Caregiver burden in different stages of Alzheimer’s disease

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Objectives

- We will discuss the relationship between caregiver burden and Alzheimer’s dementia
- Then different Theoretical models
- Literature Review
- Risk factors

Background

- **Caregiver** : a family member or significant other who provides the majority of support and personal care to a patient

- **The caregiver burden** is a multidimensional construct, which has been defined as a <u>*subjective*</u> measure of the physical, psychosocial, and economic strain experienced by individuals that take care of patients with AD

No treatment option to heal AD

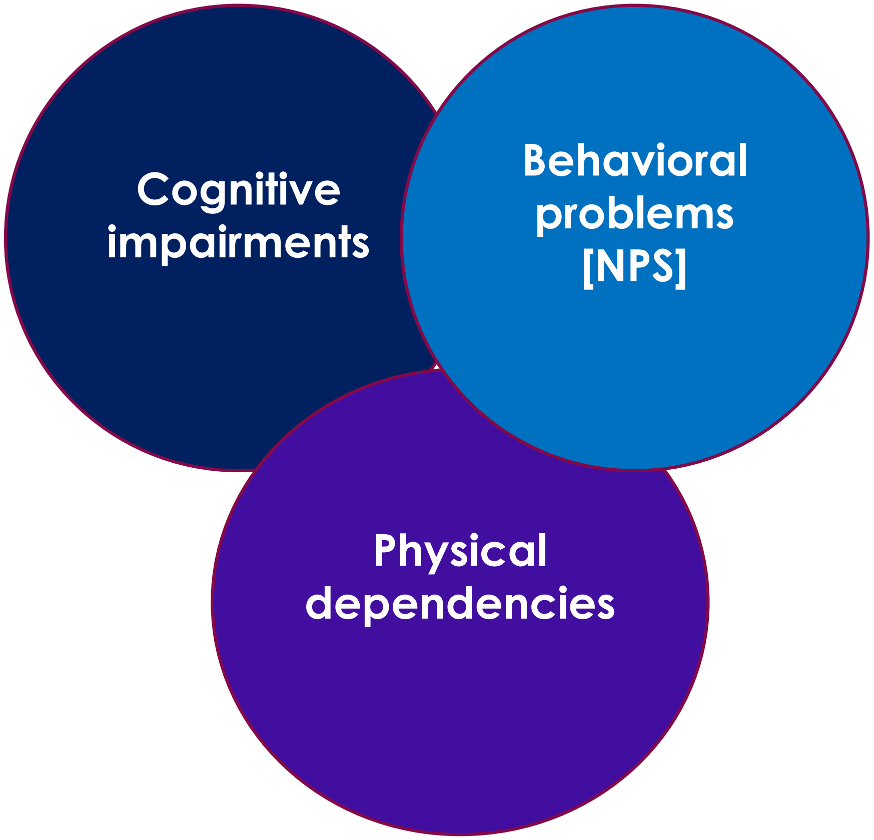
Goal should be to improve and support the quality of life in patients, their families, and their caregivers as much as possible

Some facts

- Rising number of people with dementia, doubling every 20 years, due to global aging.
- Currently, there are approximately **47 million** people with dementia in the world
- The usual course of dementia is from 3 to over 9 years.

Family as a caregiver

- The great majority of patients are cared for by **family members** in the community
- **Cultural effect:**
  - 66.5% of Taiwanese elders live with their children, whereas only one-fifth and one-quarter of the elderly live with an adult child in the United States and Europe
  - Studies on caregiving experiences conducted in Western countries are not likely to explain caregiving phenomena in different culture
  - In Taiwan, average care 43 months and spent on average 13.45 hours per day caregiving
  - (34.9%) hire care aides, who are mostly foreign



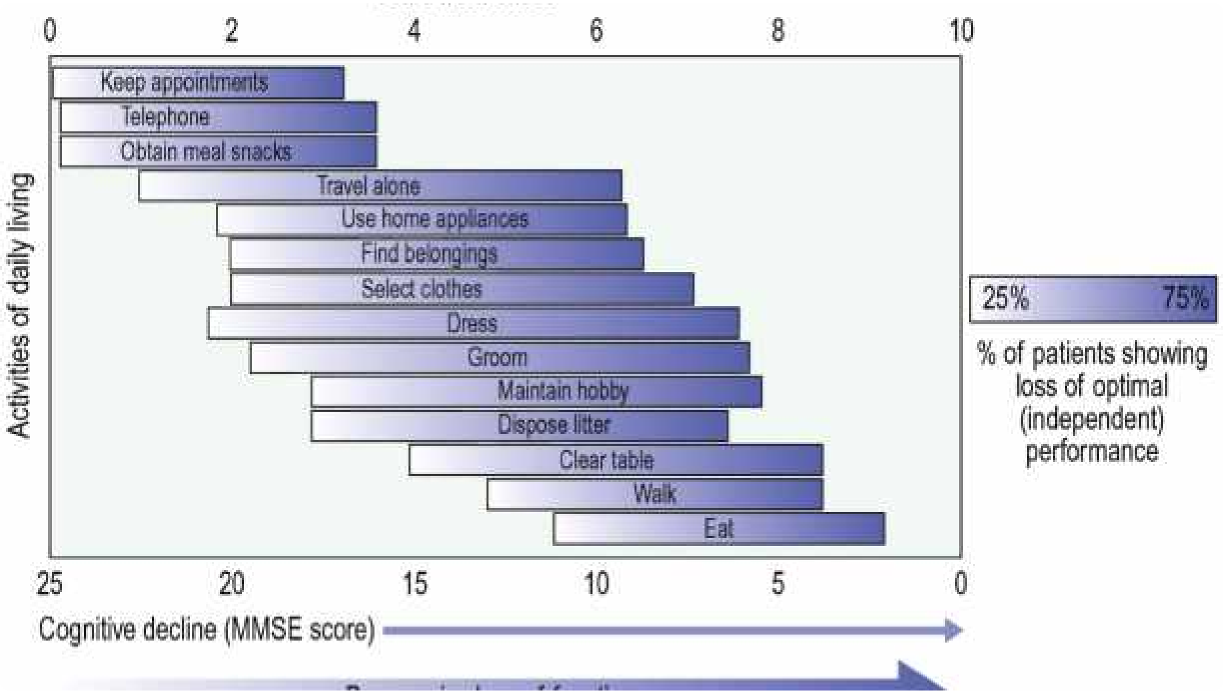
Cognitive impairments

Behavioral problems [NPS]

Physical dependencies

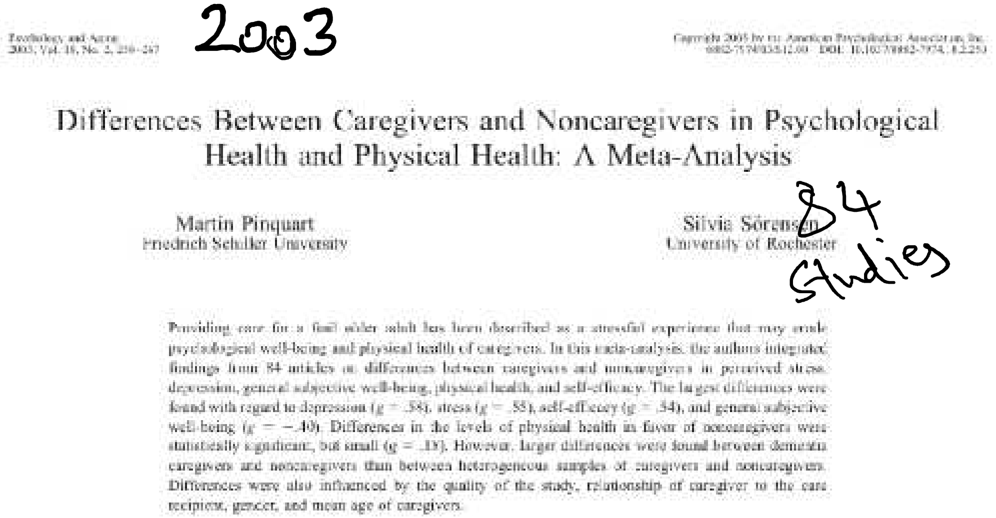
Progressive disease – increase care demands

- As the disease progresses, patients need higher levels of assistance, and the level of dependence increases.



Care Demands and Caregiver Burden

- **A meta-analysis** found dementia family caregivers to be significantly more
  - **stressed** than non dementia caregivers and
  - Suffer more serious **depressive** symptoms and **physical** problems



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Differences Between Caregivers and Noncaregivers in Psychological Health and Physical Health: A Meta-Analysis

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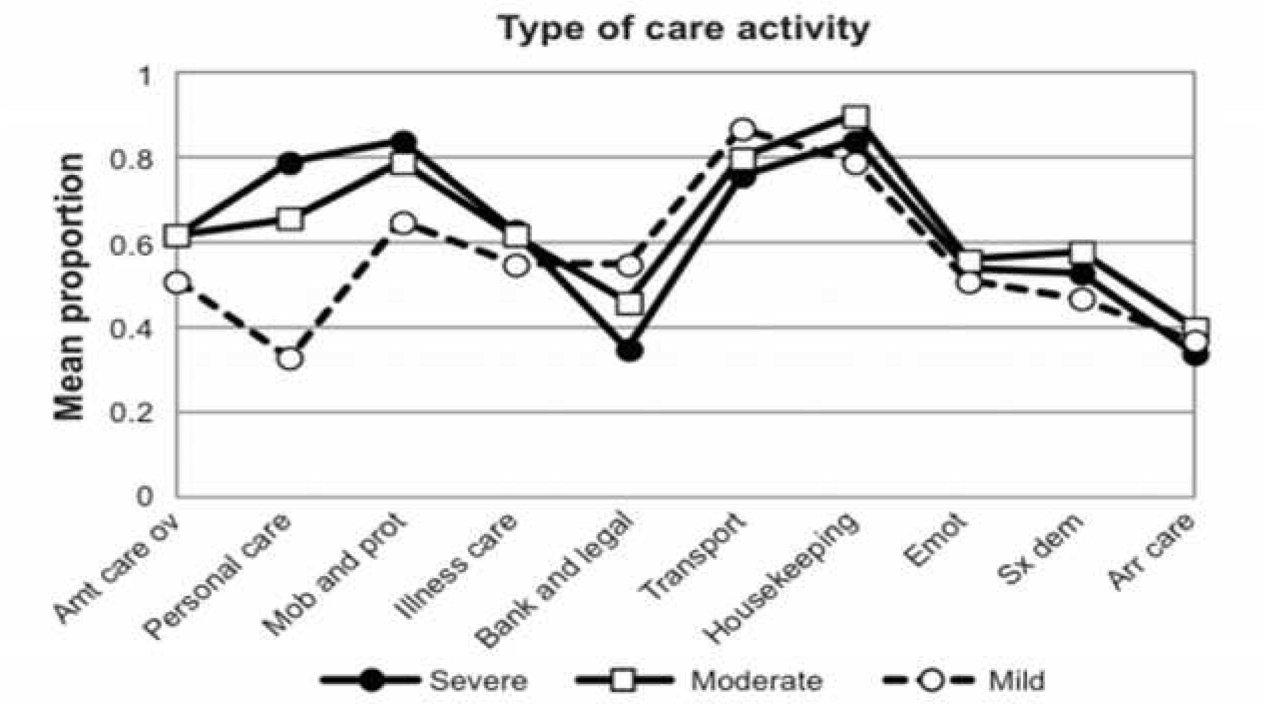
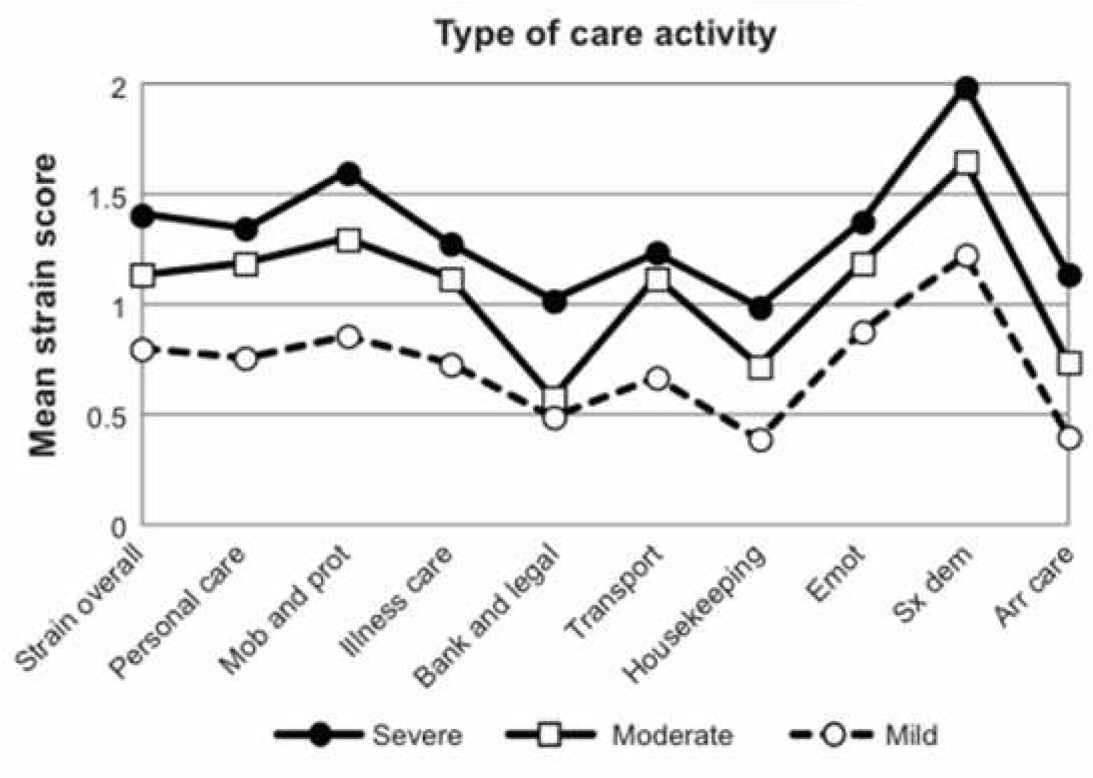
84 Studies

Providing care for a frail older adult has been described as a stressful experience that may erode psychological well-being and physical health of caregivers. In this meta-analysis, the authors integrated findings from 84 articles on differences between caregivers and noncaregivers in perceived stress, depression, general subjective well-being, physical health, and self-efficacy. The largest differences were found with regard to depression ($g = .58$), stress ($g = .55$), self-efficacy ($g = .54$), and general subjective well-being ($g = -.40$). Differences in the levels of physical health in favor of noncaregivers were statistically significant, but small ($g = .18$). However, larger differences were found between dementia caregivers and noncaregivers than between heterogeneous samples of caregivers and noncaregivers. Differences were also influenced by the quality of the study, relationship of caregiver to the care recipient, gender, and mean age of caregivers.

Caregiving Activities



Role strain


Type of care activity
Mean strain score
2
1.5
1
0.5
0
Strain overall
Personal care
Mob and prot
Illness care
Bank and legal
Transport
Housekeeping
Emot
Sx dem
Arr care
Severe
Moderate
Mild

Theoretical Models of Dementia Caregiver Burden

Theoretical Models of Dementia Caregiver Burden

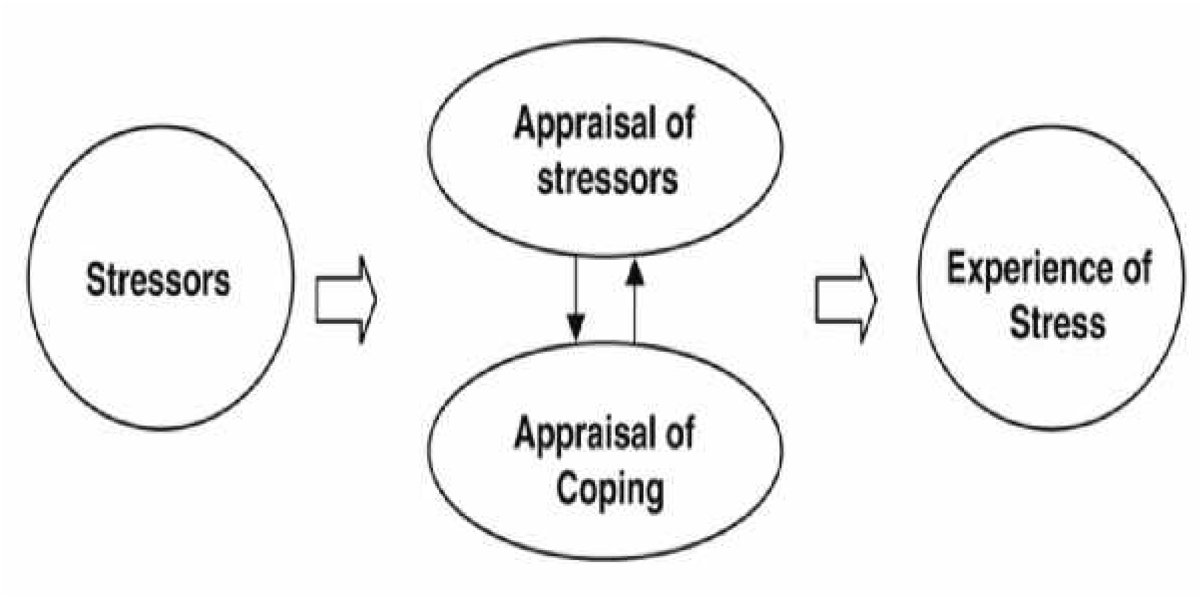
Cognitive Stress and Coping Model

Caregivers’ stress model

Sociocultural Stress and Coping Model

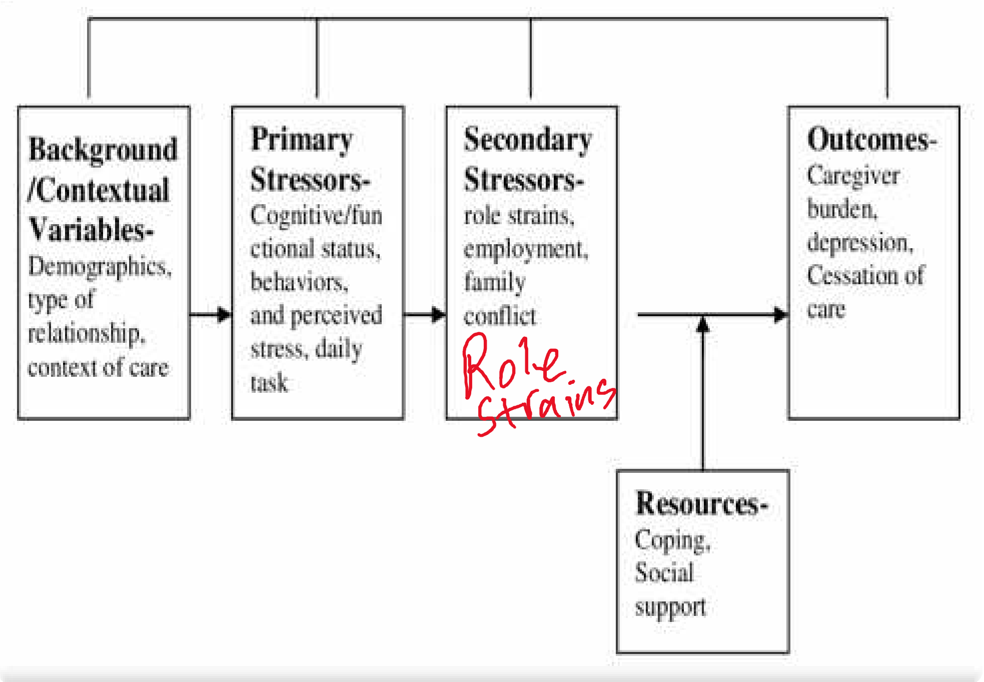
Cognitive Stress and Coping Model

(1984) *Lazarus & Folkman*



Caregivers' stress model *pearlin*

- Hypothesizes that stress is the consequence of :
  - First line **contextual elements** (cultural and socio-economic status, family network, personal history)
  - **primary stressors** (e.g., stressors directly related to caregiving activities such as problem behavior of the patient and caregiver perception of overload)
  - **secondary stressors** (e.g., strains due to conflict between caregiving responsibilities and non-caregiving roles



Background /Contextual Variables- Demographics, type of relationship, context of care

Primary Stressors- Cognitive/functional status, behaviors, and perceived stress, daily task

Secondary Stressors- role strains, employment, family conflict

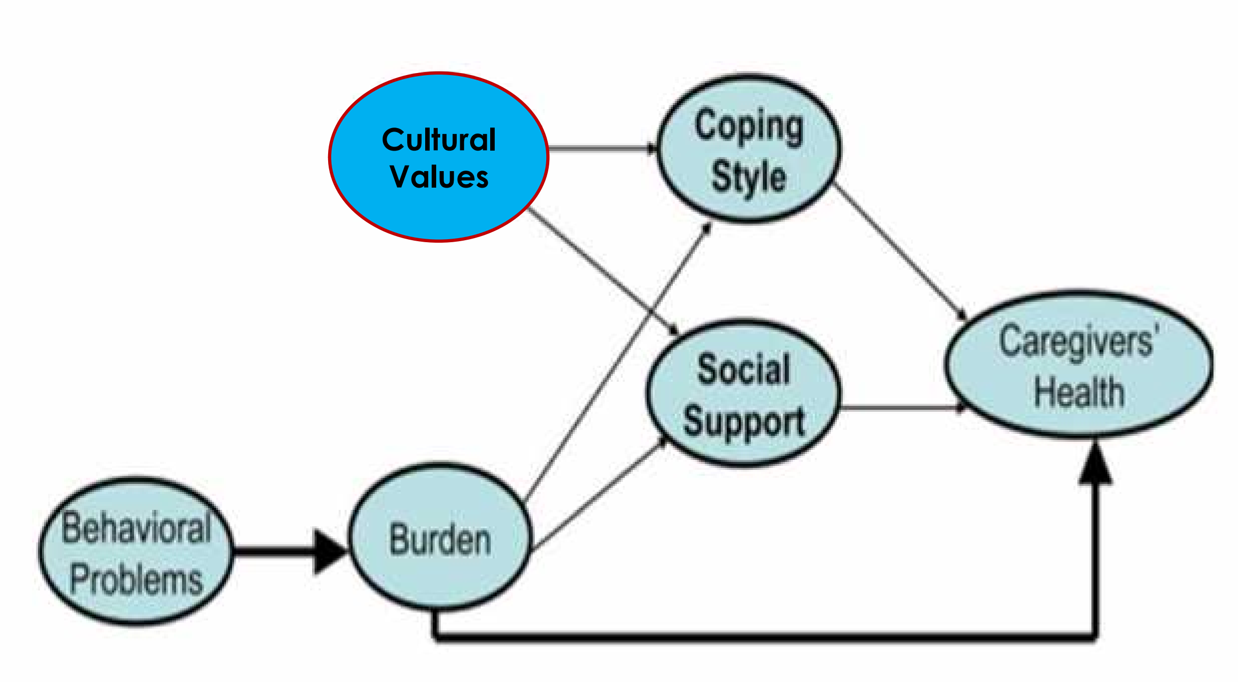
Role strains

Outcomes- Caregiver burden, depression, Cessation of care

Resources- Coping, Social support

Sociocultural Stress and Coping Model

(Aranda and Knight 1997; Knight and Sayegh 2010)



Which is more related to caregiver burden?

- Cognitive
- NPS
- Dependency

NPS

- NPS would generally be found to be the most powerful predictor, followed by physical/functional dependency, and lastly cognitive impairment.
- NPS are distressing because they are unpredictable, disruptive, difficult to manage, potentially embarrassing or abusive, and sleep deprived .

NPS & burden

- Awell-cited **meta-analysis** of 228 studies found overall correlational coefficients with caregiver burden and depression, respectively,
- 0.37 and 0.27 for NPS,
- 0.22 and 0.14 for functional impairment, and
- 0.18 and 0.16 for cognitive impairment

NPS & burden

- **Four long-term longitudinal studies** showed that NPS early in the course of dementia as well as subsequent increases in **NPS** were most predictive of increases in burden scores over time

- Compares caregivers for relatives with the behavioral variant of FTD with AD caregivers
  - bvFTD caregivers report more serious NPS in their CRs as well as higher levels of burden and depressive symptoms

Individual Neuropsychiatric Symptoms or Symptom Clusters

Is it possible that *certain symptoms* are more

challenging than others and

are more useful indicators of the caregiver’s need for assistance or intervention?

Individual Neuropsychiatric Symptoms or Symptom Clusters

- Two recent studies, one in the USA and the other in Taiwan, suggest the most distressing symptoms:
  - Delusions/hallucinations
  - Depression/anxiety
  - Agitation
  - Aggression
- Fauth and Gibbons found **disruptive behaviors** to be most disturbing to caregivers, followed by **mood disturbance**, and lastly **memory-related** behaviors.

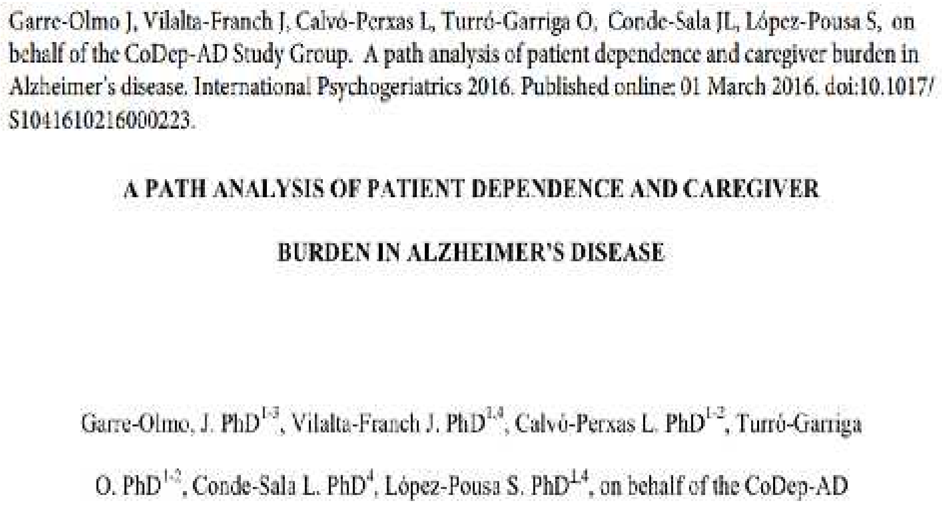
Caregiver burden and dependence

- Concept of **dependence**, defined as the level of **assistance** required by a patient with AD
- *Association between dependence and caregiver burden*
    - There few studies reporting data on the strength of this relationship
    - Results suggest that the dependence level may more accurately predict caregiver burden than the functional impairment.

A path analysis of patient dependence and caregiver burden in AD

Conclusion:

Dependence was the most important primary stressor directly related to caregiver burden irrespective of the disease severity.



Garre-Olmo J, Vilalta-Franch J, Calvó-Perxas L, Turró-Garriga O, Conde-Sala JL, López-Pousa S, on behalf of the CoDep-AD Study Group. A path analysis of patient dependence and caregiver burden in Alzheimer's disease. International Psychogeriatrics 2016. Published online: 01 March 2016. doi:10.1017/S1041610216000223.

A PATH ANALYSIS OF PATIENT DEPENDENCE AND CAREGIVER

BURDEN IN ALZHEIMER'S DISEASE

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O. PhD[1-2], Conde-Sala L. PhD[4], López-Pousa S. PhD[1,4], on behalf of the CoDep-AD

NPS-RESISTANCE OF CARE

- NPS that occurred in the context of ADL assistance largely accounted for the associations between ADL impairments and measures of burden and depressive symptoms

Resistiveness to Care during Assistance with Activities of Daily Living in Non-institutionalized Persons with Dementia: Associations with Informal Caregivers' Stress and Well-being

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Abstract

Objectives—Behavior problems that co-occur during assistance with Activities of Daily Living (Resistiveness to Care; RTC) are considered challenging, but are mostly studied in institutions with implications for patients and formal caregivers. RTC is related to, but independent from agitation, and detection of RTC may be left out of common assessments of persons with dementia in studies of informal caregiving (e.g. global assessments of dementia behavioral symptoms, standard assessments of ADL function). This study examines how RTC (frequency and caregivers' stress appraisals of RTC) are related to caregivers' well-being.

Method—234 caregivers of people with dementia reported care receivers' ADL impairment (eating, bathing, dressing), RTC frequency (of eating, bathing dressing), and their stress appraisals of these behaviors (RTC appraisals). Caregivers also self-reported their role overload, role captivity, and depressive symptoms. Hierarchical linear regression models included independent variables (demographics, ADL impairment, RTC frequency, RTC appraisals) with three separate dependent variables (overload, captivity, depressive symptoms).

Results—Two-thirds of informal caregivers reported RTC. Care recipients' ADL impairment was associated with caregiver outcomes, but only before RTC was entered into the models. RTC frequency significantly predicted caregivers' overload, captivity, and depression. RTC appraisals predicted overload and captivity.

Conclusion—RTC is common in persons with dementia residing at home, and RTC has more negative association with informal caregivers' well-being than assistance with ADL. Adding RTC frequency and appraisal items to standard ADL measures may better estimate caregiver needs and risk, and identify modifiable environmental features by assessing behavioral symptoms in context

Dimensions of Burden

- Cross-sectional study investigated the contributions of various primary stressors and contextual factors to burden and depressive symptoms.

  - Depressive symptoms—behavioral and physical
  - Relationship strain—behavioral
  - Social isolation—physical, cognitive, and behavioral
  - Emotional strain—behavioral, cognitive, and physical
  - Physical strain—behavioral and physical being equally predictive

Positive Aspect of caregiving (PAC)

Positive Aspect of caregiving (PAC)

- Researchers focus of attention in recents years (CG satisfaction, gain, or reward)
- Caregiver feels helpful, satisfied, and rewarded by looking after the patient
- Those who look after a patient feel better psychologically and render more quality care

Role of Spirituality

THE FINDINGS INDICATE THAT SPIRITUALITY IS POSITIVELY RELATED TO PAC

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Positive feelings of caregiving among Latino Alzheimer's family caregivers: Understanding the role of spirituality

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This study used structural equation modeling to examine the effects of spirituality on positive aspects of caregiving (PAC) among a sample of American Latino family members caring for a relative with Alzheimer's disease (AD). Participants consisted of 209 Latino caregivers (CGs) drawn from baseline data from the Resources for Enhancing Alzheimer's Caregivers Health II study. The findings indicate that spirituality is positively related to PAC and may partially mediate the effect of subjective stress on PAC. AD CGs typically provide better care when they perceive the caregiving experience to be satisfying and rewarding. Toward this end, gerontological practitioners should adopt a proactive stance to ensure Latino AD CGs can operationalize their spiritual strengths.

Keywords: Latino; Alzheimer's disease; caregiving; spirituality; positive aspects of caregiving

Introduction

The number of Latinos caring for a family member with Alzheimer's disease (AD) is projected to increase dramatically in the United States over the course of the next few decades (Coon et al., 2004). Despite the projected increase in the number of Latino caregivers (CGs), surprisingly little research has been conducted with this population (Morano & Sanders, 2005). Reviews of minority caregiving research have revealed

research has focused on negative outcomes (Morano & Sanders, 2005). For instance, Pearlin et al.'s (1990) stress coping model has been widely used to examine the relationship between caregiving and detrimental health outcomes such as depression and anxiety (Dilworth-Anderson et al., 2002).

More recently, researchers have begun to focus on the PAC (Hilgeman, Allen, DeCoster, & Burgio, 2007). Alternatively referred to as CG satisfaction, gain, or

Risk factors

- Major factors affecting the stress of caregivers can be listed as
    - loneliness
    - depressive mood
    - being exposed to behaviors not expected from the patient
    - insufficient knowledge about the disease
    - length of time providing care on a day-to-day basis
    - Negative attitudes towards AD
    - Previous psychiatric history
    - A poor prior relationship

What is helpful ?

- In RCT conducted with 206 caregivers in the UK, it was observed that when these caregivers were provided with:
  - support, behavior management, education and psychological support : negative effect of patient symptoms on the caregiver decreased and the quality of life of the caregiver improved
  - Social support also seems to be vitally important during the progression of this stressful disease.

Conclusion

- (WHO) recommended that every country should have a health strategy for improving the knowledge of **health professionals** and **caregivers** on dementia.
- Since there is no treatment option to heal AD or stop its progress, the goal should be to improve and support the **quality of life** in patients, their families, and their caregivers as much as possible.
- burden on the shoulders of caregiver(s) can be reduced by **educating** them on proper care and taking necessary measures toward protecting the caregiver's social life and psychological health.