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**Support for Older People with COPD in  
Community Settings: A Systematic Review  
of Qualitative Research**

**KIRKPATRICK, P., WILSON, E. and WIMPENNY, P.**

**October 2011**

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## Executive Summary

**Background-** There are an estimated three million people affected by Chronic Obstructive Pulmonary Disease (COPD) in the UK with only about 900,000 of these being diagnosed according to the Healthcare Commission, and prevalence is increasing. Significant progress has been made in respect of treatment and management of the disease. However, there is limited evidence related to the perspective of those with COPD despite an acknowledgement that lung function, as determined by spirometry, does not necessarily equate with pulmonary disease<sup>5</sup> and subsequent functional level or disability. The impact of COPD on patients, their family, carers and healthcare services demands that better ill health prevention and disease maintenance strategies be employed.

**Objective** - The objective was to explore the common and shared experiences of those in caring partnership for patients with COPD receiving care and support in their community.

**Concept of support** - For this review, the definition of support takes the view that support relates to 'any activity or intervention aimed at improving or maintaining the health status of a patient with COPD'.

### Inclusion Criteria

*Types of participants* - The review focused on the experiences of patients, carers, family members, nurses and doctors involved in providing support to patients with COPD in their own home. Patients aged 65 years and over were included.

*Phenomena of Interest* - The review considered studies that represented patient, carer, nursing and medical staff experiences and perceptions of support relating to COPD.

*Types of studies* - The review considered evidence from qualitative research including phenomenology, grounded theory, and descriptive studies, where support for COPD in a community context was the focus.

**Search Strategy** – The search set out to find published studies in English from 1990-2010.

**Methodological Quality** - The studies were appraised and findings extracted using the JBI critical appraisal tool for qualitative research. Three reviewers appraised the studies independently. 73 studies were critically appraised and 39 met the inclusion criteria.

**Data Synthesis** – Findings from included papers were aggregated, categorised and synthesised.

**Results** – Three syntheses were extracted from the categorised findings:

**Consistency of service provision** - If those with COPD received more consistent support in relation to information, rehabilitation, end of life care and other service provision then their quality of life could be enhanced

**Home based care** - Better planned and more integrated support for home based care around self-care/management and in managing exacerbations can reduce patient and carer anxiety and distress related to COPD

**Individualisation of care** - Individualisation of care, which is not based on the patient's 'disease state' (i.e. physical parameters) but on assessed need, is a necessary part of care for those with COPD.

### **Implications for Practice**

- All older patients with COPD should have a patient held Management Plan
- Because of the growing population of people with COPD it would appear appropriate from the evidence presented in the review of a need to upskill community staff, according to local need (multidisciplinary), in terms of assessment, monitoring and planning, rather than seeking to just provide specialist services.
- Nursing education that includes skills training and pays attention to attitudes, expectations and perceived therapeutic usefulness of support for those with COPD is essential.
- Increase community availability and access to pulmonary rehabilitation programmes to optimise quality of life.

### **Implications for Research**

- Explore the value of community/home based versus hospital based services/support and rehabilitation programmes
- Determine the usefulness of nurse led clinics/services for those with COPD
- Evaluate the place of self care management plans in preventing COPD exacerbations
- Review community nursing assessment approaches for those with COPD
- Determine approaches to anxiety and depression management in COPD
- Establish the links between functional ability and impact on quality of life

**Keywords:** COPD, Chronic Obstructive Lung Disease, Chronic Obstructive Pulmonary Disease, Chronic Obstructive Airways Disease, Chronic Bronchitis, Emphysema, Support, Qualitative Research, Older People.

## Background

The National Institute of Health and Clinical Excellence for England and Wales (NICE)<sup>1</sup> define chronic obstructive pulmonary disease as: "*Chronic obstructive pulmonary disease (COPD) is characterised by airflow obstruction. The airflow obstruction is usually progressive, not fully reversible and does not change markedly over several months. The disease is predominantly caused by smoking*". Normally, diagnosis is made on history, examination and spirometry results with a Forced Expiratory Volume/Forced Vital Capacity (FEV<sub>1</sub>/FVC) ratio less than 0.7 and FEV<sub>1</sub><80% predicted.<sup>1</sup>

This recent COPD guideline by NICE begins by suggesting that COPD, although common, had been largely ignored in healthcare services as it was assumed that little could be done to treat the disease and that its progression was inevitable. There is now a clear direction through the recent policy direction that pulmonary rehabilitation for example can improve quality of life of those with COPD<sup>3</sup>. However, there are an estimated three million people affected by COPD in the UK with only about 900,000 of these being diagnosed<sup>2</sup>. Globally, the number of people with the disease is estimated at 600 million and, unlike some other diseases, prevalence is increasing due to continued exposure with COPD risk factors, ageing populations and changes in health status associated with increasing age. COPD is already a leading cause of death in many countries, presently the fourth leading cause of mortality in the USA and projected to rank fifth in the global burden of disease by 2020 according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD)<sup>3</sup>.

Admission to hospital due to exacerbation of the disease with for example increased breathless or chest infection occurs frequently with cases of chronic obstructive pulmonary disease taking up more than one million hospital bed days a year in England<sup>4</sup>. Exacerbations are distressing to patients and include a sudden worsening of symptoms including a tight chest, increased wheezing and shortness of breath. As well as being distressing for patients exacerbations also have associated, significant, socio-economic costs and reductions in quality of life<sup>4</sup> that indicate a considerable impact on both individuals and healthcare services.

Guidelines, such as those developed by NICE, GOLD and many other national health services and professional bodies, highlight the significant progress and understanding that has been made in respect of treatment and management of the disease. However, there is limited evidence related to the perspective of people with COPD despite an acknowledgement that lung function, as determined by spirometry, does not necessarily equate with pulmonary disease<sup>5</sup> and subsequent functional level or disability. Pulmonary Rehabilitation programmes have sought to address functional and psychological factors and have been shown to significantly improve these as well as quality of life<sup>1</sup>, suggesting that improvements can be achieved through non-pharmacological interventions and after exacerbations<sup>6</sup>.

The considerable impact of COPD on patients, their family, carers and healthcare services demands that better ill health prevention and disease maintenance strategies be employed. In addition to prevention strategies it is crucial that community nurses and other relevant health care professionals are able to work in partnership with patients at the micro level of providing care and support with their individual symptoms aiming, where possible, to optimise health and minimise exacerbations, clinical interventions and hospitalisation.

Government policies indicate several aspects vital for supporting and caring for people with long term conditions including care that is co-ordinated in primary care, holistic in nature, involving people in their own planning and care, using community and voluntary resources well and including family and carers as being crucial to effective disease management and service sustainability<sup>7</sup>. Community health professionals must strive to develop deeper understandings of the patient experience of having COPD to be able to provide effective patient centred care and support that meets individual needs in fluctuating situations. This in itself may help those in the caring partnership work towards better patient autonomy and the development and maintenance of self mastery for optimal patient health outcomes.

## **Objectives**

The objective of the review was to explore the common and shared experiences of people with COPD receiving care and support in their community. Specifically the review sought to determine:

- What is the nature of support for people with COPD?
- What are the experiences of support for people with COPD?
- What aspects of support are considered beneficial for people with COPD?
- What are the experiences of support for COPD from nurses, family and carers?

## **Definition of support**

For this review, the definition of support takes the review team's negotiated understanding and view that support relates to 'any activity or intervention aimed at improving or maintaining the health status of a patient with COPD in a community context'. This could involve a range of supportive approaches, for example, identified by Faulkner and Davies<sup>8</sup> as: Appraisal support which involves personal coping resources; Informational support which involves information and advice; Instrumental support which is that relating to a range of resources including services and Emotional support, which involves enhancing self-esteem. However, the team acknowledge that the term 'support' may be seen as ambiguous regardless of its context and this has been a considerable challenge to capture or maintain a focus within the area of 'support'. Therefore, the reviewers continually sought to clarify the nature of support within each study considered in order to streamline the review processes, improve transparency and enhance consistency.

## **Deviation from Protocol**

Following an early scoping exercise it became apparent that the focus of this review could not manage the volume of literature that was available for all long term conditions relating to support. The initial aim to cover experiences of support for any long term condition therefore was revised to consider COPD in particular as the review team had a COPD expert from practice available. Other long term conditions could be developed as appropriate in the future.

# Criteria for considering studies for the review

## Inclusion Criteria

### *Types of studies*

The review considered evidence from qualitative research studies where support for COPD in a community context was the main focus. The qualitative studies included methodologies such as phenomenology, grounded theory, and descriptive studies.

### *Types of participants*

The review focused on the experiences of patients, as well as carers, family members, nurses and doctors involved in providing support to patients with COPD in their own home. Due to the challenges of identifying older people within research studies and age ranges that may be considered 'old', it was decided to include studies where participants had a mean age of 65 years or more. No age range was required for studies whose main focus was on carers, family or health care professionals.

### *Phenomena of Interest*

The review considered studies that represented patient, carer, family nursing and medical staff experiences and perceptions of support relating to people with COPD in a community setting.

## Search Strategy

A scoping process was undertaken to determine the volume and nature of qualitative research in COPD and to refine the search process. The search set out to find published studies in English from a selected range of databases. The search strategy was as follows, with adjustment for relevant databases undertaken with inclusion of both MeSH heading and keyword when applicable:

1. COPD or Chronic Obstructive Lung Disease
2. COAD or Chronic Obstructive Airways Disease
3. Chronic Bronchitis
4. Lung Emphysema or pulmonary emphysema or emphysema
5. 4 or 3 or 2 or 1
6. Qualitative research
7. Interview\$ or semi structured interview or unstructured interview
8. Audio-recording or audio recording/ or tape recorder
9. Phenomenology
10. Ethnography or anthropology
11. Nursing Research Methodology
12. Grounded theory
13. 12 or 11 or 10 or 9 or 8 or 7 or 6
14. 5 and 13
15. Limit 14 to 1990-current

### *Databases*

The following databases, search engines and journals were searched for citations published from January 1990 to January 2010:

Ageline  
ASSIA  
CINAHL  
Medline  
AMED  
CAB Health  
Embase  
ERIC  
PsycINFO  
Internurse  
British Nursing Index

#### *Search Engines and Journals*

ZETOC  
SCOPUS  
Open Nursing Journal  
INTUTE

Reference lists of literature reviews and included studies were scanned for any additional references. Three reviewers assessed all of the identified titles and abstracts and accessed full text reports for all studies that met the inclusion criteria. References were managed through the use of an online reference manager – Refworks (<http://www.refworks.com>).

## **Methods of the Review**

### **Assessment of Methodological Quality**

All selected studies were reviewed for methodological quality. Assessment of studies was undertaken using the critical appraisal tool as part of the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) software for qualitative studies (see Appendix I). Studies were reviewed by pairs of reviewers working independently. The paired reviewers critically appraised all studies and then conferred to reach a consensus within each theme. Differences relating to appraisal were resolved by discussion. Where no agreement could be reached a third reviewer was employed to reach a conclusion.

### **Data Extraction**

Data were extracted from papers included in the review using the standardised data extraction tool from JBI-QARI (see Appendix II). The data that was extracted included specific details about the phenomena of interest, participants, study methodology or methods, geographical context and outcomes of significance to the review question and specific objectives (see Appendix II).

### **Data Synthesis**

Findings from qualitative studies were synthesised using the JBI-QARI meta-aggregative approach. Reviewers worked on data synthesis in pairs and some

cross checking was undertaken by the third reviewer to enhance rigour and trustworthiness. After initial selection of studies, themes related to support and COPD were identified and extracted as findings. The findings were aggregated into categories on the basis of similarity in meaning. The categories were then subjected to a meta-synthesis in order to produce a set of synthesised findings that can be used as a basis for making recommendations for practice.

## Review Results

### Description of Studies

The 39 papers included one mixed methods study, two qualitative interview based studies nested within RCT's and 36 interpretive studies. Details of the included studies (design, sample, phenomena of interest, location/setting, themes and key messages) are reported in Appendix III presented under the topic headings used to organise the aggregative results below. Excluded studies are listed in Appendix IV. The Figure 1 flow chart illustrates the results from the stages in the selection process.

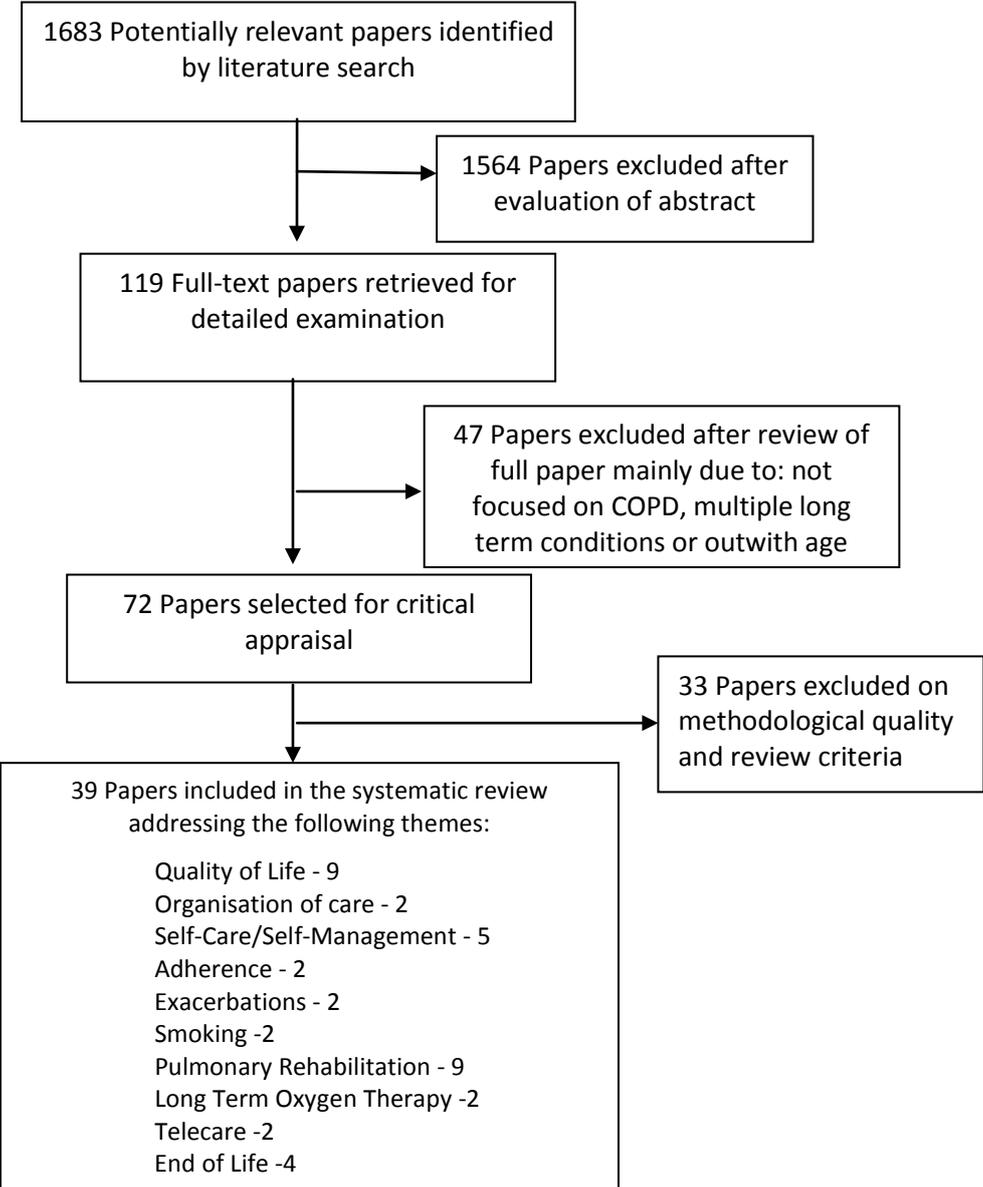


Figure 1. Overview of selection strategy.

## Methodological quality

From the literature search 72 studies were retrieved and assessed initially for inclusion in the review and subsequently for methodological quality. In total, 33 studies that underwent full text examination were excluded on the basis of low methodological quality or for incongruence to the review objectives and review eligibility criteria; most common issues included, incorrect age ranges of participants and interventions and outcomes were poorly matched to the study question (see Appendix IV). An abundance of textual and narrative studies were found at the earlier stage of the search but not included due to the high volume of primary research found.

Most of the 39 studies included were of a high methodological quality and reported in a clear manner. Most author's of studies clearly acknowledged their methodological weaknesses. The methodological approaches included phenomenology, ethnography, grounded theory, one existential philosophy and two case study approach. Close examination of the studies that met the inclusion criteria revealed some of their methodological quality was weak in terms of design, conduct and/or reporting and predominantly related to case study designs. The reviewers decided that a minimum criteria for inclusion in the study based on the components of the critical appraisal instrument was required. The essential requirements for inclusion were determined as questions 2, 3, 4, 7, 8, 9 and 10 (see critical appraisal form, Appendix I) had to be met in order for the study to be of sufficient quality and thus eligible for inclusion into the review. Omission or lack of clarity was considered acceptable for questions 1, 5 and 6). The reviewers consider the strength of the studies included are the robustness of research methods, data analysis and the representation and presentation of the participants voices and therefore a degree of transferable interpretation is possible.

## Results

In total, 216 findings were extracted from the 39 included studies. They were grouped based on similarity in meaning to produce a total of 38 categories. These categories were further analysed to produce 14 synthesised findings. A Meta-Synthesis Table depicts the relationship between these synthesised findings, categories and findings (see Appendix V). To assist clinicians, the synthesised findings are presented and discussed below under topic headings such as 'Support and Quality of Life', 'Support and Organisation of Care', *etc.* The categories they relate to are also presented next. The individual findings (and their supporting illustrations) that were grouped together to form these categories are shown in the Meta-Synthesis Table (Appendix VI).

### ***Support and Quality of Life***

The first two synthesised findings were based on eight categories (collectively derived from 40 findings from nine studies).

#### **Synthesis 1:**

***People with COPD can be reluctant to seek help due to self blame and a lack of understanding from others about breathlessness. Those with COPD often blame themselves for their condition which can result in less willingness to seek help and more frustration and anger when having breathing difficulties.***

## **Synthesis 2:**

***Support for people with COPD needs to take account of their personal situation.*** COPD appears to impact in a myriad of different ways that is influenced by a range of factors - knowledge, social situation, self blame, control.

The experiences of older people with COPD and those who care for them highlighted the perspective that quality of life was significantly diminished by the disease. Although this did not seem to be associated with the progression of the disease as the reviewed papers covered moderate to severe levels of COPD, including those who required palliative care. The eight categories on which these two synthesised findings are based are:

- ***Functional disability leads to reduced self care and autonomy***
- ***There is stigma associated with having COPD***
- ***Those with COPD identify loneliness and a need for support in their home***
- ***Carers are often in a paradoxical situation where they are needed but are also struggling with the situation***
- ***Carers identify some factors that can support their role***
- ***Flexibility of support***
- ***Knowledge of factors that impact on individuals need to be known so that support can be appropriate***
- ***The breathlessness of COPD and associated panic needs emotional support***

### ***Functional disability leads to reduced self care and autonomy***

Those with COPD often blame themselves for their condition which can result in less willingness to seek help and more frustration and anger when having breathing difficulties. For example, Robinson, in a study exploring the experience of severe hypoxic COPD, highlights how the disease impacts on all aspects of quality of life:

*I couldn't do anything without getting out of breath. So I just have to sit here and look at things*<sup>9</sup>(p40).

This may be related to all physical activities including those considered relatively mundane, albeit fundamental such as eating and shopping<sup>10</sup>. Activities which could be readily discussed and supported by a range of health and social care professionals.

### ***There is stigma associated with having COPD***

Stigma often prevented people seeking health advice as they considered their illness to be self-inflicted through smoking. However, this often extended to a range of social settings where those with COPD when they experienced:

*...embarrassment when becoming breathless in the company of friends*<sup>11</sup>(p455).

And not wanting people to keep asking if they are OK when resting or 'catching their breath' in a public place and also not applying for monetary benefits as they believed they should not receive these.

### ***Those with COPD identify loneliness and a need for support in their home***

The issue of loneliness was identified through the lack of social engagement that now occurred:

*I have no opportunity to meet with old friends. That's a disadvantage. ....and time goes by, but it's not very inspiring... and I don't do much now...*<sup>12</sup> (p.614).

However, Elofsson and Ohlen<sup>12</sup> also identified some key connectedness with family being particularly important and continuation of hobbies that don't require physical strength, such as reading and playing a musical instrument. In addition those who lived in their own homes reported less feelings of loneliness than those who lived in care homes or similar settings.

What was apparent here was that the impact of COPD appeared to be personal. By this we mean the extent of reported impact on quality of life didn't seem to be associated with severity of disease with the result that the major synthesis in this section of quality of life appeared to us to be one which needed to illuminate each person's personal situation, as the extent of disease progression didn't appear to correspond with perceptions of quality of life.

***Carers are often in a paradoxical situation where they are needed but are also struggling with the situation***

Those who care for older people with COPD (in these studies normally spouses) also develop an understanding of what helps and are reluctant to seek help from others. The stresses and strains of caring for someone are evident in comments from carers and highlight the need to ensure that support is available in the form of advice and communication, respite and opportunity for their own health needs to be considered:

*I had become so depressed just after Christmas that I used to sit down at night, just crying....still I am awfully tired mentally, and sad, terribly sad, mentally I am worn out*<sup>13</sup>(p.617).

In addition, the loss of the person with COPD leaves a void and so support is also needed for the carer beyond the death.

***Carers identify some factors that can support their role***

Whilst carers identified the challenges of caring they also highlighted aspects of their lives that were supportive, such as employment;

*My job saves me from losing my wits...*<sup>13</sup>(p.615).

Or through spiritual support via religion and prayer. They also highlighted the satisfaction they got from caring well for their husbands and also not being seen to ask for help from health services whilst at the same time, paradoxically hoping that it would be more supportive:

*If I could get more support from the health system I would rather accept the situation of caring for him at home*<sup>13</sup>(p.615).

***Flexibility of support***

The support that people and their carers need is often variable:

*Well every day is different. Some days are worse. A bad day to some people is reasonable... A bad day to me is a nightmare*<sup>14</sup>(p.809).

Such variability makes planning challenging but highlights the need for flexibility from those in supportive positions, such as health and social care professionals.

***Knowledge of factors that impact on individuals need to be known so that support can be appropriate***

This category had the greatest number of themes from reviewed studies. This follows on from the flexibility requirements as support needs to take account of older people with COPD and their carers know what helps them in particular circumstances and that support needs to work with this rather than seeking to impose a uniform approach:

*Like my American Express card, I never leave home without it... Using an inhaler correctly while controlling his panic was what worked best for him.....I do the deep breathing. In through the nose and .. pursed lip breathing.....*

*...Well, I get short of breath...so I set the oxygen higher.. After I've finished bathing and drying myself and dressing, I can put it back down....*

*...Sometimes it takes a while to get a handle on it but you gotta do it yourself cause nobody else can <sup>15</sup>(p.553).*

Older people, who have COPD, have considerable experience of what helps and what hinders their functional ability in living with the disease <sup>14,16</sup>. For their own condition they have expertise but still want to have opportunity to discuss what was happening to them:

*I'd like someone knowledgeable to discuss it with. The one criticism I have of the NHS is the little time people have to talk... <sup>17</sup>(p.622).*

It was clear that whilst they valued regular contact with someone who knew them and their disease, rather than ad hoc contact, the regular hospital visit could be challenging for those with COPD as they negotiated, for example, travel and long hospital corridors<sup>17</sup>. What seemed to be of concern was that when they visited their general practitioner or were visited at home by a health care practitioner they were often not exhibiting major signs of breathlessness or distress and it was a case that; *they look at you and conclude, oh you look alright, that's it* <sup>11</sup> (p457). As Gysels and Higginson<sup>11</sup> highlight, this maintains an 'invisibility' of breathlessness that prevents effective understanding of the impact of the disease on individual older people and reduces the likelihood that support, including emotional support, will be sought or available when it is required<sup>11,14,17</sup>.

***The breathlessness of COPD and associated panic needs emotional support***

Perhaps the final feature of quality of life is to highlight the emotional response that older people with COPD can experience and which seems to pervade much of the evidence:

*Some days I can't do anything and I get very frustrated. I cry a lot, this happens a few times a week.....panic attacks resulted in 'you feel as if you are on your last breath'. It's very frightening. When this happens I need someone to hold my hand and talk to*

*me, that gives me comfort.....I panic in case I don't wake up*  
<sup>14</sup>(p.810).

Providing support for those with COPD and those who provide care is challenging as there would appear to be a multiplying effect of COPD that impacts on quality of life. The perspectives of those with COPD, and their carers, suggest that there is a need to identify factors that impinge on their lives so that appropriate support can be provided.

## **Support and Organisation of Care**

The third synthesised finding was based on four categories (collectively derived from 11 findings from two studies).

### **Synthesis 3**

***Providing home services which seek to take account of the person and their context can improve care and outcomes for those with COPD. Personalised care that is accepting of the person's views appears to be more likely to be influential in reducing the impact of COPD.***

The majority of studies sought views and experiences of community based services as these are usually 'new' and evaluation is more likely to occur. The two included papers sought experiences of GP services and a nurse-led urgent care team. The resultant four categories highlighted the value of community based services but also the need to ensure that services were personalised:

- ***Care teams of nurses can be viewed as equally credible to medical staff***
- ***Home based services are viewed as more acceptable by patients and can improve outcomes***
- ***Lack of willingness to discuss impacts or medication due to imbalance in power***
- ***The empathy and understanding of the person's situation by a healthcare practitioner can impact on those with COPD***

### ***Care teams of nurses can be viewed as equally credible to medical staff***

Older people with COPD reported a more personalised approach to care provided at home. This was illustrated through the category which identified where care given by a range of community staff was credible and acceptable and influenced by the approach of the healthcare practitioner.

Providing services through a community based nurse-led urgent care team (UCT) was viewed as advantageous by patients and ensured a quicker response for service delivery than that provided by general primary care services, who would have been the first port of call prior to the introduction of such a service:

*You wait for hours for the doctor....the UCT come straight out*  
<sup>18</sup>(p.443).

### ***Home based services are viewed as more acceptable by patients and can improve outcomes***

Urgent care teams could then prevent admission to hospital, where the perception of those with COPD is that it can be less personalised and contribute to the trauma of the exacerbation:

*They seem closer to you, they speak to you and explain everything ... They tell you things and they are willing to open up .... they are not the same in hospital*<sup>18</sup>(p.444).

### ***Lack of willingness to discuss impacts or medication due to imbalance in power***

Relationships with general practitioners were seen as important, although there was a perceived imbalance of power that sometimes prevented discussion of important issues such as medication use:

*Need to be seen as a 'good patient' and not a nuisance - My daughter asked for him. I didn't ask for him, she sent for him .....*<sup>19</sup>(p.435).

Stockpiling of steroids and antibiotics so that 'self medication' could be carried out was undertaken as a means of taking control and prevent having to contact the GP:

*I try and control it. I generally get antibiotics in store ....I have the cure at hand (stockpile of antibiotics and steroids) I don't have to go bothering the doctor and making a nuisance of myself .....*<sup>19</sup>(p.435-6).

### ***The empathy and understanding of the person's situation by a healthcare practitioner can impact on those with COPD***

For whatever reason older people are often reluctant to seek medical help and this can be exacerbated if there is a perception of self blame for the condition, or the response has been unhelpful in the past:

*.. All he is interested in is giving me a prescription...you have had your 10 minutes ... on your way*<sup>19</sup>(p.435).

This does not appear to be as significant if the person is given more time, particularly at home where it also allows carers to receive support at the same time:

*The nurse sat down and explained what they did and how to take them[inhalers] .... I said to myself you are a mug...now I have done everything she said and I am 100% better and haven't had any more trouble*<sup>18</sup>(p.444).

## **Support and Self Care/Management**

The fourth synthesised finding was based on five categories (collectively derived from 30 findings from five studies).

### **Synthesis 4**

***Support for self-care is needed, as it can impact on daily activities and capabilities. Maintaining life with COPD requires engagement with a range of physical, psychological and social factors. However, this may be poorly supported by health care professionals.***

There was (often forced due to necessity) a need to be self-caring as the impact on life was often viewed as 'survival'. Whilst self-care often revolved around physical aspects of daily life and the lack of ability to complete simple tasks this was interwoven with emotional and social factors that held an importance to well-being. The support from health professionals was often lacking from the perspective of those with COPD or their carers. The five categories on which this synthesised finding is based are:

- ***People with COPD, and their carers, see life as survival and attempt to attain a satisfactory level of quality of life.***
- ***People with COPD, and their carers, have to adjust physically to their condition through reduction (often forced) in total activity and use of strategies to overcome limitations.***
- ***Emotional adjustment is important to those with COPD – acceptance and the value of social support are essential***
- ***Connectedness with other people, spiritual beings, nature or one's inner self are important reference points for people with COPD***
- ***Misinterpretation or lack of awareness of need occurs from others, including health professionals***

***People with COPD, and their carers, see life as survival and attempt to attain a satisfactory level of quality of life***

This category seemed to pervade all the papers in this theme but was only explicit in two. These suggested that supporting self-care in those with COPD, and their carers, is challenging as they are often struggling with life as the following illustrate:

*He's completely and utterly spent, you know. He couldn't even talk to me because he was just completely breathless, lethargic and you know just no spark of life in him.....he hadn't the energy.....There were days I thought to myself, where are we going from here? But we mastered it together and tried to do things at his pace.. <sup>20</sup>(p.371).*

*It's completely irreversible and what happens when you get COPD...you ever tried to glue a balloon back together, no way.....  
.....I don't want to get any worse. I know I'm not going to get any better... No, it doesn't get better <sup>21</sup>(p.170/171).*

Providing support in such an environment appears to require significant understanding of the nature of the disease and the impact this has on people and their families.

***People with COPD, and their carers, have to adjust physically to their condition through reduction (often forced) in total activity and use of strategies to overcome limitations***

This category had the most findings attached to it, which may reflect the very specific need for support related to physical functioning and ability to self care/manage this. Unpredictability related to COPD was again reflected here:

*Some days I can wake up, don't even look like I have it. I'm not shortness of breath or nothin and I can just about do anything I want to*

*do. Other days I wake up, I just don't have it. I don't even have it to even come down the steps, let alone go up it...and if I have an extremely bad day, I don't hardly leave the machine...<sup>22</sup>(p.71).*

The evidence from those with COPD suggests that there is a decline in physical functioning which involves loss of ability to do everyday household chores, work, sports and hobbies. The result of this loss was a need to plan for any activity and to prepare and pace yourself otherwise there were consequences:

*I've got to figure out what I have to do, and not do ten things one day, and do nothing the next week<sup>21</sup>(p.172).*

Even the completion of simple household chores was seen as a source of accomplishment and pleasure and sometimes provided the means by which prescribed physical exercises could be undertaken:

*I've got to do my vacuuming, so I pick up the vacuum cleaner and use it to do my exercises, and when I'm cooking, I do the arms out (and with) reading, I sit right down or squat down, (and) I do quarter squats...<sup>21</sup>(p.171).*

The benefits of a pulmonary rehabilitation programme was also evident:

*I was there more often last year cos there was this gym and it was specifically wanted for those lung patients...that you could with these devices...push a bit and then it was nice that you could listen to yourself and stop in time<sup>23</sup>(p.43).*

Participating in rehabilitation programmes for people with pulmonary problems was viewed as particularly meaningful and safe and an opportunity to meet others with the disease and gain peer support<sup>23</sup>. It could also take over the person's life and reduce the necessary balance that they had identified as important:

*...I spent my whole day doing exercises and I wanted to belong to things, I wanted to be doing things and I'd always have to explain, well I can't come until after 11.00 because I have two sets of exercises to do<sup>21</sup>(p.172).*

Such adherence to exercise programmes may be unusual as others described their ability to fit into their daily lives and how the breathing exercises, in particular, were beneficial in helping them to master everyday physical tasks.

### ***Emotional adjustment is important to those with COPD – acceptance and the value of social support are essential***

Emotional support appears to be a critical feature as the experiences and perspective of those with COPD is often pessimistic, although such perspectives can be overcome:

*You need to stand up bravely even if you are uncomfortable....to live one more day, exercising is good for your health. If you don't do it, you die soon....Sometimes I do feel pessimistic. The only thing I can do is to continue the treatment and take care of myself*

*until I can't live anymore...I used to be depressed and uncomfortable, but now I am used to it*<sup>24</sup>(p.560).

However, such stoic responses to COPD may not be mirrored in all cultures.

Adjusting to COPD also means adjusting emotionally as well as physically. The view was that there needed to be an acceptance of the disease. If you didn't manage to accept and adjust emotionally then this would impact on other aspects of life:

*If you don't have that emotional help, you can exercise all you want but if your heart is aching, you're feeling so depressed, you'll give it up.....What works for me is actually, the more happy I am the better I feel, the more I can do...*<sup>21</sup>(p.174).

Family and peer support were viewed as 'central to survival'. For carers, often the spouse of the person with COPD, there was also a sadness that appears in COPD perspectives but also a desire to provide care:

*Our life has come down. The two of us used to go dancing. We loved dancing and then it all stopped..... It's like having another child sometimes because you are sort of responsible and I feel he is my responsibility.....*<sup>20</sup>(p.370).

Emotional adaptation could also be facilitated through very practical means such as allowing flexibility with medication management:

*When I saw Dr X he gave me a range (referring to medication dosage) that I could fiddle with myself and then after that I was more comfortable.*<sup>21</sup>(p.173).

***Connectedness with other people, spiritual beings, nature or one's inner self are important reference points for people with COPD***

This category stemmed from one paper<sup>22</sup>. Leidy and Haase<sup>22</sup> describe how participants in their study derived '*personal integrity*' from some broad and in-depth connectedness with objects and others. One participant described how her nasal cannula and oxygen made her feel conspicuous when she went shopping or ate with friends in a restaurant and impacted on her desire to shop or socialise. In addition, connectedness with health care providers or institutions occurred when participants perceived that the providers were consistently responsive, conscientious and personally invested in the participant's well being. If they perceived that the relationship with the health care professional was unconditional then they would seek support, if not then they would often see them as a '*last resort*'.

***Misinterpretation or lack of awareness of need occurs from others, including health professionals***

The association of lung function and physical ability is a feature that occurs in many forms and is reported elsewhere. In addition the outward appearance of an individual, particularly if seated and sedentary can be misleading and result in others making judgements about their state of health:

*...they said to her, 'Why don't you do something, you're as fit as a fiddle,' cos you can't see it, this breathing..*<sup>23</sup>(p.44).

All of the subjects with COPD said they have had some kind of difficulty in receiving the care they needed in local health centres, which often necessitated use of emergency services. Even then there was often shortcoming in assessment and care<sup>23</sup> or shortcomings in the amount of engagement or information available:

*I've never been sat down and told...no-one had warned me about this, nobody had said the admissions will come more rapidly... When I go to the hospital and speak to the consultants I can't get to see them, you know. They are trying new medications and nothing was explained to me. Nobody had time. I just find that very frustrating*<sup>20</sup>(p.370/1).

Whilst this may not be exclusive to COPD there appears to be an indication throughout this review that health care professionals may see COPD as a disease that is progressive, self-inflicted, untreatable and the person and their carer, will know all about it.

However, wherever there was a good and accessible doctor or primary health care team then those with COPD, and their carers, believed this meant 'an awful lot' and they knew and felt comfortable contacting them. Limited support from other services existed and there appears to be a lack of awareness about available services and benefits and often an uncertainty about admissions and discharges from hospital due to the 'unpredictable' nature of the disease and it not being 'classed as a terminal illness', which was viewed as potentially assisting with a range of support.

## **Support and Adherence**

The fifth synthesised finding was based on two categories (collectively derived from 18 findings from two studies).

### **Synthesis 5**

***Attitudes, knowledge and perceived support and medication specific factors impact on adherence to interventions and treatments in COPD patients. Adherence is multifactorial and can be influenced by a range of inputs. The two categories on which this synthesised finding is based are:***

- ***Adherence to treatments and interventions can be influenced by attitudes, knowledge and perceived support*** and that
- ***Medication regimen related factors affect adherence.***

### ***Adherence to treatments and interventions can be influenced by attitudes, knowledge and perceived support***

Patients received mixed messages from health care professionals with regard to their medication and treatment regimes with internal conflict within the patient adding to this. There appeared to be a lack of consistent clarity in instructions given to patients. In addition, patients juggled with issues such as addiction to medication and embarrassment in using inhalers or oxygen in public. Faith in the treatment was the most important factor. Faith in treatment varied:

*I found a while ago some tightness in my chest. Couldn't get breathing, [went] down to the doctor. He put me on a nebuliser*

*for ten minutes and I found it good, and I started going on that first thing in the morning*<sup>25</sup>(p.280).

*... so I go back a third time and they give me something else and nothing happens. I said I'll get better myself*<sup>25</sup>(p.280).

As patients' conditions deteriorated, higher rates of adherence were more likely, which appeared to be linked directly to the experience of symptoms. Medication that helped relieve symptoms such as breathlessness therefore encouraged compliance in some instances:

*No I don't forget (to use inhaler). It's a regimen in my house. Anything to help you breathe*<sup>26</sup>(p.151).

and another noted that 'you got no choice' but to take medication. It appears that the fear of dyspnoea is a strong encourager of inhaler compliance, as one patient put it when asked about compliance with medication:

*I wouldn't dare do otherwise*<sup>26</sup>(p.151).

Whilst most patients appear to have a good understanding about regular medication use in respect of purpose, frequency and on an 'as needed' basis, some patients reported receiving inconsistent advice from health professionals regarding techniques such as using a spacer or rinsing their mouth after medicating:

*... every doctor seems to tell you something different actually...*<sup>25</sup>(p.280).

In respect of dietary and nutritional advice, in one case a patient was told to eat a 'healthy diet' but this came without specific support on how to achieve this or a patient management plan in how to develop self care in this respect. Significant advice for patients with COPD such as eating small, regular meals was largely missing for most people learning to cope with their condition. Information was also seen to be lacking in relation to levels of exercise and how much or how far individuals should push themselves:

*Nobody has actually told me whether it is good or not to get out of breath when taking exercise. I would have thought that was something very basic that they need to explain*<sup>26</sup>(p.152).

### **Medication regimen-related factors affect adherence**

Several medication related factors are reported as affecting adherence, though those with strict routines found they fitted their medication into their daily lives easily<sup>25</sup>. One patient had reported that they never forget to take their medication as they have 'rituals'<sup>26</sup>(p.151). Events including holidays or emergencies were likely to interrupt patients disciplined approach to medication management.

The frequency of the prescribed medication was significant with one patient noting the possible clashes with mealtimes and another forgetting at bedtime. Inconvenient and physically challenging dosage forms and equipment had a detrimental effect on adherence:

*When you do the Accuhaler, you are not too sure whether you've got it. You're not too sure whether you are going to get a dose or*

*not, 'cause it's all bloody concealed. But when you've got the (metered dose inhaler), you can hear it*<sup>25</sup>(p.281).

*If you are in trouble, the [spacer] would be the one if you are at home, but when I'm out I find instead of carrying that big one, I just carry that little portable [spacer]*<sup>25</sup>(p.281).

Some of the less appealing physical properties of the medication prescribed is also questioned as having an effect on adherence. One particular patient noted the powder 'clung to my throat'<sup>25</sup>(p.281) whilst another had preferences of which medication was more palatable:

*I don't like the taste of (Ipratropium). It tastes foul... acidy sort of. It's not very nice. (Salbutamol) is much smoother and easier to take*<sup>25</sup>(p.281).

The use of nebulisers at set times in the day also had an effect with one patient omitting it if 'they had to go out'<sup>25</sup>(p.281).

By and large the findings supported the notion that the more severe the condition became and the more symptoms the patient experienced the greater the adherence to medication and lifestyle regimes. A number of additional factors had an impact on this including patient's faith in the medication and their experience and satisfaction in using it. Worries about tolerance, side effects and dependency dwindled with this deterioration.

The Jones et al<sup>26</sup> study found that the relationship and contact with an approachable health care professional was crucial in building a supportive partnership. Whilst access to a primary care respiratory nurse was seen as unanimously helpful, contact with a specialist consultant, at a chest clinic, 'did not make much difference to their everyday lives' as the time spent with them was too short. Good support was seen as a balance between control of symptoms, minimising side effects, their attitude towards treatment regime, satisfaction with health care professional relationships and knowledge of their condition and how they could plan for future change or exacerbations.

## **Support and Exacerbations**

The sixth synthesised finding was based on two categories (collectively derived from seven findings from two studies).

### **Synthesis 6**

***Exacerbations of COPD have a dramatic effect on individuals and on their disease progression. However, they may still delay seeking professional help. Peoples' experience of the significant emotional and physical effects of an exacerbation is individual to them and during this time they prefer to be cared for in their own home by an effective team.***

The majority of studies explored the patient experience of exacerbation and the support services that may help. The resultant two categories highlighted the considerable impact that exacerbations have on the stability of peoples COPD which affects them on various levels including both psychological and physical. It further illustrates the individual experiences of the deterioration process including cues and alarms useful for alerting impending exacerbations and the

benefit of support in the home by specialised teams. *The two categories on which this synthesised finding is based are:*

- ***Exacerbations have a negative emotional and physical impact on patients which are personal to them and also***
- ***During deterioration and exacerbation patients prefer to be looked after in their own home.***

***Exacerbations have a negative emotional and physical impact on patients which are personal to them***

Exacerbations of COPD have a significant burden on everyday functioning and emotional well being, causing anxiety and worries about suffocating and dying. During this time, most people require additional help with activities of daily living such as household chores, shopping, cooking and 'everything'. For many patients, all activities stopped as they reported that '*...movement is hardly possible*' <sup>27</sup>(p.5).

Mood changes are also significant factors in exacerbations with many patients experiencing depression, bad temper, irritability, anxiety, isolation, anger and guilt having a subsequent effect on relationships with some patients stopping socialising <sup>27</sup>(p.5). These experiences also have an effect on family members leaving them feeling '*afraid*', '*worried*' or '*scared*' <sup>27</sup>(p.6).

Most patients with COPD and their family members are able to identify warning signs of an impending exacerbation and note the same signs from one exacerbation to another. Bodily changes indicating deterioration in their condition include breathlessness as the most common followed by fatigue, cough, upper respiratory tract infection and pain <sup>27,28</sup>. A change in sputum colour was also an indicator:

*You get used to your own body, it's amazing, how you get used to, what's wrong with you, I know when I've got an infection because it goes greenish and then it goes yellow* <sup>28</sup>(p.471).

Family members living with the COPD patient can also be attuned to the signs indicating an exacerbation. Whilst outsiders saw no changes in the patient, family members saw subtle changes that were significant:

*Oh there's nothing wrong with her, but we know that's just the start of it, if we don't catch it in the bud early then it's going to be a hospital case ...* <sup>28</sup>(p.471).

However, for some patients, exacerbations were unpredictable having differing signs and symptoms each time. This poses a challenge for both patients and health care staff who have to plan for and respond to quickly and appropriately with support.

Whilst some patients appear to be pro active and plan for and self manage their deterioration through taking additional medication without the support of a doctor or resting; others seemed to be in 'denial' and didn't want to admit something was wrong:

*I'll suffer anything till I realise that I've got to get help,...* <sup>28</sup>(p.471).

Other patients put off contacting health professionals believing they were not ill enough to bother hard pressed staff.

***During deterioration and exacerbation patients prefer to be looked after in their own home***

This category considered the value of an Acute Respiratory Assessment Service (ARAS) to patients providing intensive care and support in patients' own homes during exacerbations. Having support during exacerbations provided by the ARAS was seen as beneficial as Schofield et al<sup>28</sup> highlight, its accessibility, ease of use, specialist clinical skilled health professionals and one to one care in peoples' own home being highly regarded by patients . One patient noted:

*They're treating you, as if you are somebody special, not as if you're a number on their book* <sup>28</sup>(p.472).

Whilst another patient preferred to be in their own environment commenting that *I feel more contented ... I feel my own wee home is familiar to me* <sup>28</sup>(p.471).

Accessibility was seen as important with people either contacting the ARAS directly or through a GP. One patient expressed his enthusiasm for the service seeing it as a speedy way to access effective care:

*... my wife would have been dead, that's how badly she was, now to me that's a godsend that clinic, I can phone up any time and I can take my wife in...* <sup>28</sup>(p.472).

## **Support and Smoking**

The seventh and eighth synthesised findings were based on three categories (collectively derived from eight findings from two studies).

### **Synthesis 7**

***People have a smoking story and history which influences their choice to quit.*** This story needs to be understood if support is to be offered.

### **Synthesis 8**

***The right health care professionals need to use the right words at the right time:*** health and social care professionals, and others, need to be aware that maintaining effort in promoting smoking cessation appears to create action at appropriate points in people's lives.

Smoking is a key risk factor in COPD and contributes to its development and exacerbations. However, the degree of support that is identified by those with COPD is difficult to ascertain as the majority of studies focus on experiences of smoking and only tangentially touch on supportive factors. The categorisation of the papers highlighted four significant areas which may assist practitioners to understand the perspectives of those with COPD who have or who still smoke and to incorporate these into supportive interventions. The two categories on which this synthesised finding is based are:

- ***Paradoxical positions between smoking and not smoking***

- ***People reach a tipping point in their smoking history where they give up.***
- ***Using the right words at the right time can be influential in smoking cessation***

### ***Paradoxical positions between smoking and not smoking***

Understanding the smoking stories of those with COPD appears to be important and could contribute to the provision of support. This paradoxical position between smoking and not smoking was an ongoing issue that needed to be aired if the person was to be supported. It appears important to those with COPD to be able to tell their story without judgement as circumstances have often dictated their smoking or non-smoking. Smokers saw themselves as trapped in a web or having to make excuses for their smoking:

*...if I stopped for good I think it could do me more harm because see I could have a lot of side effects if I stopped, like I could get bad tempered.....<sup>29</sup>(p.1730).*

### ***People reach a tipping point in their smoking history where they give up***

Smokers are often vacillating between smoking and giving up and both have their own pressures. However, it is often not possible to know when this is for each person and is perceived as effective at a 'tipping point' in their lives. For some this came at the time of diagnosis:

*Frances claimed that no-one would ever tell her not to smoke, but a diagnosis of emphysema led her to give up immediately. *When it's your life, I think it's different you know..... It was so difficult. But my doctor prescribed me these Zyban tablets and that helped. Never touched another cigarette....<sup>30</sup>(p.9).**

For others it related to other aspects of their lives:

*....I'll need to stay off it this time, I know myself, I'll not see my two granddaughters grown up if I don't, it's as simple as that<sup>29</sup>(p.1732).*

### ***Using the right words at the right time can be influential in smoking cessation***

Whilst not possible to know when the tipping point may be there was an indication that practitioners and other should keep raising the issue of smoking cessation and this would, at some time, be the right time. Using the right words at the right time appears to be helpful in reducing smoking amongst those with COPD. This can be at a time of vulnerability, for example during an acute exacerbation and maintaining a persistent approach but not 'preaching' at these times appears to have some success, from the perspective of those with COPD.

*They said you've got to stop smoking, you've got emphysema, blah, blah. And I took no notice of it. I couldn't stop smoking; I'd tried everything in the book. Even double doses of that dangerous drug (buporion). They had to put this thing into my mouth and force air into me. And this young Doctor got the x-*

*rays and he said 'phew, you've only got a little bit of lung left. If I was you I'd take care of it. And it struck me then, and from that day to this, I've never smoked (crying)... Well, he just said it at the right time you know? ....<sup>30</sup>(p.9).*

## **Support and Pulmonary Rehabilitation**

The ninth and tenth synthesised findings were based on seven categories (collectively derived from 67 findings from nine studies).

### **Synthesis 9**

***Pulmonary rehabilitation programmes provide a significant degree of support for those with COPD. The programmes appear to increase physical, psychological well being.***

### **Synthesis 10**

***There is inconsistency and lack of knowledge in the way in which COPD is managed, the information available and the level of support available. People with COPD report inconsistencies in a variety of aspects of their care that suggest limitations in provision of support that could be addressed through pulmonary rehabilitation programmes.***

It is important to note at the outset that there were a variety of rehabilitation programmes represented, although most appeared to have an exercise and educational component. The recency of publications suggests increasing numbers of programmes being available and interest in evaluating the impact of programmes through the experience of the individuals who attend.

Overall, the experience of those with COPD validates the provision of pulmonary rehabilitation programmes with perceived increases in physical, psychological and social well being. However, those with COPD also report that they often receive limited information and conflicting advice and care for their condition. Additionally they also report such inconsistency as a feature of referral for pulmonary rehabilitation. These are reflected in the categories for this theme: The seven categories on which the synthesised findings are based are:

- ***Rehabilitation programmes impact on strength, confidence and capability.***
- ***Setting achievable goals enabled participants to reach out for achievement.***
- ***The rehabilitation programme has an effect that is more than just the programme itself.***
- ***The structural aspects of the programme need to be considered.***
- ***Explanation of diagnosis, symptom recognition and management is inconsistent.***
- ***There is need for support outwith and beyond the programme which is not readily available or known about***
- ***The referrer has an influence on the patient starting or dropping out of the programme.***

### **Rehabilitation programmes impact on strength, confidence and capability**

Participants in rehabilitation programmes reported significant changes to the ability to undertake 'normal' everyday<sup>31</sup> often with increased strength and capability:

*I've been doing heavier things in the house. I've been carrying bags of groceries rather than sort of putting them in the trolley and then unloading them ... I do feel stronger*<sup>32</sup>(p.138).

In addition, participants also highlighted the value of focusing on breathing and exercises that may assist improvement:

*.... I have built up more endurance and breath. I have really benefited from it. and At the start ... I was very short of breath. When I was walking with my wife, I frequently had to stop. Now she has to stop*<sup>33</sup>(p.179).

However, the outcomes from the programme were not only physical, as participants developed greater confidence in their own abilities and felt less isolated by their disease as they met others in similar circumstances:

*It gave you a chance to push your body that bit further .. I could do more because I felt safer, I knew how far I could go .. And it gives you confidence and you meet people like we are now who's got the same problems*<sup>34</sup>(p.199).

The positive perspective from participants was reported from a variety of programmes suggesting that a definite format may not be required. However, any programme needed to be achievable.

### **Setting achievable goals enabled participants to reach out for achievement**

These goals were ones which may involve everyday activities of living:

*.. you become more dependant when it comes to dressing and undressing.. I hate that idea .... And that's why I want to dress myself again. And take a shower. I'm sure I will be able to do that*<sup>35</sup>(p.217).

Or ones related to recreational activities such as playing a round of golf or keeping in touch with family and friends<sup>36</sup>. The key feature was that individuals were setting personal goals that they believed could be achieved and which would then feed into increasing confidence and likelihood they would continue to undertake work from the programme at home.

### **The rehabilitation programme has an effect that is more than just the programme itself**

The support received from the programme went beyond the formal programme and included emotional and motivational support from other group members<sup>37</sup> and also from those supervising the programme:

*.. see, the good thing is you're being supervised when you're busy* <sup>35</sup>(p.215).

The result was that participants gained more than just an exercise programme:

*..once I'd gone once I wouldn't have missed it for anything ...It made me feel so good that I was achieving so much' .. I think psychologically I got really low without realising it ... it (PR) was a real turning point.. I improved 100% in being able to get around...* <sup>38</sup>(p.1719/1720).

Furthermore, this again appeared to have potential for a longer term impact:

*.....giving me the opportunity to help myself and do something positive instead of just taking this, taking that...* <sup>38</sup>(p.1719).

### ***The structural aspects of the programme need to be considered***

Programmes may be more useful if run at times convenient to participants or when they might feel most able to participate <sup>34</sup>, for example:

*..I'd say afternoon really (would be the ideal time for the programme to take place)...when I've been on my nebulizer I'm not so bad.* <sup>39</sup>(p.708).

Being in place where parking and access are 'convenient' are also factors<sup>37</sup> to consider that may encourage participation.

### ***Explanation of diagnosis, symptom recognition and management is inconsistent***

One of the major concerns existed around diagnosis when those with COPD indicated that the provision of information about the condition was poor:

*..they say 'Oh yes, you have COPD' but that's the end of it, nobody tells you or explains anything to you* <sup>38</sup>(p.1706).

Subsequently, they appeared to gain from specialist involvement (Rodgers et al 2007) often found in rehab programmes, and felt empowered by having a supply of medication that they could use to prevent exacerbation.

*Being able to treat my own symptoms gave me a feeling of pride; the fact that I survived without a Doctor for another day or ten* <sup>33</sup>(p.181).

### ***There is need for support outwith and beyond the programme which is not readily available or known about***

The level of support available to those with COPD may often be considered to be appropriate and available, however;

*..there are so many things out there to help us but many of us don't know about them* <sup>37</sup>(p.1706).

Such lack of awareness of what might help in financial, physical, psychological and social terms may mean that available support is not optimised. Rehab programmes may be more likely to disseminate this information through the

organisers/facilitators or through other members of the group, although uncertainty may still exist that could impact on support.

*Yeah you can do that can't you? There was certain things you could join weren't there after the rehab...<sup>34</sup>(p.201).*

Meeting other people with COPD would appear to be helpful and in addition involving, family and friends in the programme may assist in on-going commitment and access. Ensuring on-going provision of some form seemed to be important:

*...you had someone caring for you for six weeks and them being interested in you and then it's gone you know...we've gone through this course and now it's come to an end, I mean there's nothing down the line is there?<sup>34</sup>(p.200).*

### ***The referrer has an influence on the patient starting or dropping out of the programme***

Those with COPD often report a need for their GP to sanction their attendance on the programme<sup>35,39</sup> as this may not promote attendance or adherence if the perception of the medical practitioner is ambivalent or negative, as one GP had stated:

*..this may or may not help you..<sup>38</sup>(p.1720).*

Or if the person sees it as suggested because there is nothing else that can be done. Additionally, if the programme is too intensive then drop out may also occur<sup>35</sup>. There was a clear indication that, on the whole participants with COPD find rehab programmes supportive on a number of fronts that go beyond just the physical. The mainly positive perspective of those with COPD is influenced by those who refer and facilitate the programme and this needs to be carefully considered as it can impact on attendance.

## **Support and Long Term Oxygen Therapy**

The eleventh synthesised finding was based on one category (collectively derived from 11 findings from two studies).

### **Synthesis 11**

***People with COPD who have long term oxygen therapy question their own need and seek compromises in their lives to accommodate use.***

*There appears to be a constant review of functional, health, and social and symptom management by individuals in respect of oxygen use.*

The terms associated with oxygen therapy for those with COPD varies, with supplemental, long-term, chronic, continuous and domiciliary among the most used terms to describe the use of oxygen by an individual in their home or during their daily activities, which may also be outwith the home. The studies highlighted the constant adaptation and negotiation that people using oxygen have to make and the restrictions that it can place on their lives and resulted in the following category.

- ***People with COPD who have long term oxygen therapy question their own need and seek compromises in their lives to accommodate use.***

The support required for those with COPD who use oxygen at home or outside the home appears to be essential as, whilst it provides relief from the symptoms of breathlessness it also brings with it a range of limitations that may be overlooked.

Firstly, there is the need to establish perceptions of oxygen and level of use. Earnest<sup>40</sup> describes this as a 3 stage path whereby those with COPD move from a stage of Initiation – ‘Do I need Oxygen?’ through a stage of Negotiation – ‘Given that I do need oxygen, under what circumstances do I need it or will I use it?’ and finally a stage of Compromise – ‘Given that I cannot be without oxygen, what activities will I continue to participate in?’ The compromise stage is reported as having a profound impact on individuals with the likelihood that most activities are given up. It is not clear if this stage process is linear or if iteration occurs as those with COPD become increasingly breathless.

Secondly, as Ring and Danielson<sup>41</sup> and Earnest<sup>40</sup> clearly highlight, there is considerable restriction placed on those using oxygen at home that impacts significantly on their lives. For example, Ring and Danielson<sup>41</sup> show, the restriction to ‘time and room’:

*...it's hard when you can never walk where you want to and travel anywhere....What's terrible is to be confined and that one must sit with that thing and go to bed during the day-time like that. And during the nights...then I lie very still because one is afraid to squeeze the tube...<sup>41</sup>(p.341).*

Balancing particular domains of life is illuminated by Earnest (2002) as he shows how those with COPD seek to balance functional activities, health needs, social engagement and symptoms of COPD. The result was often a compromise in what could be achieved, possible because of the equipment required but also due to issues such as the reinforcement of the stigma experienced:

*I think I feel like it's shameful because I have to do it because I smoked<sup>40</sup>(p.753).*

The sense of isolation and embarrassment is clearly shown in both studies, although one woman identifies the value of a pulmonary rehabilitation programme and how this stopped the downward spiral of the disease progression/oxygen need cycle:

*It opened up a whole new vista for me. All of a sudden I was getting more active. I was doing the grocery shopping and the laundry, and driving and just becoming self sufficient...<sup>40</sup>(p.753).*

It is acknowledged that the two selected papers are between 8-10 years old and the equipment and approaches to oxygen at home in many countries may be different to that described in the US<sup>40</sup> and Sweden<sup>41</sup>.

## Support and Telecare

The twelfth synthesised finding was based on two categories (collectively derived from 12 findings from two studies).

### **Synthesis 12**

***Usability and clinical effectiveness issues are important considerations for both patients and health care staff when thinking about using telecare.*** *Burses experience increase work load, concerns about legalities, equipment, relationships and professional issues with using telecare. However, patients find it increases their level of engagement and ability to self-care.*

Whilst there are issues around technical set up, reliability and quality of information issues in using telecare, benefits are identified by patients. Health care professionals have more concerns for its widespread use though could see a role for monitoring the stable, well patient rather than those who are ill. The two categories on which the synthesised finding is based are:

- ***The usability and effectiveness of telecare is an important consideration for health professionals, patients and carers;***
- ***Patients and nurses experience different benefits and drawbacks in using telehealth.***

### ***The usability and effectiveness of telecare is an important consideration for health professionals, patients and carers***

On one hand nurses were satisfied with being able to successfully implement new technologies but concerned regarding their effect on patient relationships because of their limited interactional ability. Of note here was the quality of the signal and image with telecare which affected the style of communication. One of the main problems highlighted was to do with picture quality:

*Sometimes you didn't see the patient clearly at all ... you wouldn't know what colour she was, what shade of blue or grey ... I found it really difficult to observe her breathing because the picture quality wasn't good*<sup>42</sup>(p.112).

Another perspective illustrated in the studies was to do with nurses expressing themselves as there was a delay in the voice exchange during conversation. Nurses felt it was like a two way radio and that they were frequently '*talking over each other*'<sup>42</sup>(p.112). Thus telecare is seen as impacting negatively on the effectiveness of clinical communication and relationship building.

Privacy and confidentiality was seen as a major concern for nurses though patients did not share this view<sup>42</sup>. Nurses felt therefore, that telecare was less safe and secure than face to face interactions because:

*We don't know who is in the room with them see, .... We don't know, unless they are sitting behind the patient ...*<sup>42</sup>(p.112).

On the whole patients reported positive experiences in using telehealth thinking it was a good idea<sup>42</sup> and showed willingness to use telecare because of high levels of satisfaction with it<sup>43</sup>. One patient noted the privacy benefits of having telecare in her own home:

*It was on my territory... just one invasion .... I prefer that than sitting in a hospital bed .... there is no privacy in there* <sup>42</sup>(p.112).

Patient problems and concerns were also identified. Telecare was also described as 'not user friendly' and alarms leading to repeated measurement led to the patient continuing with its use beyond the agreed time <sup>43</sup>(p.178). One patient felt the equipment was bigger than expected thinking it discreet enough to 'hide in a corner' <sup>43</sup>(p.178). Some nurses felt the technical aspects of telecare were too much for a patient and slow equipment hampered this further:

*.. he could not cope with it because it was not easy to use the blood pressure cuff and the temperature probe .... It takes ten minutes, ten minutes to work* <sup>43</sup>(p.176).

### ***Patients and nurses experience different benefits and drawbacks in using telehealth***

The nurses concerns around the quality of communication continued as a drawback within this category. Telecare was seen as a barrier to effective clinical communication where specific tasks and outcomes were required:

*I think you need the patient in front of you, .... It's when you start talking to them and getting more of a rapport with them that they open up and tell you things...* <sup>42</sup>(p.113).

Being in a patient's home and having equipment and medication at hand was felt to enhance not only the interaction but also support self monitoring processes, therefore, telehealth was reducing the likelihood of the nurse successfully carrying out key roles such as acquiring an accurate patient history or employing educational interventions with the patient. In addition to the compromised communication and relationship building some nurses felt telecare gave them extra work with installation, training demands and technical difficulties<sup>42</sup>. A further concern was that more regular use of telecare may risk job losses for nurses as new technology 'impinged on their role' and that the future role of nurses may be qualitatively different and offer less scope for face to face support<sup>42</sup>.

Patients reported positive experiences as they took on a more active role and greater responsibility for their condition when using telecare. One patient described the use of telecare as an 'added bonus' because it gave them a greater sense of control <sup>43</sup>(p.177) and another coped well with monitoring equipment and that:

*... both she and her husband were very reassured by being able to perform her clinical measurements at home and happy that we were able to access these figures* <sup>43</sup>(p.177).

This sense of patient control and autonomy was further highlighted with the following quote:

*I can see the girl, talk to her, she can explain things back to me, she can turn round and say put everything on and we will check you over,.... I don't have to wait an hour or two or anything for her to come ... The main advantage is that I can do it for myself* <sup>42</sup>(p.114).

Important in this excerpt is the notion of a willing patient who is clinically stable and readily engaging in self management activities for their condition. The role of telecare however may be more suited to ongoing monitoring of stable lung disease than for ill patients who exacerbate regularly.

Nurses however, did not have as much confidence in the patient to be able to record, for example, a blood pressure as accurately as a health professional<sup>42</sup> raising issues of patient safety. Concerns around the medico-legal position with telecare should something go wrong had one nurse thinking:

*I don't know how I would be fixed in a court if I had to go and tell the judge - well she looked fine from the waist up*<sup>42</sup>(p.113).

## **Support and End of Life Care**

The thirteenth and fourteenth synthesised findings were based on four categories (collectively derived from 12 findings from four studies).

### **Synthesis 13**

***People with COPD struggle with the negative effects of their disease.***

*There are physical, social and psychological restrictions placed on them towards the end of life.*

### **Synthesis 14**

***End of life health needs are not well understood and provision is variable and inconsistent. This is across all aspects of provision from all groups.***

- ***Living is a continual 'struggle' for patients with COPD towards the end of their life which has a negative impact on their physical, psychological and social well being.***
- ***Care, support and resources are obtained from a number of individuals though appears variable and inconsistent.***
- ***Some patients want regular monitoring.***
- ***Managing end of life care is complex and doesn't appear to be well understood by patients, health professionals or carers.***

***Living is a continual 'struggle' for patients with COPD towards the end of their life which has a negative impact on their physical, psychological and social well being***

Physical functioning and lifestyle are profoundly restricted at the end of life stage for COPD patients. They describe severe difficulty with breathing on minimal exertion and movement in terms of not being able to walk far or climb a few stairs without being out of breath. Their declining physical capacity in some cases is so severe they become housebound or even chair bound as was the case with this man:

*He had his chair there in the corner and he used to eat, sleep and do everything in it like*<sup>44</sup>(p.442).

One patient, on continuous oxygen became restricted to the home because she wanted to be near her oxygen. Some carers knew it was pointless trying to go

out further highlighting the 'shrinking world' of the patient as the disease progresses:

*... by the time we'd got her to the doctors, she'd be fighting for her breath even if we'd had a car*<sup>44</sup>(p.441).

A number of psychological symptoms were also noted towards the end of life. Elkington et al (2004) noted links between breathlessness, and anxiety, panic attacks and depression. Severe breathlessness triggered panic attacks as illustrated in this case:

*She had panic attacks terrible didn't she where she'd wake up and she couldn't breathe even with the oxygen*<sup>44</sup>(p.442).

Depression was also seen as another limiting factor occurring as a result of underlying depressive illness or co morbid conditions. Physical deterioration and mobility appeared to have a direct link:

*We knew he was depressed. He was sitting indoors all day, can't do anything*<sup>44</sup>(p.442).

Fear of being left alone and of dying are also identified as issues for people as illustrated by the following quotes which tap into the experience of how frightening and inhibiting their disease state is for them:

*I worry in the middle of the night if I can't get my breath I shall be on my own and die*<sup>45</sup>(p.312).

*... she was too frightened to go into a deep sleep in case she didn't wake up*<sup>44</sup>(p.442).

*he said. You're not here, none of you are here when I wake up in the morning*<sup>44</sup>(p.442).

The final quote came from a carer of a deceased patient who poignantly noted the paradox of the man being too frightened to live finding the '*...whole business absolutely intolerable and horrendous*', but at the same time, too frightened to die as he was '*very afraid of death*'<sup>44</sup>(p.442). Anxiety and fear are therefore significant factors to consider in end of life assessment and support.

### ***Care, support and resources are obtained from a number of individuals though appears variable and inconsistent***

End of life support provision appears to be provided by patients themselves, family members, informal carers, the primary care team, respiratory care nurses, respiratory care teams and palliative care teams<sup>44-46</sup>. Many health professionals believed that all patients who required basic practical support and equipment such as oxygen and nebulisers, received those as a priority whilst some acknowledged long waiting periods for things such as wheelchairs, toilet seats and hand rails for example<sup>46</sup>.

In relation to health care, Spence et al<sup>46</sup> noted that professionals dealt with those issues immediately presenting from patients as time and resources were restricted:

*If you are out on house calls you can't afford to spend 45 minutes sitting at that time, I wish we did, but realistically we could give it maybe as a one off but it's really not feasible* <sup>46</sup>(p.128).

However, frustration was voiced from another who could not deliver the specific psychological skills required at this emotional time. This health professional records the dilemma of not being able to refer a patient on to someone more suitable whilst at the same time not feeling skilled enough to deliver the required care:

*I'm not a qualified counsellor, I can provide some support, I'm very limited and it's very difficult to refer them on* <sup>46</sup>(p.128).

The type and quality of contact with health professionals also varied from prescription only contact with a GP to regular reviews and support from a respiratory nurse which was valued. This is mirrored as patients also vary in how and why they access care from health professionals:

*... he didn't want help from anybody. He did not like going to the doctors, we really had to force him to go to the doctors you know* <sup>44</sup> (p.443).

Whether patients expressed a need for health care or not the lack of support and active monitoring for patients in some cases was particularly evident:

*But when you leave hospital he knew that there was nothing after that. Nothing there was just me and him* <sup>44</sup>(p.443).

*I know there was nothing they could do for him and he knew, but it was a feeling of you're abandoned, we don't want to see you no more* <sup>44</sup>(p.442).

Whilst this illustrates a sense of 'giving up' by patients and doctors, the carer from the final quote also acknowledges the 'tender loving care' that is vital when active medical care has ceased or been withdrawn <sup>44</sup>(p.443). The need for effective back up for carers was highlighted and whilst a 'panic button' or 'named person to contact' was suggested by one it was clear that not all carers knew what they were entitled to in terms of support and respite care. Given the centrality of many carers' roles in successfully maintaining and managing COPD stability for patients in a community context, particularly if they are spouses, this would seem a crucial point for future action.

### ***Some patients want regular monitoring***

Many patients feel cared for with regular monitoring and contact with health professionals and most know when to ask for help.

*My son is always here"...."I think with this sort of thing you should be on a an automatic visiting list, not constantly having to ring them up to come* <sup>45</sup>(p312).

### ***Managing end of life care is complex and doesn't appear to be well understood by patients, health professionals or carers***

Given the complexity and unpredictability of stable COPD the nature of end of life disease is understandably equally complex. Patients needs and information requirements differ and what is best for one person is evidently not required for another. These points are illustrated in the following quotes:

*How long I've got to live, well how long I'm still likely to last and how it deteriorates ... I'm interested, not that I'm worried just that I'd like to know what's happening to me No, what I know is enough for me*<sup>45</sup>(p.311).

Palliative care nurses and teams are seen as an option for providing support for people at this end stage though there is a lack of clarity around its definition, timing and benefit<sup>46</sup>. Some health professionals considered all COPD patients to have palliative care needs whilst others felt this was not the case. The difficulty of timing was indicated through relating to cancer patients who may have shorter end stage duration than COPD patients because of its unpredictability. Given these considerable challenges, at times of crisis health professionals note that:

*It's a matter of trying to manage them the best we can at that level and help them make the most out of that time*<sup>46</sup>(p.127).

There is a paradox with referral for palliative care. The benefits of referring patients for specialist palliative support were countered by the concern that patients might view this as 'giving up' on them therefore a gradual change to palliative care through the focus of patient 'comfort' is seen as an appropriate way ahead<sup>46</sup>. Most crucially, the timing and appropriateness of the palliative care information and support offered was clearly emphasised by one health professional:

*Getting the right information to the right people at the right time is much more difficult than we sometimes imagine ... Information at the wrong time they ignore it or if it's inappropriate, it can frighten them or raise their anxiety..*<sup>46</sup>(p.129).

The findings here illustrate the need for individual patient need and effective communication being the main driver for palliative care assessment, planning and delivery for patients with severe COPD nearing the end of their life.

## **Discussion**

### ***Consistency of Service Provision***

There was a strong message, from those with COPD, across a number of themes in this review, that the provision of services is often inconsistent and lacks multiprofessional consensus. This lack of consensus appears to span care from diagnosis through exacerbations and into end of life care. Why there should be such inconsistent provision when there is a range of guidance that exists<sup>1,3</sup>, is questionable, although guidance is more aimed at diagnosis and treatment, where evidence of effectiveness exists. Support, as defined at the outset covers a further range of emotional and informational needs which requires further consideration in service provision.

For example, nurses' express frustration and powerlessness with patients with COPD as they may consider the disease to be degenerative and unlikely to improve with increasing diminishment of quality of life. Such a view, suggests that nurses have a negative view of COPD and that this will impact on the care that they give and may reflect the negative perception of service provision

provided in this review. Additionally, community nurses may be limiting their role to reflect the, predominant and powerful, pharmacological approach to care that pervades healthcare and as such this will limit proactive approaches and increase their passivity to develop new skills. This seems to be a major challenge for community nursing and yet they are ideally placed to influence patients with COPD and their families through relationships and their potential to anticipate and prevent poor health and well-being.

This review has found that specialist services are not available to all patients with COPD being supported in the community. The provision of specialist respiratory services and nurses may assist in improving consistency and support in all its guises. The NICE guideline<sup>1</sup> does seek to provide recommendations related to specialist respiratory nurses specifically as they are now considered "...part of the multidisciplinary COPD team". However, the evidence on which this is based is not robust and the roles identified appear to reflect those already undertaken by a large number of community nurses or which could be enhanced with additional education and training. There may, of course, be differences between urban and rural areas in terms of availability of specialist nursing input, particularly those remote from services where there is a reliance on generalist support. In other words provision may be "naturally" patchy and may require a change in knowledge, skills and attitudes as well as service provision.

One key intervention for health professionals is related to smoking. As COPD is a disease mostly related to smoking it seems appropriate to maintain support for cessation, even in older people<sup>1</sup>. Encouragement, information, advice and follow up in conjunction with other pharmacological approaches and awareness of individual situations are important. However, as indicated in the review, some patients may be reluctant to discuss smoking cessation due to the stigma associated with the "self-inflicted" nature of COPD, which may be balanced with acceptance of the person's story and healthcare professionals willingness to maintain their input and keep offering the "right advice at the right time" in the knowledge that it may have an impact.

Concomitantly, exercise for those with COPD presents an ongoing challenge as patients are often afraid of dyspnoea and so adopt a sedentary lifestyle to prevent occurrence. Levels of exercise tolerance are often unknown, not explored or left with the patient to decide and therefore may result in no action because of the fears and anxieties related to breathlessness. How this should be addressed more generally by community staff is not clear as exercise tolerance varies and limited goal setting occurs, other than through pulmonary rehabilitation programmes which may have appropriate structures and processes in place to achieve improvement in functional ability.

From the patient perspective, pulmonary rehabilitation programmes are valued and supportive. There is also a range of quantitative evidence that highlights their effectiveness in increasing quality of life and functional capacity<sup>1</sup> (based on a number of studies). It is also clear that, as this review has identified, people with COPD are keen to undertake such programmes. However, the level of availability of community based programmes is unknown and probably limited in number compared to those provided in hospital.

Whilst there is strong evidence of effectiveness and, in this review, meaningfulness for pulmonary rehabilitation for those with COPD and their

carers, it appears to have little impact on depression<sup>1</sup>. Depression may be represented in this review by the comment that coping with COPD is likened to “gluing a balloon back together” which aptly alludes to the challenges that confront patients and carers all of the time. Depression is prevalent in those with COPD (about 40% of older people with COPD), which may be helped by improved service provision, including home care management and input from nurses<sup>48</sup>.

Enabling people to have increased control of planning and treatment related to their COPD may also be helpful, as it can reduce anxiety associated with dyspnoea and enable self medication to prevent or reduce the impact of exacerbation. Quicker symptom relief and treatments that prolong periods between changes in conditions and exacerbations are most desirable. As the disease progresses there appears to be greater adherence to medication and a desire to be able to self medicate as soon as signs of exacerbation occur, which will differ between patients. There are specific challenges related to those on long term oxygen therapy as there are clearly limitations imposed by this, although interventions and support can be effective in ameliorating some of the problems. The supportive nature of self-care/management should not be underestimated in having a general positive effect on the well being of those with COPD.

End of life care seems to be particularly challenging and COPD appears to be a “poor relation” to other diseases, such as cancer. The last phase of life for COPD patients can be very long and indistinct, which makes it difficult to determine what type of supportive care is most appropriate at what time. The result is that there is limited consensus by healthcare professionals on when and how to intervene to support patients at this stage.

It may be possible to consider the three triggers of the Gold Standard Framework<sup>49</sup> (UK framework for palliative care) particularly the surprise question ‘Would you be surprised if this patient were to die in the next 6-12 months?’. This could assist practitioners to identify if palliative care is implemented, in conjunction with other disease and personal markers. Furthermore, even at the end of life for those with COPD information is still important and should consist of the non-curative nature of the disease, treatment options, for example symptom management and future directives, all factors identified across this review.

### ***Home Based Care***

The review identified a clear desire by patients to be cared for in their own homes as home “is familiar” and contextual factors clearly impact on those with COPD. Such an approach could also be seen as cost saving. NICE<sup>1</sup> report that over half of the costs related to COPD are for provision of care in hospital with COPD identified as one of the most costly inpatient conditions treated by the NHS. There is evidence that this is also the case in other countries<sup>50</sup>. Therefore there is an argument to be made that cost savings could be achieved by seeking to manage people with COPD at home and in addition, from the patient’s point of view in this review, this would be both preferred and likely to lead to greater satisfaction with care and be supportive. Of course the extent of any cost savings may be variable depending on the epidemiological make up of the population and the need for acute care. On a cautionary note however, preferences of the patient should be taken into account as there is often fear

and anxiety evoked with an acute exacerbation and the security of hospital may, at times, be preferable.

Supporting patients with COPD at home may require more specialist skills for community staff<sup>1</sup>. What may be significant here is the level of expertise, knowledge and understanding that needs to be introduced to the community through specialist engagement at a local level and available support and advice for general practitioners and those with COPD. Based on evidence from other areas of disease management and care it is essential not to deskill the general community practitioner but to provide more opportunity to enhance knowledge and skills through developing practice. A key strategy in effective COPD support should relate to self care/management.

Self management is identified as an important supportive strategy for those with COPD as the disease's long term nature means there are significant opportunities to promote healthy behaviours that might result in fewer exacerbations, visits to health centres and hospitalisations, in addition it is suggested that the quality of life and control can be enhanced<sup>1</sup>. Whilst some of this could be part of pulmonary rehabilitation programmes, there is a need to adopt a more planned and programmatic approach if attitudes and behaviour are to be affected and in particular if those with COPD are going to believe that change can be achieved. Additionally, links between functional ability and levels of, for example independence need to be carefully considered as the relationship is equivocal and there is an essential need to incorporate the person's perspective into clinical management plan. Nurses in community settings are well placed to share the intimacies and understandings of those with COPD and to develop plans based on shared understandings and appropriate negotiated interventions.

A number of other aspects may also be helpful in home care settings in conjunction with self management, for example, improved use of IT solutions (telecare), use of breathlessness scales to assess severity, awareness of the impact of climatic changes with increased follow up or anticipatory care. Those with COPD would, from the findings in the review, find such approaches helpful as they would provide evidence of positive and supportive actions.

### ***Individualisation of Care***

The review suggests that the experience of having COPD in older people can be limiting, frightening and poorly understood by health professionals and others. The provision of guidance for COPD can be seen to emphasise treatment at the expense of the personal perspective of those who may be "suffering". The review highlights the impact of the disease on daily life and seeks to put this on an equal footing to that of the professional perspective.

Individualisation of care, in the context of this review, also includes spouses and other family members as the experience of caring for those with COPD can be tiring, isolating and overwhelming, because they lack support. Spouses, in particular, have voiced these concerns about the challenges and also identified the lack of support from services. However, they also highlight the positive elements in caring and the desire to stay the distance with their partner. Ensuring family involvement appears an essential element in any care management approach and may be viewed from a "family nursing" perspective.

## **Limitations**

It became apparent early on in the review process that 'support' (see previous definition) was not always explicit within the review papers and most of the critical appraisal and analysis involved the reviewers making judgements and decisions on the intervention/activity discussed, as to whether it constituted 'support' or not. This continual revisiting of the concept of 'support' was challenging but was crucial for review process consistency to enhance the trustworthiness of the review's findings. However, we are aware that other interpretations of support could be equally valid.

Determining the age range for "older people" with COPD was not straightforward, particularly as many studies had a broad age range within studies. The decision to use papers which had a mean age of  $\geq 65$  years for participants was considered appropriate, although we are aware that this also, at times, included participants who were under this age. Where no ages or mean age was described a decision was taken based on participant evidence provided.

A further limitation of this review is the time lag between completing the search and developing the review to the time of publication which may mean valuable insights within this time frame have been missed.

## **Conclusions**

In reflecting on the process for this review we were struck by the overwhelming struggle for support described by those with COPD in most of the 39 papers reviewed. This seemed, to us, unprecedented. Even papers which just focused on COPD experiences in general, of which there were many more than anticipated, described a predominance of negative perspectives and experiences. Why should this be for a particular disease? It may of course be that there has been greater interest from qualitative researchers in exploring COPD due to its perceived lack of "cure" and the significant numbers of people affected. It may be that exploration of support in other diseases would highlight similar challenges. However, the review included the perspective of 651 older people with COPD and 65 carers and professionals from 11 countries, which we would argue is an important consideration and leads us to consider it has some degree of transferability to community settings globally.

It may therefore be argued that the review, because of its ability to illuminate the major need for community based support for older people with COPD has created the opportunity to begin to address this. Whilst, this may require some additional resource it also requires a change in perspective from professionals and health services about the disease and how support can be achieved. For example, from the perspective of those with COPD this may relate to flexibility and accessibility of services and knowing that support is available. There may also be cost benefits in reducing hospital admissions and use of health services and increasing control and autonomy and satisfaction for those with COPD.

## **Implications for Practice**

A number of relevant points for practice can be discerned from this review of older people's experiences of support in COPD:

- All older patients with COPD should have a patient held Management Plan
- Because of the growing population of people with COPD it would appear appropriate from the evidence presented in the review of a need to upskill community staff, according to local need (multidisciplinary), in terms of assessment, monitoring and planning, rather than seeking to just provide specialist services
- Nursing education that includes skills training and pays attention to attitudes, expectations and perceived therapeutic usefulness of support for those with COPD is essential
- Community availability and access to pulmonary rehabilitation programmes to optimise quality of life should be increased
- If those with COPD received more consistent support in relation to information, rehabilitation, end of life care and other service provision then their quality of life could be enhanced
- Better planned and more integrated support for home based care around self-care/management and in managing exacerbations can reduce patient and carer anxiety and distress related to COPD.
- Individualisation of care, which is not based on the patient's 'disease state' (i.e. physical parameters) but on assessed need, is a necessary part of care for those with COPD.

## **Implications for Research**

The review has identified significant gaps in research related to supporting those with COPD. These cover a range of research from effectiveness of interventions and treatments, feasibility of service provision, appropriate and timely support and meaningfulness for patients.

- Explore the value of community/home based vs hospital based services/support and rehabilitation programmes
- Determine the usefulness of nurse led clinics/services for those with COPD
- Evaluate the place of self care management plans in preventing COPD exacerbations
- Review community nursing assessment approaches for those with COPD
- Determine approaches to anxiety and depression management in COPD
- Establish the links between functional ability and impact on quality of life.

### **Conflicts of Interest:**

There are no conflicts of interest noted.

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**JBI-QARI Critical Appraisal Tool for Interpretive and Critical Research**

Reviewer \_\_\_\_\_ Date \_\_\_\_\_

Author \_\_\_\_\_ Year \_\_\_\_\_

Record Number \_\_\_\_\_

Yes No Unclear

1. Is there congruity between the stated philosophical perspective and the research methodology?
2. Is there congruity between the research methodology and the research question or objectives?
3. Is there congruity between the research methodology and the methods used to collect data?
4. Is there congruity between the research methodology and the representation and analysis of data?
5. Is there congruity between the research methodology and the interpretation of results?
6. Is there a statement locating the researcher culturally or theoretically?
7. Is the influence of the researcher on the research, and vice-versa, addressed?
8. Are participants, and their voices, adequately represented?
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Overall appraisal:                      Include                      Exclude                      Seek further info.

Comments (Including reasons for exclusion)

**JBI -QARI Data Extraction Form for Interpretive and Critical Research**

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Reviewer \_\_\_\_\_ Date \_\_\_\_\_  
Author \_\_\_\_\_ Year \_\_\_\_\_  
Journal \_\_\_\_\_ Record Number \_\_\_\_\_

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**Study Description**

Methodology \_\_\_\_\_  
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Method \_\_\_\_\_  
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Intervention \_\_\_\_\_  
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Setting \_\_\_\_\_  
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Geographical \_\_\_\_\_  
\_\_\_\_\_  
Cultural \_\_\_\_\_  
\_\_\_\_\_  
Participants \_\_\_\_\_  
\_\_\_\_\_  
Data analysis \_\_\_\_\_

**Authors' Conclusions**

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**Comments**

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## Appendix III

### Table of Included Studies

#### Support and Quality of Life

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/ Setting	Themes	Authors' Conclusions
BERGS, D. <sup>13</sup>	2002	'The Hidden Client' – women caring for husbands with COPD: their experience of quality of life.	Phenomenological approach	6 women who cared for husbands with COPD (age range 47-69yrs)	The experience of quality of life of women taking care of husbands with COPD	Community based (Iceland)	No time to worry about my physical health; Having employment is important; On the alert even at night; Weakening of marital relationship; The emotional straitjacket of living with him, Too proud to ask for help; Becoming mentally worn out; The feeling of isolation; positive sides of caregiving; spiritual help; Need for an increased social support system; To walk the road with him to the very end;	Quality of life is defined by their role as caregiver. They may then neglect their own health. Nurses need to provide support, information and understanding which will enhance the total care for those with COPD

							The dreadful prospect of adjusting to a single life.	
ELOFSSON, LC. and ÖHLEN, J. <sup>12</sup>	2004	Meanings of being old and living with chronic obstructive pulmonary disease.	Phenomenological-hermeneutic	6 people with COPD (all over 75 yrs)	Lived experiences of elderly persons who are severely ill with COPD and in need of everyday care	Community based (Sweden)	Living with COPD: it's a hard life; Resignation – contentedness; Loneliness – connectedness; Being homeless – being at home;	Experiences were dialectic in nature and reflected the challenges of living with COPD. It is suggested that the dying process is present for a long time and so palliative care should reflect the person's hopes and fears.
LEIDY, NK. and HAASE, J. <sup>16</sup>	1996	Functional Performance in People with Chronic Obstructive Pulmonary Disease: A Qualitative Analysis	Naturalistic Inquiry	12 people with COPD (6 men and 6 women) (mean age 66.8yrs)	Describe functional performance	Community based (USA)	Household maintenance ; Movement; Family activities; Social activities; Work; Altruistic avocation; Recreation; Deriving satisfaction; Intruders; Enablers;	There is a need for a personal understanding of people's lives if appropriate activity based interventions are to be utilised for those with COPD.
ODENCRANT S, S. EHNFORSS, M. and GROBE, SJ. <sup>10</sup>	2005	Living with chronic obstructive pulmonary disease: Part 1. Struggling with meal-related situations: experiences among	Descriptive design with qualitative interviews	13 people with COPD (8 women and 5 men) (mean age (68.7 yrs)	Experiences of meal-related situations in those with COPD	Community based (Sweden)	Physical influences; Positive and Negative feelings associated with meal-related situations; Activity and feelings of	There is a need to undertake nutritional assessment of older people with COPD as a variety of factors such as eating with others, being

		persons with COPD.					dependence; Transport of groceries; Having company and being alone; Appetite and hunger; Altered intake of food; The need of time.	able to cope with buying, cooking and eating have a significant effect on nutrition.
ROBINSON, T. <sup>9</sup>	2005	Living with severe hypoxic COPD: the patients' experience.	Phenomenological approach	10 people with COPD (6 men and 4 women) (mean age 65.4yrs)	Experience of living with severe oxygen dependent COPD	Community based (England-UK)	Smoking; Physical effects; Emotional effects; Needs; Relationships	Severe COPD impacts on all aspects of life and an earlier palliative and interdisciplinary approach needs to be adopted more fully than at present.
GYSELS, M. and HIGGINSON, IJ. <sup>11</sup>	2008	Access to services for patients with Chronic Obstructive Pulmonary Disease: The Invisibility of Breathlessness	Based on Grounded Theory	18 people with COPD (11 women and 7 men) (median age 69/70, mean >64.5)	Experience of breathlessness through accounts of interactions with services.	Community focused (England – UK)	The nature of breathlessness; Stigma; The response from services.	The principles of palliative care could assist in developing care for those with COPD, particularly related to symptom control, distribution of skills, public awareness and information needs.
BARNETT, M. <sup>14</sup>	2005	Chronic obstructive pulmonary disease: a phenomenological study of patients'	Phenomenological approach	10 people with COPD (age not stated)	Experience of living with COPD	Community based (England – UK)	Perception of severity of symptoms; Functional disabilities; Emotional	COPD is frightening and debilitating and there is greater need to support people to

		experiences					trauma of coping with COPD;	develop coping strategies
FRASER, DD. KEE, CC. and MINICK, P. <sup>15</sup>	2006	Living with chronic obstructive pulmonary disease: insiders' perspectives	Hermeneutic phenomenology	10 people with COPD (5 women and 5 men) (mean age 71yrs)	Experiences of older adults with severe COPD	Community based (USA)	Knowing what works; Hanging on..Barely; Losing Control – Gaining Control.	Nurses must recognise the severe impact COPD has on daily life. Those with COPD have extensive experience of managing their disease and nurses should synthesise this with nursing knowledge.
SEAMARK, DA. BLAKE, SD. SEAMARK, CJ. and HALPIN, DMG. <sup>17</sup>	2004	Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers	Interpretative phenomenology	10 people with COPD (9 men and 1 woman) and the carers of 8 of the men. (men age 75 yrs)	Experiences of COPD, particularly with regard to ongoing and palliative care needs	Community based (England – UK)	Symptoms; Losses; Relationships with health care professionals ; The effect on the carer; Adaptation.	Whilst GP centric the study highlights the need for advanced care planning and better follow up and surveillance of those with COPD.

## Support and Organisation of care

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/ Setting	Themes	Authors' conclusions
CURRY, R. <sup>18</sup>	2006	Vision to Reality: using patients' voices to develop and improve services.	Action research	11 people with COPD (no sex or age described)	Experiences of using health services linked to COPD	Community based (England – UK)	Structure of services; Process of service delivery and Outcomes of care.	Service structure, access points and response times need to be changed to match patient needs. Need for individual assessment of

								care needs. Information is at present poor.
OLIVER, S M. <sup>19</sup>	2001	Living with Failing Lungs: the doctor-patient relationship.	Qualitative study using semi-structured interviews	16 people with COPD (12 men and 4 women) (mean age 68 yrs)	Perceptions and needs of people with COPD	Community based (England – UK)	The beginning of the doctor-patient relationship; The agenda of consultation; Illness pathway; Medication; Power in the doctor-patient relationship.	People as COPD patients may be compromised by need to be seen as a good patient (powerlessness) whilst struggling to cope with symptoms. The relationship with the doctor can impact on adherence with treatment.

### Support and Self Care/Management

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/Setting	Themes	Authors' conclusions
CICUTTO, L. BROOKS, D. and HENDERSON, K. <sup>21</sup>	2004	Self-Care from the Perspective of Individuals with Chronic Obstructive Pulmonary Disease.	Focus groups	42 people with COPD (7 focus groups) (Mean age 71 yrs)	Factors that influence self-care from the perspective of those with COPD	Community based (Toronto- Canada)	Surviving COPD: the context of living; Adjusting physically: shift from active to sedentary lifestyle, reduction in activity, planning and pacing, balancing living life with disease management, disease management strategies; Adjusting emotionally: social supports, importance of family, health	Health care professionals need to recognise and understand the complexity of factors that influence self care in those with COPD.

							care professionals, peer support, emotional health.	
CHEN, KH. CHEN, ML. LEE S, CHO, HY. and WENG, LC. <sup>24</sup>	2008	Self-management behaviours for patients with chronic obstructive pulmonary disease: a qualitative study	Qualitative, descriptive design	18 men with COPD (mean age 74.06 yrs)	Explore the self-management behaviours of patients with COPD.	Community focused although data collected in secondary care (Tao-Yuan, Taiwan)	Symptom management, activity and exercise implementation, environmental control, emotional adaptation, maintaining a health lifestyle	Nurses should adopt an active role in supporting and helping patients to adapt to physiological and psychosocial changes by maximising self-management behaviours, which are varied and may be culturally specific.
KANERVISTO, M. KAISTILA, T. and PAAVILAINEN, E. <sup>23</sup>	2007	Severe Chronic Obstructive Pulmonary Disease in a Family's Everyday Life in Finland: perceptions of people with chronic obstructive pulmonary disease and their spouses.	Qualitative – thematic interviews.	5 people with COPD (3 female and 2 male) and 4 spouses	Describe the coping of families of people with COPD in advanced stages	Community focused (Tampere – Finland)	Impairment of body functions and structure; activities; participation, environmental factors.	The WHO International Classification of Functioning, Disability and Health provided a framework for the themes here. There was also a clear indication that health care professionals are not well informed about COPD and therefore care is not optimal.
LEIDY, NK. and	1999	Functional Status from	Phenomenology	12 people with COPD	The meaning of functional	Community focused (USA)	Effectiveness (being able):	The decline associated

HASSE, JE. <sup>22</sup>		the Patient's perspective: The challenge of preserving personal dignity.		(6 men and 6 women) (mean age 66.8yrs)	performance in COPD		physical predictability, energy, variety in the form of expression, expertise, responses. Connectedness (being with): desire for a sense of familiarity and comfort, enhanced connectedness through shared experiences, heaving understanding and trustworthiness, responses	with COPD challenges personal integrity and effectiveness and connectedness with their world. Participants were very clear that they did not feel connected with health care providers
SPENCE, A. HASSON, F. WALDRON, M. KERNOHAN, W. G. MCLAUGHLIN, D. COCHRANE, B. and WATSON, B. <sup>20</sup>	2008	Active carers: living with chronic obstructive pulmonary disease.	Descriptive, qualitative	7 carers of those with COPD (6 female and 1 male)	To explore specific care needs of informal caregivers	Community based (Northern Ireland – UK)	Impact of family care giving, Unmet support needs and Carers' perceptions of patients.	Informal carers of people with COPD receive inadequate support and have a number of unmet needs that are rarely acknowledged

## Support and Adherence

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/ Setting	Themes	Authors' conclusions
JOHNSON, G. KONG, D. C. M.,SANTAMARIA, N. M. LLOANNIDES-DEMOS, L. and	2006	Adherence to Disease Management Interventions for COPD Patients: Patients'	In depth interviews nested within a large RCT	28 people with COPD (21 male 7 female) (mean age 70.1 yrs)	To explore factor associated with adherence to disease management	Community based (Victoria – Australia).	Attitudes to treatment, Knowledge about treatment, Deviations form recommended	Adherence is influenced by many factors, for example experiences of treatment disease and health professionals. Health

STEWART, K. 25		Perspectives.			interventions from COPD patients' experiences.		treatment.	professionals can enhance adherence by empathy, improving knowledge and faith in treatment and reducing concerns.
JONES, R C. M. HYLAND, M E., HANNEY, K. and ERWIN, J A. <sup>26</sup>	2004a	Qualitative Study of Compliance with Medication and Lifestyle Modification in Chronic Obstructive Pulmonary Disease (COPD).	Focus groups	29 people with COPD (20 male, 9 female)(mean age 67 yrs)	To examine issues for patients concerning compliance with treatment for COPD.	Community focused (England – UK).	Understanding of inhaled drug therapy What to do in an emergency Exercise behaviour, exercise related beliefs and exercise related information given by health professionals Information on diet given by health professionals	In general, due to severity of symptoms, adherence to medication regimes is good. However, the quality of diagnosis, advice, information and support from health professionals was poor.

## Support and Exacerbations

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/Setting	Themes	Authors conclusions
SCHOFIELD, I.KNUSSEN, C. and TOLSON, D. 28	2006	A Mixed Method Study to Compare use and Experience of Hospital Care and a Nurse-Led Acute Respiratory Assessment Service Offering Home Care to People with an Acute Exacerbation of Chronic Obstructive	Mixed methods	28 people with COPD (17 men and 11 men) (median age 68, mean age >65). Part of 104 who took part in the survey component.	Experiences and preferences for care in acute exacerbations	Community based/focused (Scotland UK)	The illness experience; Care preferences and decision-making; Service experiences; Hospital.	If possible, patients and families would prefer to be treated at home by specialist nurses. Understanding of smoking cessation and coping strategies are important for interventions by nurses.

		Pulmonary Disease.						
KESSLER, R. STAHL, E. VOGELMEIER, C. HAUGHNEY, J. TRUDEAU, E., LOFDAHL, C G. and PARTRIDGE, M R. <sup>27</sup>	2006	Patient Understanding, Detection, and Experience of COPD Exacerbations: an observational, Interview-based study.	Qualitative, multinational, cross sectional, interview based study	125 people with COPD (82 men, 43 women)(mean age 66.4yrs) 25 – France 25 – Germany 27 – Spain 28 – Sweden 20 - UK	Patients' comprehension, recognition and experiences and burden of exacerbations of COPD	Community based in 5 European countries	Patients' understanding of Exacerbation; Exacerbation profile and Use of Health Services; Warning Signs/Symptoms Associated with Exacerbations and Actions Taken; Global impact of COPD and Exacerbations; Burden of COPD Exacerbations from the patient's perspective;	People have no understanding of the term exacerbation whilst they are likely to have warning signs and seek to manage this themselves. More could be done to enhance this preventative approach. The level of psychological impact is greater than estimated.

## Support and Smoking

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/Setting	Themes	Authors' conclusions
GULLICK, JG. AND STAINTON, MC. <sup>30</sup>	2006	Smoking in Chronic Obstructive Pulmonary Disease: A Need of the Taken-for-Granted Body	Heideggerian phenomenology, Semi-structured Interviews	15 people with severe emphysema who had chosen to have a lung reduction procedure (9 men and 6 women) (median age 63 yrs, mean >66yrs) 14 close family members.	The experience of smoking addiction in those with COPD and their families	Community focused(Sydney-Australia)	The struggle with smoking as a need of the body. Overcoming the need to smoke. The right words at the right time: Using vulnerability as opportunity. The family dealing with the persons' need to smoke.	A variety of prompts for cessation can be successful in the right circumstances. The right words at the right time may be a useful maxim. However, smokers can have difficulty reconciling smoking behaviour.
SCHOFIELD,	2007	An	Semi structured	22 people with	Explore the	Community	Perceived threat.	Health gain

I. KERR, S. and TOLSON, D. <sup>29</sup>		Exploration of the Smoking-Related Health Beliefs of Older People with Chronic Obstructive Pulmonary Disease.	interviews – secondary analysis of data	COPD (15 men and 7 women). (Median age 68, mean age >65)	smoking-related health beliefs of older people with COPD	based(Scotland, UK)	Perceived benefits. Perceived barriers to/costs of quitting smoking. Cues to Action. Self-efficacy	can be achieved in older people if they quit smoking. However, this is challenging due to length of time smoking and nicotine addiction.
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## Support and Pulmonary Rehabilitation

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/ Setting	Themes	Authors' conclusions
DAVIS, A. <sup>36</sup>	2007	Exercise Adherence in Patients with Chronic Obstructive Pulmonary Disease: an exploration of motivation and goals.	Prospective Cross sectional study	14 (9 men and 5 women). Mean age 69.7yrs) with COPD	Relationship between motivation and goal orientation.	Community based (USA)	Activities related to recreation; connection and independence. Exercise goals related to explicit and self-directed goals; explicit and other-directed goals and preservation goals.	Highlights how the relationship between activity and exercise goals is not aligned. The importance of goal setting as part of interventions is important.
RODGERS, S. DYAS, J. MOLYNEUX, AWP. WARD, M J. and REVILL, SM. <sup>34</sup>	2007	Evaluation of the Information Needs of Patients with Chronic Obstructive Pulmonary Disease Following Pulmonary Rehabilitation	Focus groups	23 people with COPD (14 men and 9 women) in four focus groups (Mean age 66.75)	Understand information needs and how best to meet these to improve rehab provision and self-management	People who had attended a community hospital based Rehab Programme (England, UK)	Information needs: Understanding COPD. Rehab Process: positive aspects of the programme; aspects for modification. Continued Support: peer	A need for better information and understanding of their disease. Pulmonary rehabilitation programmes have considerable value to those who attend.

		: a focus group study.					support, individual support.	
WILSON, JS. O'NEILL, B. REILLY, J. MCMAHON, J. and BRADLEY, J. M. <sup>37</sup>	2007	Education in Pulmonary Rehabilitation : the patient's perspective.	Focus groups	32 people with COPD (6 focus groups). 8 Health professionals (1 focus group).(mean age 67.1yrs)	Ascertain perspectives of what should be included in the educational component of pulmonary rehab programme.	Patients recruited from a regional respiratory centre and OPD (Northern Ireland- UK)	Disease education, management of breathlessness and the physical impact of COPD, medication, psychosocial impact of COPD, welfare and benefits system, format for delivery, educator, location, duration and frequency, supplementary information and long term support.	There are deficits in knowledge, understanding and management of COPD that should be addressed in community based rehab programmes.
HARRIS, D. HAYTER, M. and ALLENDER, S. <sup>39</sup>	2008	Improving the Uptake of Pulmonary Rehabilitation in Patients with COPD: qualitative study of experiences and attitudes.	Qualitative interviews	16 (12 men and 4 women) people with COPD(mean age 66.8yrs)	To identify strategy for improving uptake of pulmonary rehab	Community based (England-UK)	Losing control, regaining control, pulmonary rehabilitation.	Rehabilitation programmes may be a way of those with COPD regaining control of their lives.
MONNINKHOF, E. VAN DER AA, M. VAN DER VALK, P. VAN DER PALEN, J. ZIELHUIS, G. KONING, K. and	2004	A Qualitative Evaluation of a Comprehensive Self-Management Programme for COPD Patients: effectiveness	In depth semi structured interviews	20 people with COPD (mean age 66yrs)	To explore the lack of impact on health related quality of life in a large RCT of a self management programme	Recruitment in outpatient pulmonary clinic (England – UK)	Fitness programme, self-management education course, self-treatment of exacerbations and general factors.	A self-management programme (particularly the exercise component)can impact positively on people's daily lives and well-being. However,

PIETERSE, M. <sup>33</sup>		of the patients' perspective.						existing QoL tools may fail to pick up changes.
ARNOLD, E. BRUTON, A. and ELLIS-HILL, C. <sup>38</sup>	2006	Adherence to Pulmonary Rehabilitation : a qualitative study.	Qualitative study	20 people with COPD (mean age 67 yrs)	Experience of those invited to join a pulmonary rehab programme.	People who had been invited to attend a hospital based rehab programme. (England –UK)	Adherence: positive influence of the referring medical practitioner, self-help, enjoying the programme, seeing the improvement, the effect of the group. Non-Adherence: negative influence of the referring medical practitioner, social support and motivation	People enjoy and have a sense of achievement in undertaking pulmonary rehab. The influence of the referring medical practitioner can influence adherence as can recognition of the support required for those living alone.
NORWEG, A. BOSE, P. SNOW, G. and BERKOWITZ, ME. <sup>31</sup>	2008	A Pilot Study of a Pulmonary Rehabilitation Programme Evaluated by Four Adults with Chronic Obstructive Pulmonary Disease.	Exploratory design with semi-structured interviews	4 people with COPD (1 male and 3 females) (mean age 73 yrs)	Perceptions of a pulmonary rehabilitation programme	People who attended an OPD pulmonary rehab programme (NY – USA)	Programme features: Using biofeedback – helpful in the beginning, finding support – I am not alone. Pulmonary rehabilitation benefits: building confidence – this I can do, reducing shortness of breath – I am in control, regaining hope – I have made	Controlled breathing and dyspnoea self-management perceived as essential combined with exercise programme and this can continue post programme.

							progress, coping with emotions – I feel calm with diaphragmatic breathing, maximizing energy – I am more active, exercising regularly – maintaining a routine.	
FISCHER, MJ. SCHARLOO, M. ABBINK, J. J. THIJS-VAN NIES, A. RUDOLPHUS, A. SNOEI, L. WEINMAN, JA. and KAPTEIN, A. <sup>35</sup>	2007	Participation and Drop Out in Pulmonary Rehabilitation : a qualitative analysis of the patient's perspective.	Qualitative study – semi-structured interviews	12 people with COPD referred to a rehabilitation clinic (mean age 65.5 without 2 young patients)	Examine patients' pre-treatment goals regarding pulmonary rehabilitation	Referrals to a rehabilitation clinic (Leiden, Netherlands)	Referral to rehabilitation, beliefs about pulmonary rehabilitation, self-set treatment goals, attitudes towards participation	COPD patients' beliefs about their illness and treatment play a role in uptake and drop-out of pulmonary rehab.
O'SHEA, S. D., TAYLOR, N. F. and PARATZ, J. D. <sup>32</sup>	2007.	Qualitative Outcomes of Progressive Resistance Exercise for People with COPD.	Interviews as part of an RCT.	22 people with COPD	Perceptions of outcomes from a home based progressive resistance exercise program.	A location nominated by the participant.	Short term outcomes of PRE Physical, Psychological, Social, Negative outcomes. Long term outcomes.	Demonstrated benefits of significant ability to undertake 'normal' activity.

### Support and Long Term Oxygen Therapy

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/Setting	Themes	Authors' conclusions
EARNEST, MA. <sup>40</sup>	2002	Explaining Adherence to Supplemental Oxygen	Grounded theory	20 COPD patients on oxygen.(mean age 69yrs)	To describe and explain the patterns of adherence to	Community based (Colorado – USA)	Patterns of oxygen use; Adopting a pattern of	People with COPD on LTOT express need

		Therapy.			supplemental oxygen in individuals with hypoxemic COPD.		adherence and moving toward full-time use.	for support with physiological, psychological needs and increasing social isolation
RING, L. and DANIELSON, E. <sup>41</sup>	1997	Patients' Experiences of Long-Term Oxygen Therapy.	Interviews	10 COPD patients on oxygen. (mean age 72yrs)	Describe experiences of the self-management of continuous oxygen therapy and their view of managing their chronic disease.	Community based (Sweden)	Restricted to time and room, An advantage for the body, Living in one's own life rhythm, put up on order to live.	People evolve level of adherence through experience, trial and error and struggle to balance competing demands and deal with profound loss.

## Support and Telecare

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/Setting	Themes	Authors' conclusions
HORTON, K. <sup>43</sup>	2008	The use of, Telecare for People with Chronic Obstructive Pulmonary Disease: implications for management.	Case study approach	Focus group with care home staff and patient case studies	Evaluation of the telecare service offered by a COPD Home Care team.	Community based(England –UK)	Experience and expectation in the use of telecare; Usability of equipment; A lot of wasted time; An added bonus to the patients; Changes in practice and for the future; Telecare and managing COPD	The benefits of telecare for older people are highlighted but this is tempered by the technological and logistical difficulties of using this approach
MAIR, F. S. HISCOCK, J. and BEATON, S	2008	Understanding Factors that Inhibit or Promote the	Ethnography	9 people with COPD and 11 nurses	Process evaluation of an RCT of home telecare for	Community based (UK).	Equipment issues; Communication issues; Nurse-	There is real promise in telecare but this requires

C. <sup>42</sup>		Utilization of Telecare in Chronic Lung Disease.			management of acute exacerbations of COPD		patient relationship; Attitudes; Nurses' and Patients' work; safety; Professional issues;	increased congruity between nurses and patients and greater acceptance on the part of nurses. .
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## Support and End of Life

Authors	Year	Title	Methodology	Participants	Phenomenon of Interest	Location/ Setting	Themes	Authors' conclusions
EK, C. and TERNESTEDT, BM. <sup>47</sup>	2008	Living with Chronic Obstructive Pulmonary Disease at the End of Life: a phenomenological study.	Phenomenology	8 people with COPD (mean >63.5 yrs)	Lived experience of living with severe COPD during palliative care phase.	Community based/ focused (Sweden)	Limited living space, changed lifestyle and challenged self-image; Lacking physical strength; Being forced to forgo activities and material things; Being socially and existentially alone; Experiencing meaninglessness;	Whilst affirming the negative consequences of COPD there is a need to focus on positive elements but these are problematic as the philosophy of palliative care is not in place for these patients.
ELKINGTON, H. WHITE, P. ADDINGTON-HALL, J. HIGGS, R. and PETTINARI, C. <sup>44</sup>	2004	The Last Year of Life of COPD: a qualitative study of symptoms and services.	Qualitative	25 carers of people who had died 3-10 months previously (Age of those who died not known but assumed to be >65yrs)	Experience of the last year of life in those with COPD.	Community based (England –UK)	Symptoms; Breathlessness; Psychological symptoms; Oxygen; Services in the community.	There is a mismatch between patients' needs and the services received by those with COPD. Palliative care involvement was not mentioned by carers.

JONES, I. KIRBY, A. ORMISTON, P. LOOMBA, Y. CHAN, K. K. ROUT, J., NAGLE, J. WARDMAN, L. and HAMILTON, S. <sup>45</sup>	2004 b	The Needs of Patients Dying from Chronic Obstructive Pulmonary Disease in the Community.	Semi-structured interviews	16 people with COPD and having maximal therapy and likely to die in the next year (mean age 74.1)	To determine, prospectively the needs of patients dying at home	Community based (England –UK)	Patients' information needs and the future course of their illness; Impact of symptoms on patients lives; Attitudes to help received; Expressed needs;	There is poor control of symptoms, a feeling of being a burden on carers and a need for further knowledge about COPD.
SPENCE A, HASSON, F. WALDRON, M. KERNOHAN, G. MCLAUGHLIN, D. WATSON, B. COCHRANE, B. and MARLEY, A. M. <sup>46</sup>	2009	Professionals Delivering Palliative Care to People with COPD: a qualitative study.	Qualitative approach – focus groups	23 health care professionals (palliative, specialist respiratory services and primary care)	Perceptions of palliative care – facilitators and barriers to delivery to people with COPD	Community based(Northern Ireland- UK)	Management of patients; Resources and support; Access to support and equipment; Palliative care;	There are shortcomings in current provision of palliative care for those with COPD and their carers. Skills of health professionals need to be enhanced.

### Excluded studies and reason(s) for exclusion

ADAMS, R., CHAVANNES.N., JONES.K., SUUBBE OSTERGAARD, N. and PRICE. D. 2006. Exacerbations of chronic pulmonary disease - A Patients Perspective. *Primary Care Respiratory Journal*, 15, pp 102-109.

**Reason for Exclusion:** Does not sufficiently meet the review criteria for support.

ARNE, M., EMTNER, M., JANSON, S. and WILDE-LARSSON, B. 2007. COPD Patients' Perspectives at the time of Diagnosis: a qualitative study. *Primary Care Respiratory Journal*, 16, (4), pp 215-221.

**Reason for Exclusion:** The participants in this study had a mean age of 63 years.

BERG, J. 1996. Quality of Life in COPD Patients Using Transtracheal Oxygen. *Medsurg Nursing*, 5, (1), pp 36-40.

**Reason for Exclusion:** Methods unclear and evidence of support negligible to meet review criteria.

CAMP, P. G., APPLETON, J. and REID, W. D. 2000. Quality of Life after Pulmonary Rehabilitation: assessing change using qualitative and quantitative methods. *Physical Therapy*, 80, (10), pp 986-995.

**Reason for Exclusion:** Predominantly quantitative and does not sufficiently meet the review criteria for support.

COWIE, L., MORGAN, M., WHITE, P. and GULLIFORD, M. 2009. Experience of Continuity of Care of Patients with Multiple Long-Term Conditions in England. *Journal of Health Services Research Policy*, 14, 2, pp 82-87.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

GODELIEF, M. J. M., KEMPEN, G. I. J. M., MESTERS, I., PROOT, I. M. and van EIJK, J. T. M. 2008. Characteristics of Social Participation as Defined by Older Adults with a Chronic Physical Illness. *Disability and Rehabilitation*, 30, (17), pp 1298-1308.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

GODELIEF, M. J. M., PROOT, I. M., JANSSEN, P. P. M., van EIJK, J. T. M. and KEMPEN, G. I. J. M. 2007. How do People with COPD or Diabetes Type 2 Experience Autonomy? An exploratory study. *Disability and Rehabilitation*, 29, (6), pp 485-493.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

GRUFFYDD-JONES.K., LANGLEY-JOHNSON.C., DYER.C., BADLAN.K., WARD.S. 2007. What are the needs of patients following discharge from hospital after an acute exacerbation of chronic obstructive pulmonary disease (COPD). *Primary Care Respiratory Journal*, ;16, (6): pp 363-368.

**Reason for Exclusion:** Focus on patient needs and not support.

GULLICK, J. G. and STAINTON, M. C. 2008. Living with Chronic Obstructive Pulmonary Disease: developing conscious body management in a shrinking life-world. *Journal of Advanced Nursing*, 64 (6), pp 605-614.

**Reason for Exclusion:** Focuses on lung reduction surgery.

GUTHRIE, S. J., HILL, K. M. and MUERS, M. F. 2001. *Respiratory Medicine*, 95, pp 196-204.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

HABRAKEN, J. M., POLS, J., BINDELS, P. J. E. and WILLEMS, D. L. 2008. The Silence of Patients with End-Stage COPD. *British Journal of General Practice*, 58, pp 844-889.

**Reason for Exclusion:** Focus on what does not provide support and the remainder is not sufficiently focused on support to meet review criteria.

HANSEN, E. C., WALTERS, J. and WOOD BAKER, R. 2007. Explaining chronic obstructive pulmonary disease (COPD): perceptions of the role played by smoking. *Sociology of Health and Illness*, 29 (5), pp 730-749.

**Reason for Exclusion:** Not sufficiently focused on smoking cessation support.

HASSON, F., SPENCE, A., WALDRON, M., KERNOHAN, G., MCLAUGHLIN, D., WATSON, B and COCHRANE, B. 2008. I can not get a breath: experiences of living with advanced chronic obstructive pulmonary disease. *International Journal of Palliative Nursing*, 14, (11), pp 526-531.

**Reason for Exclusion:** Data not relevant to review criteria.

HILL BAILEY, P. 2004. The Dyspnea-Anxiety-Dyspnea Cycle-COPD Patients' stories of breathlessness: "It's scary when you can't breathe". *Qualitative Health Research*, 14, (6), pp760-778.

**Reason for Exclusion:** Focuses on vulnerability and emotion and does not sufficiently meet the review criteria for support.

JENG, C., TSAO, L. I., HUA-HO, C. and CHANG, P. C. 2002. Experiences of Daily Living activities Within two weeks After Hospital Discharge Among Taiwanese Elderly Patients with Chronic Obstructive Pulmonary Disease. *Journal of Nursing research*, 10, (3), pp 168-175.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

JOHNSON, G., KONG, D. C. M., SANTAMARIA, N. M., LLOANNIDES-DEMOS, L. and STEWART, K. 2006. Adherence to Disease Management Interventions for COPD Patients: Patients' Perspectives. *Journal of Pharmacy Practice and Research*, 36 (4), pp 278-285.

**Reason for Exclusion:** Not sufficiently related to smoking cessation support.

LIDDY, C., DUSSEAU, J. J., DAHROUGE, S., HOGG, W., LEMELIN, J. and HUMBERT, J. 2008. Telehomecare for Patients with Multiple Chronic Illnesses. *Canadian Family Physician*, 54, pp 58-65.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

LUNDH, L., ROSENHALL, L. and TORNKVIST, L. 2006. Care of Patients with Chronic Obstructive Pulmonary Disease in Primary Health Care. *Journal of Advanced Nursing*, 56 (3), pp 237-246.

**Reason for Exclusion:** More about nursing approach to care delivery than support.

NIELD, M. 2000. Dyspnea Self-Management in African Americans with Chronic Lung Disease. *Heart and Lung*, 29, pp 50-55.

**Reason for Exclusion:** The average age of participants was 60 years.

ODENCRANTS, S., EHNFOR, M and GROBE, S. J. 2007. Living with chronic obstructive pulmonary disease (COPD): Part II. RNs' experience of nursing care for patients with COPD and impaired nutritional status. *Scandinavian Journal of Caring Science*, 21, pp 56 – 63.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

O'SHEA, S. D., TAYLOR, N. and PARATZ, J. D. 2007. But watch out for the weather: factors affecting adherence to progressive resistance exercise for persons with COPD. *Journal of Cardiopulmonary Rehabilitation Prevention*, 27, (3), pp 166-174.

**Reason for Exclusion:** Predominantly quantitative and does not sufficiently meet the review criteria for support.

PARKER, D. R., GOLDMAN, R. E and EATON, C. B. 2008. A Qualitative Study of Individuals at Risk or Who Have Chronic Obstructive Pulmonary Disease: what do they understand about their disease? *Lung*, 186, pp 313-316.

**Reason for Exclusion:** The participants in the study had an average age of 58 years.

RAHIMPOUR, M., LOVELL, N. H., CELLER, B. G. and MCCORMICK, J. 2007. Patients' Perceptions of a Home Telecare System. *International Journal of Medical Informatics*, 77, pp 486-498.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

REINKE, L. F., ENGELBERG, R. A., SHANNON, S. E., WRENCH, M. D., VIG, E. K., BACK, A. L. and CURTIS, J. R. 2008. Transitions Regarding Palliative and End-of-Life Care in Severe Chronic Obstructive Pulmonary Disease or Advanced Cancer: themes identified by patients, families and clinicians. *Journal of Palliative Medicine*, 11, (4), pp 601-609.

**Reason for Exclusion:** A comparison study about the shift from treatment to palliation which does not highlight sufficient differences in support.

ROBINSON, A., COURTNEY-PRATT, H., LEA, E., CAMERON-TUCKER, H., TURNER, P., CUMMINGS, E., WOOD-BAKER, R. and WALTERS, E. H. 2008. Transforming Clinical Practice amongst Community Nurses: mentoring for COPD patient self-management. *Journal of Clinical Management*, 17, (11), pp 370-379.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

SHACKELL, B. S., JONES, R. C. M., HARDING, G., PEARSE, S. and CAMPBELL, J. 2007. Am I going to see the next Morning? A qualitative study of patients' perspectives of sleep in COPD. *Primary Care respiratory Journal*, 16, (6), pp 378-383. **Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

SKILBECK, J., MOTT, L., PAGE, H., SMITH, D., HJELMELAND-AHMEDZAI, S. and CLARK, D. 1998. Palliative Care in Chronic Obstructive Airways Disease: a needs assessment. *Palliative Medicine*, 12, pp 245-254.

**Reason for Exclusion:** Data not relevant to review criteria.

SMALL, S. and LAMB, M. 1999. Fatigue in Chronic Illness: the experience of individuals with chronic obstructive pulmonary disease and with asthma. *Journal of Advanced Nursing*, 30, (2), pp 469-478.

**Reason for Exclusion:** The mean age of participants was 63 years.

TAKATA, S., WASHIO, M. and MORIWAKI, A. et al. 2008. Burden Among Caregivers of Patients with Chronic Obstructive Pulmonary Disease with Long-Term Oxygen Therapy. *International Medical Journal*, 15, (1), pp 53-57.

**Reason for Exclusion:** Mainly quantitative data.

WALTERS, J. A., HANSEN, E. C., WALTERS, E. H. and WOOD-BAKER, R. 2008. Under-Diagnosis of Chronic Obstructive Pulmonary Disease: a qualitative study in primary care. *Respiratory Medicine*, 102, pp 738-743.

**Reason for Exclusion:** Main focus is on diagnosis delay.

WATSON, B., MYLOTTE, A. and PROCTER, S. 2003. A Community Outreach Service for People with COPD. *Nursing Times*, 99, (17), pp 33-36.

**Reason for Exclusion:** Insufficient detail of qualitative Methods to be certain of approach.

WILKES, L., CIOFFI, J., WARNE, B., HARRISON, K. and VONU-BORICEANU, O. 2007. Clients with Chronic and Complex Conditions: their experiences of community nursing services. *Journal of Nursing and Healthcare of Chronic Illness*, 17, (7b), pp 160-168.

**Reason for Exclusion:** Very general rather than specific to meet the review criteria.

WILLIAMS, V., BRUTON, A., ELLIS-HILL, C. and MCPHERSON, K. 2007. What Really Matters to Patients Living with Chronic Obstructive Pulmonary Disease? An exploratory study. *Chronic Respiratory Disease*, 4, pp 77-85.

**Reason for Exclusion:** Not sufficiently focused on support to meet review criteria.

**Appendix V**

**Meta-Synthesis Table**

**(C = Credible; US = Unsupported; U = Unequivocal)**

## Support and Quality of Life

Synthesis	Categories	Findings	
<p><b>People with COPD can be reluctant to seek help due to self blame and a lack of understanding from others about breathlessness</b></p> <p>Those with COPD often blame themselves for their condition which can result in less willingness to seek help and more frustration and anger when having breathing difficulties</p>	<p>Functional disability leads to reduced self care and autonomy</p>	Food related activity and feelings of dependence (C)	
		Functional disability needs support (U)	
		People with COPD struggle with the dialectic of resignation and contentedness (U)	
		Physical activity - reduction in level due to breathlessness (U)	
		There are losses of previous activities (U)	
	<p>There is stigma associated with having COPD</p> <p>Those with COPD identify loneliness and a need for support in their home</p>	COPD can be stigmatised as it is experienced as shameful and self-inflicted (U)	
		People with COPD struggle with the dialectic of loneliness and connectedness (U)	
		People with COPD view the dialectic of being homeless and being at home as important. (U)	
		Carers are often "on the alert even at night" (U)	
		Carers are often "too proud to ask for help" (U)	
<p><b>Support for people with COPD needs to take account of their personal situation</b></p> <p>COPD appears to impact in a myriad of different ways that is influenced by a range of factors - knowledge, social situation, self blame, control.</p>	<p>Carers are often in a paradoxical situation where they are needed but are also struggling with the situation</p>	Carers are "becoming mentally worn out" (U)	
		Carers feel bowed down by the multiple roles they have to undertake (U)	
		Carers find that there is an "emotional straightjacket living with him" (U)	
		Carers have "no time to worry about my physical health" (U)	
		Carers have a "feeling of isolation" (U)	
		Carers have "the dreadful prospect of adjusting to a single life" (U)	
		Carers report a "weakening of marital relationship" (U)	
		Carers consider that "having employment is important" (U)	
		Carers feel a "need for an increased social support system" (U)	
		Carers gain support through "spiritual help" (C)	
	<p>Carers identify some factors that can support their role</p>	Carers report some "positive sides of caring" (C)	
		Carers want "to walk the road with him to the very end" (U)	
		Perceptions of severity and symptoms vary (U)	
		<p>Flexibility of support</p>	"Enablers" can facilitate or make possible continuation of activities. (C)
			"Intruders" can interfere with the activities that those with COPD want to perform (C)
			Deriving satisfaction from various activities (C)
			Knowing what works to manage dyspnoea (U)
			Patients adapt to cope with their illness (U)
			People with COPD have a number of physical influences that impact on eating (C)
			Perception of severity and symptoms - varying conditions (U)
	Problems exist in the transportation of groceries (C)		
	Relationships with health care professionals can be both positive and negative (U)		
	Social loss is increased with COPD (U)		
	<p>Knowledge of factors that impact on individuals need to be known so that support can be appropriate</p>	Sometimes those with COPD cannot manage all situations and they are Hanging On..Barely (U)	
		The social aspect of eating alone or in company can influence intake (C)	
		Those with COPD adapt to restrictions through a process of losing control-gaining control (U)	
		Those with COPD experienced difficulties with access and responses from health professionals (U)	
		<p>The breathlessness of COPD and associated panic</p>	Breathlessness can be elusive, covert and insidious in COPD (U)
			Emotional trauma of coping with COPD (U)

	needs emotional support	Symptoms of COPD can be profound (U)
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## Support and Organisation of Care

Synthesis	Categories	Findings
<p><b>Providing home services which seek to take account of the person and their context can improve care and outcomes for those with COPD</b></p> <p>Personalised care that is accepting of the person's views appears to be more likely to be influential in reducing the impact of COPD.</p>	Care teams of nurses can be viewed as equally credible to medical staff	Patients view outcomes from care by an urgent care team as accessible and credible (U)
	Home based services are viewed as more acceptable by patients and can improve outcomes	Access to services at home can reduce the restrictions of COPD (U)
		An outcome of a UCT is that patients and their families report effective emotional support. (U)
		The process of care in hospital is viewed as systems-focused and appears to disempower (U)
		The structure of services, particularly related to access, impact on care (U)
	Lack of willingness to discuss impacts or medication due to imbalance in power	Patient's management and understanding of medication varies (U)
	The empathy and understanding of the person's situation by a healthcare practitioner can impact on those with COPD	Power in the doctor-patient relationship inhibits discussion (U)
		Illness pathway is a sense of loss resulting from deterioration (U)
		One-to-one time can improve outcomes for on-going self care (U)
		The agenda of the consultation appears not to be the patients' (U)
The beginning of the doctor-patient relationship remains in patient's memory (U)		

## Support and Self Care/Management

Synthesis	Categories	Findings
<p><b>Support for self-care is needed, as it can impact on daily activities and capabilities.</b> Maintaining life with COPD requires engagement with a range of physical, psychological and social factors. However, this may be poorly supported by health care professionals</p>	<p>Connectedness with other people, spiritual beings, nature or one's inner self are important reference points for people with COPD</p>	<p>People with COPD have a desire for a sense of familiarity and comfort (U) Shared experiences can enhance connectedness (U) The understanding and trustworthiness of others are important to illness management (U)</p>
	<p>Emotional adjustment is important to those with COPD - acceptance and the value of social support are essential</p>	<p>Emotional adaptation to the disease through positive thinking (U) Emotional state changes as a result of living with COPD (U) Impact of family caregiving is unpredictable, changeable and carers are both anxious and satisfied (U) Importance of family as social support (U) Importance of health care professionals as support and partners in decision making (U) Peer support is central to surviving COPD (U)</p>
	<p>Misinterpretation or lack of awareness of need occurs from others and health professionals</p>	<p>Environmental factors impact on day-to-day life for those with COPD and this can be misinterpreted and not recognised (U) Unmet support needs are apparent for carers (U)</p>
	<p>People with COPD, and their carers, have to adjust physically to their condition through reduction (often forced) in total activity and use of strategies to overcome limitations</p>	<p>Activity and exercise implementation is used to keep condition stable and avoid dyspnoea (U) Balancing living life with disease management - achieving this balance is often seen as difficult and affiliated with stress and tension (U) Being able can be expressed in a variety of forms (U) COPD interferes with ability to perform activities of expertise easily. (U) Coping with symptoms - symptom management using a variety of approaches (U) Disease management strategies to help with adjusting physically to COPD can be helpful and difficult (U) Environmental control - household appliances and clothing are used to maintain stability (U) Fatigue and lack of energy are a challenge to being able to perform activities (U) Impairment of body functions, treatments and structure impacts on life (U) Knowledge of their disease - expertise about their own symptoms is important (U) Maintaining a healthy lifestyle as a means of preventing occurrence of symptoms (U) Participation in activity can maintain physical condition and enhance contact with peers (U) Physical predictability is no longer possible (U) Planning and pacing yourself (U) Preparation for activities (C) Reductions in activity (U) Shifting from an active to a sedentary lifestyle (U)</p>
	<p>People with COPD, and their carers, see life as survival and attempt to attain a satisfactory level of quality of life</p>	<p>Carers' perceptions of patients as struggling emotionally and physically (U) Surviving COPD: the context of living (U)</p>

## Support and Adherence

Synthesis	Categories	Findings	
<p><b>Attitudes, knowledge, perceived support and medication specific factors impact on adherence to interventions and treatments in COPD patients</b></p> <p>Adherence is multifactorial and can be influenced by a range of inputs</p>	<p>Adherence to treatments and interventions can be influenced by attitudes, knowledge and perceived support.</p>	A minority of patients felt they had a good relationship with their GP. (U)	
		Concerns about future, disease and poor quality of life influenced adherence (desperation) (U)	
		Concerns about side effects, dependence and tolerance (U)	
		COPD symptoms prompted medication taking whereas lack of symptoms resulted in non adherent behaviours. (U)	
		Faith in treatment can influence adherence (U)	
		Having knowledge about the disease and its treatment can help or hinder medication adherence (U)	
		Many patients lacked information on minor points of correct usage e.g. rinsing the mouth after use and using a spacer device. Some patients felt that the instructions for inhaler/spacer use were inconsistent between health professionals. (U)	
		Most patients had been told it was good to exercise; however, it was thought to be 'not enough information' by almost all patients. (U)	
		Most patients reported good compliance with their inhaler and rarely forgot to take them (U)	
		Patients can be embarrassed by having to use inhalers and oxygen in public (embarrassment) (U)	
		Patients can delay initiation of drug therapy and visits to their GP (Procrastination) (U)	
		Patients have different expectations regarding effects of treatment (U)	
		Patients stayed in denial of their illness until impacted by critical incidents such as hospitalisation or an acute incident of shortness of breath. (U)	
		Those with concerns about tolerance still reported taking their medicine as instructed as the fear of dyspnoea was an important factor in compliance. (U)	
		Unintentional deviations in the recommended treatment included reasons such as routine disruption due to television, alcohol, reading and visitors. (U)	
		<p>Medication regimen-related factors affect adherence.</p>	Changes to the usual medication regime risk being rejected (U)
			Medication properties such as size, odour and taste made them less appealing and raised adherence challenges (U)
Type of dosage form affects perceived efficacy (U)			

## Support and Exacerbations

Synthesis	Categories	Findings
<p><b>Exacerbations of COPD have a dramatic effect on individuals and on their disease progression. However, they may still delay seeking professional help.</b></p> <p>Peoples' experience of the significant emotional and physical effects of an exacerbation is individual to them and during this time they prefer to be cared for in their own home by an effective team</p>	<p>During deterioration and exacerbation patients prefer to be looked after in their own home.</p>	<p>People have positive experiences of an outreach Acute Respiratory Assessment Service (U)</p>
	<p>Exacerbations have a negative emotional and physical impact on patients which are personal to them</p>	<p>There are personal, perceived care and support preferences for home care during an acute exacerbation. (U)</p>
		<p>Patients experience a variety of warning signs and symptoms when exacerbations are developing and take various actions (C)</p>
		<p>Patients have little or no understanding of the term exacerbation (C)</p>
		<p>Patients illness experience is varied and individual to them (U)</p>
		<p>Patients indicate the time for recovery from an exacerbation (C)</p>
<p>Patients perceive exacerbations as a considerable burden (C)</p>		

## Support and Smoking

Synthesis	Categories	Findings
<p><b>People have a smoking story and history which influences their choice to quit.</b> This story needs to be understood if support is to be offered.</p>	<p>Paradoxical positions between smoking and not smoking</p>	<p>Older people with COPD do not necessarily perceive a threat from smoking (U)</p> <p>Perceived barriers to/costs of quitting smoking (U)</p> <p>The struggle with smoking is the need of the body with an understanding of the need to stop (C)</p>
<p><b>The right Health care professionals need to use the right words at the right time:</b> Health and Social Care Professionals, and others, need to be aware that maintaining effort in promoting smoking cessation appears to create action at appropriate points in people's lives</p>	<p>People reach a tipping point in their smoking history where they give up.</p> <p>Using the right words at the right time can be influential in smoking cessation</p>	<p>Overcoming the need to smoke (U)</p> <p>Perceived benefits (U)</p> <p>Self-efficacy can be assistive (U)</p> <p>There can be cues to action for older people with COPD who smoke (U)</p> <p>The right words at the right time. Using vulnerability as an opportunity. (U)</p>

## Support and Pulmonary Rehabilitation

Synthesis	Categories	Findings
<p><b>Pulmonary Rehabilitation programmes provide a significant degree of support for those with COPD.</b></p> <p>The programmes appear to increase physical, psychological and social well being.</p>	<p>Rehab programmes impact on strength, confidence and capability.</p>	Building confidence - this I can do. Participants reported being more confident about their abilities, including exercising and exerting themselves. (U)
		Discovering own limitations within a safe environment. (U)
		Finding support - I am not alone. Participants benefited from a supportive environment from their therapists during exercise and activity exertion. (U)
		Guided practice helped people with COPD to use breathing patterns correctly. (U)
		Maximizing energy and an increase in activity levels (U)
		Physical - After PRE, participants noted reduction in breathlessness, fatigue and improved stamina during a range of activities. (U)
		Physical - Increase in muscle strength is reported from PRE training (U)
		Physical - PRE had a Positive influence on balance and mobility during task performance (U)
		Physical inabilities led to some negative outcomes from PRE. (U)
		Psychological-The discipline of exercise progression led to some participants feeling a sense of achievement, satisfaction and pride. (U)
		Reducing shortness of breath - I am more in control. Participants reported being able to control their breathing patterns and having less shortness of breath. (U)
		The 1 hour group fitness session 1-2 a week included strength training and breathing exercises and allowed patients to recognise their individual capacity and was viewed as the most important aspect of the programme. (U)
		The person leading the group (educator) needs to be competent (C)
		There are also long term outcomes of PRE. (U)
	<p>Setting achievable goals enabled participants to reach out for achievement.</p>	Connection(keeping in touch)with their support networks such as family and friends was expressed by some participants as a goal. (U)
		Goals which may give a greater sense of freedom and independence were a main focus for some participants. (U)
		Participants found exercise goal setting difficult, only 2 of the 14 participants had explicit goals. (U)
		Patients were encouraged to set goals and were categorised into strength and condition, weight, dyspnoea and psychological well being. (U)
		Recreational activity goals were expressed by participants wanting to get back to the activities they enjoyed previously. (U)
		That Pulmonary Rehab was a tailored, regular exercise session was a concern to many patients. (U)
	<p>The Rehab programme has an effect that is more than just the programme itself</p>	Anticipated Benefits - Patients saw pulmonary rehab as an opportunity for improvement within a safe exercise environment. (U)
		Anticipated benefits - Patients felt it was important that staff were familiar with COPD (U)
		Anticipated benefits - The social aspect of exercising with other patients was enjoyable, patients feeling they could 'learn from one another. (C)
		Coping with emotions - "I feel calm with diaphragmatic breathing. (U)
		Group format is considered most appropriate for PR (U)
		Motivation such as being able to be able to play with grandchildren encouraged participants to take part. (U)
		People with COPD described how much they enjoyed going to the programme and seeing an improvement (U)
		Psychological - Activity performance was positively influenced by improved feelings of confidence in some participants. (U)
		Psychological- An improved sense of well being and a sense of control and increased confidence was reported after PRE. (U)
		Self Help - some participants described how they wanted to help themselves and to be active partners in the management of their condition. (U)
		Social - Positive social benefits were reported by attending the group. (U)
		The group fitness sessions allowed social interaction. (U)
		There is a positive group effect on individuals (U)

	The structural aspects of the programme need to be considered	<p>Location and timing of the classes for some participants would ensure attendance. (U)</p> <p>Location, duration and frequency need to be carefully considered (C)</p> <p>The timing of rehab classes determined attendance, for those who worked and for those whose condition was better in the mornings. (U)</p> <p>Transport is not a problem (U)</p> <p>Transportation to the centre was seen as a reason for drop out. (C)</p>		
<p><b>There is inconsistency and lack of knowledge in the way in which COPD is managed, the information available and the level of support available</b></p> <p>People with COPD report inconsistencies in a variety of aspects of their care that suggest limitations in provision of support that could be addressed through PR programmes</p>	<p>Explanation of diagnosis, symptom recognition and management is inconsistent.</p>	<p>Breathlessness was described as the most distressing symptom of COPD. (U)</p> <p>Difficulty in coming to terms with the condition of COPD (U)</p> <p>Early self treatment with steroids and antibiotics at the onset of exacerbation were seen as an advantage to patients. (U)</p> <p>Information is required early in primary care settings (U)</p> <p>Management of exacerbations is not optimal (U)</p> <p>Participants felt they required more comprehensive instructions on the use of inhalers related specifically to their COPD. (U)</p> <p>Participants liked receiving leaflets for individual support (U)</p> <p>Participants received information about COPD mainly from leaflets and books often given or recommended from secondary care. (U)</p> <p>Participants were dissatisfied about the information they were given when diagnosed with COPD. (U)</p> <p>Self management education enhanced the patients disease knowledge and increased their symptom control. (U)</p> <p>There is uncertainty as to when and how medication should be taken. (U)</p> <p>Understanding COPD - Participants were unfamiliar with the term COPD despite being referred with this from primary care. (U)</p>		
		<p>The referrer has an influence on the patient starting or dropping out of the programme</p>	<p>Attitudes towards pulmonary Rehab displayed four varying attitudes, Optimistic, Wait and See, Sceptic and Pessimistic. (C)</p> <p>Participation may be governed by GP sanctioning as appropriate. (U)</p> <p>People with COPD may see PR as a last chance option (U)</p> <p>Perceived intensity of the programme was cited as a potential reason for drop out. (U)</p> <p>Some participants looked to others to direct their goals as they were vague and had difficulty identifying these. (U)</p> <p>There is a negative influence of the referring medical practitioner on non starters or drop outs (U)</p> <p>There is a positive influence from the referring Medical Practitioner to rehab on those who have COPD (U)</p>	
			<p>There is need for support outwith and beyond the programme which is not readily available or known about</p>	<p>Concerns about participation - Patients concerns reflected the need for them to adapt their routine to accommodate the classes. (U)</p> <p>COPD affects more than just the individual (U)</p> <p>Irrespective of their own illnesses, many patients had other responsibilities such as the provision of childcare, working or caring for an older relative, which could affect their attendance. (U)</p> <p>Participants had analysed their own condition and had perceptions of what had brought it on. (U)</p> <p>Peer support - Confusion surrounded the availability of clubs and ongoing opportunities. (U)</p> <p>Social support and motivation to continue is affected by social isolation (U)</p> <p>Some participants would have liked the rehab to continue for support. (U)</p> <p>There is a need for long term support beyond the programme (C)</p> <p>There is considerable psychosocial impact on people's lives. (U)</p> <p>There is difficulty in acquiring information about welfare and benefits (U)</p>

## Support and long term oxygen therapy

Synthesis	Categories	Findings
<p><b>People with COPD who have long term oxygen therapy question their own need and seek compromises in their lives to accommodate use.</b></p> <p>There appears to be a constant review of functional, health, social and symptom management by individuals in respect of oxygen use.</p>	<p>People with COPD who have long term oxygen therapy question their own need and seek compromises in their lives to accommodate use.</p>	<p>An awareness of the body's need for oxygen helps acceptance - "An advantage for the body" (U)</p> <p>Functional management of everyday tasks (C)</p> <p>Managing the social milieu of daily life - social management. (C)</p> <p>Optimally managing health. (C)</p> <p>Patients living with long term oxygen are restricted to time and room, day and night, throughout the year. (U)</p> <p>Patients who are dependant on long-term oxygen therapy become short of breath with minimal physical activity - "living in one's own life rhythm". (U)</p> <p>People with COPD have to balance functional, health, social and symptom management (C)</p> <p>The experience of managing symptoms is a powerful motivator (C)</p> <p>There are distinct patterns of adherence to supplemental oxygen therapy (C)</p> <p>There is a 3 stage path to full time oxygen use (C)</p> <p>Those on LTOT have to learn in another way and adapt to new situations - "put up in order to live". (U)</p>

## Support and Telecare

Synthesis	Categories	Findings
<p><b>Usability and clinical effectiveness issues are important considerations for both patients and health care staff when thinking about using telecare.</b></p> <p>Nurses experience increased work load, concerns about legalities, equipment, relationships and professional issues with using telecare. However, patients find it increases their level of engagement and ability to self-care</p>	<p>Patients and nurses experience different benefits and drawbacks in using telehealth</p>	Nurse and patient roles change when using telecare (C)
		Nurses fear risk of missing things and are concerned about the medico-legal aspects (U)
		Nurses felt the telecare system affected their nurse-patient relationship in a negative way and was not 'as good' as home visiting. (U)
		Nurses report patients positive experiences of using telecare (C)
		Some older patients are perceived as finding telecare positive and were confident using the machine. (U)
		Telecare threatened some nurses professional identity (U)
		There was a mixture of satisfaction and dissatisfaction with using the system (attitudes to telecare) (U)
	<p>The usability and effectiveness of telecare is an important consideration for health professionals, patients and carers</p>	Healthcare professionals report a lot of wasted time (U)
		Participants experience usability challenges (U)
		The equipment is described as 'not user friendly' (U)
		There are deficiencies and concerns in communication using telecare (U)
		There are technical and equipment issues related to implementing telecare (U)

## Support and End of Life

Synthesis	Categories	Findings
<p><b>People with COPD 'struggle' with the negative effects of their disease.</b> There are physical, psychological and social restrictions placed on them towards the end of their life.</p>	<p>Care, support and resources for people with COPD appear variable and inconsistent</p>	<p>Health professionals believe patients have access to practical support and equipment (U)</p>
		<p>Health professionals identify access to resources and support as specific issues for palliative care for patients with COPD (U)</p>
		<p>Services in the community varied depending on service available and patients expressed need (U)</p>
	<p>Managing end of life COPD is complex and doesn't appear to be well understood by patients, health professionals or carers</p>	<p>Health professionals have differing views on the nature, definition and timing of palliative care (U)</p>
		<p>Health professionals viewed the management of Patients as being 'crisis managed' (C)</p>
		<p>There are variations in what patients information needs are around their illness and the course it will take (U)</p>
<p><b>End of life health needs are not well understood and provision is variable and inconsistent.</b> This is across all aspects of provision from all groups.</p>	<p>Some patients want regular monitoring</p> <p>Living is a continual 'struggle' for patients with COPD towards the end of their life which has a negative impact on their physical, psychological and social well being</p>	<p>People with COPD know when and how to seek help (U)</p>
		<p>Being left alone and falling asleep induced psychological experiences such as anxiety and panic (U)</p>
		<p>Expressed needs of COPD patients vary (U)</p>
		<p>Impact of physical symptoms affects patients and carers lives (U)</p>
		<p>Patients struggle to breathe on minimal exertion limits physical functioning and restricts lifestyle. (U)</p> <p>Symptom relief from oxygen therapy allowed greater mobility in the home (U)</p>

## Appendix VI

### Table of findings and illustrations

#### **ADHERENCE**

Findings for : Johnson, G., Kong, DCM., Santamaria, NM., Lloannides-Demos, L. Stewart, K. -  
Journal of Pharmacy Practice and Research (2006)

Finding	Illustration from Study	Evidence
<a href="#">Changes to the usual medication regime risk being rejected</a>	A few weeks ago I went to my specialist and he said ... there is some noise at the base of your lungs. I think you better get your nebuliser out and of course use it four times a day. So I'm using it four times a day. If you've got to go out, well maybe three times a day. Sometimes you are working and you forget.(p281)	Unequivocal
<a href="#">Faith in treatment can influence adherence</a>	I found a while ago some tightness in my chest. Couldn't get breathing [went] down to the doctor: He put me on the nebuliser for ten minutes and I found it good, and I started going on that first thing in the morning.....Nothing happens and so I go back the third time and they give me something else and nothing happens. I said I'll get better myself.... I am taking them because I was told to (p280)	Unequivocal
<a href="#">Patients have different expectations regarding effects of treatment</a>	...I got very discouraged when I found(COPD medications) weren't working at all; I thought (they would be an)instant miracle.....I'm simply taking them because experts in their field told me it is the thing I should be doing, likewise the oxygen at night (p280)	Unequivocal
<a href="#">Concerns about side effects, dependence and tolerance</a>	.....I think its like glasses; you put glasses on so that you can read properly and then you get so used to having them on, you can't read without them....I am damned if I do (take prednisolone) and I am damned if I don't.....The less medication you can take the better...(p280)	Unequivocal
<a href="#">Patients can delay initiation of drug therapy and visits to their GP (Procrastination)</a>	I don't take my (salbutamol) now because I use my relax breathing technique..... I'm going to be on (the nebuliser) until I kick the bucket. So I've got to get used to it...(p280)	Unequivocal
<a href="#">Concerns about future, disease and poor quality of life influenced adherence (desperation)</a>	...As long as it clears me you know, helps my breathing. I don't want to sit here on this (nebuliser) any more all the time (p280)	Unequivocal

<p><a href="#">Patients can be embarrassed by having to use inhalers and oxygen in public (embarrassment)</a></p>	<p>...That's what made him put off getting oxygen in the first place because of people seeing that he was on it..(p280).</p>	<p>Unequivocal</p>
<p><a href="#">Having knowledge about the disease and its treatment can help or hinder medication adherence</a></p>	<p>The emphysema is ongoing; I think the medication is keeping it at bay. That's what I think. I will need them, unless something comes up in the future. (p.281)..... I certainly don't want to start on (bupropion) when I've heard so many stories about, you know, bad reactions. (p281)</p>	<p>Unequivocal</p>
<p><a href="#">Type of dosage form affects perceived efficacy</a></p>	<p>When you do the Accuhaler, you are not too sure whether you've got it. .... But when you've got the (metered dose inhaler), you can hear it. (p.281) If you are in trouble, the (Spacer) would be the one if you are at home, but when I'm out I find instead of carrying that big one, I just carry that little portable (Spacer). (p281)</p>	<p>Unequivocal</p>
<p><a href="#">Unintentional deviations in the recommended treatment included reasons such as routine disruption due to television, alcohol, reading and visitors.</a></p>	<p>Watching television, getting involved in the newspaper or something like that and all of a sudden you realise that it's bedtime and go to bed and forget to take it. (p282).</p>	<p>Unequivocal</p>
<p><a href="#">Patients stayed in denial of their illness until impacted by critical incidents such as hospitalisation or an acute incident of shortness of breath.</a></p>	<p>The reason I gave up smoking was, I was at a friend's place in the evening, autumn, winter out in the country where I'd been smoking like mad all night. Went outside for a breath of fresh air and my air supply went; I thought I was going to die..... but it frightened the hell out of me, because I thought I was looking at my future, 'the man with no air'. I gave up smoking like that. (p282).</p>	<p>Unequivocal</p>
<p><a href="#">COPD symptoms prompted medication taking whereas lack of symptoms resulted in non adherent behaviours.</a></p>	<p>If I am breathless I'll take (salbutamol). Somebody told me you should take it before you start exercising; I keep forgetting ..... because I feel good. (p282).</p>	<p>Unequivocal</p>

<p><a href="#">Medication properties such as size, odour and taste made them less appealing and raised adherence challenges</a></p>	<p>I don't like the taste of (Ipratropium) It tastes foul ... acidy sort of. It's not very nice. (Salbutamol) is much smoother and easier to take. (p.281). 'clung to my throat' Holidays and emergencies had an impact on adherence (Credible).</p>	<p>Unequivocal</p>
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Findings for : Jones, RCM., Hyland, ME., Hanney, K. and Erwin, J. - Primary care respiratory journal (2004)

Finding	Illustration from Study	Evidence
<p><a href="#">Many patients lacked information on minor points of correct usage e.g. rinsing the mouth after use and using a spacer device. Some patients felt that the instructions for inhaler/spacer use were inconsistent between health professionals.</a></p>	<p>But as how to take them every doctor seems to tell you something different actually. One doctor said take a puff and carry on breathing, another one says take a big puff and hold your breath. It's a bit of a worry.</p>	<p>Unequivocal</p>
<p><a href="#">Most patients reported good compliance with their inhaler and rarely forgot to take them</a></p>	<p>No I don't forget (to use inhaler). It's a regimen in my house. Anything to help you breathe.(p151). I never forget - I have rituals, so I don't. (p151). You got no choice. (p151) ....I wouldn't dare do otherwise.</p>	<p>Unequivocal</p>
<p><a href="#">Those with concerns about tolerance still reported taking their medicine as instructed as the fear of dyspnoea was an important factor in compliance.</a></p>	<p>I always remember (to use inhaler) but I often wonder what it would be like if I ever forgot it. I would never risk it though I'm so dependent on it to breathe. (p151).</p>	<p>Unequivocal</p>
<p><a href="#">A minority of patients felt they had a good relationship with their GP.</a></p>	<p>"He will come out within half an hour. If I ring the surgery, I can always see somebody the same day". (p151)</p>	<p>Unequivocal</p>
<p><a href="#">Most patients had been told it was good to exercise; however, it was thought to be</a></p>	<p>"Nobody has actually told me whether it is good or not to get out of breath when taking exercise. I would have thought that it was something very</p>	<p>Unequivocal</p>

<p><a href="#">'not enough information' by almost all patients.</a></p>	<p>basic that they need to explain". (p152) being breathless was 'frightening' and 'embarassing'. Exercise important but not strenuous exercise (Credible p152).</p>	
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## END OF LIFE

Findings for : Spence, A., Hasson, F., Waldron, M., Kernohan, WG., McLaughlin, D. Watson, B., Cochrane, B. and Marley, AM. - Palliative Medicine (2009)

Finding	Illustration from Study	Evidence
<p><a href="#">Health professionals viewed the management of Patients as being 'crisis managed'</a></p>	<p>... acknowledge the difficulties faced by patients with advanced "COPD such as breathlessness, fatigue, pain, poor symptom management, chronic coughing, anxiety, panic attacks and loss of independence. Often patients were in urgent need of care as a result of an acute exacerbation (p127). It's a matter of trying to manage them the best we can at that level and help them make the most out of that time and not lie down under it. (p127)</p>	<p>Credible</p>
<p><a href="#">Health professionals identify access to resources and support as specific issues for palliative care for patients with COPD</a></p>	<p>"If you are out on house calls you can't afford to spend 45 minutes sitting at that time , I wish we did, but realistically we could give it maybe as a one off but it's not really feasible". (p128) Professionals dealt with immediate issues raised by the patients (p128) " I'm not a qualified counsellor, I can provide some support, I'm very limited and it's very difficult to refer them on". (p128)</p>	<p>Unequivocal</p>
<p><a href="#">Health professionals believe patients have access to practical support and equipment</a></p>	<p>Patients have access to support and equipment such as oxygen, nebulisers and wheel walkers (Credible p128) "... everybody who needs these things needs them now ..... there is nobody that gets these things if it isn't an urgent need for them." (p128)."They (carers) are the real backbone of a patient's care, so they have to be well supported." (p128) "However, many felt that few carers accessed respite services due to a lack of awareness amongst family members of what services were available and feeling that they were not entitled to any support" (p128).</p>	<p>Unequivocal</p>
<p><a href="#">Health professionals have differing views on the nature, definition and timing of</a></p>	<p>'... often equated palliative care with end-of-life care; therefore they suggested that not all COPD patients had palliative care needs.' (Credible) p.128</p>	<p>Unequivocal</p>

<p><a href="#">palliative care</a></p>	<p>"Patients with end stage COPD very much have palliative care needs." p.128 'a patient with COPD might be at the end stage for a longer duration than a patient with end-stage cancer; therefore difficulties experienced in identifying the end-of-life stage in their patients' progression resulted in reluctance among medical staffs to refer patients to palliative care' (Credible) p.128 The significance of symptoms is an indicator of when to refer (Credible) p.128 "... we need to think about how you feel and accessing the best people to make you the most comfortable" p.128 Participants perceived reluctance on the part of the medical staff to refer patients to palliative care (Credible p.129). "They don't really understand it, how the care can help" p.129. Poor understanding of others roles and the possible benefits of palliative care services resulted in a reluctance to use such services (Credible p.129). some felt that patients and families were well educated in COPD, others felt that patients and families did not understand its chronic nature (Credible p.129). "Getting the right information to the right people at the right time is much more difficult than we sometimes imagine. ... information at the wrong time they ignore it or if it's inappropriate, it can frighten them or raise their anxiety ..." P.129. Many felt such topics would result in patients viewing them as 'giving up' on them. (Credible p.129). Introducing palliative care as a gradual change of emphasis or focus on the patients' comfort was preferred (Credible p.129).</p>	
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Findings for : Jones, I., Kirby, A., Ormiston, P., Lomba, Y., Chan, KK., Rout, J., Nagle, J., Wardman, L and Hamilton, S. Family practice (2004)

Finding	Illustration from Study	Evidence
<p><a href="#">There are variations in what patients' information needs are around their illness and the course it will take</a></p>	<p>how long I've got to live, well how long I'm still likely to last and how it deteriorates ..... its just that I'm interested, not that I'm worried just that I'd like to know what's happening to me".p.311 "No, what I know is enough for me. I know it won't go and better, it'll go worse if anything" p.311</p>	<p>Unequivocal</p>
<p><a href="#">Impact of physical symptoms affects patients</a></p>	<p>anxieties were common, with more than half the patients expressing fear of becoming a burden on</p>	<p>Unequivocal</p>

<a href="#">and carers lives</a>	their carers (Credible p.312) "Well for one thing its my wife's health that I am bothered about ..... in the night she's up out of bed to see that I am all right, if she can't hear me she's out..." p.312. "I worry in the middle of the night if I can't get my breath I shall be on my own and die" p.312	
<a href="#">Attitudes towards and opinions on smoking</a>	"Oh its 100% contributed" p.312	Unequivocal
<a href="#">Expressed needs of COPD patients vary</a>	Few patients felt that further input from the primary care team was necessary or realistic, most were grateful for their nebulisers and oxygen, with few believing further medication would help" p.312	Unequivocal
<a href="#">People with COPD know when and how to seek help</a>	"My son is always here"...."I think with this sort of thing you should be on a an automatic visiting list, not constantly having to ring them up to come" p312	Unequivocal

Findings for : Elkington, H., White, P., Addington-Hall, J., Higgs, R and Pettinari, C. - Respiratory Medicine (2004)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">Patients struggle to breathe on minimal exertion limits physical functioning and restricts lifestyle.</a>	"Well x couldn't walk very far without getting out of breath, climbing stairs, he climbed one flight and stopped for about 10 minutes" p.441 " ... by the time we'd got her to the doctors, she'd be fighting for her breath even if we'd had a car" p.441 ".... The only times he could go out, was when I took him in the car. And he could never walk very far at all. So it was a case of going in the car to somewhere and that was it" p.442. "He had his chair there in the corner and he used to eat, sleep and do everything in it like" p.442. If she didnt have me she would have been a very lonely person." p.442 "He (the consultant) said This is how it should be done in the community, you know look after your own, with back up p."442 Breathlessness was not always seen as a significant problem by carers (Credible) "she wasn't struggling for breath; you know she wasn't fighting for breath. you know, like I've seen some people really fight for breath. But she wasn't fighting for breath, she wasn't desperate" p.442.	Unequivocal

<p><a href="#">Being left alone and falling asleep induced psychological experiences such as anxiety and panic</a></p>	<p>"he said. You're not here, none of you are here when I wake up in the morning" p.442 (14) "... she was too frightened to go into a deep sleep in case she didn't wake up" p.442 "She had panic attacks terrible didn't she, where she'd wake up and she couldn't breathe even with the oxygen" p.442 Carers noted a sense of 'giving up' by patients' and Doctors' (Credible p.443) "I know there was nothing they could do for him and he knew, but it was a feeling of you're abandoned, we don't want to see you no more. There is nothing we can do, no, but there is tender loving care. Even if there is nothing they can do" p.443</p>	<p>Unequivocal</p>
<p><a href="#">Symptom relief from oxygen therapy allowed greater mobility in the home</a></p>	<p>"It (home oxygen) was a good thing for the fact that she weren't fighting for her breath." p.443 Contrast - "... she wanted to be near her oxygen, she didn't want to go to far away .... so she spent most of her time at home. p.443</p>	<p>Unequivocal</p>
<p><a href="#">Services in the community varied depending on service available and patients expressed need</a></p>	<p>"... he didn't want help from anybody. He did not like going to the doctors, we had to really force him to go to the doctors you know". p.443 Some care was prescription only contact (Credible p.443) "You just used to fill in your prescription and tick it off, don't you - what you want and that was it" p.443 Seeing the respiratory nurse was positive in terms of time spent with the COPD sufferer (Credible p.443) "Did the nebulizer, checked on things ... she knew her from hospital anyway. And I think mum would have told her how badly she was feeling." P.443 A lack of active monitoring in the form of regular reviews was criticized (Credible p.443) "... the doctor shouldn't have kept writing those prescriptions out. He should have had her down to the surgery or come down here to have a look at her." p.443 Back up for carers was an important aspect of service provision e.g. panic button or named person to contact (credible p.443) "But when you leave hospital he knew that there was nothing after that. Nothing there was just me and him." p.443 Carers noted a sense of 'giving up' by patients' and Doctors' (Credible p.443) "I know there was nothing they could do for him and he knew, but it was a feeling of you're abandoned, we dont want to see you no more. There is nothing we can do, no, but there is tender loving care. Even if there is nothing they can do" p.443</p>	<p>Unequivocal</p>

## SELF CARE/MANAGEMENT

Findings for : Chen Kang-Hua, Chen Mei-Ling, Lee Sheuan, Cho Hsiu-Ying, and Weng Li-Chueh  
- JAN (2008)

Finding	Illustration from Study	Evidence
<a href="#">Coping with symptoms - symptom management using a variety of approaches</a>	<p>If I perceive worsening of breathlessness, I rest. A lot of things need to be done, but I wait because of breathlessness.... some participants chose inhalation of an anti-cholinergic agent, as well as beta2 agonist bronchodilator..... I drink some warm water and walk a while at my house when I feel uncomfortable. If the situation gets worse, I call my son to give me a massage. If it doesn't help I go to ER.....He uses a hot towel to massage my chest, hands, and feet, with redflower oil</p>	<p>Unequivocal</p>
<a href="#">Activity and exercise implementation is used to keep condition stable and avoid dyspnoea</a>	<p>The pulmonary therapist told me to exercise, so now I get up at 4 in the morning to exercise.... It rains, so I stay at home and walk around my house 40 or 50 circles, about 70 steps for a circle.... Sometimes I shake my legs, not because I am sick. I do it on purpose. (p595)</p>	<p>Unequivocal</p>
<a href="#">Environmental control - household appliances and clothing are used to maintain stability</a>	<p>I will wear enough clothes.....I turn the heater to a higher temperature on colder days....I have a table in my room, about one to two metres away from my bed. That's my area....I seldom go to parties or gatherings. I don't like to dine out in restaurants that are filled with second-hand smoke. I'd rather not go if I don't have to. (p560)</p>	<p>Unequivocal</p>
<a href="#">Emotional adaptation to the disease through positive thinking</a>	<p>You need to stand up bravely even if you are uncomfortable....to live one more day, exercising is good for your health. If you don't do it, you die soon....Sometimes I do feel pessimistic. The only thing I can do is to continue the treatment and take care of myself until I can't live anymore...I used to be depressed and uncomfortable, but now I am used to it. (p?560)</p>	<p>Unequivocal</p>
<a href="#">Maintaining a healthy lifestyle as a means of preventing occurrence of symptoms</a>	<p>A healthy lifestyle means getting up early and going to sleep early....Do not eat cold food...cold food triggers coughs. It is better to warm food.....I do Chi Kung; it's very helpful. I do it every day, it works, it is great for the lungs.....I can't quit. I have been smoking for 60 years. It is not possible. My colleagues quit smoking and came</p>	<p>Unequivocal</p>

	up with many (physical) problems. So I just smoke less. (?p602)	
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Findings for : Cicutto, L., Brooks, D. and Henderson, K. - Patient education and counselling (2004)

Finding	Illustration from Study	Evidence
<a href="#">Surviving COPD: the context of living</a>	I don't want to get any worse. I know I'm not going to get any better...No, it doesn't get better (p170) Its completely irreversible and what happens when you get COPD...you ever tried to glue a balloon back together, no way...(p171)	Unequivocal
<a href="#">Shifting from an active to a sedentary lifestyle</a>	I don't play golf anymore but that's what I used to like doing...what I do now is...resting, reading and crossword puzzles and playing cards with the grandchildren. I'm a golfer, I was a golfer, I can't do it anymore, it's three years and it hurts. (both page 171)	Unequivocal
<a href="#">Reductions in activity</a>	I've got to do my vacuuming, so I pick up the vacuum cleaner and use it to do my exercises, and when I'm cooking, I do the arms out (and with) reading, I sit right down or squat down, (and) I do quarter squats. I have been a little reluctant to do the exercises ....when you've got a shortage of oxygen you don't feel like wearing yourself out on exercising. (p171)	Unequivocal
<a href="#">Planning and pacing yourself</a>	(I've got to) figure out what I have to do, and(not) do then things one day, and do nothing the next week (p172)	Unequivocal
<a href="#">Balancing living life with disease management - achieving this balance is often seen as difficult and affiliated with stress and tension</a>	I seemed to me that I spent my whole day doing exercises and I wanted to belong to things, I wanted to be doing things and I'd always have to explain, well I can't come until after 11.00 because I have two sets of exercises to do (p172)	Unequivocal
<a href="#">Disease management strategies to help with adjusting physically to COPD can be helpful and</a>	Diaphragmatic breathing...I can feel relief, so it really works. My puffers...I depend on them more than anything - morning and night. Well I'm not really into exercises; I do the breathing exercises. I hate exercise. Even if you end up in hospital and you're capable or	Unequivocal

<a href="#">difficult</a>	not, you're supposed to do your exercises...you have to try and do it, even if you are sick. (p172)	
<a href="#">Importance of family as social support</a>	Without the support of your family, well I'll tell you, believe me, you won't get very far... They (family) don't want you to give up and that's 90% of the battle. (p173)	Unequivocal
<a href="#">Importance of health care professionals as support and partners in decision making</a>	It(follow up visits) keeps everything in the forefront and uh, well it helps the doctors too. So thank God for some of those docs. When I saw Dr X he gave me a range (referring to medication dosage) that I could fiddle with myself and then after that I was more comfortable....(p173)	Unequivocal
<a href="#">Peer support is central to surviving COPD</a>	...when we look at each other we say hey we're not done by a long shot. You get an incentive to try and help yourself more when you see what other people have done, you say okay, maybe I should try this, maybe I should try that.. (p174)	Unequivocal
<a href="#">Emotional state changes as a result of living with COPD</a>	First thing is for a person, if diagnosed with this disease (is) to accept it. To accept your problem is half the battle. If you don't, well, you'll become a basket case. ... If you don't have that emotional help, you can exercise all you want but if your heart is aching, you're feeling so depressed, you'll give it up..... What works for me is actually, the more happy I am the better I feel, the more I can do...(p174)	Unequivocal

Findings for : Leidy, NK. & Haase, JE. - Research in Nursing and Health (1999)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">Physical predictability is no longer possible</a>	Some days I can wake up, don't even look like I have it. I'm not shortness of breath or nothin and I can just about do anything I want to do. Other days I wake up, I just don't have it. I don't even have it to even come down the steps, let alone go up it...and if I have an extremely bad day, I don't hardly leve the machine....10 of the 12 participants described the loss of familiar sleep-wake patterns..(p71)	Unequivocal
<a href="#">Fatigue and lack of energy are a challenge to being able to</a>	I don't have as much energy...I'm sort of like a little loose noodle....Where I always was a very energetic person, I always thought. I'm not a very energetic person anymore	Unequivocal

<a href="#">perform activities</a>	(p71_	
<a href="#">Being able can be expressed in a variety of forms</a>	...through social roles or tasks, including work outside the home. Having hobbies, being a good neighbour, and volunteering were also ways of asserting effectiveness...I used to like to play a little ball and differnt stuff but I can't do that no more...I used to sing like "O Holy Night" and songs like that. I used to get pretty high. I can't do that now..(p71)	Unequivocal
<a href="#">COPD interferes with ability to perform activities of expertise easily.</a>	I used to do the whole thing myself. Now I have to wait until somebody to wait until somebody brings me that bag of cement, puts it in the wheelbarrow, and mixes it for me. Then I can do the job, but that just aggravates me to have to wait for somebody ....(p71)	Unequivocal
<a href="#">Knowledge of their disease - expertise about their own symptoms is important</a>	I use my feel about what I can do and what I can't do. Or how long I'll be able to hold out before I have to come to hospital (p71)	Unequivocal
<a href="#">People with COPD have a desire for a sense of familiarity and comfort</a>	Mrs NT described how her nasal cannula and oxygen made her feel conspicuous when she went shopping or ate with friends in a restaurant "It feels like you're out of place when you go someplace" she said "They look at me like I have two heads".....It's a cruel world today. It was a different world when I grew up"	Unequivocal
<a href="#">Shared experiences can enhance connectedness</a>	My sister lived near me, we went out almost every day and saw each other and did something. Whern she died 2 years ago it really changed my life. I don't go out socially as much, I don't do a lot of things. It was a big blow to me (p73)	Unequivocal
<a href="#">The understanding and trustworthiness of others are important to illness management</a>	My granddaughter, when she calls me, if she detect that when I am talking to her, she tells me right away. Grandmother, get off the phone and do whatever medication you are supposed to do. She detcts it right away.....Connectedness with health care providers or institutions occurred when participants perceived that the providers were consistently responsive, conscientious and personally invested in the participant's well being.	Unequivocal

Findings for : Kanervisto, M., Kaistila, T. & Paavilainen, E. - Nursing and Health Science (2007)

Finding	Illustration from Study	Evidence
<a href="#">Impairment of body functions, treatments and structure impacts on life</a>	...when you can't just bring it along into the garden (Oxygen), or you can, but not the machine, it's that heavy, it's that heavy, that what you need is a weightlifter.....and many a time, well, when I start to move and when my lungs are all congested, like then, the big muscles get the lactic acid and I can't get enough oxygen into them and, like, it changes, moving and it's awful and hard to breathe and my muscles are sore...(p43)	Unequivocal
<a href="#">Preparation for activities</a>	....when they were in poor condition they were unable to do even light household chores.....Every participant considered that those household chores that they were able to accomplish themselves were a source of pleasure. (p43)	Credible
<a href="#">Participation in activity can maintain physical condition and enhance contact with peers</a>	I was there more often last year cos there was this gym and it was specifically wanted for those lung patients...that you could with these devices...push a bit and then it was nice that you could listen to yourself and stop in time.... ...participating in rehabilitation courses for people with pulmonary problems was particularly meaningful and safe because severely ill family members and their spouses could meet their peers there. (p43)	Unequivocal
<a href="#">Environmental factors impact on day-to-day life for those with COPD and this can be misinterpreted and not recognised</a>	...they said to her, "Why don't you do something, you're as fit as a fiddle," cos you can't see it, this breathing.. All of the subjects with COPD said they have had some kind of difficulty in receiving the care they needed.... (p44)	Unequivocal

Findings for : Spence, A., Hasson, F., Waldron, M., Kernohan, G., McLaughlin, D., Cochrane, B. & Watson, B. - International journal of palliative care. (2008)

Finding	Illustration from Study	Evidence
<a href="#">Impact of family caregiving is unpredictable,</a>	Our life has come down. The two of us used to go dancing. We loved dancing and then it all stopped..... It's like having another child sometimes because you are sort of responsible	Unequivocal

<p><a href="#">changeable and carers are both anxious and satisfied</a></p>	<p>and I feel he is my responsibility..... I just love him and I find that every day when I see him, what else could I do to try and make him a wee bit better. It's very satisfying to know that he appreciates what I do and it's nice to know you are helping someone. (p370)</p>	
<p><a href="#">Unmet support needs are apparent for carers</a></p>	<p>I've never been sat down and told..no-one had warned me about this, nobody had said, the admissions will come more rapidly... When I go to the hospital and speak to the consultants I can't get to see them, you know. They are trying new medications and nothing was explained to me. Nobody had time. I just find that very frustrating....Carers also expressed a lack of knowledge about what services were available for the patient and also for themselves.....They are very good and I know I can ring them (doctors)....I think the main thing I need as a carer is somebody to tell me what I am entitled to....If my mum is in hospital for more than 5 weeks you are not supposed to claim any benefits..having COPD means her admissions are unstable and can vary and they can't give you a discharge date because things can dramatically change....But unfortunately COPD is not classed as a terminal illness..(p370/1)</p>	<p>Unequivocal</p>
<p><a href="#">Carers' perceptions of patients as struggling emotionally and physically</a></p>	<p>He's completely and utterly spent, you know. He couldn't even talk to me because he was just completely breathless, lethargic and you know just no spark of life in him.....he hadn't the energy....There were days I thought to myself, where are we going from here? But we mastered it together and tried to do things at his pace...I've heard of it (palliative care)but to be honest I never understood what the word meant (p371)</p>	<p>Unequivocal</p>

## **QUALITY OF LIFE**

Findings for : Odenrants S, Ehnfors M and Grobe SJ - Scandinavian Journal of Caring Sciences (2005)

Finding	Illustration from Study	Evidence
<p><a href="#">People with COPD have a number of physical influences that impact on eating</a></p>	<p>Early satiety and bloated stomachs were common, fungal infections or dry mouth recurrent and the odour of food. Coughing just before or during meals. Tiredness was reported ...tired, very tired. I cannot manage standing there peeling an onion...breathlessness during shopping p233-4</p>	<p>Credible</p>

<a href="#">Food related activity and feelings of dependence</a>	...Some reported that they could no longer manage shopping on their own. To shop alone was something that the respondents had not done for a long time.	Credible
<a href="#">Problems exist in the transportation of groceries</a>	Even when going by car it was important to park nearby the target store.....(and) I take a small basket in the shop and that way I buy only a few items at a time.	Credible
<a href="#">The social aspect of eating alone or in company can influence intake</a>	...If I were alone I would starve to death"...eating with others made them nervous to the point that some started to cough.	Credible

Findings for : Gysels M and Higginson IJ - Journal of Pain and Symptom Management (2008)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">COPD can be stigmatised as it is experienced as shameful and self-inflicted</a>	Patients feared reactions from their social environment....embarrassment when becoming breathless in the company of friends. People come and say "are you alright dear, can I help you?"....So I think well just get a taxi and it'll drop you outside the house...nobody asking questions and no feeling exhausted when you get in. We got the form(attendance allowance), I filled it all in and he wouldn't sign it and that's his prerogative...	Unequivocal
<a href="#">Those with COPD experienced difficulties with access and responses from health professionals</a>	...I went to the doctor {but} she didn't know what to do with me, so she said OK get yourself into casualty....There they look at me [they ask] "What are you doing here?". Patients are also easily distracted from what they have come for when meeting the doctor and surprised by a lack of understanding....and he said to me: Where do you work?" I said Work? He said what do you do for a job? I said "Well nothing doctor"....I thought he's seen emphysema on the screen...but didn't realise the full extent of it..... But that was all. In other words, you don't get a lot of help: they look at you and conclude OH you look alright, that's it.(p457).	Unequivocal
<a href="#">Breathlessness can be elusive, covert and insidious in COPD</a>	Well it affected me but I didn't realise, I just didn't put it down to anything in particular.....You can't go to the doctor and say I can't dance. It's a strange thing to say	Unequivocal

	to the doctor. It presence (breathlessness) was often not related to exertion and it could coincide with events that were rationally not possible.	
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Findings for : Elofsson LC and Ohlen J - Palliative Medicine (2004)

Finding	Illustration from Study	Evidence
<a href="#">People with COPD struggle with the dialectic of loneliness and connectedness</a>	I have no opportunity to meet with old friends. that's a disadvantage ....time goes by, but it's not very inspiring...I don't do much now...as I can't do anything, I can just as well lie where I am....There hasn't been any work done lately (614)	Unequivocal
<a href="#">People with COPD struggle with the dialectic of resignation and contentedness</a>	So I live as long as I live. Life isn't very rewarding, certainly not(613)...I have to be satisfied with what I have (614)	Unequivocal
<a href="#">People with COPD view the dialectic of being homeless and being at home as important.</a>	"I don't think I have my home here...this is not a real home.....I did have help from the home care service..but it was hard many times. They were supposed to come in the morning....." Those who lived in nursing homes/service flats expressed more feelings of being lonely than did those who lived in their own homes. p615	Unequivocal

Findings for : Fraser D, Kee CC and Ptlene M - Journal of Advanced Nursing (2006)

Finding	Illustration from Study	Evidence
<a href="#">Knowing what works to manage dyspnoea</a>	"Like my American Express card, I never leave home without it...Using an inhaler correctly while controlling his panic was what worked best for him.....I do the deep breathing. In through the nose and ..pursed lip breathing.....Well, I get short of breath...so I set the oxygen higher..After I've finished bathing and drying myself and dressing, I can put it back down....sometimes it takes a while to get a handle on it but you gotta do it yourself cause nobody else can. p	Unequivocal

<a href="#">Sometimes those with COPD cannot manage all situations and they are Hanging On..Barely</a>	....I knew I couldn't breathe, and I knew it was what I had to do, but I did not know what to do about it.....you just don't feel like you get much out of life when you can't do anything (struggling to hang on).	Unequivocal
<a href="#">Those with COPD adapt to restrictions through a process of losing control-gaining control</a>	"I will drive two miles to the local post office to mail a letter..because it's easier..I can't walk out to mailbox and back again without severe breathing problems...It's depressing, but you get over that...it's awful to know you did it to yourself.....I just have to live with it and try and control it.....it seemed like every time I would go to the doctor, they would change my medicine or give me some more medicine...Every time it seems like I have control over the situation...something else would come up.	

Findings for : Seamark DA, Blake SD and Seamark CJ - Palliative Medicine (2004)

Finding	Illustration from Study	Evidence
<a href="#">Carers feel bowed down by the multiple roles they have to undertake</a>	...we're nurses, we're doctors, we're housewives, we're cooks, we're gardeners. We're shopping..(Irvin's wife) She's a sticker, she treats me well and she looks after me, but it's taken a toll, it's taken a toll. (Ernest) ...she won't tell me how much she is getting, but she has an idea how much I'm getting. Because we argue over money at times, you know (John).p623	Unequivocal
<a href="#">Patients adapt to cope with their illness</a>	I think far more along the lines of can do rather along the lines of what is impossible to do (Arthur). I've got to accept, make the best of your lot....Oh no certainly not (quality of life) It's been curbed, it's been curbed (Gordon). It has certainly made my spiritual awareness deeper than it used to be (Arthur).	Unequivocal
<a href="#">Relationships with health care professionals can be both positive and negative</a>	I see my own doctor who understands how I feel and he's always very understanding and I get on very well with him (Betty) I changed to Dr X....and he talks to me and that's what patients need (John) Well quite frankly the thought of going to the district hospital and going along all those bloody corridors and even when my wife pushes me, it knackers her, you know (Ernest) But I think going to the respiratory clinic, hospital or surgery is good. I like then to keep their eye on him....(Henry's wife) I'd like someone knowledgeable to discuss it with. The one criticism I have of the NHS is the little time people have to talk... (Arthur)	Unequivocal

<a href="#">Symptoms of COPD can be profound</a>	Can you imagine someone having a bag over their head? They're fighting for their breath. That's me, that is me, that is (Irvin) p621 ....you find you can't swallow so much as you'd like to swallow, you know, your throat gets choked (Donale) p621	Unequivocal
<a href="#">There are losses of previous activities</a>	A complete loss of personal; liberty and now I can't walk, I can't do anything (Arthur) p621 It stopped everything in its tracks (had to stop work)Yeah change of lifestyle completely from a doer to a non-doer. And the simplest of tasks now are a big effort (Gordon) p621 We had a lot of ideas, but you know, ill health messed it all up. That's life for you. (Gordon) p621	Unequivocal

Findings for : Robinson T - Nursing Times (2005)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">Physical activity - reduction in level due to breathlessness</a>	I couldn't do anything without getting out of breath. So I just have to sit here and look at things p40	Unequivocal

Findings for : Barnett M - Journal of Clinical Nursing (2005)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">Perception of severity and symptoms - varying conditions</a>	When it's dark my breathing is worse.....The weather seems to affect me...the wintertime is bad for me...p809	Unequivocal
<a href="#">Perceptions of severity and symptoms vary</a>	Well every day is different. Some days are worse. a bad day to some people is reasonable...A bad day to me is a nightmare p808	Unequivocal
<a href="#">Functional disability needs support</a>	I used to daily bath, which I really do miss...on a bad day I just use baby wipes to do my vital parts and get dressed....I get very upset when my husband helps....I like to go for walks but I can't. I just get too breathless p810	Unequivocal
<a href="#">Emotional trauma of coping with COPD</a>	Some days I can't do anything and I get very frustrated. I cry a lot, this happens a few times a week.....panic attacks resulted in "you feel as if you are on your last breath. Its	Unequivocal

	very frightening. When this happens I needs someone to hold my hand and talk to me, that gives me comfort.....I panic in case I don't wake up p810	
<a href="#">Social loss is increased with COPD</a>	We don't go out much now...I usually have to psych myself up and keep my fingers crossed that I'm OK on the day.....I'd like to go on holiday with my family and go shopping...most participants felt that their family and friends understood their condition p811	Unequivocal

Findings for : Bergs D - Journal of Clinical Nursing (2002)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">Carers have "no time to worry about my physical health"</a>	My health is not too good, I am physically worn out... p615	Unequivocal
<a href="#">Carers consider that "having employment is important"</a>	My job saves me from losing my wits.....He calls me possibly two or three times at work each day....I do often perceive myself as his main tie to the real world.. p615	Unequivocal
<a href="#">Carers are often "on the alert even at night"</a>	...I have got used to it by now, even if i frequently have to wake up and can hear that he has difficulties breathing(par 3)....I have this constant fear that he will stop breathing, so i need to sleep near him so I can be on the alert if something happens (par1).	Unequivocal
<a href="#">Carers report a "weakening of marital relationship"</a>	I am really in need of some form of intimate contact with him, but I do not want to press him (par 3....I do not love him as I did earlier...I would rather say that i care immensely about him. This is more like fondness and friendship (par 2)	Unequivocal
<a href="#">Carers find that there is an "emotional straightjacket living with him"</a>	Gradually we have had less and less to talk about...The disease has isolated him from the family and myself, and now we have restricted issues to talk about...it makes me sad when i think about it(par 1).....Sometimes I picture him in my mind as a difficult child (par 4)	Unequivocal
<a href="#">Carers are often "too proud to ask for help"</a>	...Indeed, I must admit I am no good at asking for help (par4)...Sometimes I have the feeling that they (children) do not have the same understanding of his condition as I do, and I know that he does not want to bother them	Unequivocal

	with his problems (par 4)	
<a href="#">Carers are "becoming mentally worn out"</a>	I had become so depressed just after Christmas that I used to sit down at night, just crying....still I am awfully tired mentally, and sad, terribly sad, mentally I am worn out (par2)....He is often in a bad mood, and that is hard....I am a light hearted person myself but he can't stand it if I am cheerful...I try not to let it affect me but sometimes his comments hurt..(par4)	Unequivocal
<a href="#">Carers have a "feeling of isolation"</a>	I am isolated from everything because of his illness(par1)...No one ever comes to visit when he is at home, never any more...when my relatives try to visit he has almost nothing to say to them....the only thing he can talk about is his sickness, and of course that does not interest people in the long run (par5).	Unequivocal
<a href="#">Carers report some "positive sides of caring"</a>	The positive sides of their caregiving situation are illuminated in the satisfaction each of the wives has in being able to ease her husband's sufferings and help him stay at home as long as possible.	Credible
<a href="#">Carers gain support through "spiritual help"</a>	Some of the women in the present study indeed feel that their faith improves their mental health; if they had not been able to pray, they would never have been able to manage.	Credible
<a href="#">Carers feel a "need for an increased social support system"</a>	I know I could do this if I could occasionally get a rest, maybe one week, a couple of weeks, three weeks at a time and then I would be happy to leave him at home in between...but I could never go to the doctor and just say 'I can't do this anymore' (par5)...If I could get more support from the health system I would rather accept the situation of caring for him at home(par2)	Unequivocal
<a href="#">Carers want "to walk the road with him to the very end"</a>	I believe it is my duty to care for him...I want to be there as long as he requires my help...I have decided long ago to travel the road with him to the very end....being a woman helps in a situation like this, I believe we can adjust better to a role like this (par1)	Unequivocal
<a href="#">Carers have "the dreadful prospect of adjusting to a single"</a>	...I do not think about myself as a single person..I can of course see that I will become more free to do whatever I want to do...no I do not long for it (par4)....I sometimes	Unequivocal

<a href="#">life"</a>	wake up in the middle of the night, terrified because I cannot hear him breathe beside me, then I realise he is gone, and i become so sad...it is difficult to adjust to the thought of him not being at home...still I miss him (5 months after the death)...I feel as if part of me is gone with him (par6)	
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Findings for : Leidy NK and Haase JE - Advances in Nursing Science (1996)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">Deriving satisfaction from various activities</a>	....satisfying activities were based on personal experiences, skills and values....activities with or on behalf of others (family, social and altruistic avocational activities) were the most satisfying and meaningful of all (p )	Credible
<a href="#">"Intruders" can interfere with the activities that those with COPD want to perform</a>	Intruders included: symptoms, treatments (e.g. O2, nebulisers), other medications e.g. steroids, some healthcare staff	Credible
<a href="#">"Enablers" can facilitate or make possible continuation of activities.</a>	A range of enablers exist that people with COPD draw upon to support their continued activities: planning ahead, pacing oneself, using assistive devices and having personal assistance available.	Credible

## **TELECARE**

Findings for : Horton K - Journal of Nursing Management (2008)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">Healthcare professionals report a lot of wasted time</a>	I had to come down to the office...access the electronic care plan...We also spent a lot of time sorting out the telephone line...(p176)	Unequivocal
<a href="#">Participants experience usability</a>	".. he could not cope with it because it was not easy to use the blood pressure cuff and the temperature probe,... it takes ten minutes, ten minutes to work"	Unequivocal

<a href="#">challenges</a>	p.176. The readings were difficult for the patient and if their patient was very ill there was no way they would be able to handle the equipment (Credible p.176).	
<a href="#">Nurses report patients positive experiences of using telecare</a>	Another professional reported patients thought telecare was an 'added bonus' in that it put them in control because they knew they were able to read their vital signs (Credible p.177).	Credible
<a href="#">Some older patients are perceived as finding telecare positive and were confident using the machine.</a>	"Mr B was reluctant to finish using the machine as it made him feel that it was something he was part of that was monitoring him daily" p.177. "Overall she coped well with the monitoring equipment and had no problems with it. She decided that both she and her husband were very reassured by being able to perform her clinical measurements at home and happy that we were able to access these figures" p.177.	Unequivocal
<a href="#">The equipment is described as 'not user friendly'</a>	"his wife was unhappy with the size of the equipment" she believed it would be a small box they could 'hide in a corner' p.178 "When the blood pressure cuff triggered an alarm that necessitated repeated reading, it led to the user opting to continue with the use" p.178.	Unequivocal

Findings for : Mair FS, Hiscock J and Beaton SC - Chronic Illness (2008)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">There are technical and equipment issues related to implementing telecare</a>	The nurses did not believe that the time-consuming and technical task of installing the equipment was nursing work (credible p. 112) "Sometimes you didn't see the patient clearly at all..you wouldn't know what colour she was, what shade of blue or grey ... I found it really difficult to observe her breathing because the picture quality wasn't good" (p. 112). "was a delay in the voice thing, ... like a two way radio ... quite often you were talking over each other ..." (p. 112). Nurses perceived the system had limited interactional ability because it made the clinical consultation more difficult and less effective (Credible p.112)	Unequivocal
<a href="#">There are deficiencies and concerns in communication</a>	Signal and image quality was a problem .... the style and content of their communication was also different (Credible p.112). "You can't express yourself the same on the phone or even on a tele-med, you need to be with	Unequivocal

<p><a href="#">using telecare</a></p>	<p>that person" (p.112. Nurses believed that clinical interactions using the system were less likely to achieve an accurate and full clinical assessment (Credible p.112). Patients however, focused on the qualities of the nurses (Credible p.112). Nurses have concerns about privacy and confidentiality issues (Credible p.112). "We don't know who is in the room with them see, .... we don't know, unless they are sitting behind the patient ..." P.112. Nurses believe the telecare system was a less secure and safe method of healthcare delivery than traditional face to face interactions. Patient's did not seem to share this view. "It was on my territory... just one invasion ... I preferred that than sitting in a hospital bed ... there is no proviscy in there" p.112.</p>	
<p><a href="#">Nurses felt the telecare system affected their nurse-patient relationship in a negative way and was not 'as good' as home visiting.</a></p>	<p>"I think you physically need the patient in front of you, ... it's when you start talking to them and getting more of a rapport with them that they open up and tell you things.." p.112. Patients dont share these views (Credible p.112). Using the teteicare system reduced the chances of fully achieving important objectives of their clinical interactions (Credible p.112).</p>	<p>Unequivocal</p>
<p><a href="#">There was a mixture of satisfaction and dissatisfaction with using the system (attitudes to telecare)</a></p>	<p>Satisfaction at mastering the use of new technology ... but seeing patients face to face was more satisfying (Credible p.112). Patients were more inclined to think that telecare was a good idea (credible p.112).</p>	<p>Unequivocal</p>
<p><a href="#">Nurse and patient roles change when using telecare</a></p>	<p>The patient had a more active role, as they were responsible for providing data regarding psychological measures..." p.114. Nurses lack confidence in the ability of patients to undertake these tasks as effectively as professionals (Credible p.113). Telecare gave nurses 'extra work' - apart from installation, additional training was needed for aptients, and if there were technical difficulties,e.g. temperature probe not woking, ... they had to spend more time taking a detailed history to compensate for the absence of clinical data (credible p.113).</p>	<p>Credible</p>
<p><a href="#">Nurses fear risk of missing things and are concerned about the medico-</a></p>	<p>"I dont know how I would be fixed in court if I had to go and tell the judge well she looked fine from the waist up" p.113Patients felt safer and gave them more autonomy. "I can see the girl, talk to her, she can explain things back to me, she can turn round and say put everything on and</p>	<p>Unequivocal</p>

<a href="#">legal aspects</a>	we will check you over, ... I don't have to wait an hour or two or anything for her to come... The main advantage is that I can do it myself" p.114	
<a href="#">Telecare threatened some nurses professional identity</a>	Increased utilisation of telecare might mean that fewer nurses might be required in the future. Also, adopting such systems would adversely affect, qualitatively, the nature of the work that nurses would be expected to undertake in the future. (Credible p.115). "There is always that threat isn't there of new technology impinging on your role. I really enjoy the one to one relationships with patients that is where I feel my skills bear really,..." p.115. They raised questions about the legitimacy of telecare as a form of service provision "I can see where there would be a role for monitoring patients baseline monitoring really, ....I can see it more for the well patients at the moment than for the ill patients" p.115.	Unequivocal

## **SMOKING**

Findings for : Gullick JG and Stainton MC - Journal of Smoking Cessation (2007)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">The struggle with smoking is the need of the body with an understanding of the need to stop</a>	....a tension between continued smoking behaviour and awareness of smoking related illness (p9)	Credible
<a href="#">Overcoming the need to smoke</a>	Frances claimed that no-one would ever tell her not to smoke, but a diagnosis of emphysema led her to give up immediately. "When it's your life, I think it's different you know.....". "It was so difficult. But my doctor prescribed me these Zyban tablets and that helped. Never touched another cigarette...." (p9)	Unequivocal
<a href="#">The right words at the right time. Using vulnerability as an opportunity.</a>	They said "you've got to stop smoking, you've got emphysema, blah, blah. And I took no notice of it. I could not stop smoking; I'd tried everything in the book. Even double doses of that dangerous drug (bupropion). They had to put this thing into my mouth and force air into me. And this young Doctor got the x-rays and he said "phew, you have only got a little bit of lung left. If I was you I'd take care of it. "And it struck me then, and from that day	Unequivocal

	to this, I've never smoked (crying)... Well, he just said it at the right time you know?"	
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Findings for : Schofield I, Kerr S and Tolson D - Journal of Clinical Nursing (2007)

<b>Finding</b>	<b>Illustration from Study</b>	<b>Evidence</b>
<a href="#">Older people with COPD do not necessarily perceive a threat from smoking</a>	But to be honest with you I do not blame smoking.....Well, the medical people ....put it down to smoking. I say it doesn't matter what the hell's the matter with you, they'll put it down, anything they'll put down to smoking eh but also well I'd just say age, I mean as one gets older you must eh sort of get rundown someway or another" p1730	Unequivocal
<a href="#">Perceived benefits</a>	...but my breathing eased off a wee bit, I could walk that wee bit longer.....after about a week and I found I could walk further and I like going, even window shopping...p1731	Unequivocal
<a href="#">Perceived barriers to/costs of quitting smoking</a>	...so when the urge comes on me, I'll have that cigarette and you know after I have it, my breathing's even better.. ..if I stopped for good I think it could do me more harm because see I could have a lot of side effects if I stopped, like I could get bad tempered....."	Unequivocal
<a href="#">There can be Cues to action for older people with COPD who smoke</a>	It was hard coming off smoking but I had to do it, I couldn't accept that the hospital were treating me and I was nipping away here to get a smoke, I couldn't accept that, that wasn't fair".....I'll need to stay off it this time, I know myself, I'll not see my two granddaughters grown up if I don't, it's as simple as that" p1732	Unequivocal
<a href="#">Self-efficacy can be assistive</a>	...so I came home and I said to my wee wife, God rest her, I said there's 18 cigarettes and my lighter and I never put a fag in my mouth since...." ...but I had stopped 2 or 3 times before that, I mean I kept stopping and starting and stopping I mean I tried everything. I tried acupuncture, tried hypnotism and this is my 5th time with the patches isn't it" p1733	Unequivocal

## EXACERBATIONS

Findings for : Schofield.I, Knussen.C, Tolson.D, - International Journal of nursing studies (2006)

Finding	Illustration from Study	Evidence
<p><a href="#">Patients illness experience is varied and individual to them</a></p>	<p>..were acutely aware of environmental and bodily changes that threatened the stability of their condition (credible p.17). "You get used to your own body , it's amazing, how you get used to, what's wrong with you, I know when i've got an infection because it goes greenish and then it goes yellow" p.17. Most had some warning of an acute exacerbation of their condition - some commented on the colour of their sputum, breathing became more difficult or they experienced fatigue. Family living with the COPD patient also became attuned to changes that signified deterioration in their condition " a lot of people would look at her and say 'Oh there's nothing wrong with her", but we know that's the start of it, if we don't catch it in the bud early then it's going to be a hospital case ..." p.471. Some people delayed seeking medical help believing they were not ill enough to bother hard pressed medical staff. Other reason for not seeking help is not wanting to admit something was wrong - denial (Credible p.471). . "I'll suffer anything till I realise that I've got to get help, .." p.471.</p>	<p>Unequivocal</p>
<p><a href="#">There are personal, perceived care and support preferences for home care during an acute exacerbation.</a></p>	<p>People prefer to be cared for in their own environment (Credible p.18). " I feel more contented .... I feel my own wee home is familiar to me, I know everything and I'm contented in it so I feel more happier if I'm in my home (p.18). The family doctor usually made the decision to refer to the ARAS team (Credible p.18). Some patients were passive (accepting the service that was offered) and some were pro active (contacting the ARAS)(Credible p.18). " ... but if I really get bad I just phone the ARAS nurses and they tell me what to do ... if they're busy that day, they'll come out the next morning ..." (p.18). Family carer saw service as a speedy route to effective care (Credible p.471). " .. my wife would have been dead, that's how badly she was, now to me that is a godsend that clinic, I can phone up any time and I can take my wife in ..." (p.472). Hospitals, whilst offering "reassurance should anything go wrong" were often associated with bad experiences (p472)</p>	<p>Unequivocal</p>

<a href="#">People have positive experiences of an outreach Acute Respiratory Assessment Service</a>	<p>accessibility, ease of use, specialist clinical skills of the health professionals, and one to one care in the home by friendly and approachable staff (Credible p.472)."... concerned as if they're treating you, as if you are somebody special, not as if you're just a number on their book" (p.20) Mixed opinions about hospital experiences</p>	<p>Unequivocal</p>
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Findings for : Kessler.K, Stahl.E, Vogelmier.C, Haughney.J, Trudeau.E, Lofdahl.C, Partridge.M - CHEST journal (2006)

Finding	Illustration from Study	Evidence
<a href="#">Patients perceive exacerbations as a considerable burden</a>	<p>Patients indicated that exacerbations caused substantial anxiety (Credible p.5). 12% were worried about dying, 9.6% worried about suffocation,9.6% had worries of their conditioning worsening, and 8% had worries of being hospitalised (p.5) Patients indicated exacerbations had an influence on their Activities of Daily living with half needing additional help with certain tasks (Credible p.5). 90 % of patients required help with certain tasks (particularly household chores, shopping, cooking and "everything") during an exacerbation. For 47.2% of patients, all activities stopped during an exacerbation with some reporting that "...movement is hardly possible" : of these 37.6% could do nothing at all (p.5). Depression, irritability/bad temper, anxiety, isolation, anger and guilt were identified. Patients most commonly cited lack of energy, depression and anxiety when describing their feelings about exacerbations (p.5). Exacerbations affected mood and caused a variety of negative feelings. Exacerbations had an effect on relationships. Patients isolated themselves, stopped socialising, felt nervous or in a bad mood and some could not talk. Family members were worried, afraid or scared. Little impact on work as they were retired.</p>	<p>Credible</p>
<a href="#">Patients experience a variety of warning signs and symptoms when exacerbations are developing and take various actions</a>	<p>Most patients and families were aware of symptoms of exacerbation, identifying breathlessness as the most common. Others, including fatigue/tiredness, URTI, cough and pain were reported. Almost a third reported no recognisable warning signs. Most patients reported having the same symptoms from one exacerbation to another though evident differences between patients (p.5).</p>	<p>Credible</p>

<a href="#">Patients have little or no understanding of the term exacerbation</a>	59.2% of patients had never heard the word exacerbation.....Patients most often said a chest infection, a crisis or an attack...(p5 HTML version)	Credible
<a href="#">Patients indicate the time for recovery from an exacerbation</a>	Patients recalled a mean time taken to return to usual levels of activity ...was 10 days....only 74.8% believed they had returned to their previous state of health...	Credible