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**Literature search results**

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**Search details**

Idiopathic pulmonary fibrosis – end of life ethics and moral issues.

**Resources searched**

- NICE Evidence; TRIP Database; Cochrane Library; CINAHL; EMABSE; MEDLINE;
- Google Scholar

**Database search terms:**

“idiopathic pulmonary fibrosis”, (“end of life" OR palliat* OR terminal* OR “advance* care plan"*)

**Evidence / Google Scholar search string(s):**

“idiopathic pulmonary fibrosis” (“end of life" OR palliative OR “advance care plan” OR “advance care planning”)

**Guidelines and Policy**

- **European Respiratory Society**
  - Idiopathic pulmonary fibrosis: evidence-based guidelines for diagnosis and management, 2011

- **NICE**
  - Idiopathic pulmonary fibrosis: The diagnosis and management of suspected idiopathic pulmonary fibrosis - guidance (CG163), 2013
Evidence Reviews

**Journal of Palliative Medicine**
End-of-life care discussions with nonmalignant respiratory disease patients: a systematic review, 2013

Background: Patients with nonmalignant respiratory diseases have limited access to palliative care services and health professionals do not adequately address discussions about end-of-life care preferences.

Objective: The aim of this systematic literature review was to highlight key components and challenges for patients and health professionals discussing end-of-life care in nonmalignant respiratory disease.

Design: A mixed methods systematic review was conducted. Included studies were assessed for quality and data were synthesized thematically, while original data were presented in tabular form.

Data Sources: PubMed, CINAHL, BNI, ASSIA, PsycINFO, Science Direct, and Web of Science were searched (1999–2010) for studies on end-of-life discussions. Additional studies were identified by hand searching key journals and reference lists of included articles.

Results: Fourteen studies were identified. Three themes involving components and challenges in end-of-life discussions were identified: the discussion, the health professional/patient relationship, and patient perceptions.

Conclusions: End-of-life discussions should be initiated by health professionals, who must be aware of patient expectations regarding palliative care and end-of-life care planning. Efforts must be made to develop relationships with patients with terminal illness and allow sufficient time to discuss the end of life during clinical encounters. Future research should address palliative care uptake in nonmalignant disease and implications for health education should be addressed.

Published Research – Databases


Author(s) Meyer, Keith C, Danoff, Sonye K, Lancaster, Lisa H, Nathan, Steven D

Citation: Chest, Jul 2015, vol. 148, no. 1, p. 242-252 (July 1, 2015)

Publication Date: July 2015

Abstract: Idiopathic pulmonary fibrosis (IPF) is strongly associated with advanced age. Making an accurate diagnosis of IPF is critical, as it remains only one of many potential diagnoses for an elderly patient with newly recognized interstitial lung disease. Optimal management of IPF, especially in older-aged patients, hinges on such factors as balancing the application of standard-of-care measures with the patient's overall health status (robustness vs frailty) and considering the patient's wishes, desires, and expectations. IPF is known to be associated with certain comorbidities that tend to be more prevalent in the elderly population. Until recently, options for the pharmacologic management of IPF were limited and included therapies such as immunosuppressive agents, which may pose substantial risk to the elderly patient. However, the antifibrotic agents pirfenidone and nintedanib have now become commercially available in the United States for the treatment of IPF. The monitoring and treatment of patients with IPF, especially elderly patients with comorbid medical conditions, require consideration of adverse side effects, the avoidance of potential drug-drug interactions, treatment of comorbidities, and the timely implementation of supportive and palliative measures. Individualized counseling to guide decision-making and enhance quality of life is also integral to optimal management of the elderly patient with IPF.

Source: Medline
Be honest and help me prepare for the future: What people with interstitial lung disease want from education in pulmonary rehabilitation.

Author(s) Holland, Anne E, Fiore, Julio F, Goh, Nicole, Symons, Karen, Dowman, Leona, Westall, Glen, Hazard, Anita, Glaspole, Ian

Citation: Chronic respiratory disease, May 2015, vol. 12, no. 2, p. 93-101 (May 2015)

Publication Date: May 2015

Abstract: Pulmonary rehabilitation (PR) is recommended for people with interstitial lung disease (ILD); however, the educational content of PR was not designed for this group. This study explored the perspectives of patients and ILD clinicians regarding the educational content of PR for ILD. A qualitative study using individual semi-structured interviews was undertaken. Transcripts were coded independently by two investigators and themes established by consensus. Participants were 18 people with ILD (9 idiopathic pulmonary fibrosis, diffusing capacity for carbon monoxide 54 (20)% predicted) and 14 clinicians from 5 countries and 5 disciplines. Major themes from patient interviews were the importance of knowing what the future might bring and the need for honesty from clinicians. Most were happy to attend standard PR education sessions but wanted ILD-specific content. Patients wanted information about end-of-life planning and most were happy to discuss it in a group. Among clinicians, there was no consensus regarding whether prognosis should be discussed in PR. Most clinicians supported discussion of advanced care planning, however, some thought it should not be discussed in a group. We conclude that people with ILD have specific educational needs that may not be met in the current PR format. Patients and clinicians have some discordant views about programme content. © The Author(s) 2015.

Source: Medline

Available in fulltext from Chronic Respiratory Disease at ProQuest
Available in fulltext from Chronic Respiratory Disease at EBSCOhost

Palliative care and location of death in decedents with idiopathic pulmonary fibrosis.

Author(s) Lindell, Kathleen O, Liang, Zhan, Hoffman, Leslie A, Rosenzweig, Margaret Q, Saul, Melissa I, Pilewski, Joseph M, Gibson, Kevin F, Kaminski, Naftali

Citation: Chest, Feb 2015, vol. 147, no. 2, p. 423-429 (February 2015)

Publication Date: February 2015

Abstract: Palliative care, integrated early, may reduce symptom burden in patients with idiopathic pulmonary fibrosis (IPF). However, limited information exists on timing and clinical practice. The purpose of this study was to describe the time course of events prior to death in patients with IPF managed at a specialty center with a focus on location of death and timing of referral for palliative care. Data were retrospectively extracted from the health system’s data repository and obituary listings. The sample included all decedents, excluding lung transplant recipients, who had their first visit to the center between 2000 and 2012. Median survival for 404 decedents was 3 years from diagnosis and 1 year from first center visit. Of 277 decedents whose location of death could be determined, > 50% died in the hospital (57%). Only 38 (13.7%) had a formal palliative care referral and the majority (71%) was referred within 1 month of their death. Decedents who died in the academic medical center ICU were significantly younger than those who died in a community hospital ward (P = .04) or hospice (P = .001). The majority of patients with IPF died in a hospital setting and only a minority received a formal palliative care referral. Referral to palliative care occurred late in the disease. These findings indicate the need to study adequacy of end-of-life management in IPF and promote earlier discussion and referral to palliative care.

Source: Medline
The palliative care needs for fibrotic interstitial lung disease: a qualitative study of patients, informal caregivers and health professionals.

**Author(s)**: Bajwah, Sabrina, Higginson, Irene J, Ross, Joy R, Wells, Athol U, Birring, Surinder S, Riley, Julia, Koffman, Jonathan

**Citation**: Palliative medicine, Oct 2013, vol. 27, no. 9, p. 869-876 (October 2013)

**Publication Date**: October 2013

**Abstract**: While there have been some studies looking at the impact on quality of life of patients with idiopathic pulmonary fibrosis, to date no qualitative research looking at the specialist palliative needs of these patients has been conducted. This study aims to explore the specialist palliative care needs of people living with end-stage progressive idiopathic fibrotic interstitial lung disease. 

**Design and Settings/Participants**: In total, 18 qualitative semi-structured in-depth interviews were conducted with patients, their informal caregivers and health professionals across two specialist interstitial lung disease centres in London and in the community. Many participants reported uncontrolled symptoms of shortness of breath, cough and insomnia, which profoundly impacted every part of patients' and informal caregivers' lives. Psychologically, patients were frustrated and angry at the way in which their illness severely limited their ability to engage in activities of daily living and compromised their independence. Furthermore, both patients and informal caregivers also reported that the disease seriously affected family relationships where strain was pronounced. There was varied knowledge and confidence among health professionals in managing symptoms, and psychosocial needs were often underestimated. This study is the first of its kind to examine in depth the impact of symptoms and psychosocial needs revealing the profound effect on every aspect of progressive idiopathic fibrotic interstitial lung disease patients' and informal caregivers' lives. Education and guidance of appropriate palliative care interventions to improve symptom control are needed. A case conference intervention with individualised care plans may help in addressing the substantial symptom control and psychosocial needs of these patients and informal caregivers.

**Source**: Medline

Available in *fulltext* from Palliative Medicine at **EBSCOhost**
Available in *fulltext* from Palliative Medicine at **ProQuest**

**Role of support measures and palliative care.**

**Author(s)**: Danoff, Sonye K, Schonhoff, Elizabeth H

**Citation**: Current opinion in pulmonary medicine, Sep 2013, vol. 19, no. 5, p. 480-484 (September 2013)

**Publication Date**: September 2013

**Abstract**: The care of patients with idiopathic pulmonary fibrosis is challenging at a time when there are no medications with proven efficacy in extending patient survival or quality of life. However, a number of recent studies suggest that patients participating in clinical trials including the placebo arm have improved outcome. This suggests that there are elements of supportive care which may prove beneficial to IPF patients. Further, control of patient symptoms should be a critical goal in care of patients with IPF. A number of both pharmacologic and nonpharmacologic therapies are available to reduce symptoms in patients with IPF. These include low-dose narcotics, pulmonary rehabilitation and oxygen therapy. Further, addressing issues of depression may be beneficial for symptom management. Palliative care can and should be more fully integrated in the care of patients with IPF. Incorporating supportive and palliative measures in the care of patients with IPF may improve both quality of life and survival, but far more research is needed in this fledgling field.

**Source**: Medline
Palliative Medicine and End-of-Life Care in Idiopathic Pulmonary Fibrosis.

Author(s) Ravaglia, Claudia, Tomassetti, Sara, Gurioli, Christian, Bucciolli, Matteo, Tantalocco, Paola, Derni, Stefania, Maltoni, Marco, Poletti, Venerino

Citation: Journal of Palliative Medicine, 01 April 2013, vol./is. 16/4(339-339), 10966218

Publication Date: 01 April 2013

Source: CINAHL

Palliative and end-of-life care for patients with idiopathic pulmonary fibrosis: challenges and dilemmas.

Author(s) Lewis, Debbie, Scullion, Jane


Publication Date: July 2012

Abstract: Idiopathic pulmonary fibrosis (IPF) is a progressive, life-threatening interstitial lung disease of unknown aetiology and with limited proven treatment options. As it is predominantly a disease of older age, a growing elderly population will increase its incidence. IPF has a poor prognosis, with a median survival of 3-5 years after diagnosis and a 5-year survival rate of 10-15%. Patients may suffer gradual decline but acute and unpredictable episodes of respiratory failure may result in death. Further research is needed to ascertain the worth of potential prognostic indicators such as age, respiratory hospitalisations, percentage of predicted forced vital capacity (FVC), and 24-week change in FVC. Integration of palliative care principles into IPF treatment is essential, including advance care planning, relief of physical and psychological burden, and patient and carer education. It is unknown whether pulmonary rehabilitation is of benefit but it may improve fatigue and functional capacity.

Source: Medline

Available in fulltext from International Journal of Palliative Nursing at EBSCOhost

Comprehensive care of the patient with idiopathic pulmonary fibrosis.

Author(s) Lee, Joyce S, McLaughlin, Sally, Collard, Harold R

Citation: Current opinion in pulmonary medicine, Sep 2011, vol. 17, no. 5, p. 348-354 (September 2011)

Publication Date: September 2011

Abstract: Recently, an expert committee endorsed by the American Thoracic Society, European Respiratory Society, Japanese Respiratory Society, and the Latin American Thoracic Society published an evidence-based guideline on the management of idiopathic pulmonary fibrosis (IPF). In the current document, we summarize and supplement this recent expert document and propose a comprehensive approach to the care and management of patients with IPF. We propose three pillars of care for the patient with IPF titled 'disease-centered management', 'symptom-centered management', and 'education and self-management'. Disease-centered management involves both pharmacological and nonpharmacological approaches. Palliative care should be an integral and routine component of the care of patients with IPF. Education and self-management strengthens the provider-patient partnership by enabling patients to set realistic goals, remain in control of his or her care, and prepare for the future. The comprehensive care of the patient with IPF involves balancing the three pillars of disease-centered management, symptom-centered management, and patient education and self-management upon a solid foundation of provider-patient partnership. Constant reassessment of the individual patient's goals of care, based on their values and preferences, is essential to the constant recalibration of these various interventions.

Source: Medline

Advanced lung disease: quality of life and role of palliative care.
Abstract: Advanced restrictive lung diseases remain a challenge for both the clinician and patient alike. Because there are few available treatment options that prolong survival for patients with diseases such as idiopathic pulmonary fibrosis, improvement in quality of life and palliation of significant symptoms become realistic treatment goals. Several validated instruments that assess quality of life and health-related quality of life have demonstrated the dramatic impact that lung disease has on patients. Quality-of-life assessments of patients with interstitial lung disease have commonly cited respiratory complaints as problematic, but other distressing symptoms often not addressed include fear, social isolation, anxiety, and depression. Not only do respiratory symptoms limit this patient population, but the awareness of decreased independence and ability for social participation also has an impact on the quality of life. Some patients describe a deepened spiritual well-being during their disease process; however, many patients’ mental health suffers with experiences of fear, worry, anxiety, and panic. Many patients express desire for more attention to end-of-life issues from their physicians. Fears of worsening symptoms and suffocation exist with an expressed desire by most to die peacefully with symptom control. Interventions to improve quality of life are largely directed at symptom control. Pharmacologic and nonpharmacologic interventions have been helpful in relieving dyspnea. Studies have demonstrated that the use of supplemental oxygen in the face of advancing hypoxemia can have both positive and negative effects on quality of life. Patients using nasal prongs describe feelings of self-consciousness, embarrassment, and social withdrawal. Pulmonary rehabilitation is recommended, with some studies noting increased quality-of-life scores and decreased sensations of dyspnea. Sleep deprivation and poor sleep quality also have a negative impact on quality of life. Recognition and correction of nocturnal hypoxemia and other sleep disturbances should enhance quality of life in patients with restrictive lung disease; however, there is currently no evidence to support this claim. End-of-life care needs more attention by clinicians in the decision-making and preparatory phase. Physicians need to maintain their focus on quality-of-life issues as medical management shifts from curative therapies to comfort management therapies. Palliative care and hospice appear to be underused in patients with advanced diseases other than cancer. Because the only curative option for some end-stage restrictive lung diseases is lung transplantation, if transplantation is not an option, palliation of symptoms and hospice care may offer patients and families the opportunity to die with dignity and comfort.

Source: Medline