Family Caregivers for Patients with Dementia: Coping and Interventions
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Caregiver Stressors and Outcomes

- 8.9 million caregivers or about 20% of the total caregivers of adults, provide care to a loved one with dementia.
- Caregivers are the largest source of care services in the United States, and it is estimated that this number will increase by 85% from 2000 to the year 2050.
- The estimated worth of the family caregiving services is twice as much as is spent on nursing homes, running around $375 billion a year.
- Locally, the state of Michigan was ranked 8th highest in number of caregivers in 2004, with 197,981 caregivers creating an annual market value of $3.3 billion dollars.
- Elderly caregivers ages 65-74 may have as much as a 63% increased death rate compared to non-caregivers the same age.

- Stressors
  - Behavioral problems of care recipients have the greatest longitudinal impact on their caregivers. (Gauger et al., 2000; Faust et al., 2006)
    - These include:
      - Ranting out.
      - Swaying easily.
      - Using foul language.
      - Threatening others.
      - Having bladder accidents.
    - Keeping caregivers up at night, and behaving in annoying or embarrassing ways.
  - Other stressors for the caregiver:
    - Tension with family.
    - Mood.
    - Restlessness.
    - Aggression.
    - Undiscipline.
    - With increasing dementia, daily tasks become more of a focus than the behavioral issues.

- Outcomes
  - Chronic stress leads to increased risk for sickness due to a weakened immune system, and it can also lead to issues with mood and anxiety (Bromann & Feist, 2010).
  - Burden and stress levels effect each person differently—reported stress levels range widely (Faust et al., 2006).
  - Depression: About 1 in 3 caregivers has depression. The top reasons that family caregivers become depressed include consistent care burdens, constraining care for the loss of the loved one, and social isolation (Schoenmakers et al., 2010).
  - Other Negative outcomes for the caregiver include:
    - Decreased self-esteem.
    - Perceived failure.
    - General psychological distress.
    - Effective symptom and anxiety (Cooper et al., 2007).
  - Positive outcomes of caregiving:
    - Personal growth.
    - Relationship benefits.
    - And changed perspective on life (Yip et al., 2010).

Coping

- Ineffective
  - Passive coping: placing control of situations externally, is more likely to have negative psychological outcomes.
    - Escape-resistance coping strategies aimed at wishing to escape the stress but not at changing the stress.
  - Correlated with increased depression levels in caregivers. (Musbach et al., 2006)
  - Dysfunctional coping style coupled with depression and anxiety is associated with physical and psychological abuse of the care recipient. (Cooper et al., 2010).

- Effective: A helping attitude predicts positive affect in family caregivers (Dulin et al., 2010).
  - Active coping strategies can decrease the level of depression in the caregiver (ex: directing the relative’s behavior and keeping them busy; Saaed et al., 1995).
  - It is effective when the caregiver believes they are able to control the situation.
  - It implies the necessity of an attitude ready to conquer the situation, and the capability of making a change.
  - One type of active coping is Problem focused coping. (Which includes planning ahead and seeking advice) (Cooper et al., 2008).
  - Personal mastery: caregivers belief that situations are under their own control.
    - Only when the caregivers had low personal mastery, was their reported overload associated with depression and negative health outcomes (Musbach et al., 2007).

- What determines how one copes with stress?
  - Healthier and more energetic people are better able to cope with external stressors.
  - Individuals with better social skills and problem solving skills are also better at coping. (Bromann & Feist, 2010)
  - Coping styles associated with less adaptive Coping: A secure attachment style is associated with less anxiety. (Cooper et al., 2007).

Perceived Control Is Key to Coping

Best Practice Approach

The goal for the future should be to find a way to make individualization part of standard practice, while also focusing on giving the caregiver more control and mastery over their situation so that they can be happier, healthier, more effective caregivers.

- Ideally, supports for the caregiver should be considered as part of the medical diagnostic process. Thus, physicians should:
  - Identify the caregiver of a newly diagnosed dementia patient.
  - Refer the caregiver to community support professionals such as psychologists or social workers who could teach coping strategies and link patients with support. This process would allow caregivers to have direct access to advice on practical care and coping strategies, psychological interventions, and the other options available in their area. (Vernooij-Dassen et al., 2004; Anvari & Browne, 2008)

- Beginning the process early would allow the caregiver to benefit from supports and interventions earlier in their development of the caregiver role.

- Ideally, caregivers would be able to:
  - Choose the type of interventions in which to engage
  - Find a program tailored to their specific needs (Vernooij-Dassen & Rikkert, 2004)

- With this support, the caregiver would be able to take control of situation, using individualized coping strategies that are as effective as possible.

Respite & Support

- Respite care directly decreases the burden of the caregiver by allowing others to take over care temporarily, whether it is other family members, a stranger, or an adult day care center. (Cookie et al., 2001).
- Support may include peer-led discussion for caregivers, with tips to deal with issues.
- Smaller effect on depression, self esteem, or anxiety.
- Greatest impact is on caregiver burden (Park et al., 2008).

Psychoeducation and Psychotherapy

- Psychoeducational support provides general knowledge of the caregiving issues or specific skills training to apply this knowledge.
- Associated with a decrease in caregiver depression, burden, and increased wellbeing, ability or knowledge (Sörensen et al., 2007).
- Psychotherapy involves one on one counseling sessions individualized to deal with the stressors effecting the caregiver, often follows a cognitive-behavioral model and focuses on addressing the coping mechanisms.
- Psychotherapy was correlated with lower caregiver burden, depression, and even ratings of care recipient symptoms.
- It holds a positive correlation with caregiver knowledge and well-being (Sörensen et al., 2001).

Multidimensional

- Includes one or more of the above with the possible addition of other components as well.
- Multidimensional studies report larger benefits, showing significant decreases in depression levels when compared to a one-dimensional support. (Metzlman, et al., 2004).
- Psychoeducational and psychotherapeutic combinations report increased levels of caregiver confidence and wellbeing (Gillen et al., 2010).