



A Systematic Evidence Review of Interventions for Non-professional Caregivers of Individuals with Dementia

EXECUTIVE SUMMARY

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PREFACE

HSR&D's Evidence-based Synthesis Program (ESP) was established to provide timely and accurate syntheses of targeted healthcare topics of particular importance to VA managers and policymakers, as they work to improve the health and healthcare of Veterans. The ESP disseminates these reports throughout VA.

HSR&D provides funding for four ESP Centers and each Center has an active VA affiliation. The ESP Centers generate evidence syntheses on important clinical practice topics, and these reports help:

- develop clinical policies informed by evidence,
- the implementation of effective services to improve patient outcomes and to support VA clinical practice guidelines and performance measures, and
- set the direction for future research to address gaps in clinical knowledge.

In 2009, an ESP Coordinating Center was created to expand the capacity of HSR&D Central Office and the four ESP sites by developing and maintaining program processes. In addition, the Center established a Steering Committee comprised of HSR&D field-based investigators, VA Patient Care Services, Office of Quality and Performance, and VISN Clinical Management Officers. The Steering Committee provides program oversight and guides strategic planning, coordinates dissemination activities, and develops collaborations with VA leadership to identify new ESP topics of importance to Veterans and the VA healthcare system.

Comments on this evidence report are welcome and can be sent to Nicole Floyd, ESP Coordinating Center Program Manager, at nicole.floyd@va.gov.

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BACKGROUND

The purpose of this report is to review systematically the evidence on the effects of caregiver (CG) interventions on CG burden, mood (including depression and anxiety), and the ability to manage problematic behavior, as well as the effects on the care recipient (CR).

METHODS

We conducted a review of good-quality trials identified from systematic reviews and additional studies identified from expert input. We conducted searches for systematic reviews of dementia CG interventions in MEDLINE (PubMed), the Cochrane Database of Systematic Reviews, and the Cochrane Database of Reviews of Effects from database inception through July 2009.

RESULTS

There were 15 systematic reviews that met our quality criteria: one review of respite care, three reviews of technology-based interventions, and 12 systematic reviews that evaluated a variety of heterogeneous psychosocial interventions. The systematic reviews of psychosocial interventions identified 30 randomized controlled trials (RCTs) that met our criteria for study design and sample size. Seven good quality RCTs recommended by expert panel members were added following review.

KEY QUESTION #1. Do CG interventions affect the CG's knowledge and ability to manage problematic behavior, CG psychosocial burden, CG health and health behaviors, or outcomes in the individual with dementia?

PSYCHOSOCIAL INTERVENTIONS

Multicomponent Interventions: Five studies evaluated a combination of varied treatment approaches such as skills training, group support, and respite care. Three of the studies examined individually tailored multicomponent interventions. Individually tailored intensive, multicomponent interventions showed promise for reducing CG depression, and in improving sense of burden, self-care abilities, well-being, confidence, and social support ratings. When examined across diverse populations, there were group effects for all Latino/Hispanic and White/Caucasian CGs as well as Black/African-American spousal CGs. Additionally, CGs who experience individually crafted interventions during their caregiving period may fare better during the bereavement phase. There was no consistent evidence that multicomponent interventions delayed CR institutionalization.

Exercise Training: We reviewed one trial that compared exercise training for the CG with an attention-control group that received supportive phone calls and nutrition guidance. Both exercise and control groups demonstrated decreased depression, stress, and burden, but there were no significant differences between groups. More studies are needed to evaluate the impact of exercise for the CG on CG burden.

Case Management Interventions: We reviewed five studies of intensive nursing case management. Overall intensive nursing case management had little effect on CR rates of institutionalization, but improvements in CG outcomes were seen in some studies. One study reported lower rates of institutionalization for the first months of the two-year program, but by the end of two years there were no differences in rates of institutionalization between intervention and control groups. Two other studies found no differences between case management and usual care in time to institutionalization, or in CG strain, burden, or depression. Two studies published in 2006 support that case management can result in improvements in CG stress (at 12 but not 18 months), confidence, mastery of caregiving skills, and depression (seen at 18 months). These same studies reported smaller declines for CR health related quality of life and fewer CR behavioral symptoms, although CR rates of institutionalization remained the same for treatment and control groups.

Behavior Management Training (BMT): Four studies were reviewed that provide limited evidence suggesting that training the CG to use behavioral management techniques with the CR may improve CG depression, although this finding was not consistent across all studies. Two studies in which BMT for the CG was augmented by a separate component – CG self-care instruction in one study; exercise for the CR in another – seemed to result in broader outcome effects, with reports of improved CR physical mobility and CG coping skills.

Individual Skills Training: Two of six studies demonstrated that individual skills training for CGs ameliorates depression in CGs, but the data show no support for impact on CGs' sense of burden, anxiety, or quality of life. In three studies, CRs showed slower declines in self-care when skills training included a component targeting activities of daily living (ADL), and improved mood when pleasant events were scheduled, but these findings were not replicated in three other studies. Two of six studies reported that disruptive behavior may be reduced when CGs receive structured training in identifying triggers of disruptive behavior and modifying the environment to reduce stress. There is no strong evidence documenting the impact of skills training programs on delaying or preventing institutionalization of the CR.

Group Skills Training Interventions: CG depression improved in three of eight intervention studies; significant effects may be associated with interventions that are individualized by in-home assessment and targeted to specific needs of the CR-CG dyad. Two studies reported reductions in CG distress. Ancillary improvements in positive interactions and nurturing, reducing aversive and hostile CG responses to problem behaviors, reducing CG burden, and increasing CG self-efficacy are supported by single studies in the skills training domain.

Individual, Group, and Combined Individual/Group Supportive CG Counseling Interventions: In seven studies reviewed, neither individual supportive counseling nor group supportive interventions *on their own* demonstrated clear superiority over control groups for CG depression. A combined individual/group approach resulted in delayed institutionalization for the CR and improved mood for the CG, with results sustained across three years in follow-up. Ancillary improvements in affective regulation for coping and aversive reaction to CR behavior disturbance were supported in single studies. None of these interventions demonstrated group treatment effects for CG burden.

TECHNOLOGY-BASED INTERVENTIONS

Three systematic reviews assessed the effectiveness of networked information and communications technology interventions (ICT). These included five interventions that used computer-telephone integrated support systems, and 13 interventions that aimed to increase patient safety and reduce CG stress, such as Global Positioning System (GPS) location systems and home-monitoring devices (e.g., boundary alarms, cooking monitors). The evidence from controlled empirical studies on the effectiveness of technology-based interventions is insufficient, but uncontrolled studies suggest that GPS location systems for wandering behavior may improve patient function and safety, as well as reduce CG depression, burden, and stress. Robust trials with sufficient follow-up are needed to determine the feasibility, effectiveness, and cost-effectiveness of ICT interventions.

RESPITE CARE

A comprehensive systematic review of the effectiveness and cost-effectiveness of respite care services was compiled in 2004 for the United Kingdom (UK) National Health Service (NHS). The review identified 45 studies on several forms of respite care, and found small, statistically-significant improvements on some outcome measures, but the evidence on how respite affects the health and well-being of CGs was inconsistent. Institutional/overnight respite promoted better sleep patterns in CGs during the period of respite; but there were no enduring improvements in health and well-being in comparison to control groups, or compared to CG baseline state associated with respite services of any form. The vast majority of CGs, however, frequently expressed high levels of satisfaction, and generally felt that respite services brought them various benefits, despite little evidence of significant and/or sustained reductions in measures of stress, depression, and burden. Many studies reported CGs' beliefs that respite enabled them to continue caregiving.

RECENT AND ONGOING VA STUDIES

A recently completed six-month implementation study of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) Veterans Affairs (VA) intervention found positive effects on CG burden and CR problem behaviors, and appears to be feasible in VA settings. The multicomponent intervention includes CG support and skills training in safety, behavior management, and self care via in-home, telephone, and telephone support group sessions. Other CG interventions recently or currently being studied in VA include the Telehealth Education Program (a telephone-based education and support group); Telephone-Linked Care (TLC, a computer-mediated telephone support system); Partners in Dementia Care (PDC), a collaborative intervention delivered by care coordinators from local VA Medical Centers (VAMCs) and Alzheimer's Association chapters; and the use of remote sensor technology to monitor Veterans in the Home-based Primary Care program.

Key Question #2. What are adverse effects of CG interventions?

The systematic review of respite care found evidence in one study to suggest that CGS using

day care service actually spend more time on caregiving activities on respite days than on non-respite days, usually in preparing the CR for the visit or transporting the CR to the day care setting. In a small study of institutional/overnight respite services, some CGs reported feelings of sadness, loneliness, or guilt while the CR was in respite care; and some reported criticism from friends and relatives for allowing relief admission. A drawback of overnight respite care reported by some CGs was that the disruption to the CR's routine had increased the patient's anxiety and confusion, and that there was an increase in short-term workload on return home.

We found no evidence of adverse effects from other CG interventions based on the systematic reviews yielded by our search, and the primary studies on psychosocial interventions we examined.

DISCUSSION

CG interventions that appear to be effective tend to be individually-tailored treatments that are more resource-intensive, such as BMT, multicomponent interventions, and individual skills training. Overall, the strongest support appears for multicomponent interventions that are designed after individual in-home assessment, and tailored to the specific needs of the CG/CR dyad. The feasibility of implementation and cost analyses of CG interventions need to be assessed within VA settings. Individualized programs may be the most effective but would require more resources of staff to evaluate the dyad and generate a tailored program.

Loss to follow-up appeared problematic for many of the studies in this review, and may be clinically important. This may highlight issues of intervention acceptability to dementia CGs, and reasons for dropout should be assessed and help guide future implementation efforts in this field.

Respite care may offer some short-term benefits to CGs though long-term benefits have not been shown. Health services research evaluating cost effectiveness of variations of this intervention within the VA setting may help identify the most beneficial length for respite and contribute to policy decisions regarding this intervention.

The wide range of outcomes used to evaluate the effects of CG interventions reflects the diversity in what CGs and researchers consider important. Qualitative studies to identify outcomes of supportive interventions that are important to individuals with dementia and their CGs within the VA system would serve future research and policy for promoting the best welfare of aging Veterans and their community CGs.