

**Chronic Obstructive Pulmonary Disease: Management of adults with
Chronic Obstructive Pulmonary Disease in Primary and Secondary
Care**

**Managing Stable COPD
Palliative Care
Index**

| Author | Publication Date | ID |
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| Heffner, J. E., Fahy, B., Hilling, L., & Barbieri, C. 1996, "Attitudes regarding advance directives among patients in pulmonary rehabilitation", <i>Am J Respir Crit Care Med</i> , vol. 154, no. 6 Pt 1, pp. 1735-1740. | 1996 | 1717 |
| Sullivan, K. E., Hebert, P. C., Logan, J., O'Connor, A. M., & McNeely, P. D. 1996, "What do physicians tell patients with end-stage COPD about intubation and mechanical ventilation?[comment]", <i>Chest.</i> , vol. 109, no. 1, pp. 258-264. | 1996 | 1528 |
| Rhodes, P. 1999, "Focus on palliative care. Palliative care: the situation of people with chronic respiratory disease", <i>British Journal of Community Nursing</i> , vol. 4, no. 3, pp. 131-136. | 1999 | 1545 |
| Elkington, H., White, P., Higgs, R., & Pettinari, C. J. 2001, "GPs' views of discussions of prognosis in severe COPD", <i>Family Practice</i> , vol. 18, no. 4, pp. 440-444. | 2001 | 117 |
| Jennings AL, Davies AN, Higgins JPT, Broadley K. Opioids for the palliation of breathlessness in terminal illness. (Cochrane Review). <i>The Cochrane Library. Oxford: Update Software 2003; Issue 3.</i> Date of most recent substantive amendment: 26.04.2001 | 2003 | 1716 |
| Jennings, A. L., Davies, A. N., Higgins, J. P. T., Gibbs, J. s. R., Broadley, K. E. (2002). A systematic review of the use of opioids in the management of dyspnoea. <i>Thorax</i> , 57, 939-944. | 2002 | 19377 |

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| Author / Title / Reference / Yr | Heffner, J. E., Fahy, B., Hilling, L., & Barbieri, C. 1996, "Attitudes regarding advance directives among patients in pulmonary rehabilitation", <i>Am J Respir Crit Care Med</i> , vol. 154, no. 6 Pt 1, pp. 1735-1740. Ref ID: 1717 |
| N= | N=105. Geographic location=USA Sites=One site in Arizona and one site in California. |
| Research Design / Tool | Cross sectional descriptive questionnaire |
| Aim | To assess the knowledge, attitudes and opinions of patients with chronic lung conditions about end-of-life decision-making |
| Population | Outpatient adults (older than 18 years) enrolled in two pulmonary rehabilitation programs |
| Characteristics | Average age 68 years Gender M/F 56/49 Lung conditions, number (%) – COPD 91 (87%), Asthma 8 (7%), Pulmonary fibrosis 3 (3%), Post lung resection 2 (2%), healed TB 1 (1%) FEV1 % predicted 40.5 Home O2 use 34 (32%). |
| Results | <p>Subject Interest in Advance Directives 95% had heard of living wills from various sources 42% had completed a living will. 89% stated that they would be interested in learning more about Advanced Directives (AD) 69% wished to learn more explicit details about intubation and mechanical ventilation.</p> <p>Patient-doctor Discussions about End of Life Issues 99% stated that they would find discussions with physicians about ADs acceptable. 22% said that they would find these discussions anxiety provoking but worthwhile. 0.9% stated that these discussions would be too anxiety provoking to pursue. 99% favoured physician discussions about intubation and mechanical ventilation. 19% said that they would find these discussions anxiety provoking but worthwhile 0.9% stated that they would be too anxiety provoking to pursue. Despite their stated interests, only 19% had already had physician discussions about AD and 15% had had discussions about life support interventions. 51% believed that physicians should initiate discussion about ADs. The remaining 49% stated that physicians should wait until patients initiate these discussions. The data showed however, that waiting for physician initiation was an ineffective strategy; of the 20 patients who already had discussions about ADs with their physicians, 19 had initiated these discussions themselves, and in only one instance had the physician initiated the discussion. 79% responded that physicians should initiate discussion about mechanical ventilation. Of the 16 patients who already had had such discussion, 12 had initiated the discussions themselves despite the fact that 15 preferred that physicians initiate the discussion. 14% of subjects reported believing that their physicians understood their wishes about life support</p> |

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| | 68% preferred that discussions about ADs and life support issues occur in the outpatient setting. Subjects Interest in Decision making Most subjects wished to actively participate in decisions about life support. In the circumstance of being hospitalised with a serious illness, 72% stated that they would want to decide themselves about life support. Under the possible circumstance of having lost decision making capacity 49% stated that they themselves would want to decide about life support through their explicit AD documents. 38% stated that they would want their surrogate appointed through an AD document to decide, 9% would want a family member to decide and 4% would want the physician to make these decisions. |
| SIGN Quality Rating | CASP + |
| Hierarchy of Evidence Grading | 111 |
| NCC CC ID | 1717 |

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| Author / Title / Reference / Yr | Sullivan, K. E., Hebert, P. C., Logan, J., O'Connor, A. M., & McNeely, P. D. 1996, "What do physicians tell patients with end-stage COPD about intubation and mechanical ventilation?[comment]", <i>Chest.</i> , vol. 109, no. 1, pp. 258-264. Ref ID: 1528 |
| N= | N=15 respirologists. Location=Ottawa. Sites=All major hospitals in Ottawa. Ten academic and five community based respirologists from seven hospitals. |
| Research Design | Design = Qualitative research, qualitative research methodology not stated (although authors state, "Data management was facilitated through the use of a computer program (Ethnograph)." Data collection: 1. Semi structured interviews, N=15 questions. 2. 1 x Hypothetical question "Imagine that I am an "x" year old woman suffering from chronic COPD in a worsening state for several years. I'd like you to run through a hypothetical visit in which you would alert me to the possible complications of my condition, including those things we already discussed for the first time". Data analysis: Tape-recorded and transcribed verbatim. |
| Aim | The purpose of the study was to examine physicians' perceptions of the decision-making process in relation to intubation and mechanical ventilation (MV) to sustain life in patients with end-stage COPD. |
| Operational Definition | N/A |
| Population | N=15 respirologists |
| Method | Respirologists were interviewed to elicit information regarding intubation and MV and the exchange of information between patients and physicians. Two researchers coded transcripts independently and emergent themes generated. An auditor experienced in qualitative research examined the process of the study and the outcomes. |
| Characteristics | 79% of respirologists in the region were interviewed. Interviews lasted approximately 1 hour. |

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| | <p>14/15 male Years of experience ranged from 4 to 37 with ad median of 12 yrs. Participants estimated the number of COPD pts they would see in a week ranging from 1 to 50.</p> |
| <p>Results</p> | <p>Emergent themes Timing of the discussion Importance of “knowing” the patient Content of the discussion Framing the information Decision difficulty Style and delivery of discussion</p> <p>Timing of the discussion 100% of the participants agreed that the option of intubation and MV is discussed with pts during their illness. 67% questioned the timing of the discussion. Agreement that an intubation and MV discussion should be initiated when a pt is in a stable condition, all physicians noted that it was frequently not introduced until a serious decline in the pts health occurred.</p> <p>Importance of “knowing” the patient Knowing the pt was seen as essential to the discussion. 14/15 physicians stated that they would not consider discussing intubation options with pts until they were familiar with them. Knowing the pt allowed physicians to determine the pts perceptions of their quality of life, satisfaction with current functioning and “expectations in life”. All 15 of the physicians use a combination of these factors in their decisions making. Physicians in the study suggested that they (rather than the pt) were most likely to initiate life support discussion. 53% highlighted that when the topic was brought up by the pt the discussion was substantially easier.</p> <p>Content of the discussion The initial intubation and MV discussion often takes place with progressive worsening of the pts condition. Content of the discussion includes a “factual, well-rehearsed description of the intubation and MV process”. All physicians described a tube being placed down the pts throat with emphasis on discomfort (9/15), inability to eat or speak (7/15), regardless of whether they chose to be intubated the availability of analgesia (13/15), following intubation and MV the best a pt may hope for was return to their pre exacerbation state of health (13/15), “death” was not stressed by name in initial discussions 9/15).</p> <p>Framing the information 14/15 physicians stated that the information presented to pts was modified in order to influence the pts choice. Information was usually framed according to the physician’s clinical judgement about the potential for a successful MV outcome and return to a suitable quality of life. Framing involved presenting the necessary information in more positive or negative terms in order to lead the pt to concur with the physician’s judgment about the appropriate course of action. Criteria used for framing included the disease status, quality of life, number of previous intubations, age, and concomitant conditions. A negatively framed discussion included palliative care.</p> |

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| | <p>Decision difficulty Difficulties mentioned included unpredictability of the disease and the outcomes of MV. Difficulty when pt perception differed from physician 80% physicians highlighted the importance of family in facilitating the decision making process.</p> <p>Style and delivery of discussion Unique to each physician. Content of narrative similar although the style and delivery of information varied. 67% physicians stated role as a consultative one, secondary to information and care provided by a family physician. 33% tended to build strong, supportive relationships with pts.</p> |
| SIGN Quality Rating | CASP qualitative appraisal tool used. Equates to “+” |
| Hierarchy of Evidence Grading | Current hierarchy of evidence utilised by NICE is reflective of a quantitative research paradigm does not potentially take adequate account of qualitative research. Hence using this hierarchy the paper equates to “111” |
| NCC CC ID | 1528 |

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| Author / Title / Reference / Yr | Rhodes, P. 1999, "Focus on palliative care. Palliative care: the situation of people with chronic respiratory disease", <i>British Journal of Community Nursing</i> , vol. 4, no. 3, pp. 131-136. Ref ID: 1545 |
| N= | N=9 Location=Yorkshire Site= One Health Authority |
| Research Design | Qualitative Research Design. Qualitative research methodology not specified. Qualitative method is described. |
| Research Tool | Pre designed topic guide. Subjects included in the topic guide were identified from the literature and from interviews with a range of key professionals. Taped recorded interviews and then partially transcribed. |
| Aim | To describe the circumstances of people with end-stage chronic obstructive pulmonary disease (COPD) or emphysema. |
| Population | Interviewed population included close relatives of the deceased person. |
| Data analysis | Broad headings contained in the topic guide (N=19) provided the framework for an initial thematic analysis with additional themes identified from the interviews (additional N=7). |
| Characteristics | Age at death ranged from 55 to 86 years. Two people died at home, two in a nursing home and the rest in hospital. |
| Results | <p>Quality of life While recognizing that carers and those they care for may assess quality of life differently, relatives reported that quality of life in the year before death was often very low. Two people were reported to have expressed a wish to die or for an end to their lives through euthanasia.</p> <p>Services in the community Frequent calls to GP for home visits reported as unable to visit surgery. Little contact with the community nursing service or with social workers.</p> |

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| | <p>None had been offered or used day care.</p> <p>Where a district nurse had visited, this was usually for the performance of a technical task such as changing a dressing and not directly related to the COPD.</p> <p>Situation of people living alone gave most cause for concern, described as lonely and socially isolated.</p> <p>The reassurance of responsive 24-hour support might have relieved anxiety.</p> <p>Adaptations and equipment</p> <p>Those transferring home from hospital were assessed for home adaptations, aids and equipment. Similar assessments for those who had not had a hospital admission were patchy.</p> <p>The central role of the GP in gaining access to services was reiterated. Respondents stressed the importance of having a GP who would listen.</p> <p>In many cases, people appeared to have received little help or had found out about services through their own initiative, usually word of mouth. Often services were provided too late to be of benefit (“fought for two years to get a shower put in and when they (social services) finally did put one in, he (father) was too ill to use it”. Those families with a stair lift had contributed to the whole or part of the cost. Another person described the difficulties the family had experience in getting piped oxygen.</p> <p>Informal care</p> <p>Many of the caregivers were elderly themselves and had their own health problems. None of those interviewed seemed to have realised that their relative’s illness had been terminal “I don’t think the doctor ever told him that he was dying. No one ever suggested to me that he was dying, though I knew he wasn’t getting any better. No-one ever said anything to me” (wife).</p> <p>After death support</p> <p>Caring had been a major part of the carers lives for many years and left some people without a sense of purpose. Bereaved people within the sample as a whole valued being able to talk to their GP, ask questions and talk through the illness and death. Those who received a post-death visit or letter appreciated it. A follow-up visit from a district nurse was also appreciated.</p> <p>Meeting needs</p> <p>Much of the medical care for this group was described as being through crisis intervention and hospital admission. “He (father) always knew when (an attack) was coming...get sorted out sooner rather than wait for a crisis admission...he probably wouldn’t have had to have an ambulance, all the medical staff, heart monitor, oxygen, face mask, intensive care and all that”.</p> |
| SIGN Quality Rating | CASP + |
| Hierarchy of Evidence Grading | 111 |
| NCC CC ID | 1545 |

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| Author / Title / Reference / Yr | Elkington, H., White, P., Higgs, R., & Pettinari, C. J. 2001, "GPs' views of discussions of prognosis in severe COPD", <i>Family Practice</i> , vol. 18, no. 4, pp. 440-444. Ref ID: 117 |
| N= | N=214 GPs. Location=UK. Sites=One inner London Health Authority. |

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| Research Design | Descriptive study |
| Research Tool | Self complete questionnaire |
| Aim | To investigate the role that discussions of prognosis play in GPs' management of patients with severe COPD and the factors that influence those discussions. |
| Operational Definition | Palliative care is the active total care of pts and their families by a multiprofessional team when the patient's disease is no longer responsive to curative treatment. |
| Population | General Practitioners |
| Characteristics | Respondents: Mean age 45yrs / gender N=121/214 male / number of partners (mean) 4.2. Non-respondents: Mean age 48yrs / gender N=118/175 male / number of partners (mean) 3.4. |
| Results | 73% reported that discussions of prognosis were often necessary or essential in the management of severe COPD 41% reported often or always discussing prognosis (compared to 15% who reported rarely or never discussing the topic). 82% of respondents agreed that GPs have an important role in discussions of prognosis. 48% of GPs were unsure whether most patients with severe COPD wanted to know about their prognosis 39% of GPs agreed that it was hard to know which patients with severe COPD wanted to discuss their prognosis. 47% of GPs agreed that some patients who would like to discuss their prognosis did not get the chance. 37% of GPs agreed that they found it hard to start the discussions about prognosis with patients (and 30% stated that they left it for patients or their relative to raise the subject of prognosis). 67% stated that they found it difficult to predict prognosis for individual cases (45% of GPs stated that there was insufficient information about COPD patients in the GP records to discuss prognosis with them). 24% of GPs reported time constraints preventing them from discussing the prognosis. 60% of GPs thought that patients valued discussions about their prognosis in severe COPD. |
| SIGN Quality Rating | CASP + |
| Hierarchy of Evidence Grading | 111 |
| NCC CC ID | 117 |

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| Author / Title / Reference / Yr | Jennings AL, Davies AN, Higgins JPT, Broadley K. Opioids for the palliation of breathlessness in terminal illness. (Cochrane Review). <i>The Cochrane Library.Oxford: Update Software 2003;Issue 3.</i> Date of most recent substantive amendment: 26.04.2001 |
| N= | N=14 RCTs COPD pts (N=18 RCTs overall). N=179 pts with COPD. (N=293 total pts). Duration=variable across studies. Location=not specified. Sites=17 studies outpatients / 2 studies palliative care pts |
| Research Design | Randomised, double blind, parallel group placebo controlled. |

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| | Double blind cross over studies (in which pts were randomised to order of treatment). |
| Aim | To determine the effectiveness of opioid drugs given by any route in relieving the symptoms of breathlessness in pts who are being treated palliatively. |
| Operational Definition | Terminal illness is defines as “any life threatening illness for which a cure is not possible”. |
| Population | Heterogeneous (includes pts with any illness suffering from breathlessness) COPD / cancer / malignant disease (unspecified) / interstitial lung disease (ILD) / heart failure / idiopathic pulmonary fibrosis. |
| Intervention | Any opioid drug, given by any route, in any dose. |
| Comparison | Placebo Studies, which involved the use of oxygen either during an exercise test or during the administration of both drug and placebo, were also eligible (if given to both arms of the trial). |
| Outcomes | Primary Breathlessness (measured by Borg and modified Borg tests, verbal categorical scales of breathlessness, visual analogue scales of breathlessness) Secondary Exercise tolerance (expressed as workload, distance walked or exercise duration) Adverse effects |
| Characteristics | As per studies included section. |
| Results | Sub group analysis (specified a priori) of the COPD studies alone did not show a significantly different result from the main analysis that included all studies. Breathlessness Statistically significant difference in favour of the treatment group for breathlessness (N=12 studies, SMD= -0.31; 95%CI -0.50 to -0.13 (p=0.0008). However there was statistically significant heterogeneity between the results of the trials for breathlessness (p=0.05). A small but statistically significant effect favouring opioids was seen on breathlessness in the analysis of studies using non-nebulised opioids (meta-regression comparing the non-nebulised and nebulised studies) p=0.02 (no other data available). Exercise tolerance Not statistically significant Adverse effects Adverse effects included nausea, vomiting, constipation, dizziness, drowsiness, and pts in longer studies had withdrawal symptoms on stopping the drug. Three patients died during the Nosedá 1997 study. Deaths were not thought to be related to the interventions but rather advanced disease. |
| SIGN Quality Rating | + (Rating is given for the methodology of the systematic review and not the trials contained within it) |
| Hierarchy of Evidence Grading | 1a |

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| Studies included | <p>COPD studies only:</p> <p>Beauford 1993 (N=8, Mean age 60.8, FEV1 0.9 sd 0.26, FVC 2.62 sd 0.83)</p> <p>Davis 1994 (N=18, Median age 66 (42-75), Mean FEV1 0.93 sd 0.23, Mean FVC 2.53 sd 0.57)</p> <p>Eiser 1991a (N=14, Mean age 65, 'Severe', 'stable' disease, Mean FEV1 32% predicted)</p> <p>Eiser 1991b (N=10, Mean age 65, Similar to Eiser A),</p> <p>Jankelson 1997 (N=16, Mean age 69 range 61-85, Mean FEV1 0.93, Mean FVC 2.21)</p> <p>Johnson 1983 (N=19, Mean age 64.9 sd 9.1, FEV1 830 sd 260 ml, FVC 2080 sd 790ml)</p> <p>Leung 1996 (COPD 10 patients (1 pt ILD), Mean age 62 range 51-71, Mean FEV1= 1.12)</p> <p>Light 1996 (N=7, Age 66.4, FEV1 0.99 sd 0.3, FEV1/FVC 0.35 sd .07, stable disease)</p> <p>Masood 1995 (N=12, FEV1<1.51, stable)</p> <p>Nosedda 1997 (N=12 COPD, 3 malignant disease, 1 heart failure, 1 idiopathic pulmonary fibrosis, all hospital in-patients, Mean age 69, distressing dyspnoea not relieved by conventional medical therapy, Mean FEV1 0.92 sd 0.18, normal cognitive function)</p> <p>Poole 1998 (N=16, mean age 70.7, FEV1 0.6,se0.4),</p> <p>Woodcock 1981 (N=12, Mean age 62, stable)</p> <p>Woodcock 1982 (N=16, FEV1 0.75 sd 0.27, FVC 2.76 sd1.03),</p> <p>Young 1989 (COPD (9) or idiopathic pulmonary fibrosis (2), Mean age 58.4 (39-74), FEV1 0.4-1.41, VC 1.1-4.01).</p> |
| NCC CC ID | 1716 |

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| Author / Title / Reference / Yr | Jennings, A. L., Davies, A. N., Higgins, J. P. T., Gibbs, J. s. R., Broadley, K. E. (2002). A systematic review of the use of opioids in the management of dyspnoea. <i>Thorax</i> , 57, 939-944. |
| N= | N=18 studies, N participant ranges from N=6 to N=79 (see N for each independent study in 'included studies' box) Sites = multiple |
| Research Design | Meta-analysis-double-blind randomised placebo controlled trials. All had cross-over designs. |
| Aim | To review systematically the evidence for the effectiveness of opioids in the management of dyspnoea. |
| Operational Definition | No details provided for the operational definition for "airways disease" or "dyspnoea". |
| Population | Patients suffering from dyspnoea caused by any disease. |
| Intervention | Any opioid, given in any dose, by any route, with the intention of alleviating breathlessness. |
| Comparison | Placebo. Same N as intervention group- all studies had crossover designs. |
| Outcome | <p>Primary outcome measure Subjective assessment of dyspnoea</p> <p>Secondary outcome measure Exercise tolerance expressed as duration, distance walked, or maximum power output.</p> |

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| Characteristics | No demographic details provided. |
| Results | <p>A highly significant effect of opioids on the sensation of breathlessness was found. Meta-regression showed a greater effect for the studies using oral or parental opioids than for those using nebulised opioids (p=0.02).</p> <p>Subgroup analysis of the three included nebulised studies failed to show a positive effect. None of the five excluded nebulised studies that measured breathlessness reported a positive effect. The authors state that the results of the subgroup analysis for the COPD studies were essentially similar to those of the main analysis. The meta-analysis did not demonstrate a significant positive effect for opioids on exercise tolerance.</p> <p>Adverse outcomes</p> <p>The side effects reported with oral opioids were drowsiness, nausea, vomiting, dizziness and constipation and, in two of the four multiple dosing studies, an opioid withdrawal syndrome.</p> <p>Multiple dosing studies in opioid naïve patients had most problems with adverse effects.</p> <p>In one study using nebulised morphine, three patients had minor side-effects involving a bitter taste in the mouth, cough, and a pricking sensation in the throat. In the other studies using nebulised morphine there were no significant problems with side effects of opioids.</p> |
| SIGN Quality Rating | + |
| Hierarchy of Evidence Grading | Ia |
| Studies included | <p>Parenteral opioid studies</p> <p>Bruera et al. (1993) N=10; Chua et al (1997) N=12; Eisler et al. (1991) N=14; Eisler et al. (1991) N=10; Johnson et al (1983) N=19; Light et al (1996) N=7; Poole et al (1998) N=16; Woodcock et al (1981) N=12; Woodcock et al (1982) N=16;</p> <p>Nebulised opioid studies</p> <p>Beauford et al (1993) N=8; Davis et al (1994) N=18; Davis et al (1996) N=79; Harris-Eze et al. (1995) N=6; Jankelson et al (1997) N=16; Leung et al (1996) N=9/1; Masood et al (1995) N=12; Noseda et al (1997) N=12/5; Young et al (1989) N=9/2)</p> |
| NCC CC ID | 19377 |