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### Family Caregivers Alliance:

- **8.9 million caregivers**, or about 20% of the total caregivers of adults, provide care to a loved one with dementia.
- Currently, family caregivers comprise the largest source of care services in the United States, and it is estimated that this number will **increase 85%** from 2000 to the year 2050.
- The estimated worth of the family caregiving service is twice as much as is spent on nursing homes, running around **\$375 billion a year**.
- Locally, the state of Michigan was ranked **8<sup>th</sup>** highest in number of caregivers in 2004, with 993,928 caregivers creating an annual market value of 10.5 billion dollars.
- Elderly caregivers ages 65-96 may have as much as a **63%** increased death rate compared to non caregivers the same age

### Caregiver Stressors and Outcomes

#### Stressors

- ❖ **Behavioral problems** of care recipients have the greatest longitudinal impact on their caregivers. (Gaugler et al., 2000 ; Fauth et al., 2006)
  - These include:
    - acting out,
    - crying 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:
  - issues with memory,
  - mood,
  - restlessness,
  - aggression,
  - and disorientation
- With progressing dementia, daily needs became 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 (Brannon & Feist, 2010).
- Burden and stress levels effect each person differently- reported stress levels range widely (Fauth et al., 2006).
- ❖ **Depression:** About 1 in 3 caregivers has depression. The top reasons that family caregivers became depressed include consistent care burdens, continuous mourning 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 burden,
  - general psychological distress,
  - affective symptoms and anxiety (Cooper et al., 2007).
- ❖ **Positive outcomes** of caregiving:
  - personal growth,
  - relationship benefits,
  - and changed perspective on life (Yap et al., 2010)

### Coping

#### ❖ Ineffective

- **Passive Coping**, placing control of situations externally, is more likely to have negative psychological outcomes.
  - Escape-avoidance coping: strategies aimed at wishing to escape the stress but not at changing the stress.
  - Correlated with increased depression levels in caregivers. (Mausbach 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; Saad et al., 1995)
  - is most effective when the caregiver believes that they are able to control the situation.
  - 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 (Mausbach 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; Andrén & Elmståhl, 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.

### Formal Interventions

#### ❖ 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 sitter, or an adult day care center. (Cooke 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 (Parker 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 (Sörenson et al. in 2007).
- Psychotherapy involves one on one *counseling sessions* individualized to deal with the stresses 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 held 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.
  - Multi-dimensional studies report larger benefits, showing *significantly decreased depression* levels when compared to a one-dimensional support (Mittelman, et al., 2004).
  - Psychoeducational and psychotherapeutic combinations report increased levels of caregiver confidence and wellbeing (Gitlin et al, 2010).