

The Relationship Between Illness Representations of
Alzheimer's Disease as Perceived by Caregivers
and Burden of Care

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Abstract

Considerable part of the information, which exists about the characteristics of Alzheimer's disease, its diagnosis and treatment, is not fully delivered to the general public and to caregivers of Alzheimer's patients. Consequently, many primary caregivers of Alzheimer's patients have to base their perceptions about the disease and cope with the problems which emerge from it based on partial and unreliable knowledge. In addition, lack of knowledge concerning the causes of the disease might lead to less effective coping and might reduce the possibility of prevention. As a result, opportunities to improve functional independence, maintain the quality of life of the patients and their family relatives, might miss for months and even for years. Many studies examined the emotional reactions of caregivers of Alzheimer's patients to caregiving and its relationship to socio-demographic, situational, social and personality factors as well as to ways of coping and burden of care. But until now no studies have examined the role of cognitive factors, such as illness representations of Alzheimer's disease as perceived by the primary caregivers, on the burden of care. The purpose of this study was to examine this missing link, its relationship to coping strategies and burden of care.

The theoretical framework of the study included a combination of the Model of Alzheimer's Caregiver's Stress, which is an elaboration and adaptation of the Stress Process Model, with the Self-Regulation Model.

The main hypotheses of the study were:

1. Illness representations will affect directly and indirectly (mediated by coping strategies) on burden of care.

2. Stress factors (patient's and caregiver's) will affect directly on illness representations.
3. Stress factors (patient's and the caregiver's) will affect directly on coping strategies.
4. Stress factors of the caregiver (self-esteem and mastery) and of the patient (behavior problems) will affect directly on burden of care.

Face to face interviews were conducted with 100 spouses and adult children (81% women, mean age 61) who function as primary caregivers of dementia patients living in the community in the center of the country. Most of the participants were recruited from five different Departments of Social Services for the Elderly and the others from three Support Groups of the Alzheimer's Association and a day-care center for demented elderly. Structural Equation Modeling was used to examine hypothesized relationships.

Results of the study showed that caregivers hold a relatively strong perception of illness identity, chronic and cyclic (fluctuating and unexpected) course, report on far-reaching consequences on the patient's lives and lack of capability of the patients to control the disease and its symptoms. Also, caregiver's reports showed they have only a moderately coherent understanding of the disease. In general, the findings showed that the caregivers hold illness perceptions that are compatible to the medical knowledge about the disease. However, part of the caregivers held wrong causal attributions (psychological factors and chance) and evaluated excessively the contribution of other attributions (heredity and aging) as causes of the disease. In addition, a notable minority of the caregivers didn't identify the symptoms that reflect behavior problems with Alzheimer's disease. These inappropriate beliefs might be problematic in the context of every day care. As related to the main relationships that were found in the model, from all the illness representations only the coherence representation was found to have a direct effect on burden of care. In addition, similar to the stress process, behavior problems and the personality characteristics (self-esteem and mastery)

were found to be the main predictors of burden of care.

Findings of this study have theoretical and applied implications. Theoretically, this is the first study to examine illness representations of Alzheimer's disease and their relationship to burden of care. Furthermore, the findings show that combining the theoretical Stress and Self Regulation models is only partially suitable for examining burden of care. The Stress Model provides a better explanation for burden of care, compared to the Self-Regulation Model. Regarding its applied implications, results of the study underline the importance of imparting reliable information to the primary caregivers about the disease and its characteristics using a Psycho-Educational intervention, computerized resources (e.g. internet) and the media. This might enable adaptation of illness representations to reduce the wrong or inaccurate perceptions about the disease. Furthermore, raising the level of knowledge of the caregivers about the disease while strengthening their coherent understanding of it has a valuable potential for reducing the burden of care. Finally, the emotional and economic consequences of the disease, which reported by the majority of the caregivers as severe, on the patients and themselves, stresses the need for broadening the support and help for the caregivers.