

# A community support program for dementia delayed but did not reduce institutionalization over 2 years

Eloniemi-Sulkava U, Notkola IL, Hentinen M, et al. Effects of supporting community-living demented patients and their caregivers: a randomized trial. *J Am Geriatr Soc.* 2001 Oct;49:1282-7.

## QUESTION

In community-living patients with dementia, does a 2-year support program based on nursing case management reduce the need for institutionalization?

## DESIGN

Randomized {allocation concealed\*}†, {unblinded}†,\* controlled trial with 2-year follow-up.

## SETTING

5 municipalities in Finland.

## PATIENTS

100 patients who were  $\geq 65$  years of age (mean age 79 y, 53% women), who were entitled to payments from the Social Insurance Institution for community care because they had dementia, and who lived at home with primary support from an informal caregiver. Exclusion criteria were other severe diseases that might lead to institutionalization or inability of caregivers to participate in annual training courses. Follow-up was 100%.

## INTERVENTION

Patients were allocated to a support program ( $n = 53$ ) or usual care ( $n = 47$ ). The support

program consisted of systematic and comprehensive support for patients and their caregivers by a family-care nurse coordinator who specialized in treating dementia and who had access to the physician. Support included advocacy for patients and caregivers, continuous and systematic counseling, annual training courses for patients and caregivers, follow-up calls, home visits, assistance with arrangements for social and health care services, and 24-hour availability by mobile telephone.

## MAIN OUTCOME MEASURE

Time to institutionalization.

## MAIN RESULTS

During the first months, the rate of institutionalization was lower in the support-program group than in the usual-care group (hazard ratio [HR] 0.12, 95% CI 0.02 to

0.93), but the benefit decreased over time (HR 1.18, CI 1.02 to 1.36). By 2 years, groups did not differ for institutionalization rates ( $P > 0.2$ ) (Table).

## CONCLUSIONS

In patients with dementia, the rate of institutionalization in the first months was lower for those in a support program than for those receiving usual care, but the difference decreased with time; by 2 years, institutionalization rates did not differ between groups.

*Source of funding:* Social Insurance Institution, Finland, and Alzheimer Foundation of Finland.

*For correspondence:* Dr. U. Eloniemi-Sulkava, University of Kuopio, Kuopio, Finland. E-mail Ulla.Eloniemi@uku.fi. ■

\*See Glossary.

†Information provided by author.

## Support program vs usual care for patients with dementia and their caregivers‡

Outcome at 2 y	Support program	Usual care	RRI (95% CI)	NNH
Institutionalization	32%	30%	7.7% (−40 to 94)	Not significant

‡Abbreviations defined in Glossary; RRI, NNH, and CI calculated from data in article.

## COMMENTARY

Institutional care accounts for a substantial proportion of the cost of caring for patients with Alzheimer disease (1). Although the study by Eloniemi-Sulkava and colleagues has limited generalizability—in part because of the small and homogeneous study population, the unique characteristics of the Finnish health care system, and the dependence on a single case manager—the results are consistent with previous research done in the United States showing that caregiver support through counseling and links with community resources can delay the institutionalization of demented patients by approximately 1 year (2).

In this study, the dementia-care coordinator addressed health and behavioral problems with the patient as well as caregiver stress. All of these interventions fall within the purview of primary care physicians, to whom families commonly turn first for help with managing a demented relative. Although primary care physicians may not have the training or time to provide extensive counseling, it is incumbent on them to be familiar with such community resources as dementia support groups and adult day health care programs to which families can be referred.

Helping families prolong dementia care at home should not come at the expense of the caregiver's well-being. Caregiver stress is common and, among elderly spousal caregivers, has been associated with an increased risk for mortality, even after adjustment for prevalent disease (3). Thus, periodic evaluation of patients with dementia should include assessment of their functional dependence and behavioral complications—important contributors to caregiver burden—as well as the health and emotional state of the caregiver.

Calvin H. Hirsch, MD  
University of California, Davis, Medical Center  
Sacramento, California, USA

## References

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