctors more due to the suppression of their immune system and use medications and remained more susceptible to memory disorders



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Positive Caregiver Outcomes

- Feeling helpful
- Satisfied
- Rewarded by looking after the patient
- Utilized more formal services



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Additions to Caregiver Strain

- Caregiver's anticipation that things will only get worse
- 55% of dementia caregivers report having to give up pleasurable activities or less time with family (52%)
- Contending with behavioral problems (ex: screaming, wandering, or destroying property)
- Caregivers to dementia patients are more effected than non-dementia caregivers
 - Dementia Caregivers are more involved and give more hours per week, they also perform more ADL and IADL tasks



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Additions to Caregiver Strain

- Dementia caregivers are more likely than non dementia caregivers to be spouses versus adult children.
- Dementia caregivers are less likely to report being employed full or part time and are more likely to be retired.
- Dementia caregivers are significantly older than non dementia caregivers
- Higher percentage of Dementia caregivers provided 40 or more hours of care and constant care than non dementia



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- 68% of caregivers are highly burdened
- 65% exhibit depressive symptoms
- Burden related to :
 - Patient psychopathology
 - Caregiver gender
 - Income
 - Level of education
- High burden associated with use of emotional-focused coping instead of problem-solving approaches



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- Aggressive behaviors were most associated with burden
- Patients memory has a weak association with caregiver burden
- 41-49% of dementia caregivers scored above the risk level for the development of clinical depression
 - Highly correlated to patients behavior



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Virtual Dementia Tours

Melanie Titzel, PhD, NHA, CTRS, CCM



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Bibliography

- Papastavrou, Evridiki, et al. “Caring for a Relative with Dementia: Family Caregiver Burden.” *Journal of Advanced Nursing*, vol. 58, no. 5, 19 Jan. 2007, pp. 446–457., doi:10.1111/j.1365-2648.2007.04250.x

- Ory, M. G., et al. “Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers.” *The Gerontologist*, vol. 39, no. 2, 1999, pp. 177–186., doi:10.1093/geront/39.2.177.

- Koca, Elif, et al. “Caregiver Burden in Different Stages of Alzheimer’s Disease.” *Noro Psikiyatri Arsivi*, vol. 54, no. 1, 2017, pp. 82–86., doi:10.5152/npa.2017.11304.

