SUPPLEMENTARY MATERIAL 1: SEARCH STRATEGIES

MEDLINE

1. Caregivers/

2. exp Family/

3. (caregiver* or care giver* or carer*).tw.

4. (support person* or wife or wives or husband* or next of kin* or significant other* or couple or dyad* or partner* or spouse*).tw.

5. 1 or 2 or 3 or 4

6. exp Pulmonary Disease, Chronic Obstructive/

7. exp emphysema/

8. (chronic obstructive pulmonary disease or copd or pulmonary emphysema or obstructive lung disease*).tw.

9. 6 or 7 or 8

10. 5 and 9

11. limit 10 to (english language and humans and yr="2000 -Current")

12. limit 11 to (case reports or clinical conference or comment or editorial or letter)

13. 11 not 12

EMBASE

1. exp caregiver/ or caregiver*.hw.

2. spouse/

3. (caregiver* or care giver* or carer* or support person* or wife or wives or husband* or next of kin* or significant other* or couple or dyad* or partner* or spouse*).tw.

4. family Health/ or family coping/

5. 1 or 2 or 3 or 4

6. chronic obstructive lung disease/

7. exp emphysema/

8. (chronic obstructive pulmonary disease or copd or pulmonary emphysema or obstructive lung disease*).tw.

9. 6 or 7 or 8

10. 5 and 9

11. limit 10 to (human and english language and yr="2000 -Current")

12. limit 11 to (book or book series or conference abstract or conference paper or conference proceeding or "conference review" or editorial or letter or note or short survey or trade journal)

13. 11 not 12

PSYCINFO

1. caregivers/ or caregiver burden/

2. exp Family/

3. exp spouses/ or significant others/

4. (caregiver* or care giver* or carer* or support person* or wife or wives or husband* or next of kin* or significant other* or couple or dyad* or partner* or spouse*).tw.

5. 1 or 2 or 3 or 4

6. exp chronic obstructive pulmonary disease/

7. (chronic obstructive pulmonary disease or copd or pulmonary emphysema or obstructive lung disease*).tw.

8. 6 or 7

9. 5 and 8

10. limit 9 to (human and english language and yr="2000 -Current")

11. limit 10 to "0200 book"

12. limit 11 to (abstract collection or bibliography or chapter or "column/opinion" or "comment/reply" or dissertation or editorial or encyclopedia entry or "erratum/correction" or letter or obituary or poetry or publication information or reprint)

13. 11 or 12

14. 10 not 13

COCHRANE

ID	Search Hits
#1	MeSH descriptor: [Caregivers] this term only 1071
#2	MeSH descriptor: [Family] explode all trees 5077
#3	(caregiver* or care giver*):ti,ab,kw 2999
#4	(support person or "next of kin" or significant other):ti,ab,kw 40724
#5	(dyad* or partner* or spouse* or wife or wives or husband*):ti,ab,kw 4187
#6	#1 or #2 or #3 or #4 or #5 50769
#7	MeSH descriptor: [Pulmonary Disease, Chronic Obstructive] explode all trees 2349
#8	MeSH descriptor: [Emphysema] explode all trees 97
#9	("chronic obstructive pulmonary disease" or copd or pulmonary emphysema or "obstructive lung disease"):ti,ab,kw 8585
#10	#7 or #8 or #9 8828
#11	MeSH descriptor: [Emotions] explode all trees 10658
#12	MeSH descriptor: [Anxiety] this term only 4490
#13	MeSH descriptor: [Catastrophization] this term only 19
#14	MeSH descriptor: [Mental Disorders] explode all trees 40997

#15 MeSH descriptor: [Depression] this term only 4922

#16 MeSH descriptor: [Depressive Disorder] explode all trees 7069

#17 depression:ti,ab,kw 29185

#18 MeSH descriptor: [Mood Disorders] this term only 409

#19 ("quality of life" or unmet need*):ti,ab,kw 27385

#20 MeSH descriptor: [Quality of Life] this term only 13581

#21 MeSH descriptor: [Social Support] this term only 2164

#22 MeSH descriptor: [Social Adjustment] this term only 793

#23 MeSH descriptor: [Social Isolation] this term only 126

#24 (social adjustment or social support or social isolation):ti,ab,kw 6335

#25 ((psycho* or physical or emotional) near/3 (wellbeing or well being or well-being or burden or distress)):ti,ab,kw 2679

#26 MeSH descriptor: [Self Care] this term only 2458

#27 MeSH descriptor: [Patient Education as Topic] this term only 6065

#28 MeSH descriptor: [Patient Advocacy] this term only 59

#29 (self-management or self management or self care or self-care or education* or advoca*):ti,ab,kw 36853

#30 #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 116830

#31 #6 and #10 and #30 161

#32 #6 and #10 455

SUPPLEMENTRY FILE 2. Study characteristics of included interventions

Reference Country Design	**Sample** N; Age; Gender; Diagnosis	**Eligibility** Inclusion criteria; Exclusion criteria	**Intervention**	**Outcome measures** **Follow-up time points**	**Findings**
Hospital at home interventions					
Aimonino Ricauda et al., 2008 Italy RCT	**N**=104 **Age:** I: M=80.1, SD=3.2; C: M=79.2, C=3.1. **% Male:** I: 56%, C: 75%. **Diagnosis:** COPD.	**Inclusion:** Aged≥75 years; admitted to the ED of the hospital with acute exacerbation of COPD and requiring acute hospitalization; appropriate care supervision in the home; telephone connection; living in the hospital at home geographic area. **Exclusion:** Absence of family and social support; severe hypoxemia; severe acidosis or alkalosis; suspected pulmonary embolism; suspected myocardial infarction; severe comorbid illness.	**I:** N=52. Geriatric home hospitalisation service, incorporating: i) multidimensional geriatric assessment at home; ii) patient and caregiver education about the disease, smoking cessation, nutrition, management of activities of daily living, medications, health management, early recognition of symptoms of exacerbation. Physicians and nurses made daily visits to patients for the first few days of the intervention, then only nurse visited every day and physician visited every 2-3 days. **C:** N=52. Admitted to general medical ward and provided with routine hospital care.	**Outcome measures:** Hospital readmissions; mortality; depression (Geriatric Depression Scale); functional status (Katz activities of daily living, Lawton instrumental activities of daily living); cognitive status (Mini-Mental State Examination), QoL (Nottingham Health Profile); nutritional status (Mini Nutritional Assessment); caregiver stress (Relatives' Stress Scale); satisfaction (ad-hoc questionnaire). **Follow-up:** 6 months after discharge.	• I patients showed lower rates of hospitalization than C (43% vs 87%, p=.001). Readmission rate per patient was lower for I (0.4 ± 0.6) than C (1.1 ±1.2; p<.001). • No difference between groups in proportion of patients admitted with COPD as main reason (I: 82%; C:85%). • No difference between groups in mortality. • I showed greater improvements in depression and quality of life scores from pre-post test relative to C (p<.01, p=.04, respectively). • No difference in functional, cognitive, nutritional or caregiver stress outcomes. • No difference in satisfaction at discharge. •
Ojoo et al. 2002 UK CCT	**N**=60 **Age:** I: M=69.7; C: M=70.1 **% Male:** I: 53; C: 50.	**Inclusion:** ≥18 years; FEV1/FVC ratio < 70%; FEV reversibility to salbutamol < 15%; worsening of symptoms with any combination of increased sputum purulence and/or	**I:** N=30. Hospital at home care. Patients sent home within 48 hours of admission with a discharge package that included bronchodilators, steroids, antibiotics and oxygen as required. Respiratory outreach nurses monitored patients daily and provided	**Outcome measures:** Satisfaction with care; spirometry; symptoms; readmission rate; mortality. **Follow-up:** Satisfaction assessment 2 weeks after	• Patients in I group significantly more likely than patients in C group to prefer hospital at home care (p=.001, p=.01, respectively). • Satisfaction with care high in both I (92%) and C (88%)

Reference Country Design	**Sample** N; Age; Gender; Diagnosis	**Eligibility** Inclusion criteria; Exclusion criteria	**Intervention**	**Outcome measures** **Follow-up time points**	**Findings**
	Diagnosis: COPD	volume, and worsening dyspnoea. **Exclusion:** Concomitant medical conditions requiring admission; residence >15 miles from hospital; complications arising from exacerbation; type 2 respiratory failure; discretionary exclusion on social grounds based on domiciliary support and performance status of patient.	patient and caregiver education and reassurance. **C:** N=30. Conventional inpatient care.	discharge; spirometry, symptoms assessed daily.	groups, however difference between groups not significant. • No difference between groups on any outcome measure.
• ***Discharge coordinator interventions***					
Abad-Corpa et al., 2013 Spain CCT	**N**: 143 **Age:** I: M=71.6, SD=8.4, C: M=73.5, SD=7.8. **% Male:** I: 89.3%, C: 92% **Diagnosis:** COPD.	**Inclusion:** Intact cognitive capacity; telephone access; residence in area serviced by participating hospitals. **Exclusion:** Residence in geriatric home or nursing home or plans for the patient to go to one of these homes after discharge; participation on discharge in a home hospitalisation program; hospital stay of <2 days or >30 days; clinical evolution likely to be fatal in 6 months.	**I:** N=56. Visits by trained nurses every 24 hours during hospitalisation for 5 days. Involved identifying caregiver; educating patient and caregiver about the disease; identifying any problems or needs arising during hospitalisation or any needs that the patient/family anticipated on arrival at home; and putting the patient, caregiver and the health care team in contact with other professionals where required. At discharge, a nursing report and healthcare plan were carried out. Patient contacted during first 24 hours, and visited within first 72 hours of discharge to record any needs or problems during this time.	**Outcome measures:** Social situation (Gijon scale); medication compliance (Morinsky-Green test); state of health (Apache II severity index, Red Cross physical incapacity scale, Katz's fragility index); use of healthcare services; readmission rate; level of knowledge of the therapeutic regime; QoL (SGRQ); satisfaction with care (Monica-Oberst Patient Satisfaction test).	• I showed greater magnitude of improvement in QoL compared to C from admission to 12 week (p=.008) and 24 week follow up (p=.028) • I showed greater improvement in level of knowledge of therapeutic regime than C at 2 weeks (p<.001) and 24 weeks (p=.003) follow up. • No significant difference between I and C in readmission rates or use of healthcare services.

Reference Country Design	**Sample** N; Age; Gender; Diagnosis	**Eligibility** Inclusion criteria; Exclusion criteria	**Intervention**	**Outcome measures** **Follow-up time points**	**Findings**
			C: N=87. Standard healthcare plan of each hospitalisation unit was followed.	**Follow-up:** Patients contacted by telephone at 2, 6, 12 and 24 weeks post-discharge.	• No difference in medication compliance or satisfaction at follow up between I and C.
Egan et al., 2002 Australia RCT	**N**=66 **Age:** I: M=67.2, C: M=687.8 **% Male:** I: 36; C: 60 **Diagnosis:** History of chronic bronchitis (with infection), emphysema, chronic airway obstruction, chronic asthma or a combination of these	**Inclusion:** Aged >18 years; FEV_1 on admission to determine severity of disease; adequate cognitive function; admission to respiratory unit bed within 72 hours of hospital admission. **Exclusion:** None.	**I:** N=33. Case manager (CM) carried out comprehensive nursing assessment to identify physical, psychological, social, spiritual and resource needs. CM facilitated ongoing communication between patient, caregiver and healthcare professionals; provided education to patient and caregiver on managing medications, rehabilitation and utilising community services; and conducted a case conference as part of discharge planning. After discharge the CM provided ongoing support and provided referral to community services. Follow up care was provided at 1 and 6 weeks post-discharge. **C:** N=33. Received standard nursing assessment and standard clinical path, with no involvement of CM.	**Outcome measures:** *Quantitative*: QoL (SGRQ); social support (The MOS Social Support Survey); depression and anxiety (HADS); well-being (The Subjective Well-Being Scale); comorbidities; unscheduled hospital readmissions. *Qualitative:* Patients and caregivers asked about satisfaction with care. **Follow-up**: 1 month and 3 months post-discharge.	• No differences between groups from baseline to 1 month apart, from a reduction in Affectionate Support from baseline to 1 month for I participants relative to C (median change -6.7 vs 0, p=.034). • No differences between 1 and 3 month follow up except for lower Activity (SGRQ) for C relative to I (-6.4 vs 0, p<.01). • No significant difference between groups regarding unscheduled hospital readmissions I patients described improved communication with healthcare professionals and improved access to resources as being beneficial.
Lainscak et al. 2013 Slovenia RCT	**N**=253 **Age**: I: M=71, SD=9; C: M=71, SD=9. **% Male:** I: 69; C: 75.	**Inclusion:** Admitted with acute exacerbation of COPD corresponding to GOLD stage II to IV. **Exclusion:** Unstable or terminal stage of disease other than COPD; unable to	**I:** N=118. Discharge coordinator intervention. Coordinator actively involved patient and caregiver in discharge planning process, which was also communicated to and discussed with community care staff, general practitioner, social workers, physiotherapists and other home service providers to enhance continuity and coordination of care across different	**Outcome measures:** hospitalization rates (verified by medical records); survival status; health-related QoL (SGRQ). **Follow-up:** Phone contact at 30 and 90 days or direct	• Significantly fewer I patients (14%) hospitalized compared to C patients (31%, p=.002). • I patients (31%) showed significantly lower all-cause hospitalization than C patients (44%, p=.033).

Reference Country Design	**Sample** N; Age; Gender; Diagnosis	**Eligibility** Inclusion criteria; Exclusion criteria	**Intervention**	**Outcome measures** **Follow-up time points**	**Findings**
	Diagnosis: COPD	deal with telephone contact when out of hospital; death or withdrawal from study prior to discharge.	providers. Patients contact by phone 48 hours after discharge, with additional calls made according to patient needs. Discharge coordinator communication with care providers was continued as appropriate. **C:** N=135. Care as usual, including patient education about COPD, supervised inhaler use, physiotherapy if required, and disease-related communication between medical staff with patients and their caregivers.	patient contact at 7-10 days and 180 days (only 180 days follow-up data reported).	• No difference between groups in mortality, days alive and out of hospital, or health-related QoL • Multivariate analysis also showed that I was associated with lower risk of COPD and all-cause hospitalization (p=.002, p=.039, respectively), but not mortality.
• ***Self-management interventions***					
Boxall et al. 2005 Australia RCT	**N**=46 **Age:** I: M=77.6, SD=7.6; C= 75.8, SD=8.1 **% Male:** I: 48; C: 65 **Diagnosis:** COPD	**Inclusion**: diagnosed with COPD by 1 of 4 hospital respiratory specialists; aged ≥60 years; dyspnea on exertion; reside locally; no symptom exacerbation in previous 2 weeks; motivated to exercise daily unsupervised; functionally housebound. **Exclusion:** Attending outpatient-based pulmonary rehabilitation; restricted shoulder movement; living in nursing home; lung volume reduction surgery; pain limiting mobility.	**I:** N=23. Consisted of i) graduated walking and arm exercises, with an exercise diary used to monitor progress; ii) physiotherapy visits (weekly, then fortnightly) to monitor progress, conduct assessments and provide encouragement; iii) education sessions for patients and carers, covering lung physiology, use of respiratory devices and medications, controlled breathing techniques, removal of secretions, energy conservation, use of aids and stress management. The number of visits was determined by patient skill acquisition. **C:** N=23. Usual medical care.	**Outcome measures:** Functional exercise capacity (6-minute walk test); QoL (SGRQ); symptomatology (Borg scale of perceived breathlessness; spirometry); activities of daily living (Barthel Activities of Daily Living Index; Instrumental Activities of Daily Living Index); mental status (Short Portable Mental Status Questionnaire); hospital admission rate; average length of stay. **Follow-up:** 12 weeks after start of program.	• Significantly greater improvement in functional exercise capacity for I vs C (24% vs 3%, p=.023) • Total SGRQ scores and 'impacts on QoL' subscore improved significantly more for I vs C (-6% vs -1%,p=.02). No difference between groups on activity or symptom sub-scores. • Significant decrease in breathlessness found for I vs C (-4% vs 6%, p=.024). • No difference between groups in number of patients admitted or average length of stay at 12 weeks. However at 6 months I showed significantly reduced length of stay compared to C (6 vs 9, p=.035).

Reference Country Design	**Sample** N; Age; Gender; Diagnosis	**Eligibility** Inclusion criteria; Exclusion criteria	**Intervention**	**Outcome measures** **Follow-up time points**	**Findings**
Jonsdottir et al. 2015 CCT Iceland	**N**=119 **Age**: I: M=59, SD=5; C: M=59, SD=4. **% Male:** I: 40; C: 52. **Diagnosis:** COPD	**Inclusion:** Aged 45-65; mild or moderate COPD (grade II and III) as the primary disease. No criteria were set for family members. **Exclusion:** Had another major disease; non-Icelandic speaking; not capable of travelling to the treatment site; had participated in a structured rehabilitation programme for people with COPD in the 6 months prior.	**I:** N=60. Consisted of: (1) Three to four 30-45 minute semi-structured conversations with a clinical nurse specialist in respiratory nursing. Patient/family had same nurse. (2) Smoking cessation treatment. Consisted of at least one face to face conversation with a clinical nurse specialist in smoking cessation followed by ≥3 conversations face to face or by telephone. (3) A group meeting consisting of educational presentations, provision of written material, presentation by a volunteer with COPD and group discussions. **C:** N=59. Usual care, which traditionally consisted of services provided by general practitioners at primary health care centres and visits to lung physicians based on referral from general practitioners or self-initiated appointments.	**Outcome measures:** QoL (SGRQ); Illness Intrusiveness Scale; Anxiety and depression (HADS); physical activity (International Physical Activity Questionnaire-Short Version); smoking status (validated point prevalence abstinence); self-reported exacerbations; satisfaction with participation. **Follow-up:** Baseline and 12 months follow, up with additional data collection 6 months following the last treatment session for I group only.	• No difference between I and C groups on total QoL score or on sub-scales. • No difference between I and C groups on the total score or subscale scores of HADS. • No difference between I and C groups on self-reported physical exercise on total score of IPAQ and the subscales 'moderate' and 'walking'. However there was a significantly higher score on the subscale 'vigorous' in the I group. • No difference between I and C on 'self-reported exacerbations' the previous 6 months • No difference between I and C on smoking status
Marques et al., 2015 Portugal RCT	**N**= 42 dyads **Age**: *Patients*: I: M=68.8, SD=7.3; C: M=65.9, SD=13.4. *Family members:* I: M=65, SD=10.5; C: M=55.1, SD=12.4.	**Inclusion:** diagnosed with COPD according to GOLD criteria; had a family member ≥18 years old who provided physical and/or supportive care without payment; able to provide informed consent.	**I:** N= 22 dyads. 12 weeks of pulmonary rehabilitation comprised of exercise training (3 sessions per week of 60 minutes duration each) and psychosocial support and education (weekly sessions of 90 minutes each). Family members participated in the psychosocial support and education component with patients.	**Outcome measures:** Family coping (F-COPES); psychosocial adjustment (PAIS-SR); exercise tolerance (6 minute walk test); functional balance (timed Up and Go test) muscle strength (knee extensors strength of	• Significant difference between I and C in family coping. Patients in I group reported the use of more strategies for acquiring social support, and were more likely to acquire and accept help. Family members in I group reported the use of more strategies for acquiring social

Reference Country Design	**Sample** N; Age; Gender; Diagnosis	**Eligibility** Inclusion criteria; Exclusion criteria	**Intervention**	**Outcome measures** **Follow-up time points**	**Findings**
	% Male: *Patients*: I: 81.8; C: 50. *Family members*: I: 23; C: 35. **Diagnosis:** COPD	**Exclusion:** exacerbation or hospital admissions 1 month prior to study; severe neurologic or musculoskeletal conditions or unstable cardiovascular disease. Dyads excluded if either person had a psychiatric condition; were unable to understand and cooperate; or if one party refused participation.	**C:** N= 20 dyads. Conventional pulmonary rehabilitation. Patients underwent 12 weeks of pulmonary rehabilitation comprised of exercise training (3 sessions per week of 60 minutes duration each) and psychosocial support and education (weekly sessions of 90 minutes each). Family members did not attend the sessions with the patient except to complete assessment data.	dominant limb); health related QoL(SGRQ). **Follow-up:** 3 days before and after the pulmonary rehabilitation program.	support, and were more likely to use coping strategies of reframing, seeking spiritual support and mobilizing to acquire and accept help. • No difference between I and C groups in psychosocial adjustment, exercise tolerance, functional balance, knee extensors strength and QoL.
Monninkhof et al. 2003 Netherlands CCT	**N**=248 **Age:** I: M=65, SD=7; C: M=65, SD=7. **% Male:** I: 85; C: 84. **Diagnosis:** stable COPD	**Inclusion:** clinical diagnosis of COPD; no history of asthma; no exacerbation in previous month; current or former smoker; aged 40-75 years; baseline FEV1 25-80% predicted; pre bronchodilator ratio FEV1/inspiratory vital capacity ≤ 60%; reversibility of FEV1 post inhalation; Total lung capacity > total lung capacity pred (1.64xSD); no maintenance treatment of oral steroids or antibiotics; no medical condition with low survival or serious psychiatric morbidity; absence of any other active lung disease.	**I:** N=127. Self-management education course and fitness programme. Patients were given a self-treatment action plan and a booklet with information on the disease and the education course. The education course was conducted across four weekly sessions and a final session 3 months later. Patient and caregiver were invited to attend. Sessions addressed the nature of the disease, coping with breathlessness, exercise, relaxation and energy conservation, communication and relationships. The fitness program was run over 2 years, consisting of 1-2 1-hour training sessions per week, which included strength training, breathing and cardiovascular exercises. Exercises were tailored to individuals' capabilities. **C:** N=121. Usual care from chest physician only.	**Outcome measures:** QoL (SGRQ); functional exercise capacity (six-minute walk test) COPD symptoms and general well-being (self-report); self-confidence regarding COPD (single item scale at 1 year follow-up) **Follow-up:** 6 months and 1 year.	• No difference in health-related QoL between groups over follow-up time points. • No difference in functional exercise capacity between groups at 1 year follow up. • Marginally significant reduction in two symptoms (cough and sputum colour) for I vs C (95% CI -0.3-0.1, -0.03-0.02, respectively). • No significant difference between groups in well-being scores. • No significant difference between groups in self-confidence, although trend in favour of I group.

Reference Country Design	**Sample** N; Age; Gender; Diagnosis	**Eligibility** Inclusion criteria; Exclusion criteria	**Intervention**	**Outcome measures** **Follow-up time points**	**Findings**
		Exclusion: None.			