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41. The COPD patient experience: care and management

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Lung cancer and COPD multidisciplinary teams: Exploring comparisons of patient perceptions

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Background/Objectives: Multidisciplinary teams (MDT's) and effective team working are considered key to providing quality, patient centred care. However there is a paucity of research regarding patient perceptions of these teams including for chest diseases. This qualitative study aims to compare the differing patient perceptions of effectiveness in two disease specific teams.

Methods: 12 patients (lung cancer n=6, Chronic Obstructive Pulmonary Disease n=6) 64-84 years in contact with their respective multidisciplinary teams for 3 months or more were interviewed using a semi-structured format. Data from interviews was analysed based on Interpretative Phenomenological Analysis.

Results: Several themes were identified, commonalities between teams were: 1) Doctors seen as core team members whilst other health professional consultations perceived as inferior. 2) GPs not considered part of a team. 3) Team effectiveness and morale often judged by attitude of frontline administrative staff. Differences: lung cancer participants perceived 1) Efficacy of service upon outpatient clinic waiting times. 2) A greater need for privacy during consultations and when leaving. 3) Greater awareness of MDT communication and meetings. 4) Greater awareness of nurse specialists. COPD participants 1. Accessibility and quicker response to request to be seen by health professional.

Conclusions: These patient groups suggest a traditionalist view of physicians providing treatment. Increasing information regarding health professional specialties, team communications and attention to psychosocial issues may increase patient satisfaction and confidence in MDTs.

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Developing a framework for palliative interventions in respiratory services in Ireland: One year into an action research project

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Background: Traditionally, palliative care services have centred on the needs of patients with malignant disease and there is little evidence of the integration of palliative care into disease-specific services in Ireland. The purpose of this research is to devise, implement and evaluate palliative care responses for people with advanced respiratory disease.

Methods: An action research methodology has been adopted for this multi-site research. This approach provides the opportunity for collaboration, reflection and exploring ways of improving service delivery. It incorporates both qualitative and quantitative methodologies and includes an expert focus group, survey of palliative care education needs, interviews with patients and families and retrospective chart reviews.

Results: To date, the initial planning and action cycles have started. The project outcomes and potential barriers have been identified through an expert focus group. Ongoing retrospective chart reviews highlight the low level of referrals to specialist palliative care. Results from the quantitative survey showed a lack of understanding of what palliative care entails, with 93% of respiratory hospital staff interested in attending palliative care education. Other actions include the establishment of multi-disciplinary, multi-site team meetings to improve patient care.

Conclusions: The reactive and reflective nature of action research has been advantageous in bringing about change in a demanding health care system. This project is developing and evaluating a palliative care model of support, intervention and referral pathways for people with advanced respiratory disease.

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COPD patients coping with breathlessness during daily living – A multi-modal grounded theory

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Introduction: Grasping the complexity of COPD patients coping with breathlessness during daily living has not yet been achieved.

Purpose: To develop a grounded theory of COPD patients' coping styles by

investigating possible interrelations between the physiological, cognitive, affective and psychosocial dimensions in coping.

Material and methods: Twelve patients with moderate to most severe COPD were included during hospitalization for an acute exacerbation of COPD. We chose a multi-modal grounded theory design with concurrent data collection and analysis, and a constant comparative analytic process of interpretation of the data material as a whole. Data were collected both at hospital and in the patients' home after discharge. Data were derived from video, interview, medical history, demographics, scores on a modified Borg Scale and recordings of SaO₂, heart rate, energy expenditure and level of Mets. The data material comprised 24 interviews, 50 recordings of video, 50 video transcriptions, 50 sets of measurements of physiological parameters, 50 set of scores on the modified Borg Scale and 12 sets of demographic information.

Results: The main concern for the participants appeared to be an endless striving for economizing on intra-, extra-, and interpersonal resources with the main purpose of preserving their existence with breathlessness. Suggesting a coping trajectory, four coping styles emerged in this self-protective process corresponding with the degree of pulmonary function, level of physical activity, energy expenditure and social status.

Conclusion: COPD patients' coping styles appear to correspond with their physical and psychosocial condition suggesting a "COPD coping trajectory".

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Living with severe chronic obstructive pulmonary disease (COPD): The male carer's story

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Introduction and objectives: The aim of this qualitative study was to gain a better knowledge and understanding of the male caring role in COPD, and to explore the ways in which individual carers live with COPD patients.

Methods: A prospective unstructured audiotaped interview using a phenomenological approach was used to collect data from ten men (mean age 70.1 years) living with wives or partners who had severe COPD.

Results: Recurrent themes emerged. Most participants reported lack of support and social isolation as they lacked the network of friends and family around them that women appear to have. Previously enjoyed activities such as holidays and sexual relationships were no longer possible for many, leading to increased stress and resentment. Hospital admissions led to increased work load and even less time for the men, and many described how the future filled them with fear, especially if their partner deteriorated further, or if their own health deteriorated. Surprisingly six men did not perceive themselves as carers, preferring the word "partner" to carer. As they did not see themselves as carers they did not think they were entitled to or asked for help. Five men felt that caring did not come naturally to men, and felt women were better suited to the role as they had historically raised children and run the family home.

Conclusion: Severe COPD impacts on all aspects of male carers' lives. The specific needs of male carers should be considered when designing and delivering services to this patient group.

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The experience of not being able to stop smoking despite having COPD

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Background: COPD (Chronic Obstructive Pulmonary Disease) is one of the most widespread lung diseases and a growing cause of suffering and mortality worldwide. It is predicted to become the third leading cause of death in the near future. Smoking is the most important risk factor and 50% of smokers develop COPD. Smoking cessation is the most important intervention to improve prognosis for individuals with COPD.

Aim: To describe the experience of not being able to stop smoking among persons diagnosed with moderate COPD.

Methods: Ten smokers (5 women) with COPD, GOLD stage II, participated in semi-structured interviews. The data was analysed using qualitative content analysis. The participants were recruited from the OLIN studies in Northern Sweden.

Results: The analysis resulted in two themes: 1) Life is governed by a long smoking history that is difficult to break and 2) To be aware of and enlightened, but lacking ability to make a decision, and in five categories: That it is the wrong time in life to stop; To break a lifelong pattern is almost impossible; That plans to stop does not lead to results; Being aware of the consequences of continued smoking and to have received help and support but not wanting to be patronized. Although they knew about the harmful effects of smoking, difficulties in everyday life aggravated smoking cessation. To have plans to stop smoking is not enough, it is also necessary to get motivation and support from the social environment at the right time.

Conclusion: The individual life situations are very important for successful smoking cessation. Health professionals should be even more sensitive and provide an individually tailored support when an individual decides to stop smoking.

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Capturing a palliative approach to COPD nursing: Engaging with the search for meaning in suffering

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COPD Palliative care debate has centred on needs assessment, symptom management, and advanced care planning. Less attention is given to the search for meaning in suffering as an integral to a palliative approach to care. This may be reducing palliative care to its more technical aspects.

This research explored the presence of meaning making in advanced COPD and its possible relationship to 1) anxiety and depression for patients; 2) how nurses respond to care in the acute medical setting.

A two phased action research project was undertaken, Palliative care needs were identified in phase one through structured patient interviews involving 26 patients applying the SGRQ and HADS. Interviews were recorded capturing qualitative data from expanded responses to the closed questions on the questionnaires. An integrated approach to data analysis examined the coded narratives behind the scores. In phase two, an action research group of respiratory and palliative care nurses met over 17 months to explore care delivery with reference to phase one findings.

The mean scores for SGRQ, and anxiety and depression were 62; 8; and 7 respectively. Of the themes from the qualitative data, loss and contextualising meaning reflected response to suffering. Past life and illness experiences were bound up in participants' meaning making. In phase two, illness oriented care narratives in which nurses engaged with their patients in making meaning of suffering represented "corridor speak" and so rarely entered official documentation or discourse. Current focus on palliative care in advanced COPD needs to be carefully debated by respiratory nurses if we are to engage with the palliative concept.

Methods: An analysis of service activity data was undertaken for the period 1st April, 2010 to 31st January, 2011.

Key Achievements: The IRT has managed 2778 referrals, reduced the oxygen prescribing budget by £120,000, avoided the admission of 255 patients, supported the early discharge of 446 patients and reduced the average length of stay from 6 to 3 days. The IRT has managed 1366 new and follow up patients in the specialist community clinics. This equates with a potential predicted annual cost-saving of £163,079.63 in the oxygen prescribing budget, suggests a annual cost-saving of between £453,269 and £634,577 as a result of the reduction in length of stay and in addition an annual saving of approximately £481,162 for those patients on the early and supported discharge programme.

Conclusion: The Integration and collaboration of Respiratory Specialist Services is not only providing the best care, it is cost effective.

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The individual social and financial burden of COPD

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Introduction: An increasing number of people with COPD are under 65yrs. The aim of this study was to ascertain the social and financial impact of COPD on this age group. The country level data are presented from a multi-country cross-sectional survey.

Method: 2426 respondents from Brazil, China, Germany, Turkey, UK and US were recruited utilising a mixed methods design. Data was collected on the financial impact of COPD on individuals and their families, including effect on household income, ability to maintain lifestyles, planning for the future, and social impact.

Results: 49% (1180) males, m 56.4yrs, and 29% employed. Respondents felt unable to plan for the future or maintain lifestyles. Over 1/3 felt household income had decreased, 17% a burden to friends and family, and 26% unable to care for children/family as before. Over 50% went out less, and similar numbers felt embarrassed by their cough. Over half felt their condition had stopped them achieving life goals or dreams.

Table 1. Country-level concerns for the future, earning ability, and social factors

	Total %	Brazil (n=408)	China (n=398)	Germany (n=400)	Turkey (n=416)	UK (n=400)	USA (n=404)
Total household income decreasing	38	33.8	23.9	34.8	34.4	43.3	51.5
Unable to maintain lifestyle	79	80.4	56.8	77.7	90.2	84.4	82.2
Unable to plan for future	41	39.2	15.3	33.5	59.1	54	45.8
Going out less visiting people	58	62	42	42	29	64	64
Cough embarrassing in public	52	61	65	51	47	55	36
Burden to family/friends	17	15	7	9	21	26	26

Conclusions: Respondents felt they were restricted by their COPD in terms of achieving life goals, socialising with others and providing usual family care. The results confirm the high social impact of COPD and financial concerns are of particular importance for working age patients.

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The integration of respiratory services... Is it the way forward?

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Aim: To assess the impact of the introduction of an Integrated Respiratory Service in Central and East Cheshire by looking at admission avoidance, reduction in admissions, length of patient stay and oxygen prescribing costs.

Introduction: The Integrated Respiratory team (IRT) is an in-reach and out reach specialist respiratory service for patients with COPD and other lung diseases in Central and East Cheshire. The IRT offers a 7 day service which incorporates acute hospital care, same day & early discharge services for patients with COPD, patient assessment and support within their place of residence to facilitate hospital admission avoidance, community & hospital based specialist nurse led clinics, a oxygen assessment service, pulmonary rehabilitation, respiratory education and palliative care.