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November 2013

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Neil Gaiman
Lincolnshire Knowledge and Resource Service

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**Literature Search Results**

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**Enquiry Details**

Evidence around carers of people with dementia, where the carers are given 1:1 support in their caring role.

Impact of this support;
Benefits are for the carer,
Costs v potential cost savings to services etc.

**Comment**

I have searched for ‘one to one / 1-to-1 / 1-2-1’, 'individual / individualised' and 'befriending' interventions. There is only a small body of research which explicitly address one-to-one support for carers.

Much research relates to peer support and social support but - although the Social Care Institute for Excellence document ‘Working in Partnership with Carers’ notes that: carers can also offer or receive another particularly valuable type of one-to-one support – known as ‘peer support’. – the term Peer Support in the research literature frequently relates to support groups rather than one to one support. I have included systematic reviews and research papers at the end of this document relating to peer support in groups, and to how carers seek support, for reference in case it is of interest.

I have also included commentary from NICE guidance relating to the difficulties encountered in undertaking research in this area.
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Every effort has been made to ensure that this information is accurate, up-to-date, and complete. However it is possible that it is not representative of the whole body of evidence available. No responsibility can be accepted for any action taken on the basis of this information. It is the responsibility of the requester to determine the accuracy, validity and interpretation of the search results.

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Word documents
Select Edit from the menu, the Find and type in your term in the search box which is presented. The search function will locate the first use of the term in the document. By pressing 'next' you will jump to further references.
This first project directly compares one-to-one with group support for dementia carers. The full text of the paper is attached.

Peer support for family carers of people with dementia, alone or in combination with group reminiscence in a factorial design: study protocol for a randomised controlled trial.
Trials [Electronic Resource], 2011, vol./is. 12/(205), 1745-6215;1745-6215 (2011)

Abstract:
BACKGROUND: Peer support interventions can improve carer wellbeing and interventions that engage both the carer and person with dementia can have significant mutual benefits. Existing research has been criticised for inadequate rigour of design or reporting. This paper describes the protocol for a complex trial that evaluates one-to-one peer support and a group reminiscence programme, both separately and together, in a factorial design
DESIGN: A 2 x 2 factorial multi-site randomised controlled trial of individual peer support and group reminiscence interventions for family carers and people with dementia in community settings in England, addressing both effectiveness and cost-effectiveness.
DISCUSSION: The methods described in this protocol have implications for research into psychosocial interventions, particularly complex interventions seeking to test both individual and group approaches.

Fidelity and acceptability of an adaptive intervention for caregivers: an exploratory study.
Aging & Mental Health, 2013, vol./is. 17/2(197-206), 1360-7863;1364-6915
Zarit SH, Lee JE, Barrineau MJ, Whitlatch CJ, Femia EE

Abstract:
OBJECTIVE: There has been growing interest in providing tailored or adaptive interventions to family caregivers as a way of addressing their heterogeneity of risk factors and other needs. A particular challenge in an adaptive study is to implement the individualized intervention protocol as planned (program fidelity). This study explores the fidelity of implementation of an adaptive intervention for family caregivers of persons with dementia and its acceptability to caregivers.
METHOD: Using a sample of 35 caregivers of person with dementia who participated in a program development study, we gathered information on acceptability and fidelity of the program from multiple sources, including caregiver and counselor reports and ratings of recordings of sessions.
RESULTS: Findings show that caregivers have high levels of acceptance of the intervention plan and high ratings of satisfaction with the program. Ratings of satisfaction and counselor competence were not associated with the amount of treatment provided. Ratings by counselors and independent raters found good fidelity for two of the three program domains.
DISCUSSION: The results demonstrate that trained counselors can follow a tailored intervention plan and that caregivers’ experience of the program did not differ depending on how much intervention was provided. A next step is to determine how an adaptive protocol would affect caregiver outcomes.
Healthbridge: the national evaluation of peer support networks and dementia advisers in implementation of the national dementia strategy for England
CLARKE Charlotte L., et al  Publisher: Department of Health Publication year: 2013
Pagination: 367

‘Living with dementia’, the national dementia strategy for England (Department of Health, 2009) recommended Dementia Adviser and Peer Support Network services, and established 40 demonstration sites in a range of organisational settings. These services aimed to provide people with dementia and carers with information, guidance and advice, thus enabling access to a wide range of support including social groups that enabled peer learning. ‘Healthbridge’ is independent research commissioned by the Department of Health, which provides evidence on the importance of post diagnostic support for people with dementia and their carers, and the role that dementia advisers and peer support networks have in this. A mixed methods approach to data collection was used, which included activity and outcome monitoring; organisational surveys and collaborative discussions; and in-depth case studies. Among themes considered were: social networks; independence, control and choice; and awareness raising. People with dementia and carers saw dementia advisers and peer support networks as having a positive impact on their wellbeing and quality of life. Demonstrator sites provided evidence of both dementia advisers and peer support networks filling a gap in service provision that often occurs after diagnosis but before there is a need for more intensive support. There were also resource saving implications for the local health and social care economy. This report is also available in two other much shorter formats: a brief report written primarily for service commissioners and providers, and a lay summary.

The modelling of the 40 demonstration sites within the implementation of the National Dementia Strategy acknowledges the part that lay and peer support and advisers can play in supporting communities and families. It may be that parallels can be drawn with lay health advisers in public health. Such roles have three broad aims: access to individuals who are marginalised, access from marginalised communities into health and social care systems, and alternative delivery mechanisms to a professional provider. Broadly, these roles are theoretically underpinned by social network theory, social learning theory and self-efficacy theory. The mechanisms of intervention fall into three broad groups:
• Embellishment of standard care such as a ‘bridge’ between individuals and organisations.
• Providing social network support: affective support (caring, trust, love), informational support (advice, suggestions) and instrumental support (tangible aid and services).
• Information transmission such as individual one-to-one tailored message giving.

Peer Support Networks
• Some groups within Peer Support Networks were activity-based, others had more of a focus on dementia and discussion. There were some groups where both took place. Some people kept in touch with one another outside of formal meetings, others chose not to or were not able to.
• Peer Support Network groups included socialising, and developing interests, within the context of interpersonal interaction with people who had common experiences of living with dementia. The groups enabled people to remain active, whether that be through maintaining memory, or getting out and about and socialising.
• The facilitator’s role within Peer Support Networks included recruitment, processing referrals and publicity; ensuring the smooth running of groups and, at times, providing information, advice and one-to-one support.
Within Peer Support Network services, the emphasis was on advice within the context of supportive groups or one-to-one relationships in which there was a commonality of experience. The following example is from a person with dementia who had attended a Peer Support Network group:

Denise, person with dementia who had accessed PSN group: I know people have asked about claiming benefits and somebody else asked about… Do they call it…? When you’re not competent to do something and you want to…. There’s a form you can fill in or something for somebody else to do things… You know, sign for you and… I can’t remember what it’s called.

There were instances where carers, or people who had previously cared from someone with dementia, were volunteers. In addition to the intensive one-to-one support provided in end-of-life issues within one site, carers were also involved in running specific groups, fundraising and training, and awareness raising. There were instances where carers who had been part of support groups had continued attending those groups once their loved one was no longer there, providing continued support within the social network:

Laurie, person with dementia who had accessed PSN group: And one of the ladies – the carers – her husband is now in [care home] ……. But she’s still coming as a helper.

Flexibility was also reflected in ways in which Peer Support Network and Dementia Adviser services were able to respond to fluctuating needs:

Eleanor, volunteer from PSN site: The couple of times that I’ve been asked to go in and do a little bit of extra one-to-one it’s because they are picking up that actually someone is experiencing huge burden. Carer burden.

Tim, local professional from memory clinic who had worked alongside PSN site: And then, certainly, some of the other groups that we set have been about trying to bring in isolated groups for some of the older people that don’t have family or other supports and they might not be able to access some of our groups within the memory service, because you need a carer to come along with you. How can we offer them a service? Where actually they would feel able to engage. And it’s much more activity-based, rather than actually thinking about some of the… Our other groups are very, sort of, theory led about implementing coping strategies. Which, for them, they would need one-to-one support from a member of staff to go home and to be able to implement it. It needed to be a different set of goals, if you like, for those individuals.

Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence.
Counselling & Psychotherapy Research, 01 June 2013, vol./is. 13/2(106-125), 14733145
Elvish, Ruth, Lever, Sammi-Jo, Johnstone, Jodie, Cawley, Rosanne, Keady, John

Abstract:
Rationale: Carers of people with dementia experience significant levels of stress in their everyday role. The National Dementia Strategy in England identifies the key role that carers play in supporting people with dementia living at home, often to the detriment of their social, emotional and physical health.
Aims: To add to the substantive knowledge-base by combining search criteria used by Pinquart and Sörensen (2006) and Gallagher-Thompson and Coon (2007) to update the literature on psychological interventions for carers of people with dementia published between 2005 and 2011.
Method: Following the study inclusion criteria, comprehensive searches were conducted using the electronic databases Medline, PsycINFO, ERIC, and PubMed. Twenty studies were identified, graded and synthesised into the reported systematic review with both quantitative and qualitative studies included to maximise practice application.
Results: Consistent with previous findings, three categories of psychological intervention were identified: (i) psychoeducational-skill building (n=8); (ii) psychotherapy-counselling (n=1); (iii) multicomponent (n=6). Our review also identified a fourth intervention category, (iv) technology-based (n=5). The majority of studies in the updated review examine the constructs of depression, burden, social support and well-being. The development of focused interventions for carers, whether individually tailored interventions or group interventions around a common issue, was significant for developing practice. Future studies across all categories should continue to embed supervision arrangements within their psychological intervention protocols.

Personalised caregiver support: effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia.
International Journal of Geriatric Psychiatry, January 2012, vol./is. 27/1(1-14), 0885-Van Mierlo LD, Meiland FJ, Van der Roest HG, Drees RM

Abstract:
OBJECTIVE: Insight into the characteristics of caregivers for whom psychosocial interventions are effective is important for care practice. Until now no systematic reviews were conducted into the effectiveness of psychosocial interventions for caregiver subgroups.
METHODS: To gain insight into this relationship between caregiver subgroups and intervention outcomes, a first review study was done. This study reviews the personal characteristics of caregivers of people with dementia for whom psychosocial interventions were effective.
RESULTS: Electronic databases and key articles were searched for reviews on psychosocial interventions for caregivers studies published between January 1990 and February 2008. Based on these reviews, twenty-six studies met the inclusion criteria (i.e. having positive outcomes described in subgroups). Most positive effects were found in caregivers of people with a diagnosis of 'dementia not otherwise specified' and in the subgroup of female caregivers. Examples of outcomes were decreased depression and improved self-efficacy.
CONCLUSIONS: This study gives a first overview of successful psychosocial interventions in subgroups of caregivers of people with dementia. It makes clear that until now, relatively little research has been done into subgroups of these caregivers. It also suggests that more research is needed to better understand which psychosocial interventions are effective for specific subgroups of caregivers of people with dementia.

A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community.
International Psychogeriatrics, 01 January 2012, vol./is. 24/1(6-18), 10416102
Jones C, Edwards RT, Hounsome B

The evidence for this systematic review was limited to 12 intervention studies covering pharmacological, psychosocial, and service delivery interventions. The overall conclusion is that there is a lack of evidence on the cost-effectiveness of interventions to support caregivers, although some evidence of the beneficial effects on caregiver outcomes is reported.

Context
In the UK, two-thirds of people with dementia are supported at home by informal caregivers. This informal care contributes 55% of the estimated annual cost of dementia to the economy so it is essential that, when reviewing dementia care, the benefits and adverse effects on caregivers is taken into account. The aim of this systematic review was to examine the evidence on health-related outcomes for caregivers following interventions targeting people with dementia and/or their caregivers.

Methods

What criteria were used to decide on which studies to include?
Studies of pharmacological and non-pharmacological interventions involving persons with dementia being looked after by an informal caregiver in a community setting, were eligible for inclusion if they also reported cost data and a health-related outcome measure for the caregiver.

How many studies were included and where were they from?
A total of 6,139 articles was obtained after the removal of duplicates; title and abstract screening resulted in the removal of a further 5,959 articles, leaving 180 papers for full-text review. Twelve studies were eventually selected for systematic review. The flow of articles through the stages of selection, including the reasons for exclusion, is reported in Figure 1. There were four studies from the UK, three from the USA, two conducted in Canada, and one study each from the Netherlands and Finland; a multinational study conducted in Canada, Australia, and France was also included.

How were the study findings combined?
The diverse nature of the interventions and study participants meant that the review was best suited to a narrative approach to data synthesis. Study effectiveness is reported as the difference in means of the carer outcome measures between the intervention and control groups. The outcomes are considered under separate headings for pharmacological interventions, psychosocial interventions, and service delivery interventions.
Findings of the review
Four pharmacological, four psychosocial, and four service delivery interventions were included in the review. All four pharmacological interventions examined the effect of donepezil for dementia on caregiver outcomes and found no significant difference compared to controls. The results for the psychosocial interventions were mixed although some significant caregiver benefits, compared to controls, were reported in two studies; in one a tailored in-home/telephone occupational therapy programme led to a higher sense of competence and in another the provision of one-to-one problem-solving therapy sessions for caregivers of persons with dementia resulted in improved coping skills.

Two of the four service delivery interventions, defined as involving a change in management or delivery of existing services to the person with dementia or the caregiver, reported beneficial effects. One study in which a case manager based in a community mental health team for the elderly provided regularly updated care plans resulted in a lower perceived burden in the caregivers; the other study found that the implementation of a care coordination and support strategic partnership between a home healthcare agency and a telephone support service provided by nurses led to increased nursing knowledge in caregivers, but the methodological quality of the study was weak. Three studies, two of service delivery interventions and one psychosocial intervention, reported significant difference in costs between intervention and control groups.

Authors’ conclusions
The main conclusion from this systematic review is that there is ‘a lack of evidence of the cost-effectiveness of interventions to support informal caregivers of people with dementia residing in the community.’

Implications for policy or practice
None are discussed.

A systematic review of networked technologies supporting carers of people with dementia.
Journal of Telemedicine and Telecare, 2008, vol./is. 14/3(154-156), 1357-633X
Powell, John, Chiu, Teresa, Eysenbach, Gunther

Abstract: We conducted a systematic review of the effectiveness of networked ICT interventions in supporting carers of people with dementia. Five bibliographic databases were searched and a total of 1,456 abstracts were identified as potentially relevant. From these we identified 15 papers describing five interventions: ComputerLink, AlzOnline, Caring for Others and two studies from the REACH project (TLC and CTIS). The interventions reviewed were multifaceted with elements of networked peer support. Outcomes were inconsistent but suggested that the interventions had moderate effects on improving carer stress and depression. Treatment effects were found to vary with care-giver characteristics such as ethnic groups, formal support and baseline burden. Further evaluation is needed in robust trials with good follow-up.
A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia.

Abstract: Historically, there have been many attempts to develop interventions to support the carers of people with dementia. To date the evidence of effectiveness has been limited. However, the success of psychosocial interventions for carers of people with schizophrenia has suggested the possibility of utilizing this approach. A systematic review was undertaken to assess the evidence of effectiveness for psychosocial interventions with carers of people with dementia. Thirty controlled trials that evaluated a psychosocial approach were identified. The overall methodological quality of these studies was poor, particularly with regard to sample size, and methods of random allocation. Individualized interventions that utilized problem solving and behaviour management demonstrated the best evidence of effectiveness. This approach is also closest to the effective model of psychosocial interventions currently in use with other severe and enduring illnesses. This suggests that there is scope for developing interventions, based more specifically on this model, for supporting the carers of people with dementia.
Qualitative Studies

Peer Support for Carers: A Qualitative Investigation of the Experiences of Carers and Peer Volunteers.
American Journal of Alzheimer's Disease & Other Dementias, 2013, vol./is. 28/6(617-626), 15333175
Greenwood, Nan, Habibi, Ruth, Mackenzie, Ann, Drennan, Vari, Easton, Nicky
Being a carer of someone with dementia can be rewarding and also challenging. Volunteer peer support schemes for carers are being introduced, little is known about either their impact on carers and volunteers or about volunteers' and carers' experiences. This study investigated peer volunteer and carer recipient experiences of a peer support service. Thematic analysis of 13 in-depth interviews with 9 carers and 4 peer volunteers revealed that peer support helped both carers and peer volunteers through the realization that they were "not alone" in their experiences and emotions. Additional carer benefits included opportunities to talk freely about difficult experiences and learning how others cope. Volunteers found their role rewarding, describing satisfaction from putting their own experiences to good use. These findings highlight the isolation and exclusion experienced by current and former carers of people with dementia and draw attention to the benefits of peer support for both the groups.

Development of support networks in informal dementia care: guided, organic, and chance routes through support.
Canadian Journal on Aging, December 2012, vol./is. 31/4(445-55), 0714-0714
Egdell V
Abstract: Increasing knowledge about factors that shape the development of care networks for people with dementia is imperative in countries with aging populations that are relying increasingly on informal care. This study used a qualitative approach to identify the complex routes through support taken by informal caregivers for people with dementia in the development of their care networks. Interview data were collected from 13 caregivers. Three routes through support were identified: guided routes, organic routes, and chance routes. This article's principal argument is that these routes are the outcomes not only of the resources that caregivers draw upon, but also of their varying expectations regarding the role of the informal caregiver. The identification of the three routes through support provides a potentially valuable framework for examining the experiences of caregivers for individuals with other long-term health conditions.

Telephone support met the perceived needs of dementia caregivers for convenient access to information, referral, and emotional support.
Evidence Based Nursing, 01 July 2006, vol./is. 9/3(94-94), 13676539
Spilsbury K
Abstract: What are the dimensions of telephone support for caregivers of family members with dementia? What are the experiences of telephone support providers and caregivers related to telephone support?, DESIGN, Qualitative descriptive study., SETTING, South central Ontario, Canada.
PARTICIPANTS, 8 female caregivers (age 50-80 y) who had been caring for a spouse (n = 3) or parent (n = 5) with dementia for a median 3-5 years, and 4 female telephone support providers (age 30-65 y) from the Alzheimer Society (n = 3) or a multiservice community agency (n = 1), who had educational qualifications in nursing or gerontology and 3-15 years of telephone support experience (3 providers also had personal caregiver experience).

METHODS, Participants were interviewed in person or by telephone. They were asked about their experiences of receiving (or providing) telephone support and their views of the strengths and limitations of such support. Data from transcribed interviews were analysed through the processes of categorical aggregation, direct interpretation, pattern formation, and creation of generalisations.

MAIN FINDINGS, Both caregivers and providers identified 4 dimensions of caregiver needs that were met by telephone support. (1) Information and education. Telephone support provided an immediate source of individualised advice and strategies to effectively manage problematic situations. (2) Referral to other sources of support. Telephone support connected caregivers with other support services in the community and helped them to navigate through the often complex systems. (3) Emotional support. Providers helped caregivers to cope by listening, acknowledging their efforts, and providing encouragement, reassurance, and coping strategies. (4) Support that is convenient and hassle free. Caregivers appreciated the convenience of telephone support because they could access it immediately from home, without worrying about booking appointments or finding substitute care for their family members. Telephone support was comfortable in that it could be used as a single resource for different types of problems, and it continued after the person with dementia moved to institutional care. Limitations of telephone support included restricted hours and lack of service for non-English speaking clients. Caregiver and provider experiences. The aspect of telephone support that caregivers valued most was the sense of companionship and connection it provided. Providers reported feelings of helplessness and frustration in not being able to do more or gauge how their advice was received. However, they enjoyed the satisfaction of empowering caregivers to cope with difficult situations. Both groups agreed that the experience of telephone support was more rewarding when caregivers and providers had met face to face and when the provider knew the person with dementia.

CONCLUSION, Telephone support met some of the needs of caregivers of family members with dementia by providing convenient access to information and education, referral to other sources of support, emotional support, and companionship.

Full Text: Available from Highwire Press in Evidence-Based Nursing
Cost-effectiveness studies

Health economics research into supporting carers of people with dementia: a systematic review of outcome measures.

Health & Quality of Life Outcomes, 2012, vol./is. 10/(142), 1477-7525;1477-7525 (2012)

Jones C, Edwards RT, Hounsome B

Abstract: Advisory bodies, such as the National Institute for Health and Clinical Excellence (NICE) in the UK, advocate using preference based instruments to measure the quality of life (QoL) component of the quality-adjusted life year (QALY). Cost per QALY is used to determine cost-effectiveness, and hence funding, of interventions. QALYs allow policy makers to compare the effects of different interventions across different patient groups. Generic measures may not be sensitive enough to fully capture the QoL effects for certain populations, such as carers, so there is a need to consider additional outcome measures, which are preference based where possible to enable cost-effectiveness analysis to be undertaken.

This paper reviews outcome measures commonly used in health services research and health economics research involving carers of people with dementia. An electronic database search was conducted in PubMed, Medline, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, the National Health Service Economic Evaluation Database (NHS EED), Database of Abstracts of Reviews of Effects (DARE) and Health Technology Assessment database. Studies were eligible for inclusion if they included an outcome measure for carers of people with dementia. 2262 articles were identified. 455 articles describing 361 studies remained after exclusion criteria were applied. 228 outcome measures were extracted from the studies. Measures were categorised into 44 burden measures, 43 mastery measures, 61 mood measures, 32 QoL measures, 27 social support and relationships measures and 21 staff competency and morale measures. The choice of instrument has implications on funding decisions; therefore, researchers need to choose appropriate instruments for the population being measured and the type of intervention undertaken. If an instrument is not sensitive enough to detect changes in certain populations, the effect of an intervention may be underestimated, and hence interventions which may appear to be beneficial to participants are not deemed cost-effective and are not funded. If this is the case, it is essential that additional outcome measures which detect changes in broader QoL are included, whilst still retaining preference based utility measures such as EQ-5D to allow QALY calculation for comparability with other interventions.

Full Text: Available from National Library of Medicine in Health and Quality of Life Outcomes

Befriending carers of people with dementia: a cost utility analysis.


Abstract: OBJECTIVE: There is very little evidence on the cost-effectiveness of social care interventions for people with dementia or their carers. The BEfriending and Costs of Caring trial (BECCA, ISRCTN08130075) aimed to establish whether a structured befriending service improved the quality of life of carers of people with dementia, and at what cost.
METHODS: We performed an economic evaluation alongside a single blind, randomised controlled trial in a community setting of 236 carers of people with a primary progressive dementia. The intervention was contact with a Befriender Facilitator (BF), and offer of match with a trained lay volunteer befriender compared with no BF contact. Main outcome measures were health and social care, voluntary sector, and family care costs and quality adjusted life years (QALYs) in carers over 15 months.

RESULTS: Mean QALYs per carer over 15 months were 0.017 higher in the intervention group compared with control (95%CI: -0.051, 0.083). Mean costs from a societal perspective were £1,813 higher (-£11,312, £14,984). The point estimate Incremental Cost Effectiveness Ratio (ICER) is thus £105,954 per incremental QALY gained. Probabilistic sensitivity analysis suggests a 42.2% probability that the ICER is below 30,000 per QALY. Inclusion of dementia patient QALYs reduces the ICER to 28,848 (51.4% probability below 30,000).

CONCLUSIONS: Befriending leads to a non-significant trend towards improved carer quality of life, and there is a non-significant trend towards higher costs for all sectors. It is unlikely that befriending is a cost-effective intervention from the point of view of society.


Objectives: To determine whether a social support intervention (access to an employed befriending facilitator in addition to usual care) is effective compared with usual care alone. Also to document direct and indirect costs, and establish incremental cost-effectiveness.

Design: The Befriending and Costs of Caring (BECCA) trial was a cost-effectiveness randomised controlled trial. Data on well-being and resource use were collected through interviews with participants at baseline and at 6, 15 and 24 months.

Setting: This research was carried out in the English counties of Norfolk and Suffolk, and the London Borough of Havering. It was a community-based study. Participants: Participants were family carers who were cohabiting with, or providing at least 20 hours’ care per week for, a community-dwelling relative with a primary progressive dementia.

Interventions: The intervention was ‘access to a befriender facilitator’ (BF). BF, based with charitable/voluntary-sector organisations, were responsible for local befriending schemes, including recruitment, screening, training and ongoing support of befriending volunteers, and for matching carers with befrienders. The role of befrienders was to provide emotional support for carers. The target duration for befriending relationships was 6 months or more. Main outcome measures: Depression was measured by the Hospital Anxiety and Depression Scale (HADS) at 15 months postrandomisation. The health-related quality of life scale EQ-5D (EuroQol 5 Dimensions) was used to derive utilities for the calculation of quality-adjusted life-years (QALYs).

Results: A total of 236 carers were randomised into the trial (116 intervention; 120 control). At final follow-up, 190 carers (93 intervention; 97 control) were still involved in the trial (19% attrition). There was no evidence of effectiveness or cost-effectiveness from the primary analyses on the intention-to-treat population. The mean incremental cost per incremental QALY gained was in excess of £100,000, with only a 42.2% probability of being below £30,000 per QALY gained. Where care-recipient QALYs were included, mean incremental cost per incremental QALY gained was £26,848, with a 51.4% probability of being below £30,000 per QALY gained.
Only 60 carers (52%) took up the offer of being matched with a trained lay befriender, and of these only 37 (32%) were befriended for 6 months or more. A subgroup analysis of controls versus those befriended for 6 months or more found a reduction in HADS-depression scores that approached statistical significance (95% CI –0.09 to 2.84).

Conclusions: 'Access to a befriender facilitator' is neither an effective nor a cost-effective intervention in the support of carers of people with dementia, although there is a suggestion of cost-effectiveness for the care dyad (carer and care recipient). In common with many services for carers of people with dementia, uptake of befriending services was not high. However, the small number of carers who engaged with befrienders for 6 months or more reported a reduction in scores on HADS depression that approached statistical significance compared with controls (95% CI –0.09 to 2.84). While providing only weak evidence of any beneficial effect, further research into befriending interventions for carers is warranted.


Cost-effective quality service : dementia care support.
Clinical Governance Bulletin, 2000, vol./is. 1/1(9-10)
Winter, Jane

Abstract: The design of a service must include carers if their needs are to be met. Carers and users, where possible, should be involved in the matching of support workers to them. Continuity of support worker is necessary to build effective relationships with the carer, the user, and their family and friends. Supervision of the support worker should facilitate the development of this 'special relationship', which goes beyond normal boundaries. The provision of a flexible, person-centred service can help carers to continue caring for longer and delay institutionalisation. 2 refs. [Summary]
Randomised Studies

Does a family meetings intervention prevent depression and anxiety in family caregivers of dementia patients? A randomized trial.
PLoS ONE [Electronic Resource], 2012, vol./is. 7(1(e30936), 1932-6203;1932-
Joling KJ, van Marwijk HW, Smit F, van der Horst HE, Scheltens P, van de
Abstract:
BACKGROUND: Family caregivers of dementia patients are at increased risk of
developing depression or anxiety. A multi-component program designed to mobilize
support of family networks demonstrated effectiveness in decreasing depressive
symptoms in caregivers. However, the impact of an intervention consisting solely of
family meetings on depression and anxiety has not yet been evaluated. This study
examines the preventive effects of family meetings for primary caregivers of community-
dwelling dementia patients.
METHODS: A randomized multicenter trial was conducted among 192 primary
caregivers of community dwelling dementia patients. Caregivers did not meet the
diagnostic criteria for depressive or anxiety disorder at baseline. Participants were
randomized to the family meetings intervention (n=96) or usual care (n=96) condition.
The intervention consisted of two individual sessions and four family meetings
which occurred once every 2 to 3 months for a year. Outcome measures after 12
months were the incidence of a clinical depressive or anxiety disorder and change in
depressive and anxiety symptoms (primary outcomes), caregiver burden and quality of
life (secondary outcomes). Intention-to-treat as well as per protocol analyses were
performed.
RESULTS: A substantial number of caregivers (72/192) developed a depressive or
anxiety disorder within 12 months. The intervention was not superior to usual care either
in reducing the risk of disorder onset (adjusted IRR 0.98; 95% CI 0.69 to 1.38) or in
reducing depressive (randomization-by-time interaction coefficient=-1.40; 95% CI -3.91
to 1.10) or anxiety symptoms (randomization-by-time interaction coefficient=-0.55; 95%
CI -1.59 to 0.49). The intervention did not reduce caregiver burden or their health related
quality of life.
CONCLUSION: This study did not demonstrate preventive effects of family meetings on
the mental health of family caregivers. Further research should determine whether this
intervention might be more beneficial if provided in a more concentrated dose, when
applied for therapeutic purposes or targeted towards subgroups of caregivers.
l.pone.0030936&representation=PDF

Translation of a dementia caregiver support program in a health care system--
REACH VA.
Archives of Internal Medicine, February 2011, vol./is. 171/4(353-9), 0003-9926;1538-
Nichols LO, Martindale-Adams J, Burns R, Graney MJ, Zuber J
Abstract:
BACKGROUND: Based on the National Institute on Aging/National Institute of Nursing
Research Resources for Enhancing Alzheimer's Caregiver Health (REACH) randomized
controlled trial (REACH II), REACH VA (Department of Veterans Affairs) was the first
national clinical translation of a proven behavioral intervention for dementia caregivers,
running from September 2007 through August 2009. This article describes the
population and outcomes of the REACH VA translation of REACH II into the VA.
METHODS: Clinical staff members from 24 VA Medical Center Home-Based Primary Care programs in 15 states delivered the intervention to stressed caregivers of patients with dementia. Like REACH II, the 6-month REACH VA intervention, structured through a protocol and individualized through a risk assessment, targeted education, support, and skills training to address caregiving risk areas of safety, social support, problem behaviors, depression, and health through **12 individual in-home and telephone sessions and 5 telephone support group sessions**. Staff members of the Memphis VA Medical Center, Memphis, Tennessee, collected data on burden, depression, health and healthy behaviors, caregiving frustrations, social support, dementia-related behaviors, and time spent providing care and on duty.

RESULTS: From baseline to 6 months, caregivers reported significantly decreased burden, depression, impact of depression on daily life, caregiving frustrations, and number of troubling dementia-related behaviors. A 2-hour decrease in hours per day on duty approached significance. Caregivers (96%) believed that the program should be provided by the VA to caregivers.

CONCLUSIONS: This clinical translation achieved outcomes similar to the REACH II randomized controlled trial, providing clinically significant benefits for caregivers of a veteran with a progressive dementing disease. This model of caregiver support can inform public policy in providing assistance to caregivers.

**Full Text:**
Available from *Silverchair Information Systems* in *Archives of Internal Medicine*

**Telephone-delivered psychosocial intervention reduces burden in dementia caregivers.**
Dementia (14713012), 01 November 2008, vol./is. 7/4(503-520), 14713012
Tremont G, Davis JD, Bishop DS, Fortinsky RH

**Abstract:** The objective of this study was to examine the preliminary efficacy of Family Intervention: Telephone Tracking -- Dementia (FITT-D), a multi-component intervention that is delivered in 23 telephone contacts over 12 months. Thirty-three dementia caregivers were randomly assigned to receive either FITT-D (n = 16) or standard care (n = 17) using urn randomization to balance the groups on dementia severity, caregiver gender and relationship type (spouse versus other). Inclusion criteria included formal dementia diagnosis, caregiving for at least six months, residing with the care recipient, and providing at least four hours of direct supervision per day. Master's-level therapists contacted caregivers by telephone over 12 months. Each contact followed a standardized treatment manual, involving assessment and individualized application of interventions to address mood, family functioning, social support and health. Outcomes included Zarit Burden Interview, Revised Memory and Behavior Problem Checklist, and the Geriatric Depression Scale at baseline and 12 months (end of treatment). Caregivers receiving FITT-D exhibited significantly lower burden scores and less severe reactions to memory and behavior problems than caregivers in the standard care condition. Findings provide preliminary evidence for the efficacy of FITT-D, a potentially highly accessible, low-cost intervention for dementia caregivers.
Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease.
Social Science & Medicine, August 2006, vol./is. 63/4(957-67), 0277-Drentea P, Clay OJ, Roth DL, Mittelman MS
Abstract: Those who provide care at home for a spouse with Alzheimer's disease (AD) endure considerable challenges, including social isolation and increasing caregiving responsibilities. We examine the extent to which an intervention that helps spouse-caregivers mobilize their social support network, helps them better adapt to the caregiving role. We used detailed social support information collected from 200 spouse-caregivers participating in a randomized, controlled trial of enhanced social support services in the USA. Using random effects regression models, we found that individuals in the intervention group reported higher levels of satisfaction with their social support network over the first 5 years of the intervention than those in the support group. Higher levels of emotional support, more visits, and having more network members to whom they felt close were all individually predictive of longitudinal changes in social support network satisfaction. We conclude with a discussion of the importance of having psychological respite when caregivers spend their days in the home and are isolated.
Service Examples

Cambridge and Peterborough NHS Trust Dementia Carers’ Support Service
The Dementia Carers’ Support Service is an innovative new project that has the capacity to consistently support carers of people with dementia throughout the journey of their caring role.
This will be achieved by developing a robust pool of volunteer befrienders. They are likely to be ex-carers or others who have had an extensive hands-on experience of caring for people with dementia. They will be linked to current carers who will have had the opportunity to be supported by someone who understands the challenges that living with dementia presents. This has many benefits to the person with dementia and their carer and to the ex-carer who wishes to offer their time, knowledge and expertise to others.
http://www.cpft.nhs.uk/services/dementia-carers-support-service.htm

Dementia UK - Admiral Nurses
Admiral Nurses are available to support families throughout the dementia journey. They provide family carers with the tools and skills to best understand the condition, as well as emotional and psychological support through periods of transition.

They work with family carers in the following ways:
• They focus on the needs of the family carer, including psychological support to help family carers understand and deal with their feelings
• They help families better understand dementia and use a range of interventions that help people live well with the condition and develop skills to improve communication and maintain relationships
• They are an invaluable source of contact and support for families at particular points of difficulty in the dementia journey, including diagnosis, when the condition advances, or when tough decisions need to be made such as moving a loved one into residential care
• They provide advice on referrals to other appropriate services and liaise with other healthcare professionals on behalf of the family

Admiral Nurses also uniquely join up the different parts of the health and social care system and enable the needs of family carers and people with dementia to be addressed in a co-ordinated way. In addition, Admiral Nurses provide consultancy and education to professionals to model best practice and improve dementia care in a variety of care settings. Dementia UK works in partnership with NHS providers and commissioners, social care authorities and voluntary sector organisations to promote and develop new Admiral Nursing services. We’re responsible for upholding standards, sustaining service and supporting Admiral Nurses in practice.
http://www.dementiauk.org/what-we-do/admiral-nurses/
The following scheme are aimed at people with dementia but will presumably impact upon the wellbeing / burden of carers.

**Dementia Buddy Service**
Aimed at people with Dementia but role will presumably impact upon the wellbeing / burden of carers.
The **Dementia Buddy Service** is a pilot project, initially running for one year, to the end of June 2013. It is funded by Kent Adult Social Services and went live in August 2012.

Role of Dementia Buddy:
Ensure patients with dementia receive increased social interaction.
Escort patients with dementia to appointments within hospital grounds.
Engage in activities with patients with dementia to maintain cognitive capabilities.
Encourage and assist with food and drink.
Provide information and support to carers including signposting to support services.
Work in partnership with ward staff to ensure best outcomes for patients with dementia.
Keep basic records.

**One-to-one effective support.**
Journal of Dementia Care, 01 November 2009, vol./is. 17/6(8-9), 13518372
Beaumont H

**Abstract:** Helen Beaumont describes how The Clive Project, supporting younger people with dementia and their families, has developed over the last 11 years. 
Now known as Young Dementia UK, the one to one support offered here is to dementia sufferers.
www.youngdementiauk.org/downloads/YDUK%20generic%20leaflet%202012-09.pdf
9.5.7 Evidence summary
There is now extensive literature on interventions with family carers of people with dementia. A wide range of interventions has been developed and evaluated using an equally wide range of outcome domains and measures. This makes comparisons between studies difficult at times, both in terms of judging whether two intervention programmes share common features and in relation to the comparability of different outcomes.

The most recent meta-analysis (Brodaty et al., 2003d) included 30 controlled trials and concluded that the quality of studies had improved over the period searched (1985–2001). Although outcomes were variable, overall there appeared to be at least a small intervention effect. Interventions involving training or stress management or involving the person with dementia alongside the carer appeared to have the largest effect on the carer's psychological health and well-being.

Sorensen and colleagues (2002) report a larger meta-analysis, including studies where carers of people with dementia were not specifically targeted, although in all the studies the care recipients had an average age of 60 or over. The results from this analysis (considering RCTs only), suggested that psychological therapy (typically CBT) and psychoeducation programmes had the best outcome in relation to depression although effect sizes were still small), whereas multi-component interventions were associated with effects of medium size on carer burden and well-being. It is noteworthy that effect sizes were lower in studies where only carers of people with dementia had been included.

For this review, 25 new studies have been identified, meeting the criteria established for the Sorensen meta-analysis. Again, the results from these studies are mixed, with around a quarter not identifying a significant effect of the intervention being evaluated on relevant outcome variables; others had effects on some measures but not others.

Several of the recently reported studies form part of the REACH (Resources for Enhancing Alzheimer’s Caregiver Health) initiative in the USA, where six centres collaborated to use common measures and procedures, whilst evaluating interventions developed and implemented independently at each site. At a 6-month evaluation, active interventions, whatever the type, were superior to control conditions in relation to carer burden (Gitlin et al., 2003). Differences in treatment response were identified in relation to gender, ethnicity, education and relationship with the person with dementia. Gitlin and colleagues conclude that interventions should be ‘multi-component and tailored’.
It is clear that carer interventions can be effective in relation to psychological health, burden and well-being, although the relatively small effect sizes for some domains and the large variability between studies suggest that there is much to be learned regarding which interventions will be most helpful for which carers.

No one approach is sufficient to meet the range of needs, situations and preferences of carers. Multi-component interventions perhaps offer the best chance of success, in combining, say, psychoeducation, skills training and support groups, and there is increasing development of telephone and internet-based systems for provision of information and support, which may be a useful additional component.

The relative efficacy of psychological therapy, usually CBT, on symptoms of depression and anxiety is evident and is likely be most helpful when targeted at those care givers whose anxiety and depression levels are within, or close to, the clinical range.

The carer literature also gives encouraging indications that interventions with carers will often have a positive effect on the care recipient, in relation to the person’s behaviour or function, or the length of time remaining at home.

The qualitative review identified evidence that carers benefit from and/or value educational/information-giving interventions, support groups and helplines, all of which can be provided by voluntary sector organisations.

However, evidence suggests that providers of educational interventions for carers of people with dementia at an early stage after diagnosis should be aware of the possibility that education about dementia may sometimes have an adverse effect on a carer’s anxiety.

The qualitative review also identified evidence of particular needs relating to interventions for carers: interventions providing education and information for carers, including at the time of diagnosis, and addressing medication management; support groups where carers may learn from one another and which can provide education and information with support from local services; and educational and supportive interventions for black and minority ethnic carers that are culturally oriented.

Further evidence suggests that when designing educational and training interventions for carers it may be useful to take account of gender differences in approaches to caring.

9.6 RESEARCH RECOMMENDATIONS
9.6.1 Psychological interventions for carers of people with dementia
For carers of people with dementia, is a psychological intervention cost effective when compared with usual care?

Why this is important
Those providing care for people with dementia are one of the most vulnerable groups of carers and often have high levels of stress, feelings of guilt, depression and other psychological problems. They often ignore their own health needs in favour of those of the person for whom they care. They may become exhausted, have poor physical health and feel isolated.
Current research suggests that psychological interventions may be effective, but there is insufficient evidence to establish cost effectiveness.

Support for carers in general has been given priority in England and Wales through Carers’ Strategy documents. Further research is urgently needed to generate a better evidence base for the update of this guideline.

The effectiveness of support services for carers of people with dementia: a review of the literature

Summary
A literature review of support services for carers of people with dementia has been carried out. It identified few meta-analyses or randomised controlled trials, effectiveness or cost-effectiveness studies but large numbers of descriptive outcome studies of variable quality.

The methodological problems associated with the heterogeneity of carers and their situation, the nature of the interventions, and the difficulties in establishing comparative groups all militate against obtaining reliable evidence in this difficult area.

In consequence conclusions must be circumspect: respite and individual psychosocial interventions reduce caregiver distress moderately; the evidence that community-based services prevent institutionalisation is ambiguous; there is a paucity of health economic studies.

6.1 Which services do carers find most useful?
Respite interventions and individual psychosocial interventions are moderately effective compared with usual treatment or uncontrolled use of community services in reducing caregiver distress although group psychosocial interventions are not effective in the same comparison. In so far as there is a simple answer to the question posed by the brief, there is evidence that carers find most useful services which provide them with recognition of their role, emotional support, practical help in caring tasks, information and training, and respite time, both as a break from the 'unremitting grind' of caring and in order to maintain other areas of their life.

Assisting caregivers to support people with dementia
This Best Practice information sheet has been derived from a systematic review published in the International Journal of Evidence Based Healthcare 2008, 6: 137-172.

Recommendations:
Offer individualised programs for caregivers rather than group sessions.
Level of recommendation: Grade B Moderate support that warrants consideration of application
Related Research – Effectiveness of Peer and Social Support

Reports and Case Studies

**Think Local Act Personal**
Think Local Act Personal is a national, cross sector leadership partnership focused on driving forward work with personalisation, community-based social care. **The site hosts case studies relating to improving the support for carers. These are not directly relevant to this request but are included as a source of reference information.**

Supporting the transformation of support for carers
[www.thinklocalactpersonal.org.uk/Regions/EastMidlands/carers/](http://www.thinklocalactpersonal.org.uk/Regions/EastMidlands/carers/)

The needs of informal carers for people with dementia.
British Journal of Healthcare Management, 01 December 2012, vol./is. 18/12(628-635), Egdell, Valerie

New approaches to supporting carers’ health and well-being: evidence from the National Carers’ Strategy Demonstrator Sites programme
*CIRCLE (Centre for International Research on Care, Labour and Equalities) (2011)*
This report presents the findings of the national evaluation of the Department of Health’s Demonstrator Sites (DS) programme which aimed to improve carers’ health and well-being in line with the 2008 National Carer’s strategy for England. The report discusses the impact and effectiveness of 25 multi-agency projects which were set up to explore new ways of supporting carers in England and illustrates with examples. **New Approaches to Supporting Carers’ Health and Well-being: Final Report**

The effectiveness and cost effectiveness of support and services to informal carers of older people
*A review of the literature prepared for the Audit Commission, 2004*
Part 2: Review of individual services and their effects
Breaks from caring or respite care
Mixed respite care services: evidence from the US
Daycare services
In-home respite care
Institutional respite care
Carer support groups
Social work and counselling
The home help/care service
Multi-dimensional approaches
Guidelines for psychosocial interventions in dementia care: a European survey and comparison. Vassee E, Vernooij-Dassen M, Cantegreil I
International Journal of Geriatric Psychiatry, January 2012, vol./is. 27/1(40-8), 0885-90

Abstract:
OBJECTIVE: The effectiveness of psychosocial interventions in treating people with dementia and their carers is increasingly emphasised in the literature. Dementia guidelines should summarise the scientific evidence and best practice that is currently available, therefore, it should include recommendations for psychosocial interventions. The aims of our study were (1) to collate dementia guidelines from countries across Europe and to check whether they included sections about psychosocial interventions, and (2) to compare the methodological quality and the recommendations for specific psychosocial interventions in these guidelines.

METHODS: The European dementia guidelines were inventoried. The methodological quality of the guideline sections for psychosocial interventions was assessed with the (AGREE) Appraisal of Guidelines Research and Evaluation instrument. The recommendations for specific psychosocial interventions were extracted from each of these guidelines and compared.

RESULTS: Guidelines for psychosocial interventions were found in five of 12 countries. Guideline developers, methodological quality and appreciation of available evidence influenced the inclusion of psychosocial interventions in dementia guidelines from Germany, Italy, the Netherlands, Spain and the UK. The UK NICE SCIE guideline had the best methodological quality and included the most recommendations for psychosocial interventions. Physical activity and carer interventions were recommended the most across all guidelines.

CONCLUSION: The inclusion of psychosocial interventions in dementia guidelines is limited across Europe. High-quality guidelines that include psychosocial interventions and are kept up to date with the emerging evidence are needed. Throughout Europe, special attention to the implementation of evidence-based psychosocial care is needed in the next few years.

Personalised caregiver support: effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia.
International Journal of Geriatric Psychiatry, 2012, vol./is. 27/1(1-14), Van Mierlo LD

Abstract:
OBJECTIVE: Insight into the characteristics of caregivers for whom psychosocial interventions are effective is important for care practice. Until now no systematic reviews were conducted into the effectiveness of psychosocial interventions for caregiver subgroups.

METHODS: To gain insight into this relationship between caregiver subgroups and intervention outcomes, a first review study was done. This study reviews the personal characteristics of caregivers of people with dementia for whom psychosocial interventions were effective.

RESULTS: Electronic databases and key articles were searched for reviews on psychosocial interventions for caregivers studies published between January 1990 and February 2008. Based on these reviews, twenty-six studies met the inclusion criteria (i.e. having positive outcomes described in subgroups). Most positive effects were found in caregivers of people with a diagnosis of 'dementia not otherwise specified' and in the subgroup of female caregivers. Examples of outcomes were decreased depression and improved self-efficacy.

CONCLUSIONS: This study gives a first overview of successful psychosocial interventions in subgroups of caregivers of people with dementia. It makes clear that until now, relatively little research has been done into subgroups of these caregivers. It also suggests that more research is needed to better understand which psychosocial interventions are effective for specific subgroups of caregivers of people with dementia.
Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. Corbett A, Stevens J, Aarsland D
International Journal of Geriatric Psychiatry, June 2012, vol./is. 27/6(628-36), 0885-

Abstract:
BACKGROUND: Information is a key part of service provision to people with dementia and their carers, but there is no systematic review of the evidence. This study aimed to determine whether information services confer significant benefit for quality of life, neuropsychiatric symptoms and carer burden.

METHOD: A systematic review of intervention studies in people with dementia was carried out, focussing predominantly on the provision of information and/or advice.

RESULTS: Thirteen randomised controlled trials were identified. Two of the three studies measuring quality of life indicated benefit. Significant benefits were also evident for neuropsychiatric symptoms (points difference, -1.48; confidence interval, -2.11 to 0.86), but not carer burden. Most interventions included other key elements such as skills training, telephone support and direct help to navigate the medical and care system.

CONCLUSION: There is some support for the value of information services, but studies are needed to determine the specific elements that are effective.

Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. Lilly, Meredith B., Robinson, Carole A., Holtzman, Susan, Bortorff, Joan L.

Abstract: After more than a decade of concerted effort by policy-makers in Canada and elsewhere to encourage older adults to age at home, there is recognition that the ageing-in-place movement has had unintended negative consequences for family members who care for seniors. This paper outlines findings of a qualitative descriptive study to investigate the health and wellness and support needs of family caregivers to persons with dementia in the Canadian policy environment. Focus groups were conducted in 2010 with 23 caregivers and the health professionals who support them in three communities in the Southern Interior of British Columbia. Thematic analysis guided by the constant comparison technique revealed two overarching themes: (1) forgotten: abandoned to care alone and indefinitely captures the perceived consequences of caregivers' failed efforts to receive recognition and adequate services to support their care-giving and (2) unrealistic expectations for caregiver self-care relates to the burden of expectations for caregivers to look after themselves. Although understanding about the concepts of caregiver burden and burnout is now quite developed, the broader sociopolitical context giving rise to these negative consequences for caregivers to individuals with dementia has not improved. If anything, the Canadian homecare policy environment has placed caregivers in more desperate circumstances. A fundamental re-orientation towards caregivers and caregiver supports is necessary, beginning with viewing caregivers as a critical health human resource in a system that depends on their contributions in order to function. This re-orientation can create a space for providing caregivers with preventive supports, rather than resorting to costly patient care for caregivers who have reached the point of burnout and care recipients who have been institutionalised.

Full Text: Available from EBSCOhost in Health & Social Care in the Community
Development of support networks in informal dementia care: guided, organic, and chance routes through support. Egdell V
Canadian Journal on Aging, December 2012, vol./is. 31/4(445-55), 0714-
Abstract: Increasing knowledge about factors that shape the development of care networks for people with dementia is imperative in countries with aging populations that are relying increasingly on informal care. This study used a qualitative approach to identify the complex routes through support taken by informal caregivers for people with dementia in the development of their care networks. Interview data were collected from 13 caregivers. Three routes through support were identified: guided routes, organic routes, and chance routes. This article’s principal argument is that these routes are the outcomes not only of the resources that caregivers draw upon, but also of their varying expectations regarding the role of the informal caregiver. The identification of the three routes through support provides a potentially valuable framework for examining the experiences of caregivers for individuals with other long-term health conditions.

Caregiver support groups in patients with dementia: a meta-analysis.
Abstract:
OBJECTIVES: Meta-analysis studies of specific types of support groups are limited. We conducted a review and assessment of the effectiveness of support groups for caregivers of demented patients, and examined the impact of support group characteristics.
METHODS: A search of multiple, electronic databases including the Cochrane Library, Medline, PUBMED, and others was conducted; studies published between 1998 and 2009 were collected. Thirty quantitative journal articles that were true and quasi-experimental controlled trials on support groups for non-professional caregivers, including mutual support, psychoeducational, and educational groups were analyzed. Outcome indicators were psychological well-being, depression, burden, and social outcomes.
RESULTS: Support groups showed a significant positive effect on caregivers' psychological well-being (Hedge's g=-0.44, 95% CI=-0.73, -0.15), depression (Hedge's g=-0.40, 95% CI=-0.72, -0.08), burden (Hedge's g=-0.23, 95% CI=-0.33, -0.13), and social outcomes (Hedge's g=0.40, 95% CI=0.09, 0.71). The use of theoretical models, and length and intensity of group sessions had a significant impact on the effect sizes for psychological well-being and depression. Ratio of female participation (for psychological well-being and depression) and average age (social outcomes) were significant predictor variables.
CONCLUSIONS: Support groups benefit caregivers and findings of this meta-analysis serve as immediate guidance for group facilitators. Future research should include additional outcome variables with our defined factors on effectiveness collected as demographic characteristic data for comparison. A more comprehensive understanding of the effectiveness of support groups is indicated to enhance outcomes for caregivers and patients.
Effect of Educational and Supportive Strategies on the Ability of Caregivers of People With Dementia to Maintain Participation in That Role.
American Journal of Occupational Therapy, 01 September 2011, vol./is. 65/5(541-549), Thinnes, Andrea, Padilla, René

Abstract: A systematic review of evidence of the effectiveness of educational and supportive strategies for enabling caregivers of people with Alzheimer's disease (AD) or related dementias to maintain participation in that role was conducted as part of the American Occupational Therapy Association's Evidence-Based Literature Review Project. Forty-three articles met inclusion criteria. Results suggest that interventions that jointly engage people with AD and their caregivers in education and training in the home setting are more successful than strategies that focus solely on people with AD. Greater carryover is noted when education and training are implemented at the time that the caregiver identifies concerns. Interventions should provide caregivers with problem solving, technical skills, support, simple home modification strategies, and referral to community resources. Interventions mediated by technology have a positive effect on the caregiver and are especially important for those who live in rural areas.

Supporting the dementia family caregiver: the effect of home care intervention on general well-being.
Aging & Mental Health, January 2010, vol./is. 14/1(44-56), 1360-7863;1364-6915 (2010 Schoenmakers B, Buntinx F, DeLepeleire J

Abstract: OBJECTIVES: Although high volumes of literature have been written on interventions in dementia home care, only a poor efficiency has been proved. Nevertheless, caregivers often express strong feelings of satisfaction about the proposed support. In this meta-analytic review, a quantitative analysis of the effect of the different types of professional dementia home care interventions was made. METHOD: A systematic literature search, covering the years 1980 until 2007, was performed using Medline, Embase, Cochrane DSR, Dare, CCTR, and ACP Journal Club). Limitations on publication type were determined as randomized controlled trial and controlled trial. RESULTS: Psychosocial intervention in dementia home care was found to be beneficial in a non-significant way on caregivers' burden. An almost negligible decrease in depression was found in the psychosocial intervention arm while multidisciplinary case management contributed to a larger though insignificant decrease of depression in caregivers. Respite care was responsible for an increase in burden. CONCLUSION: This review demonstrated, in accordance with other qualitative reviews, the weak evidence that supporting family caregivers could be beneficial. Although the rather small benefits of formal support, supporting family caregivers is an indispensable issue in dementia home care. Professional caregivers should keep in mind that family caregivers highly appreciate the intervention and that they feel less burdened or depressed in the short time follow up but that premature home care remains more rule than exception.

Full Text: Available from EBSCOhost in Aging & Mental Health
Support/services among family caregivers of persons with dementia--perceived importance and services received.
International Journal of Geriatric Psychiatry, March 2010, vol./is. 25/3(240-8), Alwin J, Oberg B, Krevers B
Abstract:
OBJECTIVE: The aim of this study was to examine what family caregivers of persons with dementia perceive as important types of support/services in relation to experienced negative impact (NI) due to the caregiver situation, and to investigate if caregivers receive the support/services perceived as important.
METHOD: The study was based on the Swedish part of the EUROFAMCARE project and included 110 caregivers of persons with dementia. Data were collected primarily through structured telephone interviews. The caregivers were divided into two groups, a higher NI group and a lower NI group, based on the NI scale from the COPE index.
RESULTS: Getting information and having someone to talk to were perceived as very important types of support/services by the highest proportion of caregivers in both groups. Data indicated only one significant difference; a higher proportion of caregivers in the higher NI group reported being able to participate in activities outside of caring as very important. There was also an indication that a higher proportion of caregivers in the lower NI group perceived information about the disease as very important.
Support/services perceived as important by the caregivers were received both to a high and a low degree.
CONCLUSION: The results from this study suggest that there is almost no difference between groups of caregivers experiencing higher and lower NI regarding their perception of what are important types of support/services. The caregivers rated different types of support/services within the areas of information, relief and counselling as very important.

The influence of service factors on spousal caregivers' perceptions of community services.
Journal of Gerontological Social Work, 01 May 2009, vol./is. 52/4(406-422), 01634372 Sussman T
Abstract: The literature clearly denotes that spouses differ from other family members in their reactions to caregiving, their patterns of service use and their assessment of specific services. Yet, despite their prevalence as caregivers, little is known about their unique perceptions of community services and the factors that impact their experiences with the service system. The purpose of this study was to explore the relative influence of (a) spouses' personal factors (e.g., gender, family support) and (b) service factors (e.g., one-on-one professional support), on spousal caregivers' perceptions of community services. The study employed a survey design with a sample of 73 spousal caregivers caring for their partners with dementia at home. This study found that spousal caregivers have more negative perceptions of the service system when their in-home workers are not informed about their spouses' likes, dislikes and routines. This service factor was the most significant predictor of caregivers' service perceptions. The study further found that most spousal caregivers receive fewer than five consultations from a non-medical professional over a one year period. While spouses longed for more professional support, this service factor was not uniquely associated with service related stress. The policy and practice implications of these findings are discussed.
The influence of community-based services on the burden of spouses caring for their partners with dementia.
Health & Social Work, 01 February 2009, vol./is. 34/1(29-39), 03607283
Sussman T, Regehr C

Abstract: Despite the vast literature on caregiver stress, few studies have explored how community services affect the stress process for spousal caregivers. The current study explores the differential effects of emotional and tangible support provided by family and friends and by formal services, and caregivers' perceptions of community services on spousal caregivers' burden. The study used a survey design with a sample of 85 spousal caregivers caring for their partners with dementia in the community. The study found that in-home services, as they are currently offered, do little to reduce the burden of spouses caring for their partners with dementia. Rather the most effective service is the provision of adult day programs, which provide not only respite for the spousal caregiver, but also opportunities for social interaction for their partners with dementia. This study further found that spousal caregivers experience a relatively high level of service-related stress. However, when examined alongside care recipient behavioral challenges and frequency of day program use, caregivers' perceptions of and experiences with the service system did not uniquely explain their burden. Implications of the findings for policy, research, and practice are discussed.

Full Text: Available from EBSCOhost in Health & Social Work

(Cost)-effectiveness of family meetings on indicated prevention of anxiety and depressive symptoms and disorders of primary family caregivers of patients with dementia: design of a randomized controlled trial.
BMC Geriatrics, 2008, vol./is. 8/(2), 1471-2318;1471-2318 (2008)
Joling KJ, van Hout HP, Scheltens P, Vernooij-Dassen M, van den Berg B,
Abstract: BACKGROUND: Dementia is a major public health problem with enormous costs to society and major consequences for both patients and their relatives. Family members of persons with dementia provide much of the care for older adults with dementia in the community. Caring for a demented relative is not easy and fraught with emotional strain, distress, and physical exhaustion. Family caregivers of dementia patients have an extremely high risk developing affective disorders such as major depression and anxiety disorder. Family meetings appear to be among the most powerful psychosocial interventions to reduce depression in caregivers. An American landmark study reported substantial beneficial effects of a multifaceted intervention where family meetings had a central place on depression in family caregivers as well as on delay of institutionalization of patients. These effects were not replicated in other countries yet. We perform the first trial comparing only structured family meetings with significant others versus usual care among primary family caregivers of community dwelling demented patients and measure the effectiveness on both depression and anxiety in the primary caregiver, both on disorder and symptom levels.METHODS/DESIGN: In this randomized controlled trial effectiveness as well as cost-effectiveness of family meetings is evaluated. The intervention group receives four family meetings with family and close friends of the primary family caregiver of a community dwelling patient with a clinical diagnosis of dementia. Dyads of patients and their primary caregiver are followed up to one year after baseline assessment.
The main outcome measures are the incidence of anxiety and depressive disorders assessed with the Mini-International Neuropsychiatric Interview (MINI) and the severity of anxiety and depressive symptoms in caregivers is measured by validated self report instruments: the Centre for Epidemiologic Studies Depression Scale (CES-D) for depression and the anxiety scales of the Hospital Anxiety and Depression scales (HADS) for anxiety. The economic evaluation is performed from a societal perspective.

**DISCUSSION:** By evaluating the effectiveness of only structured family meetings organized in the Netherlands, this study will contribute to the existing literature about the value of psychosocial interventions for dementia caregivers.

**TRIAL REGISTRATION:** Dutch Trial

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**Understanding the outcomes of a psycho-educational group intervention for caregivers of persons with dementia living at home: a process evaluation.**

Aging & Mental Health, 01 January 2005, vol./is. 9/1(25-34), 13607863

Lavoie J, Ducharme F, Lévesque L, Hébert R, Vézina J, Gendron C, Préville M, St-

**Abstract:** This qualitative process evaluation study aimed to identify the primary processes of a psycho-educational group for caregivers of persons with dementia, in order to better understand intervention outcomes. Semi-structured interviews were conducted with 30 participants recruited from the experimental group of a randomised controlled trial. At pre-test, participants reported their expectations of the group. At post-test, they described their group experience, the most/least helpful aspects of the intervention, their most useful learning and their responses during a recent episode of disturbing behaviour by their relative. Results showed that the group delivered both educational and support processes. Support processes complemented educational processes. Participants learned coping strategies, with reframing playing a more important role than problem-solving or seeking social support. Daughters benefited more than spouses from educational processes. This study of group processes contributes to our understanding of the reported reduction in frequency of disturbing behaviours and of the change in caregivers’ behaviours.

**Full Text:** Available from EBSCOhost in Aging & Mental Health

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**Who participates in psychosocial interventions for caregivers of patients with dementia?**

Wettstein A, Schmid R, Konig M

Dementia & Geriatric Cognitive Disorders, 2004, vol./is. 18/1(80-6), 1420-8008;1420-

**Abstract:**

**OBJECTIVE:** The purpose of the present study is to evaluate if the participants in psychosocial interventions for dementia caregivers are representative of the whole population of dementia patients or if some socioeconomic groups are over- or underrepresented.

**DESIGN:** The demographic and socioeconomic characteristics of the 128 participants of a randomized controlled study on the effects of caregiver education were compared with those of all the elderly residents of the City of Zurich (n = 64,856, elderly group), of all demented patients entering a City of Zurich nursing home in a 6-month period (n = 218, NH entry group) and of all demented inhabitants evaluated during a 20-month follow-up at a community memory clinic (n = 187, memory group).

**METHODS:** Data on income and wealth were derived from official tax records. The characteristics of the different groups were compared by chi² or t tests.

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RESULTS: As expected in a study on caregiver education, the demented patients were younger, more often male and married than all other study groups (p < 0.01). The participants in the psychosocial intervention had significantly (p < 0.01) higher education than all other groups; this effect is caused in part by the higher proportion of males. The NH entry group was less well educated than the elderly group (p < 0.05). The intervention group had a higher income and was wealthier than the three other groups (p < 0.01), but there was no significant difference with respect to the wealth of the memory group. The 25% poorest of the elderly group made up only about 10% of the participants in the intervention group. However, the 25% richest of the elderly group made up 42% of the intervention group. The method of recruitment for the psychosocial intervention (by media, referral of physicians and by a memory clinic) was not significantly related to any of the demographic or socioeconomic parameters.

CONCLUSION: The lower socioeconomic strata are clearly underrepresented in psychosocial interventions.

Seeking support: caregiver strategies for interacting with health personnel.
Canadian Journal of Nursing Research, December 2003, vol./is. 35/4(38-56), 0844-Heinrich M, Neufeld A, Harrison MJ

Abstract: Support from health professionals can assist family caregivers and have a positive impact on their health. The purpose of this study was to explore women's perceptions of support from community resources while caring for a family member with dementia. The research questions were: What factors influence female caregivers' interactions with health personnel when seeking support? What strategies do women employ in interactions with health personnel to secure support? Symbolic interaction was the theoretical foundation for the study, which included secondary analysis of 62 interviews with 20 women concerning their caregiving experience. In addition, new data were collected from 2 focus groups with 8 volunteers recruited from among the original 20 participants. The data indicated that the women's expectations of their caregiving role and their appraisal of the care recipient influenced their interactions with health personnel when seeking support. They employed 4 broad strategies: collaborating, getting along, twigging, and fighting/struggling. A woman's use of strategies varied according to the degree of mutuality in decision-making with staff and was accompanied by both positive and negative experiences. These findings confirm the importance of mutuality in relationships with health personnel and support the use of partnership and empowerment models of professional practice.

Scoping the field: services for carers of people with mental health problems.
Health & Social Care in the Community, July 2003, vol./is. 11/4(335-44), 0966-Arksey H

Abstract: Mental ill health is very common. Most people with mental health problems live in the community, and as many as 1.5 million people in the UK may be involved in caring for a relative or friend with a mental illness or some form of dementia. Recent legislation and policy initiatives such as the National Strategy for Carers, and the National Service Frameworks for Mental Health and Older People emphasise the importance of providing support for this particular group of carers. The present paper reports the findings of a scoping study to identify what the research tells us about the effectiveness and cost-effectiveness of interventions for the carers of people with mental health problems, and also where there are gaps in the knowledge base. Some 204 evaluation studies were included in the review, just 13 of which had an economic component. The majority of studies were conducted in the USA, and were aimed at carers of people with Alzheimer disease or other forms of dementia.
Overall, there was a lack of strong evidence to support any specific interventions, although almost all studies were able to identify some positive outcomes of services provided. In contrast to the relatively narrow approach to effectiveness adopted in most of the studies reviewed, the contributors to a consultation exercise perceived this concept in a far more rounded and holistic way. For them, the process of service delivery was as important as the outcome. There was relatively little research evaluating interventions and services singled out in UK policy initiatives as potentially useful in supporting this group of carers, and further evaluation studies are needed.

Full Text: Available from EBSCOhost in Health & Social Care in the Community

Friends and social support in dementia caregiving. Assessment and intervention. Journal of Gerontological Nursing, January 2003, vol./is. 29/1(29-36), 0098-9134;0098-
Lilly ML, Richards BS, Buckwalter KC

Abstract: The purpose of this article is to explore the topic of friends as a spontaneously occurring response in open-ended interviews with dementia caregivers and to propose guidelines for assessment and intervention based on current knowledge. The sample includes 176 open-ended baseline interviews with dementia caregivers drawn from the National Caregivers Training Study, a 4-year multi-site, randomized, community-based, psycho-educational intervention study. References to friends were present in 60 of the 176 baseline transcripts. More than 50% of the references were positive, 63% referred to the present, 80% of the content scores were greater than 1, and 66% were categorized as emotional support or social integration for caregivers. Meaningful categories exist and can be helpful in structuring the assessment of support from friends. Data support prior research suggesting that friends are providers and facilitators of emotional support and social integration. Although further research is needed on the concept of social support in general and social network providers in particular (e.g., friends), current knowledge allows for preliminary recommendations for assessment and intervention of friends and social support.

Full Text: Available from EBSCOhost in Journal of Gerontological Nursing

Psychosocial interventions for caregivers of people with dementia: a systematic review.
Aging & Mental Health, May 2001, vol./is. 5/2(120-35), 1360-7863;1360-7863
Cooke DD, McNally L, Mulligan KT, Harrison MJ, Newman SP

Abstract: The content of interventions for caregivers of dementia patients is highly varied. None of the reviews conducted to date have focused on evaluating the effects of the content of interventions exclusively for dementia caregivers, and this issue is not well understood. The purpose of this review was to first identify the type of components (e.g. education, counselling) that have been utilized in psychosocial/psycho-educational interventions for dementia caregivers, and to evaluate the success of the different components or combination of components in producing positive outcomes for dementia caregivers. Forty studies were included in the review. Approximately two-thirds of the interventions did not show improvements in any outcome measures. Among those studies, which did demonstrate improvements, the inclusion of social components (e.g. social support) or a combination of social and cognitive (e.g. problem solving) components seemed to be relatively effective. It is important to note, however, that these analyses were based on small numbers and the review was limited by a number of methodological issues (e.g. poor description of interventions). To advance our understanding of the efficacy of psychosocial interventions for caregivers of people with dementia, a more systematic approach is required. Intervention components need to be carefully contrasted in appropriately designed studies of sufficient size.