Alzheimer Knowledge Exchange

Caregiver Interventions Scan

Annotated Bibliography

Supporting Family Caregivers, AKE Community of Practice

Created by:

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INTRODUCTION

The *Caregiver Interventions Scan: Annotated Bibliography* has been created as a part of the development of a Supporting Family Caregivers Community of Practice within the Alzheimer Knowledge Exchange (AKE). A Community of Practice is a group of people engaged in similar work who have committed to work together to advance practice. This can be accomplished in part by enhancing individual and group ability to find and use knowledge through activities such as knowledge exchange, knowledge dissemination, knowledge translation, and knowledge generation.

It is hoped that this document will serve as a helpful resource to individuals engaged in planning and providing psychosocial support services such as individual and family counselling and support groups for caregivers of persons with dementia, who wish to advance practice by understanding and incorporating knowledge found in the literature about effective caregiver interventions.

While using evidence found in the literature is an important way to ensure quality in practice, an equally important source of knowledge about best practice is field-based evidence. As such, the AKE via the Supporting Family Caregivers Community of Practice has begun the development of a scan of current practices in Ontario for providing psychosocial support to caregivers of persons with dementia. Contributions from professionals providing these services to the document will help to make it as comprehensive as possible. To share your contributions or to learn more about how you can connect with others in this role please visit the AKE Resource Centre http://www.akeresourcecentre.org/SFC.

CAREGIVER INTERVENTIONS

Reference:

Akkerman, R. L. & Ostwald, S. K. (2004). Reducing Anxiety in Alzheimer's Disease Family Caregivers: The Effectiveness of Nine-Week Cognitive-Behavioral Intervention. *American Journal of Alzheimer's Disease and Other Dementias*, 19(2), 117-23.

Brief Description:

Nine-week Cognitive Behavioural Therapy (CBT) intervention designed for anxious family caregivers of persons diagnosed with Alzheimer's Disease. Intended to reduce anxiety by altering appraisals and coping behaviors to enhance resistance to environmental demands and reduce vulnerability. Participants attended 2 hour meetings weekly with a focus on addressing the physiological, cognitive, and behavioral components associated with anxiety. Each meeting had designated time for social interaction, education and relaxation.

Benefits:

Reduced caregiver anxiety as measured by self-report and clinician-administered psychological assessment scales and results were maintained during a six-week follow-up period.

Reference:

Bass, D.M., Clark, P.A., Looman, W.J., McCarthy, C.A., & Eckert, S. (2003). The Cleveland Alzheimer's Managed Care Demonstration: Outcomes after 12 months of implementation, *The Gerontologist*, 43(1), 73-85.

Brief Description:

Care Consultation is a telephone-based, empowerment intervention that helps family caregivers and care receivers by providing information about health problems and available resources enabling the use of informal supports and formal services; and providing emotional support. Care consultants act as coaches and work in partnership with caregivers, care receivers, and other family members. Care Consultants are typically social workers or nurses, with supplemental assistance by trained volunteers. A key component of Care Consultation is the action steps that outline practical, behavioral tasks intended to address problem areas. For each action step, one or more persons are designated as being responsible for task completion, and a date for follow-up monitoring is established.

Benefits:

Care Consultation was effective in reducing care-related strain and increasing satisfaction with health care services; decreased hospital and emergency department use were observed.

Reference:

Belle, S, Burgio, L., Burns, R., Coon, D., Czaja, S.J., Gallagher-Thompson, D., Gitlin, L.N., Klinger, J., Mann Koepke, K., Lee, C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L., & Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine*, 145(10), 727-738.

Brief Description:

Caregivers within each racial or ethnic group (Hispanic or Latino, white or Caucasian, black or African-American) were randomly assigned to an intervention or to a control group. The intervention addressed caregiver depression, burden, self-care, and social support and care recipient problem behaviors through 12 in-home and telephone sessions over 6 months. Caregivers in the control group received 2 brief "check-in" telephone calls during the 6-month intervention.

Benefits:

Hispanic or Latino and white or Caucasian caregivers in the intervention group experienced significantly greater improvement in quality of life than those in the control group. Black or African-American spouse caregivers also improved significantly more. Prevalence of clinical depression was lower among caregivers in the intervention group.

Reference:

Bourgeois, M.S., Schulz, R., Burgio, L.D., & Beach, S. (2002). Skills training for spouses of patients with Alzheimer's Disease: Outcomes of an intervention study. *Journal of Clinical Geropsychology*, 8(1).

Brief Description:

Two, 12-week intervention groups (patient-focused skills training, caregiver-focused skills training) were compared with a control group. In Week 2, each caregiver attended 1 of 2 3-hr workshops: 1) Patient-Change Workshop, consisting of introductions, presentation of general behavioral principles as they relate to dementia symptoms, overview of in-home training sessions, and review of caregiver-completed Problem Behavior Tracking forms 2) Self-Change Workshop, consisting of introductions, presentation

of three self-change strategies, overview of in-home training sessions, and review of completed Problem Behavior Tracking forms. In Weeks 3-12, trained staff visited caregiver for 1 hr at home to individualize skills training to caregivers' needs.

Benefits:

Both training groups acquired skills that enabled them to improve targeted behaviours (patient and caregiver mood). Caregiver depression, perceived stress, strain and self-efficacy were also affected to a lesser degree.

Reference:

Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51(5), 657-664.

Brief Description:

The research quality and clinical significance of 30 controlled trials of interventions for caregivers in the community published between 1985 & 2001 was examined. Psychological morbidity and burden combined with caregiver coping skills and social support were the main outcome measures.

Benefits:

Results indicated significant benefits in caregiver psychological distress, caregiver knowledge, and main caregiver outcome measure and patient mood, but not caregiver burden. Successful outcomes were more likely if patients were also involved. 4 of 7 studies indicated delayed nursing home admission.

Reference:

Brodaty, H., Gresham, M. (1989). Effect of a training programme to reduce stress in carers of patients with dementia. *British Medical Journal*, 299, 1375-1379.

Brief Description:

96 patient-carer dyads took part in this study to assess a carer training program. 33 were assigned to a carers' programme group with carers receiving training in coping with the difficulties of caring for someone with dementia while the patients had sessions in subjects like memory retraining. 31 were in the memory retraining group with carers receiving 10 days of respite while patients had sessions like those patients in the carers' programme. 32 were on the waitlist and waited 6 months to participate in the carers'

programme. Effects on carers' general health and rate of placement of patients in institutions were measured.

Benefits:

The carers' programme resulted in significantly lower psychological stress among carers than the memory retraining programme at 12 months follow-up. At 30 months follow-up 65% of patients in the carers programme were still living at home compared to 26% of those in the memory retraining programme.

Reference:

Buckwalter, K. C., Gerdner, L. A., Hall, G. R., Kelly, A., Kohout, F., Richards, B., & Sime, M. (1999). Effects of family caregiver home training based on the progressively lowered stress threshold model. In S. H. Gueldner & L. W. Poon (Eds.), *Gerontological nursing issues for the 21st century: A multidisciplinary dialogue commemorating the international year of older persons* (pp. 81-98). Sigma Theta Tau International: Nursing Center Press.

Brief Description:

The Progressively Lowered Stress Threshold (PLST) model provides the foundation for a psychoeducation intervention to assist caregivers in understanding behaviors and planning care for persons with dementia. To achieve this purpose the model addresses the dimensions of 1) losses associated with cognitive decline and their accompanying symptom clusters, 2) behavioral states, and 3) stage of the disease process and the interaction of these dimensions across the disease process.

Benefits:

Benefits to the caregiver include: decreased depression, diminished uncertainty and unpredictability associated with managing the secondary symptoms of dementia, more positive appraisal of the stressors and burden associated with the caregiving experience, higher levels of satisfaction with the caregiving role, and reduced negative reactions to behavioral symptoms.

Reference:

Buckwalter, K. C., Gerdner, L., Kohout, F., Hall, G. R., Kelly, A., Richards, B., & Sime, M. (1999). A nursing intervention to decrease depression in family caregivers of persons with dementia. *Archives of Psychiatric Nursing*, 13(2), 80-88.

Brief Description:

Individualized plan of care based on the Progressively Lowered Stress Threshold (PLST) model (reducing stress by modifying

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environmental demands promotes functional adaptive behaviour). Community-based psychoeducational intervention compared with routine information and referrals. Approximately 3 or 4 hours of in-home intervention, and biweekly follow-up phone calls for 6 months.

Benefits:

The study showed decreased caregiver depression in those in the intervention group.

Reference:

Callahan CM, Boustani MA, Unverzagt FW, Austrom MG, Damush TM, Perkins AJ, Fultz BA, Hui SL, Counsell SR, Hendrie HC. Effectiveness of Collaborative Care for Older Adults with Alzheimer Disease in Primary Care: A Randomized Controlled Trial. *JAMA*. 2006 May 10, 295(18), 2148-57.

Brief Description:

The Collaborative Care program is a multidisciplinary team approach to care for patients with dementia. The team included primary care and specialist physicians, psychologists, other health care workers, and relevant social service agencies working to adhere to recommended standards of care for primary care patients with dementia. Therapeutic interventions in the Integrated Program of Collaborative Care include: Tailored patient and caregiver education and support program, Individual and family counseling, Support group participation, Exercise program for patients, Telephone support, Consideration for referral to specialty care, Active case-finding and treatment for depression, psychoses, behavioral disturbances and hazardous activities, Active case-finding and treatment for excess disability due to comorbid conditions, Consideration of treatment with cholinesterase inhibitors, Facilitated communication among care providers both within the heath care system and the community, Active surveillance and tracking of patient outcomes with feedback to health care team, Active monitoring and support of the caregiver's emotional and physical health.

Benefits:

The program resulted in significant improvement in the quality of care and in behavioral and psychological symptoms of dementia among primary care patients and their caregivers. These improvements were achieved without significantly increasing the use of antipsychotics or sedative-hypnotics.

Clancy Dollinger, S.M., Chwalisz, K., Zerth, E.O. (2006). Tele-help Line for Caregivers (TLC): A comprehensive telehealth intervention for rural family caregivers. *Clinical Gerontologist*, 30, 51-64.

Brief Description:

Supportive services and resources through the Tele-Help Line for Caregivers are provided during structured telephone counseling sessions. Caregiver knowledge, problem-solving skills, and help-seeking behavior and affect are the major components addressed during the intervention. An eight-session structured telephone intervention and a call-in helpline (in which all components are available but tailored to individual participants based on caller presenting concerns and assessed needs) are being compared.

Benefits:

Caregivers who have completed the telephone intervention report significantly less stress and improved social role functioning support that is still evident at 6 months. These positive effects are especially true for highly distressed and overwhelmed caregivers.

Reference:

Ducharme, F., Lévesque, L., Giroux, F., Lachance, L. (2005). Follow up of an intervention program for caregivers of a relative with dementia living in a long term care setting: Are there any persistent and delayed effects? *Aging and Mental Health*, 9 (5), 461-469.

Brief Description:

Taking Care of myself is a psychoeducational group program for caregivers of persons with dementia living in a long-term care setting. The purpose of the program is: Cognitive appraisal of stressors; Empowerment through awareness by caregivers of their strengths and capacity to change their perception of stress and exercise control over their environment and Utilization of the coping strategies of problem solving, reframing and stress symptoms management. The program consists of 10, 90 minute sessions for groups of 6 to 8 caregivers and covers various themes related to dealing with stress and loss.

Benefits:

The program demonstrated significant effects on competence dealing with health care staff, on perceived challenge of the caregiver role and perceived control, as well as on role overload, informal and formal support and on the use of the coping strategy of reframing.

Eisdorfer, C. E., Czaja, S. J., Loewenstein, D. L., Rubert, M. P., Arguelles, S., Mitrani, V., & Szapocznik, J. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *The Gerontologist*, 43 (4) 521-531.

Brief Description:

Two intervention conditions, a structural ecosystems therapy (SET), a family-based therapy intervention; and the SET intervention enhanced with a computer-telephone integrated system (SET + CTIS) were tested. The aims of the SET intervention were to identify specific problems caregivers were experiencing; identify efficacious family problem-solving styles and solutions, harness the range of useable family resources available and accessible to the family, and enhance the capacity of caregivers and their families to collaborate in the caregiving effort. The CTIS system was designed to enhance the intervention by facilitating linkages of the caregivers with both their family and with supportive resources outside of the home and providing the family therapist with enhanced access to both the caregivers and their family members (e.g. inclusion of family members at a distance or with physical limitations) for participation in therapy. Caregivers could also participate in support groups without having to leave their homes. Treatment involved weekly in-home family therapy sessions for the first 4 months of the intervention period, bi-weekly sessions for months 5 and 6 and monthly booster sessions for months 7-12. The duration of each session is approximately 90 minutes.

Benefits:

The SET + CTIS intervention was effective in decreasing depression in Cuban American and White American caregivers at both the 6 and 18 month follow-ups. The technology also enhanced the ability of caregivers to access resources, communicate with family members and knowledge about caregiving.

Reference:

Garand, L., Buckwalter, K. C., Lubaroff, D. M., et al. (2002). A pilot study of immune and mood outcomes of a community-based intervention for dementia caregivers. The PLST intervention. *Archives of Psychiatric Nursing*, 16, 156-167.

Brief Description:

Community-based psychoeducational intervention designed to help manage patient behavioral problems based on PLST model (progressively lowered stress threshold) was compared with routine info and referrals. Phase 1 is approximately 3 to 4 hours of inhome intervention teaching family caregivers about behavior management techniques and how to use behavioral logs, which serve as a basis for planning care strategies and focusing discussions on troublesome behaviors during the second phase of the

intervention. A plan for home safety is also outlined during this phase. Phase 2 includes biweekly follow-up phone calls for 6 months. For the comparison group, During the first phase of the intervention, routine information on dementia is provided, behavioral logs are discussed, a plan for home safety is outlined, and referrals are made for community-based services. Family caregivers in the comparison intervention group also receive follow-up telephone contacts every other week to offer routine information and support. At the study conclusion, family caregivers who receive the comparison intervention are offered the opportunity to learn the experimental intervention.

Benefits:

Family caregivers who receive the PLST intervention show improved mood states and immune function (T-cell function) over time.

Reference:

Gitlin, L. N., Winter, L., Corcoran, M., Dennis, M., Schinfeld, S. & Hauck, W. (2003). Effects of the Home Environmental Skill-Building Program on the caregiver-care recipient dyad: Six-month Outcomes from the Philadelphia REACH Initiative. *The Gerontologist*, 43(4), 532-546.

Brief Description:

Home-based environmental intervention designed to help family caregivers of persons with dementia learn specific strategies through education, skill-building, and environmental strategies. These strategies are designed to help caregivers so that they can modify their living space so that they develop a more supportive environment such that the person with dementia will exhibit fewer disruptive behaviors and experience a slower rate of decline and dependence in instrumental and basic activities of daily living (IADLs and ADLs). The intervention involves 5, 90-minute home visits by an occupational therapist who evaluates the home environment, observes performance of the person with dementia and the caregiving and communication style of the caregiver.

Benefits:

Compared with controls, caregivers in the intervention group reported less upset with memory-related behaviors, less need for assistance from others, and better affect. Intervention spouses reported less upset with disruptive behaviors; men reported spending less time in daily oversight; and women reported less need for help from others, better affect, and enhanced management ability, overall well-being, and mastery relative to control group counterparts. Benefits from the intervention are apparent at both 3 and 6 month-follow-up.

Gitlin, L.N., Hauck, W.W., Dennis, M.P., & Winter, L. (2005). Maintenance of effects of the Home Environmental Skill-Building Program for family caregivers and individuals with Alzheimer's Disease and related disorders. *Journal of Gerontology*, 60(3), 368-374.

Brief Description:

A randomized clinical trial was conducted to measure the effects of the Home Environmental Skill-building Program. In this program the treatment group received 6 in-home education sessions with education, problem-solving and technical skills (such as communication) and simple home modifications. After 6 months this group received 1 home visit and 3 brief telephone sessions to reinforce strategy use. Treatment and control groups were assessed at baseline, 6 months and 12 months.

Benefits:

At 6 months the treatment group experienced reduced upset with behaviours, receiving less help with daily care, improved affect as well as greater use of effective management strategies and fewer behavioural occurrences. At 12 months much of the treatment effect had been lost. Improved caregiver affect and maintenance of skill along with reduced behavioural occurrences remained.

Reference:

Gonyea, J.G., O'Connor, M.K., & Boyle, P.A. (2006). Project CARE: A randomized controlled trial of a behavioural intervention group for Alzheimer's disease caregivers. *The Gerontologist*, 46(6), 827-832.

Brief Description:

5-week (1x week, 90 min) group-based behavioral intervention led by trained interventionists aimed to reduce caregiver distress and burden related to neuropsychiatric symptoms of persons with Alzheimer's disease, and to decrease neuropsychiatric symptoms among individuals with dementia. Intervention utilizes 3 primary behavioral components: behavioral management training, pleasant events training, and relaxation training.

Benefits:

Compared with caregivers in the control group, the intervention group had greater reductions in caregiver stress related to neuropsychiatric symptoms in the person they were caring for. There was also a trend toward greater reductions in the severity of neuropsychiatric symptoms in the person with dementia.

Hébert, R., Lévesque, L., Vézina, J., Lavoie, J.-P., Ducharme, F., Gendron, C., Préville, M., Voyer, L., & Dubois, M.F. (2003). Efficacy of a psychoeducative group intervention program for caregivers of a demented persons living at home: A randomized controlled trial. Journal of Gerontology, Social Sciences, 58B(1), S58-S67.

This program consists of fifteen 2-hour weekly meetings offered to a small group of caregivers (6 to 8 per group). The primary objective is to train caregivers to cope more effectively with daily sources of stress. A participatory approach is used (discussions, written exercises, role playing) and a great deal of importance is placed on each participant's own perception of the caregiver experience. Assignments that caregivers do alone at home are the means through which coping strategies are learned and practiced. The first 4 sessions cover strategies to identify stressful situations with precision, to distinguish between the changeable and unchangeable aspects of a specific stressful situation and to ensure a tight match between the choice of coping strategy to use and the changeable and unchangeable aspects of a specific stressful situation. The other 11 sessions are devoted to three coping strategies: problem solving (problem-focused strategy), reframing (emotion-focused strategy) and seeking social support (problem-and emotion-focused strategy).

Benefits:

Results showed a 14% decrease at 8-month follow-up (post-intervention) in the reactions of caregivers in the intervention group to the behavioral problems of the care-recipient as opposed to a 5% decrease in the control group. The frequency of behavior problems also decreased significantly as did the cross-product frequency/reaction.

Reference:

Hepburn, K.W., Tornatore, J., Centre, B. & Ostwald, S. (2001). Dementia family caregiver training: Affecting beliefs about caregiving and caregiver outcomes. *Journal of the American Geriatrics Society*, 49(4), 450-457.

Brief Description:

This study tested role-training intervention as a way to help 94 family caregivers in the community have a more clinical belief about caregiving and thereby ameliorate the adverse outcomes of caregiving. Training effectiveness was measured in dyads that began immediately or after waiting for 5 – 6 months following completion of data collection. Beliefs about caregiving, burden, depression, and reaction to care receiver behaviour were administered to caregivers.

Benefits:

Significant improvements occurred within the treatment group on measures of beliefs about caregiving and reaction to behaviour. There was a relationship found between stress, beliefs and response to behaviour, depression and burden, suggesting benefits of providing information, linkage and role coaching to dementia family caregivers.

Reference:

Hudson PL, Aranda S, Hayman-White K (2005) A psycho-educational intervention for family caregivers of patients receiving palliative care: A randomized controlled trial. *Journal of Pain and Symptom Management*, 30(4), 329-341.

Brief Description:

A caregiver guidebook and audiotape focused on caring for a dying person were used as the basis for nurse interactions (2 home visits with phone calls in between visits) with caregivers of people with cancer receiving palliative care.

Benefits:

The intervention group reported a more positive caregiving experience both initially and over time.

Reference:

Logsdon, R., McCurry, S. & Ten, L. (2006). Time-limited support groups for individuals with early stage dementia and their care partners: Preliminary outcomes from a controlled clinical trial. *Clinical Gerontologist*, 30(2), 5 – 19.

Brief Description:

An ongoing randomized controlled clinical trial comparing early stage support groups with a wait-list control condition is described.

Benefits:

Results suggest improved quality of life and decreased family conflict following support group participation.

Reference:

Logsdon, R.G., McCurry, S.M., Teri, L. (2005). STAR-Caregivers: A community-based approach for teaching family caregivers to use behavioral strategies to reduce affective disturbances in persons with dementia. *Alzheimer's Care Quarterly*, 6(2), 146-153.

Brief Description:

STAR-C is a behavioral intervention designed to decrease depression and anxiety in individuals with Alzheimer's disease and their family caregivers. The intervention consisted of 8 weekly in-home sessions followed by 4 monthly telephone calls. Treatment components included: general education about Alzheimer's Disease, practice using a systematic approach to identifying and reducing behavior problems in dementia (the ABC model of behavior change), communication skill training, and information about the relationship between mood and pleasant events, and caregiver support.

Benefits:

Caregivers in STAR-C showed significant improvements in ratings of depression, burden, and reactivity to behavior problems in the person with Alzheimer's Disease, compared to usual medical care control subjects. There were also improvements in the frequency and severity of dementia-related behavior problems in care-recipients, and improved quality of life. Improvements were maintained at 6-month follow-up.

Reference:

Mahoney, D., Tarlow, B, & Jones, R. (2003) Effects of an automated telephone support system on caregiver burden and anxiety: Findings from the REACH for Telephone-Linked Care intervention study. *The Gerontologist*, 43(4),556-567.

Brief Description:

In this randomized controlled trial with 100 caregivers an automated telephone support system on the bothersome nature of caregiving, anxiety, and depression given different levels of caregiving mastery was studied. Using Telephone linked care (TLC) caregivers pressed designated keys on the touch-tone keypad of the regular home telephones to communicate with TLC and the system spoke to them using a human voice controlled by an interactive voice response (IVR) computer system. The program queried the primary caregiver's stress level on a weekly basis and made recommendations to lower and referrals when necessary; provided a voice mail caregiver support network; offered voice mail access to a panel of experts in Alzheimer's Disease; and provided a twenty minute personalized but automated caregiver "respite"/ patient distraction telephone conversation.

Benefits:

Results indicated a significant intervention effect for participants with lower mastery at baseline on bother, anxiety, and depression. Additionally, wives exhibited a significant intervention effect in the reduction of the bothersome nature of caregiving. Unsatisfied non-users had expressed preference for personal interactions and reluctance to use IVR technology at baseline and this was

predictive of non-use.

Reference:

McCurry, S.M., Logsdon, R.G., Teri, L. (1996) Behavioral treatment of sleep disturbance in elderly dementia caregivers. *Clinical Gerontologist*, 17(2), 35-50.

Brief Description:

The intervention was a combination cognitive-behavioral treatment for insomnia designed for use with caregivers of persons with dementia. The treatment included education about good sleep practices ("sleep hygiene" and "stimulus control" recommendations), as well as training in stress management/relaxation techniques and behavioral management skills for reducing dementia-related behavior problems. Caregivers were also placed on a sleep compression schedule to reduce total time in bed at night. The treatment was initially implemented as a 6-week, group intervention then, based upon feedback from caregivers, modified to be a 4-week, individual treatment.

Benefits:

Caregivers in active treatment showed significant improvements in self-reported sleep quality at post-treatment and 3-month follow up, compared to control subjects.

Reference:

Mei Chan, S., & O'Connor, D.L. (2008). Finding a voice: The experiences of Chinese family members participating in family support groups. *Social Work with Groups*, 31(2).

Brief Description:

This study examined how culture influenced the family support group experience of Chinese family caregivers. In-depth interviews from an earlier study with 6 Chinese family caregivers about their experiences with a family support group were analyzed.

Benefits:

Experiences of these participants were not inconsistent with those of mainstream participants, but the overarching theme was strongly linked to culture. Participants framed their experience with the family support group as pivotal for helping them become more assertive in relation to the care needs of their relative and themselves.

Mittelman, M.S., (2008). A three-county randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer Disease: Effects on caregiver depression. *American Journal of Geriatric Psychiatry*. 16(11), 893-904.

Brief Description:

Volunteer sample of 158 spouse caregivers of persons with AD living in the community participated in this study with half receiving 5 sessions of individual and family counseling and continuous availability of ad hoc telephone counseling within the first 3 months of enrollment. All persons with dementia were prescribed for all patients. Caregiver depression was measured at intake and follow-up assessments for 24 months.

Benefits:

Depressions scores for caregivers receiving counseling decreased over time and those who did not receive counseling increased. The benefits of the psychosocial intervention increased over time.

Reference:

Mittelman, M.S., Haley, W.E., Clay, O.J., & Roth, D.L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease. *Neurology*, 67, 1592-1599.

Brief Description:

A randomized controlled trial of an enhanced counseling and support intervention consisting 6 individual and family counseling sessions, support group participation, and continuous availability of ad hoc telephone counseling was compared to usual care.

Benefits:

Patients whose spouses took part in the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with the control group. The median difference in time to placement was 557 days. Caregivers experienced improvements in satisfaction with social support, response to patient behavior and symptoms of depression (accounting for 61.2% of the beneficial impact on placement).

Mittelman, M.S., Roth, D.L., Clay, O.J., & Haley, W.E. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *American Journal of Psychiatry*, 161(5), 850-856.

Brief Description:

The long-term effect of a counseling and support intervention on symptoms of depression in spousal caregivers was examined. Caregivers in the treatment group had 6 sessions of individual and family counseling, support groups for 4 months after enrollment and received ongoing ad hoc counselling. This group was compared with a control group receiving usual care.

Benefits:

Caregivers in the treatment group had less depressive symptoms than the control group. The effects lasted for 3.1 years after baseline.

Reference:

Mittelman, M.S., Roth, D.L., Clay, O.J., & Haley, W.E. (2007). Preserving health of Alzheimer caregivers: Impact of a spouse caregiver intervention. *American Journal of Geriatric Psychiatry*, 15(9), 780-789.

Brief Description:

The effectiveness of a counseling and support intervention for 406 spouse caregivers of persons with dementia living in the community over 9.5 years. The intervention included 6 sessions of individual and family counseling, support group participation and continuous availability of ad hoc telephone counseling. Effects of the intervention on time of nursing home placement were measured.

Benefits:

Patients whose spouses received the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with usual care controls. The difference predicted a median time to placement of 557 days. Improvements were also seen in caregivers' satisfaction with social support, response to patient behavior problems and symptoms of depression. Together these accounted for 61.2% of the intervention's impact on placement.

Molinari, B., Nelson, N., Shekelle, S., Crothers, M.K. (1994). Family support groups of the Alzheimer's Association: An analysis of attendees and nonattendees. *Journal of Applied Gerontology*, 13(1), 86-98.

Brief Description:

The perceptions about support groups of family caregivers who attend Alzheimer's Association support groups and those who do not were compared.

Benefits:

Those who attend were almost uniformly positive about their experiences. They tended to have fewer people in their households, say that the time and location of the groups are convenient and are more clear about the purpose of support groups, had someone advise them to attend, perceive that groups yield emotional support not received elsewhere, and believe that groups allow them to show concern for others with similar problems compared with those who do not attend support groups.

Reference:

Nobili A, Riva E, Tettamanti M, et al. The effect of a structured intervention on caregivers of patients with dementia and problem behaviors. A randomized controlled pilot study. *Alzheimer Disease and Associated Disorders* 2004, 18, 75-82.

Brief Description:

One, 1 hour home visit by psychologist to discuss family dynamics, caregiver stress and psychologic consequences, verbal and nonverbal communication, personality changes, and problem behavior. One 90 min. home visit by occupational therapist who gave strategies to prevent/manage problem behavior, maintain and/or improve patient's functional abilities, adapt environment. Caregivers also provided with information manual and medical referral list if needed.

Benefits:

The effect of the structured intervention was seen mostly on the reduction of the frequency of behavioral problem, particularly psychic agitation and delusion, and to a lesser extent on time spent for caring. Another positive effect was the reduction of caregivers' stress.

Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist*, 39(3), 299-309.

Brief Description:

Savvy Caregiver is a 12-hour training program that is usually delivered in 2-hour sessions over a 6-week period. The program focuses on helping caregivers think about their situation objectively and providing them with the knowledge, skills, and attitudes they need to manage stress and carry out the caregiving role effectively.

Benefits:

Research has demonstrated significant positive outcomes for caregivers who participated in the program versus those in the control group with respect to the caregivers' beliefs about caregiving, their reactions to the behavioral symptoms of their care recipient, and their feelings of stress and burden.

Reference:

Pratt, R., Clare, L. & Aggarwal, N. (2005). The "Talking about memory coffee group": A new model of support for people with early stage dementia and their families. *Dementia*, 4, 143-148.

Brief Description:

The "Talking About Memory Coffee Group" is user-led model of intervention for people with early-stage dementia. Its goal is to help maintain aspects of self and also to support changes in sense of self.

Benefits:

New aspects of working with people with dementia in support groups through redefining inclusion, promoting autonomy and developing a user-led approach were explored.

Reference:

Pratt, R., Clare, L., & Kirchner, V. (2006). It's like a revolving door syndrome: Professional perspectives on models of access to services for people with early-stage dementia. *Aging & Mental Health*, 10(1), 55-62.

Brief Description:

30 professionals were interviewed about access to services for people with early-stage dementia to explore how different models of access.

Benefits:

Participants felt that the range of complex needs of persons with early-stage dementia were largely unmet, naming the framework within which services are delivered as the reason.

Reference:

Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L.M., Belle, S.H., Burgio, L., Gitlin, L., Coon, D., Burns, R. Gallagher-Thompson, D., Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist*, 42(5), 589-602.

Brief Description:

Review of intervention studies published since 1996, including psychosocial interventions for caregivers and environmental and pharmacological interventions for care recipients.

Benefits:

Caregiver intervention studies have increasingly shown promise of affecting important public health outcomes in areas such as service utilization, including delayed institutionalization, psychiatric symptomatology, including the successful treatment of major and minor depression.

Reference:

Silverberg, E. (2008). Introducing the 3-A Grief Intervention Model for Dementia Caregivers: Acknowledge, Assess, Assist. *Omega Journal of Death and Dying*, 54 (3), 215-235.

Brief Description:

The author incorporated evidence from literature as well as personal clinical practice, interviews with 4 family caregivers and peer review to develop a model of intervention that reflects the grief experience of caregivers of persons with dementia. The model uses three A's that represent the psychosocial components of grief management, Acknowledging, Assessing, Assisting.

Benefits:

This intervention model enfranchises the caregiver grief experience and so identifies different grieving styles and the role of denial and respite in adapting to the grief experience is recognized.

Reference:

Sorensen, S. Pinquart, M., Habilb, & Duberstein, P. (2002). How effective are interventions with caregivers? An updated metaanalysis. *The Gerontologist*, 42(3), 356-372.

Brief Description:

This meta-analysis was used to synthesize the effects of 78 intervention studies for 6 outcome variables and 6 types of interventions for family caregivers of older adults.

Results:

Combined, the interventions produced a significant improvement for caregiver burden, depression, subjective well-being, perceived caregiver satisfaction, ability/knowledge and care receiver symptoms. Intervention effects were larger for increasing caregivers' ability/knowledge than for caregiver burden and depression. Psychoeducational and psychotherapeutic interventions showed the most consistent short-term effects on all outcome measures. Effects were smaller for dementia caregivers.

Reference:

Sorensen, L.V., Waldorffab, F.B., & Waldemara, G. (2008). Early counseling and support for patients with mild Alzheimer's disease and their caregivers: A qualitative study on outcome. *Aging & Mental Health*, 12(4), 444-450.

Brief Description:

An intensive structured psychosocial intervention program including tailored counseling, education and support groups for homeliving patients with mild Alzheimer's disease and their spousal caregivers.

Benefits:

Patients found support groups relevant, stimulating to be with peers, supportive of their self-esteem and supportive of them finding new ways of managing everyday life and social relations. Caregivers were better able to cope with the challenges.

Stolley, J. M., Reed, D., & Buckwalter, K. C. (2002). Caregiving appraisal and interventions based on the progressively lowered stress threshold model. *American Journal of Alzheimer's Disease and other Dementias*, 17, 113-132.

Brief Description:

Individualized plan of care based on the Progressively Lowered Stress Threshold (PLST) model. Community-based psychoeducational intervention compared with routine info and referrals. Approximately 3 or 4 hours of in-home intervention, and biweekly follow-up phone calls for 6 months, compared with routine info and referrals.

Benefits:

Results showed improved burden and satisfaction and increased positive appraisal of caregiving situation.

Reference:

Thompson, C.A., Spilsbury, K., Hall, J., Birks, Y. Barnes, C. & Adamson, J. (2007). Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics*, 7(18). Available online: <u>http://www.biomedcentral.com/1471-2318-7-18</u>.

Brief Description:

This was a systematic review examining whether information and support interventions improve the quality of life of people caring for someone with dementia.

Benefits:

The authors found statistically significant evidence that group-based supportive interventions impact positively on psychological morbidity of caregivers.

Reference:

Whitlatch, C.J., Judge, K., Zarit, S.H., & Femia, E., (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist*. 26(5), 688-694.

Brief Description:

The Early Diagnosis Dyadic Intervention (EDDI) program of structured, time-limited protocol of one-on-one and dyadic counseling for family caregivers and care receivers who are in the early stages of dementia was tested with 31 dyads. The intention of EDDI is to increase the care receiver's active participation in his or her care plan, develop positive communication patterns within the dyad, increase knowledge about available services, and assist the dyad through the emotional turbulence of a dementia diagnosis. Caregiver and care receiver ratings of treatment acceptability and effectiveness and counselor ratings of treatment effectiveness were measured.

Benefits:

Evaluations of the EDDI program indicated that the intervention was acceptable and satisfactory to caregivers, care receivers and counselors and that the goals and objectives were achievable.

OTHER HELPFUL RESOURCES

Rosalynn Carter Institute for Caregiving, Evidence Based Interventions Resource Centre: http://www.rosalynncarter.org/caregiver_intervention_database/

Silverberg, E. (2008). *The 3-A Grief Intervention Model: For Dementia Caregivers.* DVD available from the Alzheimer Society of York Region.

CONTACTS

If you would like further information about any of the interventions described you can contact Mary Beth Forget, Seniors Health Research Transfer Network (SHRTN), Information Specialist to obtain a copy of the research article.

Mary Beth Forget - T: 416-785-2500X2393 (Toll Free: 1-866-393-4877) or email mforget@baycrest.org

To become a member of the Supporting Family Caregivers, Community of Practice contact the Knowledge Broker (<u>http://www.akeresourcecentre.org/SFC</u>).