“Social Support for Older Adults in a Clinical Context: Informal Care and Burden of Primary Carers of Dementia Patients”:

Improving Care for patients with dementia.

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Patient or caregiver?

- Caring for an elderly or disabled patient is always a hard "burden", as it compromises their welfare, and even their health.

- For some authors the "caregiver" is a "hidden" or "unknown" patient.

- The care of patients with dementia is a dynamic process that requires a gradual increase in attention and effort for several reasons:
  
  - The long duration of the disease (more than 70% of patients require attention for more than 6 years).
  
  - The progressive loss of physical and cognitive ability of the patient and his increasing dependence on family.
What is care?

- Care is a philosophy and a unique set of interventions that aims to enhance quality of life for patients, and their families.

- Quality of life is understood to be a multidimensional construct that consists of physical, emotional, social, spiritual and financial domains.

- Most dementia patients and their families do not have access to a formalized care program that addresses the specific needs of the patient and their families.
Understanding family perspective

- Decision making
  - Collaborative
  - Delegated
  - Unilateral

- Context of interactions with medical team
  - Level of trust

- Family context
  - Absence of ties
  - Conflicts

- Dimension associated with family caregiver
  - Perception of QOL

- Dimensions associated with person with dementia
  - Advance directives
  - Ethnic/cultural

- Investigation
  - Treatment
  - Invasiveness

- Life prolongation
- Comfort care

Often missing: information about the comfort/care option?
Social Representation of Dementia and Its Influence on the Search for Early Care by Family Member Caregivers

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Abstract
Introduction: Social representations (SRs) contain 3 dimensions: information, attitude, and field. These affect the recognition of the first symptoms of dementia by the patient’s caregiver. This study focused on the period from the first signs of cognitive difficulties to the diagnosis of dementia. Methods: Eight caregivers of elderly patients with dementia were interviewed to construct their SRs regarding dementia and how this influences seeking medical treatment during the first stages of the disease. Social representations were analyzed through a structural focus, based on the content analysis. Results: Decision making is related to knowledge about dementia, attitude (emotions and sensitivity), and the concept of the caregiver about the relative with dementia. The results confirm the importance of the symbolic dimension of personal experience in managing care and seeking medical treatment. Conclusion: The presence of dementia in the family creates interpersonal dilemmas that caregivers experience. The solutions are framed in the sociocultural context.
Figure 1. Construction of dimensions in social representations through the speech of a relative in charge of caring for a family member with dementia.
Figure 2. Dynamic integration between central category, dimensions, and subdimensions.
1. Natural evolution of disease

2. Information on treatment options

3. Comfort care options help to alleviate feelings of guilt

4. Respect of values and beliefs
Psychometric evaluation of a Spanish Language Version of the Screen for Caregiver Burden (SCB) in caregivers of patients with mixed, vascular and Alzheimer’s dementia

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Aims and objectives. To validate a Spanish language version of the Screen for Caregiver Burden, the full-length or long (25-item) and short (seven-item) versions in Mexican caregivers of patients with mixed, vascular and Alzheimer’s dementia.

Background. Patients with dementia display impaired executive function and neuropsychiatric symptoms such as behavioural changes and sleep disturbances. These symptoms can make patients become more dependent. The experience of caregiving for patients under these conditions is burdensome. It is important to detect this burden to protect both the caregiver and the patient from negative outcomes.

Design. Survey.

Methods. Participants were 143 primary caregivers of patients with dementia and 30 caregivers of older adults without dementia in two hospitals in Mexico City.

Results. The internal reliability was Cronbach’s α = 0.89 and 0.82 for the 25-item and the seven-item versions, respectively. The item–total correlations for two Screen for Caregiver Burden versions were significant from $r = 0.26$ to $r = 0.77$ $p < 0.001$. The test–retest was ICC = 0.78 $p < 0.001$; CI 95% (0.55–0.9) and ICC = 0.72 $p < 0.001$; CI 95% (0.41–0.86) for the 25-item and the seven-item, respectively. We found from non-significant to highly significant correlations between two Screen for Caregiver Burden versions and other measures ranged. Validity of known groups showed that the caregivers of demented patients experienced more burden than those caring for non-demented patients.

Conclusions. Given these psychometric properties, both versions of the Screen for Caregiver Burden are valid tools and can be reliably used to assess the presence and level of caregiver burden in caregivers of demented patients.

Relevance to clinical practice. The Screen for Caregiver Burden in the Spanish Language can be used in clinical practice to detect caregiver burden in family members. We recommend using the long or full-length version when the objective is to assess the caregiver burden carefully and the short version (seven-item) as a screening method of caregiver burden that requires attention.
Caregiver burden of Mexican dementia patients: The role of dysexecutive syndrome, sleep disorders, schooling and caregiver depression

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Aims: As a result of the accelerated growth of the elderly population, reconfiguration of families and member roles, and the increase of mental disorders, it is necessary to investigate the effects of this set of factors on the caregivers of patients with dementia in Mexico. Mental disorders of individuals have a negative impact on their physical and emotional quality of life, leading to greater dependence and making the caring experience a heavy burden. Several studies (none in Mexico) have used either the characteristics of the patient or caregiver to determine the burden, but few studies have included both profiles within a single study. The objective of the present study was to analyze the characteristics of the patients and caregivers associated with caregiver burden.

Methods: A multicenter study was carried out in six health institutions located in Mexico City, including 175 patients (and their caregivers) diagnosed with different types of dementia. We used the Spanish Caregiver Burden Screen. Descriptive analysis and logistic regressions were used to estimate the effect of the covariates on the caregiver burden.

Results: The results showed that patient variables have a greater impact on caregiver burden than caregiver-associated variables. Dysexecutive syndrome, sleep disorders, schooling and caregiver depression are associated with a higher level of caregiver burden.

Conclusions: Caregiver burden is a complex phenomenon. The results of the present study showed the need to implement multifactorial interventions targeting the caregiver to reduce the burden, strengthen the skills for patient management to avoid depression, improve patient health, and diminish functional dependence and future hospitalization. Geriatr Gerontol Int 2014; 14: 146–152.
Challenges and Issues

- Lack of policy and dedicated funding related to care in Dementia.

- Insufficient training for health staff on care during different stages of dementia.

- Families are not given opportunities to discuss and learn about dementia.

- Advance Care Planning focuses solely on medical interventions.

- People with dementia who could benefit from care are not identified in a timely manner.
Suggestions

- Promote the role of the Personal Support Worker to caregivers.

- Education & orientation of all new staff.

- Evaluation of health environment to create baseline understanding of practice, policy processes and resources.

- Create interprofessional teams and identify initial interventions based on evidence.

- Develop programs and evaluate interventions.

- Promote changes in policy, practice and education.
- Improve the quality of life for patients with dementia
- Develop formalized interprofessional care programs
- Create partnerships between homes, community organizations and researchers
- Create a toolkit for developing care in homes that can be shared nationally
Conclusion

- Care should benefit both people with dementia and their families.
- The family environment plays a fundamental role in the care of a disease such as dementia.
- Both the patient and his caregiver need support through education and the promotion of quality care.
- But it is important to keep in mind that although there is usually a primary caregiver, he does not bear the burden alone; other family members should collaborate with physical, economic and moral support.
THANKS