

Best Evidence Summaries of Topics in Mental Healthcare

BEST *in* **MH** *clinical question-answering service*

Question

“In adults with a diagnosis of dementia, how effective are post-diagnostic support groups (involving carers where possible), compared to no group support, in improving coping skills, independence, maintaining close relationships and delaying a need for extra care?”

Clarification of question using PICO structure

Patients: Adults with a diagnosis of dementia.

Intervention: Post-diagnostic support groups.

Comparator: No support group.

Outcome: Improved coping skills and independence, maintained close relationships, delayed need for extra care.

Clinical and research implications

There was some evidence from two trials that post-diagnostic support groups for people with Alzheimer’s disease and their caregivers, or their caregivers alone, improved self-efficacy, family communication and reduced the need for nursing home placement. Neither trial measured all the specified outcomes.

Both trials were performed in the USA so may not be generalisable to the UK setting. Further research using high-quality randomised controlled trials is needed in the UK. These should measure outcomes in the participant with Alzheimer’s disease directly using outcomes measuring improved coping skills and independence, maintaining close relationships and the need for extra care.

What does the evidence say?

Number of included studies/reviews (number of participants)

Two RCTs were included, both of people with dementia and their caregivers and both were conducted in the USA. One trial included 142 participant-caregiver pairs and evaluated an early-stage memory loss support group programme provided to both the participant and their caregiver (Logsdon (1)). The other trial was specifically of people with dementia and their spouse caregivers (n=206) and evaluated a support intervention given to the caregiver that included individual and group counselling and attending a support group (Mittelman (2))

Main Findings

One trial found that an early-stage memory loss support group intervention significantly improved family communication ($p<0.05$) compared to the waiting list control (1). They also found a significant improvement in participant health-related quality of life measured using an Alzheimer disease specific tool. Those participants with improved quality of life also had significantly improved family communication ($p<0.05$) and self-efficacy ($p<0.01$) compared to those with no improvement in quality of life.

The other trial (2) found that the caregiver intervention significantly reduced the number of nursing home placements within one year (11 placements from the intervention group and 24 from the control group, $p<0.05$). They also performed statistical modelling to identify factors which were predictive of nursing home placement. Older participants; those with younger caregivers; those on lower incomes and those who needed help with activities of daily living were more likely to enter a home. However, those with a caregiver who joined a support group were less likely to be placed in a nursing home.

Authors Conclusions

People with early-stage memory loss who participated in a nine-session support group showed significantly better quality of life and decreased depressive symptoms compared with a waiting list control (1). More research is needed into the types of services and service provision models for these diverse communities.

The other trial concluded that providing counselling and support to the spouses of people with Alzheimer's disease was effective in reducing the need to place their partners in nursing homes (2). Further analyses of the results after two years will enable better understanding of the mechanisms underlying the success of the intervention, and also its effects on caregiver well-being.

Reliability of conclusions/Strength of evidence

Both trials were considered to be at high risk of bias as some important methodological details were not reported. One didn't report the methods used for randomisation or allocation concealment (2), the other did report some details of the randomisation method but it was not clear if it was really random (1). Neither trial reported if the investigators, participants or outcome assessors were blinded to the treatment group but given the nature of the interventions, control groups and types

of outcome blinding was unlikely. However both trials were low risk for attrition bias as it appears that all participants were included in the analyses.

There were only two trials providing evidence for this question, both conducted in the USA, and neither fully addressed the question. Only one provided the intervention to both those with dementia and their caregivers, the other provided it to the caregivers only. One used a waiting list control; the other was treatment as usual although support was available if the caregiver requested it. One trial measured improved coping skills and independence (self-efficacy) and family communication. The other measured admission to a nursing home, which is a measure of the delayed need for extra care.

What do guidelines say?

NICE guidelines (2006, updated 2012, CG42) do not specifically discuss *post-diagnostic* support groups but they do mention the following;

(Page 24)

“The experience of the diagnosis of dementia is challenging both for people with dementia and family members and for healthcare professionals, so healthcare professionals should make time available to discuss the diagnosis and its implications with the person with dementia and also with family members (usually only with the consent of the person with dementia). Healthcare professionals should be aware that people with dementia and family members may need ongoing support to cope with the difficulties presented by the diagnosis.”

“Following a diagnosis of dementia, health and social care professionals should, unless the person with dementia clearly indicates to the contrary, provide them and their family with written information about:

- the signs and symptoms of dementia
- the course and prognosis of the condition
- treatments
- local care and support services
- support groups
- sources of financial and legal advice, and advocacy
- medico-legal issues, including driving
- local information sources, including libraries and voluntary organisations.”

(Page 39)

“Care plans for carers of people with dementia should involve a range of tailored interventions. These may consist of multiple components including:

- individual or group psycho-education
- peer-support groups with other carers, tailored to the needs of individuals depending on the stage of dementia of the person being cared for and other characteristics
- support and information by telephone and through the internet

- training courses about dementia, services and benefits, and communication and problem solving in the care of people with dementia
- involvement of other family members as well as the primary carer in family meetings.”

“Consideration should be given to involving people with dementia in psycho-education, support, and other meetings for carers. Health and social care professionals should ensure that support, such as transport or short-break services, is provided for carers to enable them to participate in interventions.”

The evidence found in the two trials is consistent with the guideline recommendations.

Date question received: 20/08/2013

Date searches conducted: 21/08/2013

Date answer completed:

REFERENCES

RCTs

1. Laakkonen, M., Holtta, E.H., Savikko, N., Strandburg, T.E., Suominen, M. and Pitkala, K.H. (2012). Psychosocial group intervention to enhance self-management skills of people with dementia and their caregivers-a randomized controlled trial. *European Geriatric Medicine* 3 pp. S28-S29.
2. Logsdon, R., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L. and Teri, L. (2010) Early-Stage Memory Loss Support Groups: Outcomes from a Randomized Controlled Clinical Trial. *Journal of Gerontology: Psychological Science* 65B (6) pp. 691-697.
3. Mittelman, S., et al. (1993). An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. *The Gerontologist* 33(6) pp. 730-740.

Guidelines

4. National Institute for Health and Care Excellence (2006, updated 2012) Dementia. Supporting people with dementia and their carers in health and social care. CG42. London: National Institute for Health and Care Excellence.
<http://www.nice.org.uk/nicemedia/live/10998/30318/30318.pdf>

Results

RCTs

Author (year)	Inclusion criteria	Number of participants	Summary of results	Risk of bias
Laakkonen et al (2012)	<p><i>Participants</i> Recruited from memory clinics in Helsinki, must live at home with spouse and have received a dementia diagnosis according to Finnish national guidelines.</p> <p><i>Intervention</i> Groups based on a psychosocial group rehabilitation model and on self-management supporting principles. Groups of 10 participants met once a week for eight weeks, these meetings lasted for four hours and included lunch and taxi transportation. They included topics of dementia, prevention of further cognitive decline, active lifestyle, emotional well-being, spousal relationships, future planning and community services. Lasted two and a half months.</p> <p><i>Comparator</i> Treatment as usual.</p> <p><i>Outcomes</i> The primary outcome measures are changes in patients' Health Related Quality of Life (HRQoL) was assessed by 15D and in spousal caregivers', HRQoL was assessed by RAND-36. Sense of</p>	N = 160 dyads; intervention n= 80, control n=80).	Not available yet, this trial is still ongoing and the publication is the trial protocol.	

	<p>competence was assessed by SCQ. Secondary outcome measures are patients' time spent at home and changes in patients' depression (Cornell). Feelings of acceptance and helplessness were assessed using subscales of the Illness Cognition Questionnaire and cognition (verbal fluency, the clock drawing test (CDT)). Secondary outcome measures for caregivers are psychological well-being, this was assessed by 12-GHQ and personal coping resources by the Pearlin Mastery Scale and also changes in depression will be measured by CES-D.</p>			
Logsdon et al. (2010)	<p><i>Participants</i> Recruited via referrals from the Alzheimer's Association Western and Central Washington state Chapter (AAW). Persons were eligible to participate if they</p> <ul style="list-style-type: none"> a) had a diagnosis of dementia confirmed by the individual's primary care physician b) had a Mini-Mental State Examination (MMSE) score of 18 or higher, c) were aware of their memory loss and able to communicate verbally, d) were able to participate independently in a group setting (without their family members present), e) had no significant history of severe mental illness that would impede their ability to take part in support group 	<p>N= 142 dyads, ESML (n =96), waiting list control (n=46).</p>	<p>The mean participant age was 77.1 years, 52% were male, 69% lived with a spouse or partner and 21% of participants lived alone.</p> <p>The trial outcomes relevant to this research question were communication and interpersonal relationships, and self-efficacy. ESML participants had significant improvements in family communication ($p<0.05$) compared to the waiting list control.</p> <p>The primary outcome was overall quality of life measured using an Alzheimer disease specific tool. ESML participants had significantly improved quality of life compared to the waiting list control. The ESML participants with improved quality of life also had significant improvements in family communication ($p<0.05$) and self-efficacy ($p<0.01$) compared with</p>	<p>High</p> <p>Some randomisation methods were reported but they and the method of allocation concealment were unclear. The nature of the intervention and control meant blinding was not possible. Only 4% of participants were lost to follow-up and ITT</p>

	<p>activities, and</p> <p>f) Both the person with dementia and a family care partner (husband, wife, or other adult family member) agreed to participate in the evaluation.</p> <p><i>Intervention</i></p> <p>The early stage memory loss (ESML) support group condition is a structured support group program that follows a written manual that has been revised and updated regularly by AAW staff to ensure continued accuracy and regional applicability. ESML sessions averaged 90 min in duration and met weekly for 9 weeks. Each session included both individuals with early-stage dementia and a family care partner, who met together for part of the session and separately for part of the session.</p> <p><i>Comparator</i></p> <p>Waiting list control.</p> <p><i>Outcomes</i></p> <p>Overall quality of life (The Quality of Life-Alzheimer's disease), Health-related quality of life (The Medical Outcome Study short form), mood (The Geriatric Depression Scale), Communication and interpersonal relationships (the Family Assessment Measure), stress (The Perceived Stress Scale), self-efficacy (The</p>		<p>non-improvers.</p>	<p>analyses were performed, so the risk of attrition bias was low.</p> <p>The analysis results for some outcomes were missing meaning there could be some selective reporting.</p>
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	Self-Efficacy Scale), memory-related behaviour problems, (The Revised Memory and Behavior Problem Checklist).			
Mittelman et al. (1993)	<p><i>Participants</i> Eligibility criteria for the study were:</p> <ul style="list-style-type: none"> a) the patient had a clinical diagnosis of Alzheimer's dementia (AD) b) the primary caregiver was the spouse of the patient, c) the patient was residing at home with the spouse-caregiver, d) the patient or the spouse had at least one close relative living in the New York City metropolitan area. <p>Caregivers were not eligible if they had already received formal counselling or were participating in a support group.</p> <p><i>Intervention</i> A comprehensive intervention that was designed to maximize the support provided to patients and carers. They agreed to participate in individual and family counselling sessions and to join and regularly attend an AD caregiver support group. They and their families could request additional help, advice or counselling at any time. Education was a key element of all components of the intervention.</p> <p><i>Comparator</i> Treatment as usual.</p>	<p>N = 206 caregiver-patient pairs; Intervention n= 103, Control group n= 103.</p>	<p>Around half of the dementia patients were aged between 70 and 79 years and 68% had moderately severe to severe impairment. More of the caregivers were female (58.3%) and 72% were aged between 60 and 79 years.</p> <p>The primary outcome was the decision to place the dementia patient in a nursing home. The caregiver intervention significantly reduced the number of nursing home placements within one year (11 placements from the intervention group and 24 from the control group, $p < 0.05$). Logistic regression modelling was performed to identify factors which were predictive of nursing home placement. Older patients; those with younger caregivers; and those on lower incomes were all more likely to be placed in a nursing home. Patients who needed more help with activities of daily living were more likely to enter a home but those with a caregiver who joined a support group were less likely to be placed in a nursing home.</p>	<p>High</p> <p>No details were given about randomisation or allocation concealment methods.</p> <p>The nature of the intervention and control meant blinding was not possible.</p> <p>All patients appear to be in the analysis making the risk of attrition bias low.</p> <p>A number of measures were used but it was not clear if these were outcomes or not. These results were not reported in full so selective outcome reporting was unclear.</p>

	<p><i>Outcomes</i></p> <p>Caregiver well-being (Caregiver Questionnaire, developed for this study), Caregiver mental health (Short Psychiatric Evaluation Scale and Geriatric Depression Scale), caregiver burden (Burden Interview), caregiver reaction to troublesome behaviours (Memory and Behaviour Problems Checklist) and caregiver social network (Stokes Social Network Scale), global severity of dementia (The Global Deterioration Scale), physical health of demented patient (questionnaire adapted from OARS, Duke University 1978).</p>			
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Risk of Bias: RCTs

Study	RISK OF BIAS					
	Random allocation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective Reporting
Logsdon et al (2010)	?	?	☹️	☹️	😊	☹️
Mittelman et al (1993)	?	?	☹️	☹️	😊	?



Low Risk



High Risk



Unclear Risk

Search Details

Source	Search Strategy	Number of hits	Relevant evidence identified
SRs and Guidelines			
NICE	Dementia AND support groups	166	1
DARE	(dement*) IN DARE 479 Delete 2 MeSH DESCRIPTOR Alzheimer Disease EXPLODE ALL TREES 262 Delete 3 MeSH DESCRIPTOR Dementia EXPLODE ALL TREES 499 Delete 4 MeSH DESCRIPTOR Dementia, Multi-Infarct EXPLODE ALL TREES 0 Delete 5 MeSH DESCRIPTOR Dementia, Vascular EXPLODE ALL TREES 16 Delete 6 MeSH DESCRIPTOR Frontotemporal Dementia EXPLODE ALL TREES 1 Delete 7 MeSH DESCRIPTOR Lewy Body Disease EXPLODE ALL TREES 2 Delete 8 (psycho-social* OR psychosocial*) IN DARE 640 Delete 9 (psycho-education* OR psychoeducation*) IN DARE 169 Delete	70	0

	10 (support* adj3 group*) IN DARE 159 Delete 11 (peer* adj3 group*) IN DARE 44 Delete 12 (cope OR coping) IN DARE 267 Delete 13 (carer* adj3 support*) IN DARE 6 Delete 14 (after* adj3 care*) IN DARE 42 Delete 15 (support*):TI IN DARE 323 Delete 16 (alzheimer*) IN DARE 300 Delete 17 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #16 793 Delete 18 #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 1344 Delete 19 #17 AND #18		
Primary studies			
CENTRAL	#1 dementia or alzheimer:ti,ab,kw (Word variations have been searched) 7104 #2 MeSH descriptor: [Dementia] explode all trees 3427 #3 MeSH descriptor: [Alzheimer Disease] explode all trees 1993 #4Enter terms for searc"support group"608 #5Enter terms for searc"psychoeducation group"26 #6Enter terms for searc"group therapy"1201 #7Enter terms for searc#1 or #2 or #37274 #8Enter terms for searc#4 or #5 or #61766 #9Enter terms for searc#7 and #857	42	
PsycINFO	1. PsycINFO; exp DEMENTIA/; 48935 results. 2. PsycINFO; exp ALZHEIMER'S DISEASE/; 29528 results. 3. PsycINFO; (alzheimer* OR dementia).ti,ab; 61066 results. 4. PsycINFO; 1 OR 2 OR 3; 63241 results. 5. PsycINFO; GROUP PSYCHOTHERAPY/; 16438 results. 6. PsycINFO; PSYCHOEDUCATION/; 3010 results. 7. PsycINFO; SUPPORT GROUPS/; 3390 results. 8. PsycINFO; GROUP COUNSELING/; 4614 results. 9. PsycINFO; GROUP INTERVENTION/; 832 results. 10. PsycINFO; group*.ti,ab; 621434 results.	65	

	11. PsycINFO; 6 AND 10; 1511 results. 12. PsycINFO; "group therapy".ti,ab; 9152 results. 13. PsycINFO; "group support".ti,ab; 693 results. 14. PsycINFO; 5 OR 7 OR 8 OR 9 OR 11 OR 12 OR 13; 28989 results. 15. PsycINFO; CLINICAL TRIALS/; 6930 results. 16. PsycINFO; random*.ti,ab; 121242 results. 18. PsycINFO; (doubl* adj3 blind*).ti,ab; 17524 results. 19. PsycINFO; (singl* adj3 blind*).ti,ab; 1518 results. 20. PsycINFO; EXPERIMENTAL DESIGN/; 8721 results. 21. PsycINFO; controlled.ti,ab; 75560 results. 22. PsycINFO; (clinical adj3 study).ti,ab; 7466 results. 23. PsycINFO; trial.ti,ab; 63832 results. 24. PsycINFO; "treatment outcome clinical trial".md; 24519 results. 25. PsycINFO; 15 OR 16 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24; 234020 results. 26. PsycINFO; 4 AND 14 AND 25; 65 results.		
Embase	27. EMBASE; exp DEMENTIA/; 213991 results. 28. EMBASE; exp ALZHEIMER'S DISEASE/; 117179 results. 29. EMBASE; (alzheimer* OR dementia).ti,ab; 162924 results. 30. EMBASE; 27 OR 28 OR 29; 240173 results. 31. EMBASE; GROUP THERAPY/; 15833 results. 32. EMBASE; PSYCHOEDUCATION/; 3094 results. 33. EMBASE; SUPPORT GROUP/; 6630 results. 34. EMBASE; (education* adj2 group*).ti,ab; 4524 results. 35. EMBASE; (psychoeducation* adj2 group*).ti,ab; 533 results. 36. EMBASE; "support group".ti,ab; 3129 results. 37. EMBASE; "group therapy".ti,ab; 4251 results. 38. EMBASE; GROUP DYNAMICS/; 3242 results. 39. EMBASE; 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38; 35078 results. 40. EMBASE; 30 AND 39; 1041 results.	174	

	41. EMBASE; random*.tw; 837612 results. 42. EMBASE; factorial*.tw; 21524 results. 43. EMBASE; placebo*.tw; 193823 results. 44. EMBASE; (crossover* OR cross-over*).tw; 67374 results. 45. EMBASE; (doubl* adj3 blind*).tw; 139719 results. 46. EMBASE; (singl* adj3 blind*).tw; 15990 results. 47. EMBASE; assign*.tw; 229503 results. 48. EMBASE; allocat*.tw; 78816 results. 49. EMBASE; volunteer*.tw; 171874 results. 50. EMBASE; CROSSOVER PROCEDURE/; 38161 results. 51. EMBASE; DOUBLE-BLIND PROCEDURE/; 117135 results. 52. EMBASE; SINGLE-BLIND PROCEDURE/; 18108 results. 53. EMBASE; RANDOMIZED CONTROLLED TRIAL/; 354294 results. 54. EMBASE; 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53; 1357907 results. 55. EMBASE; 40 AND 54; 174 results.		
Medline	56. MEDLINE; exp DEMENTIA/; 120268 results. 58. MEDLINE; (alzheimer* OR dementia).ti,ab; 132348 results. 59. MEDLINE; ALZHEIMER DISEASE/; 67900 results. 60. MEDLINE; 56 OR 58 OR 59; 165547 results. 61. MEDLINE; GROUP THERAPY/; 11815 results. 63. MEDLINE; SUPPORT GROUP/; 7796 results. 64. MEDLINE; PSYCHOTHERAPY, GROUP/; 11815 results. 65. MEDLINE; GROUP PROCESSES/; 11466 results. 66. MEDLINE; (education* adj2 group*).ti,ab; 3713 results. 67. MEDLINE; (psychoeducation* adj2 group*).ti,ab; 365 results. 68. MEDLINE; "support group".ti,ab; 2406 results. 69. MEDLINE; "group therapy".ti,ab; 3320 results. 70. MEDLINE; 61 OR 63 OR 64 OR 65 OR 66 OR 67 OR 68 OR 69; 35618 results. 71. MEDLINE; 60 AND 70; 644 results.	121	

	72. MEDLINE; "randomized controlled trial".pt; 382612 results. 73. MEDLINE; "controlled clinical trial".pt; 88896 results. 74. MEDLINE; placebo.ab; 160455 results. 75. MEDLINE; random*.ab; 703670 results. 76. MEDLINE; trial.ti; 128707 results. 77. MEDLINE; CLINICAL TRIALS AS TOPIC/; 173663 results. 78. MEDLINE; 72 OR 73 OR 74 OR 75 OR 76 OR 77; 1084064 results. 79. MEDLINE; exp ANIMALS/ NOT HUMANS/; 4018305 results. 80. MEDLINE; 78 NOT 79; 992226 results. 81. MEDLINE; 71 AND 80; 121 results.		
Summary	NA	NA	

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