The experience of trauma and health anxiety in complex Chronic Obstructive Pulmonary Disease (COPD): A Cross Sectional Study

Thesis submitted to the University of Leicester

Faculty of Medicine & Biological Sciences, School of Psychology

For the partial fulfilment of Doctorate in Clinical Psychology

By

Lorraine Clare Craig

May 2016
Declaration

I confirm that I am responsible for the current thesis, worked contained herein is original and has not been submitted for any other academic award.
The experience of trauma and health anxiety in complex Chronic Obstructive Pulmonary Disease (COPD): A Cross Sectional Study

Lorraine Craig

Thesis Abstract

Chronic Obstructive Pulmonary Disease (COPD) is a degenerative respiratory condition in which lung functioning is significantly impaired. COPD is one of the leading causes of morbidity and mortality worldwide and is associated with significant societal and personal costs. This thesis sought to better understand the psychological impact of COPD on individuals with the disease and those who provide familial/informal care to individuals with COPD.

Literature Review

COPD confers significant burden to individuals undertaking informal care, yet no previous reviews had focused exclusively or systematically on the psychological impact of caregiving in COPD. The current review examined quantitative studies assessing the prevalence and predictors of psychological distress in COPD carers. Twelve studies were elicited, revealing caring for individuals with COPD was associated with increased psychological distress, notably high prevalence of self-reported anxiety and depression. Findings related to the predictors of psychological morbidity in COPD carers were equivocal, not allowing for firm conclusions to be drawn; further research regarding predictors of psychological morbidity amongst COPD caregivers is warranted.

Empirical Study

The current study examined the prevalence of posttraumatic stress disorder (PTSD) and health anxiety in individuals with complex COPD, and whether these variables predicted the variance in psychological morbidity and health related quality of life. A total of sixty COPD patients were recruited from an outpatient clinic. Results indicated clinically significant PTSD in 13% of the sample, and 48% of the sample had clinically significant health anxiety. Health anxiety accounted for a small but significant amount of variance in anxiety, depression and health related quality of life. PTSD symptom severity showed no relationship with the same variables, which was surprising. Possible explanations were explored. Further research examining these relationships is recommended, to support the development of targeted interventions for those with COPD.
Acknowledgements

This research would not have been possible without a number of people who have given up their time to assist me. Firstly, I would like to thank all of the participants who took part in this project. I am very grateful for their contribution to the research, particularly at a time in their lives where many other things could have taken priority.

I would like to thank my supervisor, Dr Noelle Robertson, for inspiring the idea for this project, for her unwavering support and guidance in focusing my thoughts. Her connections also made it possible for me to join a widely recognised and respected respiratory research team, which has proved to be an invaluable personal experience.

I would like to express thanks to all staff within the COPD outpatient clinic, for helping me to get this project off the ground, as well as the vast respiratory knowledge they shared with me and enthusiasm for the research. I am particularly indebted to Professor Michael Steiner and Nicole Toms for supporting me throughout the recruitment process.

Finally, I would like to thank my friends and family for the guidance and kindness they have shown me throughout this process. In particular, I would like to express gratitude to my DClinPsy peers, who have lifted my spirits on numerous occasions and shared many sessions in the library with me during the final months of write-up.
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Acute exacerbations (AEs)
American Psychiatric Association (APA)
American Thoracic Society (ATS)
Beck Anxiety Inventory (BAI)
Beck Depression Inventory (BDI)
Body Mass Index (BMI)
Carers’ Assessment of Difficulties Index (CADI)
Caregiver Burden Scale (CBS)
Centre for Epidemiological Studies-Depression (CES-D)
Chief Investigator (CI)
Chronic Obstructive Pulmonary Disease (COPD)
Chronic Respiratory Questionnaire (CRQ)
Clinical Nurse Specialist (CNS)
COPD Assessment Test (CAT)
Cumulative Illness Rating Scale (CIRS)
Department of Health (DOH)
Diagnostic and Statistical Manual (DSM)
European Respiratory Society (ERS)
EuroQol five dimensions questionnaire (EQ-5D)
Forced Expiratory Volume in One Second (FEV1)
Generalised Anxiety Disorder (GAD)
Geriatric Depression Scale (GDS)
Global Obstructive Lung Disease (GOLD)
Health Anxiety Inventory Short Version (SHAI)
Health Related Quality of Life (HRQL)
Hospital Anxiety and Depression Scale (HADS)
Improving Access to Psychological Therapies (IAPT)
Independent Complaints Advocacy Service (ICAS)
Instrumental Activities of Daily Living Scale (IADL)
Integrated Research Application System (IRAS)
Long Term Oxygen Therapy (LTOT)
Lubben Social Network Scale (LSNS)
Medical Outcomes Studies Questionnaire Short Form Health Survey (SF-36)
Medical Research Council (MRC)
National Health Service (NHS)
National Heart, Lung, and Blood Institute (NHLBI)
Oxygen Partial Pressure (PO2)
Posttraumatic Stress Disorder (PTSD)
Posttraumatic Stress Diagnostic Scale (PDS)
Pulmonary Rehabilitation (PR)
Quality of Life (QoL)
Quality of Life Index (QLI)
Randomised Control Trials (RCTs)
Research Ethics Committee (REC)
Visual Analogue Scale (VAS)
World Health Organization (WHO)
United Kingdom (UK)
Zarit Burden Inventory (ZBI)
PART 1: Literature Review

The psychological impact of caregiving in Chronic Obstructive Pulmonary Disease (COPD): A systematic review
Abstract

Background and aims: Chronic Obstructive Pulmonary Disease (COPD) confers significant burden to individuals undertaking informal care, yet to date no reviews have focused exclusively or systematically on the psychological impact of caregiving in COPD. The current review focused on quantitative literature, examining the prevalence and predictors of psychological distress in COPD carers.

Method: Four electronic databases were searched from their inception to April 2016. Of the 577 articles generated, 51 were identified relevant for further examination. Twelve studies met the inclusion criteria and data were extracted.

Results: Studies were appraised using a modified version of the Downs and Black quality appraisal tool (Downs & Black 1998). The majority of studies had a moderate quality score. Diverse psychological outcomes were measured across studies and primary outcomes involving psychological morbidity included anxiety, depression, quality of life, loneliness and stress. The most clinically relevant data was available for anxiety and depression, with prevalence of clinically salient anxiety reported by between 59 and 70.4% of COPD carers (three studies), and between 29.2 and 73.3% for depression (seven studies). Figures were consonant with general estimates of anxiety and depression among caregivers. There was limited evidence to draw firm conclusions about the predictors of anxiety and depression in COPD carers and further research is warranted.

Conclusions: Caring for individuals with COPD appears to be associated with increased psychological distress, notably high prevalence of anxiety and depression. Given the high prevalence of psychological morbidity in COPD carers, the current review advances a case for routinely assessing psychological status within this group of carers. These carers generally do not receive attention and are rarely offered interventions. Attending to carers’ psychological needs may have benefits, notably to support carer wellbeing, enabling them to maintain support for COPD patients in the community and reducing the likelihood of unnecessary hospital admissions.
1 Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a degenerative, respiratory condition marked by progressive breathlessness (dyspnoea) and airflow limitation resulting from inflammation and damage in the bronchioles (Global Initiative for Chronic Obstructive Lung Disease, 2015). Prominent clinical features of COPD include: wheezing, chronic coughing, excessive sputum production, frequent bronchitis, tiredness and tightness in the chest (Department of Health, 2010). As the condition progresses, acute exacerbations (AEs) of breathlessness may increasingly interrupt periods of disease stability. These disabling physical symptoms of COPD may be exacerbated by co-morbid psychological issues, notably distress, loss of autonomy and isolation, with consequent adverse impacts on quality of life (QoL) (Pinnock, Kendall & Murray et al., 2011).

1.1 Societal and personal costs

Population prevalence estimates suggest in excess of 3 million individuals in the UK live with COPD (National Clinical Guideline Centre, 2010). Those who present with COPD tend to be elderly and from lower socioeconomic backgrounds (Eisner, Blanc, Omachi et al., 2009; Elofsson & Öhlén, 2004). COPD is a growing public health concern with significant associated financial costs. In the UK alone, costs are estimated at £930 million (National Clinical Guideline Centre, 2010; Young, Hopkins & Christmas, 2009). Hospitalisations for AEs are a major contributory factor, accounting for between 50 and 75% of the costs incurred (Celli & MacNee, 2004).

Since many COPD symptoms are irreversible and can lead to significant functional impairment, those living with COPD can require significant support to function independently and manage basic tasks of daily living (Gardiner, Gott & Payne et al., 2010). Whilst multi-disciplinary clinical treatment and specialist Pulmonary Rehabilitation facilitate effective symptom management (National Institute for Clinical Excellence, 2010; Nici, Donner & Wouters et al., 2006), support is also commonly provided by informal carers, most often family members. Given patients’ functional needs, accompanied by health services increasingly adopting self-management education in long-term conditions
(Spence, Hassan & Waldron, 2008) alongside a drive for community-based care (Lynn, 2005), informal carers may find they have increased care responsibilities.

1.2 Care delivery and the impact of caregiving

Definitions of what it is to provide informal care are not universally agreed, and are variably operationalised. Familial carers are commonly defined as individuals who provide unpaid support to family members, who could not otherwise manage without this provision (Carers Trust, 2015). Informal caregivers usually encompass individuals who are not classified as healthcare professionals, and who receive no pay for their caring responsibilities, yet may have a personal relationship with those given care (Beesley, 2006; Carers UK, 2011; Kasuya, Polgar-Bailey & Takeuchi, 2000).

Caring for those with chronic degenerative diseases can have deleterious effects on the carer, often understood as ‘‘invisible victims, listening, watching, waiting, and feeling powerless, helpless, and anxious’’ (Booth, Silvester & Todd, 2003, p. 342). Increasingly, studies are revealing the impact of familial/informal caring in chronic degenerative conditions that affect older adult populations, notably dementia (Garlo, Leary, Van Ness et al., 2010; Hepburn, Tornatore & Centre et al., 2001) and Parkinson’s disease (Kristjanson, Anoun & Oldham, 2005).

Development of now well-established models of psychological distress (Pearlin, Mullan & Semple, et al., 1990) have given rise to constructs such as ‘‘caregiver burden’’, the umbrella term encompassing the psychological, physical and financial impact of caring for someone (Zarit, Reever & Bach-Peterson, 1980).

In providing care for someone living with COPD, there may be exacting and distinctive challenges, such as the unpredictability of AEs, use of heavy devices in delivering oxygen, complicated medication regimes including the application of inhalers, and the need for complex care procedures, such as postural drainage. Whilst there is a common perception that caring for someone with COPD incurs high carer burden (Booth et al., 2003), comparatively few empirical studies have systematically examined the psychological impact of delivering such care. Papers that have assessed psychological distress amongst COPD carers have found well-being (Seamark, Blake & Semark et al., 2004) and QoL are adversely affected
(Kühl, Schurmann & Rief, 2008) and prevalence of psychological morbidity, notably depression, is evident in 37-41% of carers (Grant, Cavanagh & Yorke 2012).

### 1.3 Relevant reviews

To date, the impact on those offering informal care to individuals living with COPD has been explored in broadly focused reviews which have not applied explicit quality criteria to their evaluation of research evidence (Boyle, 2007; Caress, Luker & Chalmers et al., 2008; Grant et al., 2012; Simpson & Rocker, 2008). Of these, Boyle’s (2007) review sought to integrate papers into an existing conceptual framework for chronic illness. Another examined putative information needs of, and interventions directed towards carers (Caress et al., 2008). Simpson and Rocker (2008) reviewed the general impact of informal caregiving in advanced COPD, rather than any specific psychological impact across the disease trajectory and Grants’ (2012) narrative mixed methods review explored factors associated with carer wellbeing and perceived adequacy of professional support. This latter review acknowledged its partial coverage of psychological factors and made explicit recommendations to clarify psychological morbidity in COPD carers, as well as assess the factors that predict health outcomes within this population.

### 1.4 Rationale and review aims

Previous reviews suggest informal carers who look after individuals with COPD experience adverse effects on their wellbeing, yet none have focused exclusively or systematically on the psychological impact of caring. Clarifying more precisely the psychological impact of caregiving in COPD and identifying any predictors of psychological distress is important and may assist development of targeted interventions for this population. This review thus sought to provide this precision by focusing exclusively on outcome research. The overall aim was to systemically examine quantitative literature on the psychological impact of caring for individuals with COPD. Specific aims included: (1) to review the prevalence of psychological distress in COPD carers (2) to identify factors associated with psychological distress in COPD carers.
2 Method

2.1 Search strategy

Following initial scoping searches, interrogation of four electronic databases: PsychINFO; Scopus; Medline and CINAHL, was undertaken in November 2015 and again in April 2016. These databases were selected as they are the most frequently used for systematic reviews of this nature (see Appendix A for rational for database selection).

A search strategy was compiled using search terms relating to “COPD”, “caregiving” and “psychological distress”, with combinations of relevant search strings applied (see Appendix B for list of search terms and breakdown of number of articles yielded per database). The search strategy was purposefully broad, to ensure identification of relevant articles. Date limiters are generally used to reduce a set of results. However, as the current review aimed to retrieve all studies relevant to the clinical topic in order to capture accurate prevalence and predictor data, no date limiters were applied and databases were searched from their electronic inception.

2.2 Eligibility criteria

2.2.1 Participant characteristics

Included studies were required to comprise a sample of caregivers for those diagnosed with COPD, including spousal, familial or informal caregivers. No limiters were set for duration of caregiving experience or time spent caregiving, as it was noted in the initial scoping search that this data was not consistently reported. Further, due to variability across studies, no limiters regarding duration of COPD or severity of COPD symptoms were imposed. Associated implications are discussed within the methodological limitations section.

Studies that focused on broader research questions were considered for inclusion where there was sufficient discretely analysed data regarding the impact of COPD.

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1 In examining the literature, it was clear that there was a growing body of research examining the psychological impact of caregiving in COPD. Searches were therefore conducted twice to acknowledge recent proliferation of research within the field of interest and to capture the most recent research for inclusion in the current review.
on caregivers. Samples that considered multiple chronic diseases were considered for inclusion where the COPD carers’ data was separately analysed.

2.2.2 Study characteristics

Studies were required to quantitatively examine the psychological impact of caring for someone with COPD, i.e. review aims needed to state examination of some indicator of psychological distress. Empirical studies were considered for inclusion and qualitative research/narrative accounts were excluded. Studies not translated into English or published in peer-reviewed journals were excluded.

2.3 Study selection

The combined database searches generated 737 articles, 576 articles remained after the removal of duplicates. One further paper was identified through an ‘additional source’, a references list of a published article that was reviewed as part of the background reading for the current review. Thus the total number of articles screened for eligibility was 577. Many of these articles were Randomized Control Trials (RCTs) or studies exploring biomedical indices in COPD.

Once article titles were scrutinised for relevance, 51 titles were identified as eligible for this review. Examination of abstracts revealed 12 studies met the full inclusion criteria; 39 were excluded. Reasons for exclusion are noted in the Review Profile (see Appendix C). Selection of identified articles was carried out by the review author using a Data Extraction Proforma (see Appendix D).

2.4 Quality appraisal

A modified version of the Downs and Black Quality Assessment Tool (Downs & Black, 1998) was used to quality appraise included studies. The 27-item checklist considers five sub-scales: reporting, external validity, bias, confounding and power. Each domain is given a rating of ‘1’ if criteria are met or ‘0’ if criteria are not met. A score of ‘0’ is given if criteria cannot be determined. The Downs and Black checklist was selected due to its applicability to the nature of the studies reviewed (Deeks, Dinnes, D’Amico et al., 2003). The checklist has been shown to demonstrate high internal consistency and test-retest reliability of the Quality Index scores (Downs & Black 1998).
As the current review aims did not consider intervention outcomes, modifications to the original checklist were made in order to remove questions that related more specifically to intervention studies or RCTs. The version of the tool used in this review retained 12 items from the original checklist (see Appendix E).
3 Results

Twelve studies met the inclusion criteria for the current review. Table 1 summarises key features of included studies. Half of the studies (n=6) were published in the last five years, suggestive of an increase in outcome research in the field of interest. A description of excluded studies is given in Appendix F and characteristics of included studies are described below along with the research findings.

3.1 Participants and recruitment

A combined total of 834 carers participated in the twelve studies (M=70 participants per study; SD=58). The large standard deviation is noteworthy, with the smallest sample comprising 17 carers and the largest 203 carers. This disparity in sample size should be taken into account when comparing findings across studies. Mean age across eleven of the studies was calculated at 59 years (Range=49-68; SD=6.7), and combined samples across studies comprised a mean of 81% female carers (Range=70-100%; SD=10.3). The majority of studies were carried out in Portuguese speaking countries in Europe and South America (Brazil n=2; Portugal n=2). Two studies were conducted in Japan, two in the USA and single studies were carried out in Canada, Jordan, Hong Kong and Turkey.

All participants, excluding those in matched control studies (n =2), were recruited from clinical populations. Recruitment sources included inpatient and outpatient settings, as well as private pulmonary clinics. Given the breadth of recruitment sources there was considerable variability in duration of COPD diagnosis and COPD symptom severity across participants and studies. Data on patient characteristics was not always reported and where documented it was evident that characteristics such as symptom severity were often measured in different ways (see Table 1).

Care relationship was categorised and compared across studies: spousal carers only (n=6), family carers only (n=2) and ‘mixed’ carer groups (n=4). Studies that comprised mixed carer groups reported various relationships to care recipients.

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2 Two studies examined wives’ experiences and therefore employed purposive sampling to recruit females only.
Most comprised spouses, sons/daughters and siblings, with the highest percentage of carers generally indicated as spouses. All mixed carer studies had a category that stated the relationship as ‘other’, though none specified this relationship. The variation in relationship to carer was considered to be reflective of diversity in the countries of publication and cultural factors that affect familial care roles.

Mean duration of caregiving, average caregiving hours and time attending patients varied greatly across studies/was not always reported. Carer characteristics including carer health status, where reported, are noted within sample characteristics in Table 1.

### 3.2 Aims and methodological features

Two studies employed a matched control design, the remaining 10 studies used descriptive cross-sectional and/or correlational designs. Studies are grouped according to study design:

*Matched control (n=2):* Two studies were comparative and aimed to understand the impact on wives caring for husbands with COPD using non-caregiver controls (Ross *et al.*, 1997; Sexton *et al.*, 1985).

*Correlational (n=8):* Four studies examined factors associated with caregiver burden (Cedano *et al.*, 2013; Figueiredo *et al.*, 2014; Lee *et al.*, 2010; Pinto *et al.*, 2007). Two studies assessed the relationships among loneliness, depression and social support in patients with COPD and their spouses (Kara *et al.*, 2004; Keele-Card *et al.*, 1993). One study examined predictors of anxiety and depression symptomatology in familial caregivers (Jácome *et al.*, 2014), another examined the relationship between QoL and anxiety/depression in COPD patients and spouses (Al-Gamal 2014).

*Cross-sectional (n=2):* One study examined caregiver burden and subjective stress amongst carers of patients receiving long-term oxygen therapy (Takata *et al.*, 2008) another assessed depression and caregiver burden (Washio *et al.*, 2003).
3.3 Outcome measures

Nine studies examined anxiety and depression, with the Hospital and Anxiety Depression Scale (HADS; Zigmond & Snaith, 1983) most commonly used. Two studies employed Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977), one a translated version of the Beck Depression Inventory (Hisli, 1988) and another failed to specify how depression was measured. Seven studies measured caregiver burden, most using the Caregiver Burden Scale (CBS; Macera, Eaker & Jannarone et al., 1993) or Zarit Burden Inventory (ZBI; Zarit & Zarit, 1987). Five studies assessed QoL/life satisfaction employing a number of measures, the Medical Outcomes Studies Short-Form Health Survey (SF-36; Ware & Sherbourne, 1992) was most commonly used. Three studies considered stress and mood, employing subjective stress measures and the Profile of Mood States (McNair, Lorr & Doppleman, 1981). Two studies measured loneliness using the UCLA Loneliness Scale (Russell, Peplau & Cutrona, 1980).
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<th>Notable findings</th>
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<td>Al-Gamal (2014) Jordan</td>
<td>Examine the relationship between anxiety, depression and QoL in patients with COPD and their spouses</td>
<td>Spousal carers, n = 67 (70.0) Carers = majority of carers rated health as ‘fair’ (47.6%) Patients = perceived level of disease severity was rated, though descriptive statistics were not reported</td>
<td>1. Quality of Life Inventory (QLI) 2. Hospital Anxiety and Depression Scale (HADS)</td>
<td>Significant negative correlation between QLI total and HADS scores (depression r = -.594; p&lt;.005/ anxiety r = -.279; p&lt;.05). No statistically significant difference found in spouses’ QIL scores and patient disease severity (self-reported)</td>
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<td>Cedano et al. (2013) Brazil</td>
<td>Assess QoL and burden of caregiving in COPD carers of patients on long term oxygen therapy</td>
<td>Mixed carers, n = 80 (81.3) Carers = Average duration of care provision was 5 years, 13.1 hours per day. Majority had a health problem requiring medical treatment (65%) Patients = GOLD criteria indicated 47.7% had ‘severe’ COPD and 45% ‘very severe’ COPD</td>
<td>1. Medical Outcomes Studies Questionnaire Short Form Health Survey (SF-36) 2. Caregiver Burden Scale (CBS) 3. Katz Index – modified (indicating level of dependence)</td>
<td>All domains of SF-36 were negatively affected by domains of CBS; most impacted was ‘environment’. CBS was most affected by muscular-skeletal morbidity in carer (r = .36; p&lt;.0001) and hours spent caregiving per day (r = .25; p&lt;.003)</td>
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<tr>
<td>Figueiredo et al. (2014) Portugal</td>
<td>Analyse subjective burden of family carers of people with early and advanced COPD</td>
<td>Mixed carers, n = 167 (74.9) Carers = 64% had provided care &gt;4 years. Great variability in time spent caregiving and a significant difference time spent on caregiving tasks between ‘early’ and ‘advanced’ COPD group (p=.001) Patients = GOLD criteria indicated 113 carers looked after ‘early’ COPD and 54 cared for ‘advanced’ COPD</td>
<td>1. International Classification of Functioning Disability and Health checklist 2. Hospital Anxiety and Depression Scale (HADS) 3. Carers’ Assessment of Difficulties Index (CADI)</td>
<td>CADI scores were higher in the advanced COPD group, with a significant difference between the groups (p=.001). Depression symptoms were more frequent in the advanced COPD (p=.030) and both self-rated physical and mental health were significantly worse in this group (p=.035 and p=.011)</td>
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<tr>
<td>Jácome et al. (2014)</td>
<td>Examine anxiety and depression in family</td>
<td>Mixed carers, n = 203 (75.4) Carers = Majority of carers had been</td>
<td>1. Carers’ Assessment of Difficulties Index (CADI)</td>
<td>Anxiety symptoms were present in 63.5% of carers and were predicted by</td>
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<td>Study</td>
<td>Country</td>
<td>Method</td>
<td>Description</td>
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<td>Portugal</td>
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<td>carers of people with COPD</td>
<td>delivering care for ≥2 years (80.3%); most provided ≤20 hours of care per week (62.6%)</td>
<td>Patients = GOLD criteria indicted 67.5% of patients ‘early’ COPD and 32.5% ‘advanced’ COPD</td>
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<td>Kara et al. (2004)</td>
<td>Turkey</td>
<td>Identify differences in loneliness, depression and social support in COPD patients and their spouses</td>
<td>Spousal carers, n = 30 (73.3) Carers = 12 spouses reported two or more co-morbid health problems Patients = average duration of COPD diagnosis was 7.57 years. All patients reported moderate COPD symptoms, n = 18 had two or more co-morbid health problems</td>
<td>Significant relationship between loneliness and depression; those scoring highly for loneliness reported a greater number of symptoms of depression (r = -0.507, p &lt; .01). Moderate and small negative associations were found between depression and perceived social support (friends r = 0.471, p &lt; .01; family r = -0.495, p &lt; .05)</td>
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<td>* Keele-Card et al. (1993)</td>
<td>USA</td>
<td>Examine relationship and differences in loneliness, depression and social support between COPD patients and spouses</td>
<td>Spousal carers, n = 30 (76.7) Carers = 53.3% of spousal carers reported having two or more health problems Patients = 80% reported either moderate or severe COPD symptoms; 30% were homebound; 10% required assistance with daily personal care and 47% had co-morbid health problems</td>
<td>67% of carers had moderately high level of loneliness and a strong positive association between loneliness and depression was noted (r = 0.62; p &lt; 0.001). Social support not significantly correlated with loneliness or depression (p &gt; 0.05)</td>
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<td>Lee et al. (2010)</td>
<td>Hong Kong</td>
<td>Examine health related QoL and burden in carers of patients with COPD</td>
<td>Spousal carers, n = 81 (89.0) Carers = duration of caregiving was between 8-9 years; time spent attending patients ranged between 5-11 hours per day Patients = FEV1/FVC (%) was between 17-54%; duration of illness between 10-11 years</td>
<td>Analysis considered associations between: (1) health related QoL and other variables; and (2) caregiver burden (CBS) and other variables. QoL was associated with CIRS, HADS and LSNS, accounting for 29% of the variance (R² value and significance level not reported). CBS was correlated with GDS (r = 0.426, p ≤ 0.01); HADS (r = 0.334, p ≤ 0.05) and IADL (r = 0.295,</td>
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<td>Study (Year, Location)</td>
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| *Pinto et al.* (2007, Brazil) | Determine the effect of COPD on QoL of caregivers | Mixed carers, n = 42 (85.3)  
*Carers* = average duration of caregiving was 5 years  
*Patients* = GOLD criteria indicated majority of patients were classed as severe (38.1%); 19% were very severe; 24.1% moderate; 24.1% had mild symptoms  
5. Mini-Mental State Examination  
6. Geriatric Depression Scale (GDS)  
7. Hospital Anxiety and Depression Scale (HADS)  
8. Barthel Index  
9. Instrumental Activities of Daily Living Scale (IADL)  
p ≤ .05  
*Pinto et al.* (2007) Brazil | Determine the effect of COPD on QoL of caregivers | Mixed carers, n = 42 (85.3)  
*Carers* = average duration of caregiving was 5 years  
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<th>Study (Year, Location)</th>
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| *Ross et al.* (1997, Canada) | Understand the impact on wives caring for husbands with COPD | Spousal carers, n = 26 (100)  
*Carers* = health problems reported in 64% of COPD wives, 56% in control group  
*Patients* = 50% on supplemental oxygen; FEV1 ranged from 15-45% (M = 32.11%; SD = 7.88). Duration of diagnosis = M 12.02 years, SD = 9.24  
1. Medical Outcomes Studies Questionnaire Short Form Health Survey (SF-36)  
2. Caregiver Burden Scale (CBS)  
3. Quality of caregiver/patient relationship assessed using a 5-point Likert Scale  
CBS was predicted by self-rated caregiver/patient relationship (r = .93, p < .001); mental component summary score of SF-36 (r = -.020, p = .001) and the physical component summary score (r = -.017, p = .006). The model including these three independent variables accounted for 63% of the variance (R² = .638, p < .001) in caregiver burden  

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<th>Study (Year, Location)</th>
<th>Methodology</th>
<th>Findings</th>
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| *Sexton et al.* (1985, USA) | Determine the impact of husband’s COPD on spouse’s life | Spousal carers, n = 46 (100)  
*Carers* = health status is considered within the findings  
*Patients* = most had moderate symptoms, n = 5 were considered to be in the extremes (classification  
1. Profile of Mood States  
2. Relatives’ Stress Scale  
3. Rand Health Perceptions Questionnaire (Current Health Scale)  
4. Personal Resource Questionnaire  
CBS was predicted by self-rated caregiver/patient relationship (r = -.93, p < .001); mental component summary score of SF-36 (r = -.020, p = .001) and the physical component summary score (r = -.017, p = .006). The model including these three independent variables accounted for 63% of the variance (R² = .638, p < .001) in caregiver burden  

No differences in mood, stress, health status or social support were found between COPD wives and control group. COPD wives reported significantly more life upset (t(24) = 3.95, p < .001). Relationship between mood and social support differed between groups with a high correlation in COPD wives (r = -.74); low correlation in control group (r = .17)  

Significant differences between groups included: COPD wives reported higher levels of subjective stress (F(1) = 4,800, p = .032) and lower levels of life satisfaction (F(1) = 8,104, p = .006) compared to the control group. COPD
| Studies Included | Investigate burden among caregivers of elderly patients with COPD receiving Long Term Oxygen Therapy | Mixed familial carers, n = 45 (82.4) | 1. Zarit Caregiver Burden Interview (ZBI)  
2. Barthel Index (BI)  
3. Number of formal services used | 53.3% (n=24) of caregivers were classified as depressed (unclear how depression was assessed). Heavily burdened caregivers spent longer providing care (p<.05) and were more likely to desire social services input than lightly burdened caregivers. No inferential statistics were reported |
|------------------|-------------------------------------------------------------------------------------------------|---------------------------------|--------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|
| * Takata et al.  
(2008)  
Japan | Investigate depression in family caregivers of elderly patients with COPD – two groups of carers ‘depressed’ and ‘non-depressed’ | Mixed familial carers, n = 17 (94.1) | 1. Center for Epidemiological Studies Depression Scale (CES-D) /questionnaire about factors that might affect depression  
2. Zarit Caregiver Burden Interview (ZBI)  
3. Barthel Index (BI) | 41% (n=17) of caregivers were classified as depressed. Depressed caregivers had higher levels of burden (ZBI; p<.04) and had greater desire for more social services input, though no difference in actual help seeking behaviour was evident (p<.01). No other significant differences in caregiver attributes were found between the two groups (multiple characteristics assessed p>.05) |
| * Washio et al.  
(2003)  
Japan | Investigate burden among caregivers of elderly patients with COPD receiving Long Term Oxygen Therapy | Mixed familial carers, n = 45 (82.4) | 1. Zarit Caregiver Burden Interview (ZBI)  
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**GOLD = The Global Initiative for Chronic Obstructive Lung Disease, classification tool / FEV1 = Forced expiratory volume in one second.**

* * = Studies included in Grant et al. (2012)*
3.4 Findings

Psychological outcome status was variably described/encapsulated within included papers. In an attempt to synthesise the extracted data, study findings are described in terms of main psychological outcome variables measured:

a) Anxiety and depression

Four studies examined anxiety symptomatology and eight examined depression (Al-Gamal, 2014; Figueiredo et al., 2014; Jácome et al., 2014; Kara et al., 2004; Keele-Card et al., 1993; Lee et al., 2010, Takata et al., 2008; Washio et al., 2003). All except Lee (2010) reported caseness for anxiety and/or depression. The three studies assessing anxiety, indicated caseness (subscale scores for anxiety as measured using the HADS≥8) for between 59 and 70.4% of COPD carers. The highest prevalence of anxiety was reported in carers of individuals with advanced COPD (Figueiredo et al., 2014).

Caseness for depression was reported different ways according to different clinical cut-offs used for the various measures employed. In one study the clinical cut-offs used for categorisation were unclear (Kara et al., 2004). The seven studies that examined depression found prevalence rates of between 29.2 and 73.3%. Of the eight studies that considered anxiety and depression, four examined anxiety and depression only, four considered other psychological outcomes e.g. QoL, loneliness and perceived social support. Al-Gamal (2014) found a significant negative correlation between spouses’ HADS scores and QoL ratings.

Significant predictors of anxiety and depression included patients’ activity limitation and perceived burden, assessed using the Carers’ Assessment of Difficulties Index (Nolan & Grant, 1992). Depression was also predicted by older age, and anxiety by female gender (Jácome et al., 2014). Similarly, Washio et al. (2003) found higher burden to be associated with depression in COPD carers, but

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3 As multiple outcomes were considered within some of studies, categories reported here are not mutually exclusive and findings are integrated within appropriate categories where deemed relevant.
found no other significant differences between ‘depressed’ and ‘non-depressed’ caregivers.

In one of two studies to consider symptom severity, Figueiredo et al. (2014) found those caring for individuals with advanced COPD reported higher burden scores, more depression symptomatology, and their mental and physical health were affected to a greater extent (assessed using the International Classification of Functioning, Disability and Health checklist, World Health Organization, 2001). The other study examining differences between ‘lightly burdened’ and ‘heavily burdened’ caregivers (Takata et al., 2008), reported no significant difference in depressive symptomatology or patient characteristics (e.g. lung functioning).

b) Quality of life

Five studies measured QoL/life satisfaction (Al-Gamal, 2014; Cedano et al., 2013; Lee et al. 2010; Pinto et al., 2007 and Sexton et al., 1985). Of the five studies measuring QoL four considered associations between QoL and other outcomes and one was a comparison study, comparing wives whose husbands had COPD to wives whose husbands did not have a chronic illness. (Sexton et al., 1985). Two studies (Al-Gamal, 2014; Lee et al. 2010) explored the relationship between anxiety, depression, QoL and/or caregiver burden and two considered predictors of caregiver burden (Cedano et al., 2013; Pinto et al., 2007).

Translated versions of SF-36 (Ware & Sherbourne, 1992) were employed in three studies (Cedano et al., 2013; Lee et al. 2010 and Pinto et al., 2007). Combining scores across the domains of the SF-36, a physical component summary score (PCS) and mental component summary score (MCS) are computed (higher scores indicate better QoL). Across the three studies mean PCS score ranged from 46.5-75; MCS 45.9-70. The two domains of QoL most affected in COPD carers were mental health and physical functioning. Two studies employed alternative measures, Al-Gamal (2014) used the Quality of Life Index (Ferrans & Powers, 1985) and Sexton et al. (1985) used the Life Satisfaction Index-A (Neugarten, Havinghurst & Tobin, 1961). The latter was a comparison study that found COPD carers experienced lower levels of life satisfaction compared to controls.
c) Other psychological outcomes

Four studies assessed psychological constructs related to social isolation and stress (Kara et al., 2004; Keele-Card et al., 1993; Sexton et al., 1985 and Ross et al. 1997). Two studies examined differences in loneliness, depression and social support among patients with COPD and their spouses. Kara et al. (2004) found that loneliness and depression were positively related (i.e. greater depressive symptomatology was present in caregivers who scored higher for loneliness) whilst Keele-Card et al. (1993) found no significant correlations between social support, loneliness and depression.

Two comparative studies considered the difference in reported stress between control groups and wives of husbands with COPD. Sexton et al. (1985) found spousal carers reported significantly higher stress scores and lower general health ratings than the control group, but Ross et al. (1997) found no statistically significant differences between carers and controls on both stress and mood measures (Relatives Stress Scale, Greene, Smith & Gardiner et al., 1982; Profile of Mood States, Mc Nair et al., 1981).

3.5 Quality appraisal

A modified version of the Downs and Black quality appraisal tool was employed to appraise included studies (Downs & Black 1998). Quality appraisal scores are noted in Appendix E. Overall, the majority of studies had a moderate quality score, total scores ranged between 4 and 10. A general trend was observed for older publications to be rated of lower quality. ‘Reporting’ was adequate across studies, although the majority of studies did not account for variability within the data, ‘power’ in some studies was limited by small sample sizes, and ‘external validity’ was often difficult to ascertain.

3.6 Methodological limitations

A number of methodological issues were noted:

3.6.1 Sampling issues

Representativeness of included studies was questionable given most studies primarily recruited female caregivers, who are known to be more likely to report
psychological distress and experience lower levels of subjective wellbeing than men (Pinquart & Sorensen, 2005). It is possible that the prevalence and predictors of psychological outcomes are different for male and female carers however, reviewed studies were not able to make meaningful gender comparisons.

Most samples were not randomly selected, nine used convenience samples and three employed purposive sampling. Only three studies reported response rates and no studies adequately reported attrition or reasons for attrition. Absence of data makes it difficult to identify potential biases within recruitment and sample characteristics.

Sample composition may also have been affected by study location. The majority of studies were conducted in developing countries and impact of location and/or culture and indeed translation of measures, was generally not considered in relation to psychological morbidity. Though one paper did comment on the social context of female carers (Cedano et al. 2013) and another considered difficulties associated with emotional expression within the Chinese culture (Lee et al. 2010), the impact of socio-cultural factors on findings was not fully deliberated.

3.6.2 Study design

Whilst two studies used a comparison group to explore the difference between COPD carers and matched controls, cross-sectional designs dominated. This design was consistent with study aims, but since cross-sectional studies only capture responses at one particular time point, they may not adequately capture transient and dynamic symptoms of psychological distress in carers in response to patient’s disease trajectory, AEs or other factors.

3.6.3 Outcome measures/ operationalising outcome variables

Diverse psychometric tools were used across studies and some studies did not employ psychometrically valid tools (Sexton et al., 1985). Such heterogeneity in measures made comparison across studies difficult. Variability in depression rates was noted across studies, possibly attributable to disparity in the measures used to examine depression e.g. HADS, CES-D, translated version of BDI and in one study it was unclear how depression was measured (Takata et al., 2008).
Inconsistent assessment and reporting of care recipient and carer characteristics was also noted. Information relating to COPD symptom severity was often examined different ways, yet COPD is a wide ranging diagnosis that encompasses various degrees of lung damage and physical functioning. Some studies reported lung function using GOLD staging (Global Initiative for Chronic Obstructive Lung Disease, GOLD, 2013; see Appendix G for GOLD staging criteria), others reported forced expiratory lung volume (FEV1) or used Hugh-Johns dyspnoea criteria. The variability precluded arrival at clear conclusions regarding the relative contribution of patient characteristics to anxiety and depression or caregiver burden. Similarly, carer attributes, notably detail on caregiving duties and time spent delivering care, was either absent (e.g. Al-Gamal, 2014) or variably described. Consistent reporting of type and duration of care would have enhanced comparability across studies.
4 Discussion

4.1 Summary of main results

This paper aimed to systematically review quantitative literature examining the psychological impact of caring for someone with COPD. The primary objective was to establish prevalence rates of psychological distress; a secondary objective was to explore predictors of distress amongst carers of individuals with COPD. The review focused on familial and/or informal caregivers and considered the psychological rather than the social or physical impact of caregiving. In contrast to previous reviews, the current review selected only outcome studies for inclusion and prioritised consideration of the quality and methodological limitations of included studies. Twelve studies met the full inclusion criteria, the majority employed descriptive cross-sectional and/or correlational designs. Relationship between carer and care recipient varied across studies, though most samples comprised primarily of spousal carers. Diverse psychological outcomes were measured across studies and primary outcomes assessing psychological morbidity included: anxiety, depression, quality of life, loneliness and stress.

In those studies examining anxiety (Al-Gamal, 2014; Figueiredo et al., 2014; Jácome et al. 2014) prevalence of clinically salient anxiety was reported by between 59 and 70.4% of COPD carers, and between 29.2 and 73.3% for those examining depression (Al-Gamal, 2014; Figueiredo et al., 2014; Jácome et al. 2014; Kara et al., 2004; Keele-Card et al., 1993; Lee et al., 2010, Takata et al., 2008; Washio et al. 2003). These data suggested greater prevalence of depression than cited by Grant et al.’s (2012) review, in which prevalence was found to range between 37 and 41%. Indeed, prevalence rates were more consonant with general estimates of depression in carer populations, reporting between 40 and 70% to have clinically significant symptoms (Zarit, 2006). Prevalence rates for depression were also similar to those reported by carers of individuals with other long term physical conditions: renal failure (Matsuu, Washio & Arai et al. 2001), cancer (Macmillan, 2011) and degenerative cognitive conditions such as dementia (Schulz, O'Brien & Bookwala et al., 1995). The current review revealed significantly elevated levels of anxiety not previously synthesised. Anxiety prevalence rates were consonant with those reported by carers for those with
cancer (Linden, Vodermaier & Mackenzie, 2012), myocardial infarction (Lane, Carroll & Ring, 2002) and dementia (Badrakalimuthu & Tarbuck, 2012).

Findings from the correlation and predictive studies exploring anxiety and depression suggested that caregivers who reported higher levels of depression also experienced higher levels of perceived caregiver burden and were caring for individuals with more advanced COPD. Evidence from one study also indicated those reporting high levels of anxiety/depression experienced poorer QoL (Al-Gamal, 2014). However, these findings were not evidenced consistently. For example, whilst one study showed depression symptoms were more frequent in those who cared for individuals with advanced CODP (Figueiredo et al., 2014) another found no significant differences, other than self-rated caregiver burden, between ‘depressed’ and ‘non-depressed’ caregivers (Washio et al. 2003). Conflicting results may be explained by the small number of studies that considered predictors of anxiety and depression, possible sampling bias and differences in the way variables like symptom severity were operationalised.

Evidence for the impact of loneliness on mood or vice versa, was not clear. Though carers may have significant contact with their care recipient, they may also feel socially isolated. Whilst empirical evidence generally suggests that perceived social support improves adjustment in chronic illness (Keele-Card et al., 1993), the two studies in this review that considered loneliness reported contradictory findings. Whilst Kara et al. (2004) found loneliness and depression were positively related (greater depressive symptomatology was present for caregivers who scored higher for loneliness), Keele-Card et al. (1993) did not find a significant correlation between loneliness and depression. Though these studies were methodologically similar and of similar sample size and demographic, their locations (Turkey and USA) and clinic source for recruitment differed. The contradictory findings may perhaps be attributable to cultural differences and the use of different measures in examining depression.

The studies that examined stress also reported contradictory findings. One study reported significantly higher stress scores among COPD carers (Sexton et al., 1985), another found no significant difference between carers and matched controls (Ross et al. 1997). These two studies were the only comparison studies
included in the review. Although benefitting from utilising a control group, they were conducted over twenty years ago and employed comparatively small samples sizes, in which participant selection was non-randomised. Whilst there is evidence that chronic stress may be a risk factor for carers’ wellbeing e.g. for cognitive decline in caregivers (Vitaliano, Echeverria, Phillips et al., 2006), more recent publications included in the current review did not examine stress. This may reflect a shift in the way stress has come to be conceptualised in biological terms (e.g. cortisol levels) and a developing literature examining carer distress with resource to more sophisticated models.

4.2 Strengths and limitations

The current review provided the first quantitative synthesis of research examining the psychological impact of caregiving in COPD and is the first to synthesise prevalence data for anxiety, albeit from only three studies. Growth of research assessing the prevalence of psychological morbidity permitted the current review to comment more reliably on the prevalence of depression among COPD carers than earlier less comprehensive reviews. However, the review is subject to limitations of the included studies and limitations related to the process of conducting the review. Due to the timescale for completion of the current review, it was not possible to assess inter-rater reliability. In the absence of a second rater, degree of concordance/agreement could not be ascertained during the article screening, data extraction and quality appraisal procedures. Since these elements of the review were conducted by only the review author, they were less rigorous than had they been conducted with others.

Many sources of inter-study variation could have accounted for the differences in reported prevalence estimates and predictors of distress, notably diversity in outcome measures employed (as highlighted within the Results section). In addition to the variable measures employed, translated versions of standardised measures were used, which may not have assured cultural relevance or sensitivity, and measures may not have been validated within the target population. Further limitations relate to the heterogeneity of included studies, in particular sample characteristics and study location.
It is of note that there were few studies (n=3) that considered the psychological impact of caregiving amongst COPD carers in developed countries, contrasting with epidemiological data where mortality and morbidity estimates are more frequently sourced from developed countries (Pauwels, Buist, Calverley et al., 2001). Although location differences are not unexpected within reviews, the absence of research in developed countries, particularly the UK, is surprising. One explanation could relate to differences in risk factors for developing COPD, such as distribution of tobacco smoking and levels of exposure to biomass fuels, which vary between developed and developing countries and can influence COPD prevalence and/or mortality rates (Viegi, Maio & Pistelli et al., 2006). Increased prevalence of COPD and variations in age-standardized death rates could influence the public profile of COPD in particular countries, contributing to differences in public health planning and research agenda’s. At present, whilst it is acknowledged that there is considerable variation in death rates and population prevalence rates of respiratory diseases, the reasons for these discrepancies are not clear and further research is warranted (Viegi et al., 2006).

Another possible explanation could relate to cultural differences associated with attitudes to and/or barriers associated with the provision of, and access to formal and/or institutional care (Dilworth-Anderson, Brummett & Goodwin et al., 2005). In the UK, the provision of care on the National Health Service and legislation such as The Care Act 2014 (which sets out carers' legal rights to assessment and support), may engender attitudes that there are safeguards in place to support carers. It is unclear how these factors may influence the awarding of research grants locally however, the representation of south American studies herein may be associated with the PLANTIO study (lunched in 2002 with the aim of describing the epidemiology of COPD in five major Latin American cities; Menezes, Preze-Padilla & Jardim et al., 2005), as a factor stimulating COPD research in Latin America.

4.3 Clinical implications
This review highlighted that caring for individuals with COPD is associated with increased psychological distress, notably high prevalence of self-reported anxiety and depression. As the general burden of COPD on society increases along with
drives to foster self-management, increased reliance on informal carers seems inevitable. Yet anecdotal evidence indicates healthcare professionals in primary care do not routinely ask if individuals are providing care to someone, despite the negative consequences that caregiving can have on individuals’ physical and mental health. The current review advances a case for (1) routinely asking about contributions to informal care provision when patients attend clinical appointments with spouses/family members and (2) offering psychological screening and support to identified caregivers, particularly where distress is suspected or indicated.

At present, most carers only come to the attention of health care services at the point of crisis (Butler, Turner & Kaye et al., 2005), when more intensive interventions are required. Identifying carers, who are experiencing difficulties earlier through routine assessment of their psychological needs, could serve to help prevent severe mental health difficulties developing within COPD carer populations and reduce healthcare costs associated with more severe healthcare needs. COPD carers are generally unaware of formal support services that are available and are therefore limited in their access to such services (Booth et al., 2003). Thus, recognising the prevalence of psychological distress amongst carers through screening could increase dialogue about available support services, potentially resulting in increased access to support for this group of carers.

More generally, it is important to examine carer distress in long term conditions, as accurate prevalence data, in conjunction with an increased understanding of the predictor’s distress, could support early identification of psychological morbidity which is integral both to prevention of severe mental health difficulties and public health planning (Buist, Vollmer & Sullivan et al., 2005). Accurate prevalence data may increase the profile of carer support needs in order to promote investment in new interventions for caregivers of individuals with COPD and/or promote changes in COPD disease management. Possible changes to consider may include: (1) increasing community care resources, (2) greater use of paid carers, (3) models of respite care and (4) earlier residential care placements for COPD patients.
In addition to supporting COPD carer needs, revisions to current approaches to care, such as those outlined, have potential gains for COPD patients and the societal costs incurred in COPD care provision. For example, burdened caregivers are more likely to seek formal care for patients (Haupt & Kurz, 1993). Economic implications for health services are also underscored by family carers being a link between patients and formal healthcare providers (Pearlin, Schaie & Zarit, 1993), with many patients relying on carers to access healthcare themselves delaying investigation of potential worsening symptoms (Mannino, Gagnon & Petty et al., 2000). Informal caregivers play an important role in supporting COPD patients to access services and in promoting self-management, thus by ensuring caregivers are supported, this could inspire a shift towards more preventative models of care in COPD.

4.4 Directions for future research

Additional research is needed to clarify the potential interactions between the factors identified as possible predictors of psychological distress amongst COPD carers and whether there are any factors that mediate these relationships. Contradictory findings herein, related to the predictive value of patient symptom severity in explaining anxiety and depression in carers, suggest that further research assessing the contribution of care recipient characteristics to carer distress is warranted in order to clarify these relationships.

Qualitative literature in COPD suggests that carers’ perception of patients’ health status may be more important that actual symptom severity (Nakken, Janssen & van den Bogaart, 2015), although illness perception is rarely considered within this population. Exploration of cognitive variables, for example assessing how COPD carers’ perception of patients’ health status may relate to the development of anxiety and depression, is recommended. Correlates of psychological morbidity evident in other chronic conditions could also be examined, notably co-morbid cognitive difficulties, in particular dementia (Eisendorfer, Czaja & Lowenstein et al., 2003; Mittleman, Ferris & Shulman, et al., 1995), as well as socioeconomic factors that may influence caregiver burden (Zarit et al., 1980).
Evidence suggests that the approach to care provision in COPD tends to be reactive i.e. care provision focuses on AEs, with increased external support input at these times (Fromer, 2011). This should be accounted for in future research by routinely recording number of hospitalisations and controlling for additional care input that might be temporarily in place in the context of AEs. Cross-sectional designs dominated the literature in the current review and future studies could examine morbidity and its correlates over time, or across the disease trajectory. Employing alternative study designs within COPD carer research would allow for psychological distress to be considered in the context of COPD disease progression and disease instability (i.e. during AE). Lastly, of the twelve studies included in the review, none included data from UK-based samples which would be welcomed, both to establish prevalence rates of anxiety and depression and their associated predictors among familial carers, and to inform broader NHS policy.
References

*Indicates studies include in current review


PART 2: Research Report

Trauma and health anxiety in complex Chronic Obstructive Pulmonary Disease (COPD)
Abstract

Background and aims: Chronic Obstructive Pulmonary Disease (COPD) is common in older adults and research is increasingly focusing on psychological morbidity within this population. Studies to date have primarily considered anxiety and depression in COPD; few have considered more detailed experience of anxiety in models of trauma or health anxiety.

Method: Sixty COPD patients recruited from an outpatient clinic completed measures of trauma and health anxiety, and medical records were accessed to obtain demographic information and measures of anxiety, depression and quality of life. Constructs examined included: anxiety, depression and health-related quality of life (independent variables) and trauma and health anxiety (dependent variables). Analysis explored prevalence, the relationships between dependent and independent variables and whether independent variables predicted the variance in the dependent variables.

Results: Clinically significant PTSD was reported in 13% of the sample, this is higher than the general population prevalence. Participants experienced higher levels of anxiety, depression, health anxiety and impaired quality of life compared to non-clinical populations. Relationships were found between health anxiety and all of the dependent variables. However, trauma symptom severity showed no relationship with psychological morbidity or health-related quality of life. This was surprising given well established links between PTSD and psychological morbidity; possible explanations were explored. Health anxiety accounted for a small amount of variance in the dependent variables.

Conclusions: Standard intervention for those with COPD is Pulmonary Rehabilitation, in which psychological management is not integral and uptake/engagement is low. Given significant and elevated distress revealed herein, comprehensive assessment and interventions that address more specific psychological difficulties, such as health anxiety, may improve psychological morbidity, improve quality of life and reduce healthcare utilisation. The links between PTSD and psychological morbidity in COPD remain unclear. Further research would be helpful in clarifying these relationships, to inform the development of targeted interventions.
1 Introduction

1.1 Chronic Obstructive Pulmonary Disease

COPD is an umbrella term used to describe a number of conditions that affect lung functioning, such as chronic bronchitis and emphysema (British Lung Foundation, 2016). Though COPD is degenerative and impairment is considered not fully reversible (Pauwels, Buist & Ma et al., 2001), recent conceptualisations of COPD have begun to recognise its preventability and treatability:

“COPD, a common preventable and treatable disease is characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and lungs to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients” (GOLD, 2015).

The disease trajectory in COPD is variable with individuals experiencing periods of relative stability, followed by marked decline. Clinical characteristics of COPD may include: breathlessness on exertion, chronic coughing, wheezing, inflammation in the bronchial tubes, excessive sputum production, tightness in the chest and tiredness (British Lung Foundation, 2016). COPD is positively associated with age (Mannino, Gagnon & Petty et al., 2000) and risk factors associated with developing the disease are both exogenous (e.g. smoking and air pollutants) and endogenous (e.g. genetic factors, gender and socioeconomic status) (Viegi, Maio & Pistelli et al., 2006). In its early stages, COPD can go unrecognised (Decramer, Miravitlles & Price et al., 2011) however, as the disease progresses individuals commonly experience acute exacerbations of their symptoms. Acute exacerbations (AEs) can be understood as a general worsening of symptoms, particularly shortness of breath, beyond the day-to-day variability in individual’s baseline, potentially lasting for several days (Celli & MacNee, 2004).

During AEs patients experience intensification of symptoms, notably dyspnoea (breathing discomfort), which may result in respiratory failure or need for
ventilatory support (Celli & MacNee, 2004). AEs may also be associated with non-specific symptoms (insomnia, sleepiness, fatigue, low mood and confusion) and can be fatal (Pauwels et al., 2001). AEs are clinically and economically significant; periods of exacerbation are associated with increased ambulatory care and hospital admissions (Hurst, Vestbo & Anzueto et al., 2010; Miravitlles, Anzueto & Legnani, et al., 2007; Suissa, Dell'aniello & Ernst, 2012), as well as increased mortality (Lawati & FitzGerald, 2008) and reduced quality of life (Harrison, Apps & Singh, et al., 2013; Kühl, Schurmann & Rief 2008).

1.2 Societal and personal costs

COPD is one of the leading causes of morbidity and mortality in developed and developing countries (Viegi et al., 2006), with general population lifetime rates estimated to be approximately 15% (Cleland, Lee & Hall, 2007). Prevalence in the UK is estimated at 3 million (National Clinical Guideline Centre, 2010), with cost of COPD to the healthcare system in excess of £930 million per year (National Clinical Guideline Centre, 2010), attributable mostly to hospital admissions (Celli & MacNee, 2004). Globally, COPD is likely to be the leading cause of mortality worldwide by 2030 (WHO estimates, 2016), its projected increase is driven mainly by population aging and smoking frequencies (Feenstra, van Genugten & Hoogenveen et al., 2001; Murray & Lopez, 1997).

As COPD becomes more prevalent, an increasing number of people are learning how to manage and live with the debilitating effects of the disease. The approach to treatment is integrative, with a focus on lifestyle changes (smoking cessation and Pulmonary Rehabilitation (PR)), as well as disease management including medication, oxygen therapy and in some cases surgery (e.g. lung volume reduction therapy). Functional impairment in COPD is often associated with physical de-conditioning, particularly deterioration of the heart and skeletal muscles associated with sedentary behaviour. Patients with COPD have reduced physical activity compared to general populations of older adults. There is therefore focus on increasing physical activity, which is supported through

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4 Dyspnoea is functionally assessed by the Medical Research Council dyspnoea scale (National Institute for Clinical Excellence, 2010), see Appendix K.

5 Lung volume reduction therapy is surgery that removes the most affected area of the lung (British Lung Foundation 2016).
exercise components incorporated in PR programmes (Nguyen, Burr & Gill et al., 2011). AEs can also adversely impact patients’ functional ability, especially reduced ability to carry out activities of daily living following AEs (Pitta, Troosters & Probst, et al., 2006). Thus, patients with COPD can require significant support, particularly when their symptoms worsen (Nici, Donner & Wouters et al., 2006).

1.3 Psychological impact of COPD

Given significant and aversive symptoms experienced by individuals with COPD, as well as the unpredictable nature of the disease, it is unsurprising that the condition can have a significant impact on individuals’ mood and quality of life (Yohannes, Roomi & Waters et al., 1998; Harrison et al., 2013). COPD confers significant increased risk of co-morbid mental health difficulties, notably depression (van Manen, Bindels & Dekker et al., 2002; Yohannes, Willgoss & Baldwin et al., 2010), anxiety (Wagena, Arrindell & Wouters et al., 2005) and panic disorder (Rose, Wallace & Dickson et al., 2002). Reviewed data from 81 studies revealed psychological morbidity in COPD patients exceeding general population norms, prevalence rates of anxiety ranged between 10 and 100% and rates of depression between 7 and 79.1% (Hynnine, Breitve & Wiborg, et al., 2004). Panic disorder is also highly prevalent and is estimated to be ten times higher in COPD than the 1.5-3.5% in the general population (Livermore, Sharpe & McKenzie, 2011).

Psychological morbidity in COPD is clinically relevant, since elevated anxiety and depression is associated with poorer outcomes including: increased mortality (Egede, 2007), higher frequency of AEs (Yohannes, Baldwin & Connolly, 2005; Laurin, Labrecque & Dupuis et al., 2009) frequency and severity of dyspnoea (Brenes, 2003; Gift & Cahill, 1990), functional impairment (Kim, Kunik & Molinari et al., 2000), reduced quality of life (Yohannes et al., 1998; Kühl et al., 2008) and greater healthcare utilisation and cost (Xu, Collet & Shapiro et al., 2008). There is also evidence elevated anxiety is associated with treatment non-adherence in PR (Hayton, Clark & Olive et al., 2012), and that panic symptoms are associated with a higher number of AEs and increased re-hospitalisation.
Given these relationships, psychological factors are advised to be considered in routine COPD treatment (Hynnine et al., 2004).

1.4 Posttraumatic Stress Disorder

Posttraumatic stress disorder (PTSD) is a common reaction following the experience of a traumatic event (Ehlers & Clark 2000). Evidence suggests COPD symptoms may be experienced as traumatic; breathlessness has been shown to be associated with catastrophic cognitions such as ‘fear of dying’ (Bailey, 2004) and dyspnoea has been described like ‘suffocation’ (Teixeira, Porto & Kistensen et al., 2015). As well as being associated with a perceived sense of threat to self, AEs have been shown to be associated with hyperarousal (a key symptom cluster in PTSD) and body scanning for symptom alterations (Harrison et al., 2013). Whilst there is substantial research examining the prevalence and experience of panic disorder, low mood and anxiety in individuals with COPD, comparatively little attention has been paid to the possible links between trauma and symptoms of COPD, despite its ‘traumatogenic’ potential. In what follows, the symptoms and aetiology of PTSD are described.

PTSD is a psychopathological response that can occur in some individuals following exposure to a traumatic event (Diagnostic and Statistical Manual fifth edition (DSM-V) American Psychiatric Association (APA), 2013). A traumatic event is ‘... any experience that by its occurrence has threatened the health or well-being of the individual.’ (Brewin, Dalgleish & Joseph, 1996, p. 675). Four symptom clusters of PTSD are proposed (1) intrusion symptoms (including re-experiencing and flashbacks); (2) persistent avoidance; (3) negative alterations in cognitions and mood; (4) alterations in arousal and reactivity (DSM-V, 2013). Though many individuals may experience trauma symptoms following a threatening experience, for a diagnosis of PTSD the symptoms are required to be present for a period of at least one month following the traumatic incident, symptoms should cause distress and significantly impact on social and/or occupational functioning (DSM-V, 2013).

In the general population, lifetime prevalence rates of PTSD are estimated at 8% (Kessler, Chui & Demler et al., 2005) and a number of variables are shown to be
implicated in the development of the disorder, including: gender (higher prevalence in females), age and sociodemographic factors (Lauterbach & Vrana, 2001; Voges & Romney, 2003). In considering why only some people develop PTSD after exposure to a traumatic event, a number of theories have been proposed. These suggest PTSD is strongly associated with processes involved in event appraisal and autobiographical memory (Lang, 1985; Foa, Steketee & Rothbaum, 1989; Brewin et al., 1996; Conway & Pleydell-Pearce, 2000; Ehlers & Clark, 2000). Although treatable, PTSD often goes undetected, despite the debilitating impact of the disorder and associated increased risk of suicide (DSM-V, 2013). Direct screening for PTSD is recommended, as individuals can frequently fail to mention significant traumatic experiences if not explicitly asked (Solomon & Davidson, 1997).

1.5 Trauma and COPD

Research in chronic disease (myocardial infarction) has suggested that cumulative burden of traumatic experiences in chronic disease may be precipitants of PTSD (Alonzo, 2000). Applying a cumulative adversity model in COPD, AEs as traumatic episodes, potentiate vulnerability and increase risk for developing PTSD, given likelihood of recurrent trauma (i.e. risk of future AEs). A recent metasynthesis examining the experience of AEs in patients with COPD suggested the presence of trauma-type symptomatology notably a constant state of arousal and hypervigilance to symptoms and body changes arising from the unpredictability and perceived uncontrollability of acute exacerbations.” (Harrison et al., 2013 p.13). When discussing the intensity of breathlessness following AEs, the narratives in this metasynthesis indicated high levels of distress, anxiety, powerlessness and negative appraisals. Catastrophic cognitions suggested perception of breathlessness as a precursor to death (Harrison et al., 2013). Such findings are strongly suggestive of the traumatogenic potential of AEs, according to Brewin et al’s (1996) definition of a traumatic event.

Whilst there is established literature suggesting acute medical events, such as myocardial infarction and birth trauma (Chung, Berger & Jones et al., 2008; Ayres, Eagle, & Waring, 2006; Mundy & Baum 2004) can trigger PTSD, less is known about chronic conditions, such as COPD. To date, a limited number of
studies have examined the relationship between PTSD and COPD (Chung, Jones & Harding et al., 2015; Jones, Chung & Harding et al., 2009b; Teixeira et al., 2015).

Jones et al. (2009b) recruited participants undergoing pulmonary rehabilitation (n=100) examining PTSD prevalence and treatment implications for PR. PTSD prevalence was reported at 8%, consonant with general population prevalence rates for PTSD (Kessler, Chui & Demler et al., 2005). Of the participants who experienced PTSD, 75% (n=6) reported traumatic events that directly related to their COPD however, it was unclear whether participants were relating their responses on the trauma screening measure to their experience of COPD or other experiences of previous traumatic life events. Severity of PTSD symptoms did not improve following PR and PTSD symptom severity scores were inflated post-treatment.

Teixeira et al. (2015) examined the relationship between COPD exacerbations and PTSD in patients who were admitted to hospital (n=33). PTSD symptoms were present in 33.3% of patients and linear regression analysis indicated AEs significantly predicted PTSD scores, with PTSD symptoms increasing as the number of AEs increased. Airflow obstruction was also associated with PTSD symptoms, independent of the experience of having experienced an AE.

Chung et al. (2015) examined the incidence of PTSD resulting from past trauma among older patients with COPD (n=85), examining whether COPD symptom severity and PTSD were associated with morbidity and health related quality of life. Eleven percent of participants had experienced traumatic events related to their respiratory problems (though it was not clear if they were relating responses to this event specifically), 55% of the sample experienced no PTSD symptoms (n=35), 39% (n=25) had partial PTSD and 6% (n=4) had full PTSD⁶. Between-group comparisons revealed no significant differences in age, gender and smoking status between the combined group of partial and full PTSD patients, and those who did not meet the criteria for PTSD. Regression analyses indicated PTSD was

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⁶ Participants were classified as having partial PTSD if significant scores were present for one or two of the symptom-clusters, rather than all three clusters, as indicated in the DSM-IV.
significantly correlated with COPD severity and COPD severity was significantly correlated with psychological morbidity and health related quality of life. The emotional symptoms of COPD (emotional function subscale of the Chronic Respiratory Questionnaire, CRQ-SR, Guyatt, Berman & Townsend et al., 1987) mediated the relationship between PTSD symptoms and the mental component of health related quality of life (subscals on the Medial Outcomes Short Form 12; Ware, Keller & Kosinski, 1996). Emotional symptoms of COPD also mediated the relationship between PTSD and depression (measured using the Hospital Anxiety and Depression Scale, Zigmond & Snaith, 1983). The study concluded that PTSD from past trauma was not independent of COPD symptom severity, quality of life and psychological morbidity (Chung et al., 2015).

1.6 Anxiety disorders and COPD

Common anxiety disorders include panic disorder, generalised anxiety disorder (GAD) and health anxiety. GAD is characterised by “the presence of excessive anxiety and worry about a variety of topics, events, or activities. Worry occurs more often than not for at least 6 months and is clearly excessive...” (DSM-V, 2013). As already highlighted anxiety and panic disorder are highly prevalent in COPD (Hynnine et al., 2004; Livermore et al., 2011). Less considered within the COPD literature, is health anxiety. The symptoms of health anxiety overlap with GAD. However, health anxiety is characterised by debilitating excessive worry particularly relating to an individual’s health. Those who experience health anxiety are thought to be overly sensitive to changes in bodily sensations, misinterpreting these as an indication of threat or serious physical illness (Warwick & Salkovskis, 1990).

It is of note that PTSD has historically been considered to be an anxiety disorder however, recent conceptualisations of the disorder have represented a shift in thinking towards addressing PTSD under ‘Trauma and Stressor Related Disorders’ (DSM-V, 2013). One of the symptom clusters characteristic of PTSD is the experience of intrusions and dissociative reactions commonly referred to as ‘flashbacks’. Flashbacks are experiences in which individuals feel as if a traumatic event which they have experienced is recurring (DSM-V, 2013). When applied to medical trauma, individuals’ experiences may be more accurately
described as ‘flashforwards’, which are distinct to flashbacks (Mundy & Baum, 2004). The explanation relates to the observation that intrusions frequently appear to be associated with anticipated future outcomes, rather than experiences associated with the original trauma. Such observations have raised questions regarding the classification of symptomatology following traumatic medical events. It may be that anxiety related to future health, described as a flashforwards, is better described and operationalised as health anxiety (Salkovskis, Rimes & Warwick et al., 2002).

Though research to date has not specifically focused on examining health anxiety in COPD, the notion that COPD confers sensitivity to body sensations and changes has been evidenced. Research considering the affective component of dyspnoea has conceptualised a circular relationship between breathlessness and anxiety. Bailey (2004) suggested that for some individuals, breathlessness could lead to high arousal/increased anxiety levels, the presence of which could heighten the perception of breathlessness. Within this model, breathlessness can act as both a trigger and a response for increased breathlessness. Similarly, Harrison et al. (2013) suggested that symptoms such as hypervigilance may be implicated in sustaining self-regulation, which arguably has the potential to maintain and indeed exacerbate COPD symptoms. The key maintaining factor for health anxiety is the selective attention to, and misinterpretation of health information and bodily cues (Snyder & Stanley, 2001).

Individuals with acute and chronic health conditions are particularly likely to report significant degrees of health anxiety, most likely due to experiencing more bodily sensations that are perceived as dangerous (LeBouthillier, Thibodeau & Alberts et al., 2015). Furthermore, research examining older adults has shown that anxiety presentations within this population (both clinical and non-clinical samples) tend to be dominated by health-related concerns (Snyder & Stanley, 2001). Though much literature has focused on the experience of anxiety in COPD, no published studies have examined the extent of health anxiety in individuals with COPD specifically, although one study reported clinically significant health anxiety in 20.9% of patients attending a respiratory medicine clinic (Tyrer, Cooper & Crawford et al., 2011).
1.7 Rationale and study aims

Whilst there is substantial literature examining the extent of anxiety, depression and panic disorders in COPD, there is scant literature examining the association between COPD and PTSD symptoms, and a neglect of health anxiety within COPD populations. Extant literature has indicated that links between PTSD and COPD remain under-researched (Alonzo, 2000; Chung et al., 2015) and existing prevalence data (Jones et al., 2009b) may not capture distress after AEs. Other studies examining PTSD (Teixeira et al., 2015) in the context of exacerbations have not clearly reported the timeframe between hospitalisation/AE and study participation. For a diagnosis of PTSD, symptoms need to have been present for at least one month following the traumatic event, if respondents completed measures before this time had elapsed, inflated scores may have resulted.

Prevalence data is considered important in terms of accurately capturing the impact of COPD on individuals’ psychological wellbeing in order to support psychological needs and to inform service provision. The current study aimed to extend existing studies like Chung et al. (2015), utilising an outpatient clinic for recruitment. It was hoped that individuals from this recruitment source would represent an acute subset of individuals with COPD, who are not actively recovering from an AE. This subset of individuals is referred to in this study as those with ‘complex COPD’. The complex needs of those recruited are further discussed within the section noting inclusion criteria.

Studies examining PTSD in COPD to date suggest trauma symptoms are associated with AEs (Teixeira et al., 2015), COPD severity (Chung et al., 2015), poorer health status (Jones et al., 2009b) and the emotional symptoms of COPD (emotional function subscale, CRQ-SR) appear to mediate the relationship between PTSD and depression (Chung et al., 2015). The circumscribed studies are limited by not having explicitly asked participants to relate their answers directly to the traumatic experiences associated with their COPD (e.g. AEs). These studies considered trauma resultant from past traumatic events, not always related to individual’s COPD symptoms and the experience of their condition. The current research aimed to improve upon these studies by examining PTSD symptoms
specifically in relation to the experience of AEs both to add to existing prevalence data and to establish whether the presence of PTSD symptoms in COPD is related to traumatic memories associated with AEs, rather than diagnosis of chronic illness or previous experiences of traumatic events.

The rationale for considering health anxiety in the current study related to the suggestion that following medical traumas some individuals may experience ‘flashforwards’ (intrusions related to future events), as distinctive from ‘flashbacks’, (Mundy & Baum 2004). Trauma literature also suggests PTSD is associated with negative global appraisal related to future outcomes (Ehlers & Clark, 2000; Foa et al., 1989), which is characteristic of those with health anxiety. In the current study the construct of flashforwards has been operationalised as health anxiety. Given findings in birth trauma literature and that the literature base in COPD has neglected the possible role of health anxiety, it was felt important to examine the extent of health anxiety to gain a greater understanding of the psychological morbidity associated with COPD.

It was also felt important to distinguish between health anxiety and anxiety (as measured in this study using the Hospital Anxiety and Depression Scale, Zigmond & Snaith, 1983). Clinically, it has been noted that psychological morbidity (anxiety and depression) and health related quality of life (HRQL) are frequently assessed in COPD populations (Yohannes et al., 2010). In light of this observation, the current study aimed to examine whether relationships are evident between PTSD, health anxiety, anxiety, depression and health related quality of life. The nature of this study is exploratory and examination of the predictive capacity of PTSD symptoms and health anxiety could provide a greater understanding of COPD patients’ psychosocial difficulties, in order to inform the development of more targeted interventions that better support COPD patients’ psychological needs.

1.8 Research aims

The aim of this study was to examine PTSD, health anxiety, psychological morbidity (anxiety and depression) and HRQL in individuals with complex COPD. Specific aims included:
1) To examine the prevalence and extent of PTSD in relation to traumatic experiences of acute exacerbations in individuals with complex COPD.

2) To examine the prevalence and extent of health anxiety in individuals with complex COPD.

3) To examine whether relationships are evident/nature of relationships between PTSD symptom severity, health anxiety, psychological morbidity and HRQL in individuals with complex COPD.

4) To examine whether PTSD symptom severity and health related quality of life are predictive of variance in psychological morbidity and HRQL in individuals with complex COPD.
2 Method

2.1 Overview and study design

This study employed a within group cross-sectional quantitative survey design. Two questionnaires were administered to a convenience sample of COPD patients attending an outpatient COPD clinic. Additionally, medical records were accessed to obtain demographic information and routine assessment measures (biomedical and psychological). Independent variables comprised anxiety, depression, HRQL, and the dependent variables were trauma symptoms and health anxiety.

2.2 Power analysis

An a priori power analysis was carried out, using Cohen’s (1992) recommended effect size. In the absence of research examining health anxiety in those experiencing COPD, but mindful of published research on PTSD (Chung et al., 2015 n=85, Jones et al., 2009b, n=100; Teixeira et al., 2015, n=33), a putative medium effect was considered acceptable. Using G*Power 3.1 to obtain estimates for the recommend sample size for multiple regression analyses, the suggested sample size to observe a medium effect (0.15) was 107 participants (beta value set at 0.80 and significance criterion at 0.05).

2.3 Ethical considerations and procedure

Ethical approval was sought from the local Research Ethics Committee (Appendix H) and from the host trust’s NHS Research and Development department (Appendix I). Eligible participants were identified through consultation with clinical staff, Consultant Respiratory Physician and Clinical Nurse Specialist (CNS). The CNS made forthcoming clinic lists available, along with patient’s medical records; these were screened by the Chief Investigator (CI) for recipient eligibility. Patients who had consented to be contacted for future research projects relevant to COPD at the host trust site were considered for eligibility against study inclusion/exclusion criteria.

Individuals identified as suitable were informed about the study by the CNS during her assessment appointment, usually one week prior to attending the
COPD clinic. At this appointment, information pertaining to the study was given verbally and an information sheet was provided (see Appendix J). Where a pre-clinic assessment with the CNS was not required, eligible participants who were attending a review appointment at the outpatient clinic were sent an information sheet and covering letter by post in advance of their clinic appointment (see Appendix K). Through these means, it was ensured that potential participants had more than 24 hours to consider their decision to participate, before being approached by the CI within clinic.

The CI was introduced to patients by the CNS; they were reminded about the nature of the study and study requirements then asked about their decision to participate. The CI was mindful not to be coercive (e.g. making it clear that care would not be impacted if individuals did not wish to participate) and was aware that the individuals being recruited could be considered vulnerable adults. All patients who were spoken to were made aware that their decision regarding participation would not impact their care in any way. Patients were given the opportunity to ask questions, details of confidentiality/record keeping were discussed and patients were reminded of their right to withdraw at any point, without the need to give a reason. Those who agreed to take part completed a consent form (see Appendix L).

Support was offered in the event of participants becoming upset during involvement. Participants who became upset were asked if they wanted to continue with the measures and the CI was familiar with referral procedures for local Psychology and support services, should further support have been required. The CI was aware and respectful of the physical limitations of some of the participants, for example wheelchair use, and all participants were asked if they wanted to complete the measures independently, or if they wanted assistance i.e. support with reading questionnaire items and recording responses.

2.4 Participants

Participants were adults with a diagnosis of complex COPD, who attended routine clinical appointments at an outpatient COPD clinic located in an acute teaching hospital in the East Midlands. Individuals attending the clinic during the
recruitment period were invited to take part in the study according to eligibility criteria. Application of inclusion and exclusion criteria followed the referral criteria for clinic from which the sample was recruited, with additional consideration of language proficiency and capacity to consent (discussed on an individual basis with the CNS). Participants are described as having ‘complex COPD’ due to the complicated physical and functional difficulties experienced, which are detailed below. Of note, only patients who had already consented to taking part in future research projects within the host trust site were assessed for eligibility.

2.4.1 **Inclusion criteria**

(1) Diagnosis of COPD

(2) Reduced air flow, as measured by FEV1\(^7\); FEV1 was required to be predicted at <50%

(3) If spirometry results did not reveal results as above, at least one of the following was required:

- Severe disability, as defined by breathlessness and measured using the Medical Research Council (MRC) dyspnoea scale (National Institute for Clinical Excellence, 2010); MRC was required to be ≥ 4 (see Appendix M for MRC guidelines)
- Established respiratory failure, as defined by ability to oxygenate the blood measured using levels of arterial oxygen; PO2\(^8\) was required to be <8
- Two or more admissions for AEs
- Assessment for lung volume reduction therapies or having undergone lung volume reduction surgery
- Low Body Mass Index (BMI < 21) or unexplained weight loss (> %5 in the preceding 6 months)
- Active smoker

\(^7\) FEV1 = Forced expiratory volume in one second
\(^8\) PO2 = Oxygen partial pressure (tension)
2.4.2 Exclusion criteria

Individuals with a co-morbid diagnosis of bronchiectasis\(^9\) were excluded because of susceptibility to infection. Individuals who were unable to consent due to cognitive difficulties, such as dementia, were excluded. An understanding of the English language was required in order to complete the measures; those who did not have a confident grasp of English were excluded.

2.5 Measures

Measures routinely collected as part of assessment at the COPD clinic were employed (a, b and d listed below), along with a health anxiety measure and PTSD measure. The Health Anxiety Inventory Short version (SHAI; Salkovskis, \textit{et al.}, 2002) was selected as this measure appeared to be more widely used than others e.g. Health Anxiety Questionnaire (Lucock & Morley, 1996), and is employed nationally within Improving Access to Psychological Therapies (IAPT) services. The Posttraumatic Stress Diagnostic Scale (PDS; Foa, 1995) was selected as it maps on to the DSM-IV criteria for PTSD and is the only stand-alone instrument that assesses all the diagnostic criteria for PTSD (Foa, Cashman & Jaycox \textit{et al.}, 1997).

\textbf{a) COPD Assessment Test (CAT) (Jones, Harding, Berry, Wiklund, Chen \& Kline Leidy 2009a)}

CAT is an eight-item self-reported measure that assesses the impact of COPD on health status; scores for items range from 0-5, with 0 indicating ‘no impairment’ (Jones \textit{et al.}, 2009a). A total score is calculated by summing the item scores. High scores indicate more impaired health status and poorer control of COPD symptoms. The questions examine: COPD symptoms; impact of symptoms; sleep disturbance; confidence to leave the home and energy levels. Jones \textit{et al.}, (2009a) found the CAT to have excellent internal consistency (Cronbach’s alpha=0.88) and ‘very good’ re-test reliability (intra-class correlation coefficient=0.80).

\textsuperscript{9} Bronchiectasis is a long-term condition where the airways of the lungs become abnormally widened, leading to a build-up of excess mucus that can make the lungs more vulnerable to infection (NHS Choices 2015).
b) **EQ-5D (EuroQol Group 1990, updated 2009)**

EQ-5D is a self-reported HRQL measure, developed by the EuroQol Group. The second version of EQ-5D was employed (EuroQol group, 2009). This measure comprises two parts. The first requires respondents to indicate health state by selecting the statement most applicable to them on five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Responses result in a 1-digit number, the authors of the measure caution that these should not be used as cardinal scores, as they have no arithmetic properties (EuroQol Group, 2004). The second part comprises a visual analogue scale (VAS) rated from 0-100; endpoints are ‘best imaginable health state’ and ‘worst imaginable health state’. This rating can be used as a quantitative measure of health outcome and was considered for the purpose of this study.

c) **Health Anxiety Inventory Short Version (SHAI) (Salkovskis, Rimes, Warwick & Clark, 2002)**

SHAI is an eighteen item assessment that measures self-reported health anxiety. The eighteen items comprise four statements and respondents are asked to select the statement that best describes their feelings over the past six months. The SHAI elicits a rating of cognitions associated with ill health (main section score; items 1-14) and has items related to health attitude (negative consequences score; items 15-18) a total score out of 54 is also computed. High level test retest reliability has been shown (Pearson product-moment correlation coefficient=0.90) and internal consistency is considered satisfactory (alpha coefficient=0.89) (Salkovskis et al., 2002).

d) **Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)**

HADS is a self-report measure, widely used to assess caseness for anxiety and depression. The measure comprises two sub-scales: anxiety symptoms and depression symptoms, each with seven items. Each item has four response options, scored from 0 to 3. Higher scores indicate greater severity and a score of 11 or higher is suggestive of caseness for a mood disorder. The HADS has been shown to have high internal consistency for both the anxiety and depression subscales (Cronbach's alpha=0.93 for the anxiety scale; 0.90 for the depression
scale), and is recognised as a well validated measure (Moorey, Greer & Watson et al., 1991).

e) Posttraumatic Stress Diagnostic Scale (PDS) (Foa, 1995)

PDS is a self-report measure of PTSD, intended for use with individuals who have experienced a traumatic event. The measure is used to assess for PTSD and considers functioning and ongoing symptom severity for those already identified as having PTSD (Foa et al., 1997). The scale comprises 49 items that examine the DSM-IV criteria for PTSD. Part one (13 questions) focuses on experiences of previous traumatic life events; part two (8 questions) relates to the nature of the traumatic event; part three (19 questions) examines PTSD symptom prevalence and severity using a four-point scale and part four (9 questions) examines areas of functioning PTSD symptoms may have impacted.

If participants had not experienced any traumatic events (listed in part one), the rest of the measure was not completed. Items within part three are scored on a scale from 0-3, where 0 indicates symptoms are not present and 3 indicates symptoms are almost always present. Using the combined total for part three, a total symptom severity score (out of 51) is computed.

A diagnosis of PTSD is made when DSM-IV criteria are met. The DSM-IV estimates for the PDS (Foa, 1995) comprise:

(1) Exposure to a traumatic stressor
(2) Endorsement of at least one re-experiencing item
(3) Endorsement of at least three avoidance/numbing symptoms
(4) Endorsement of at least two hyper-arousal symptoms
(5) Duration of the above symptoms for at least one month
(6) Clinically significant distress or impairment in social/ occupational functioning

The PDS has demonstrated high face validity, the items have been shown to directly reflect the experience of PTSD with high internal consistency (coefficient
alpha=0.92; McCarthy, 2008) and test–retest reliability is highly satisfactory (kappa = 0.74; McCarthy, 2008).

2.6 Data analysis

Demographic data were collated from patients’ medical records and standard scoring procedures were followed to obtain total and sub-scale scores for the outcome measures employed. Data were numerically coded and Statistical Package for the Social Sciences software (SPSS Version 22) was employed in analysing the data. The first primary research questions related to examining the prevalence of health anxiety, trauma symptoms, psychological morbidity (anxiety and depression) and health related quality of life. A descriptive approach was employed in reporting mean scores and standard deviations. The prediction that the current sample would exhibit high levels of PTSD symptoms and health anxiety was examined by comparing the scores obtained in the current study to those reported in other research, using z tests. In considering whether trauma symptomatology or health anxiety better explain psychological morbidity (anxiety and depression) and health related quality of life, inferential statistics were employed (Pearson’s correlations and regression analyses).
3 Results

3.1 Recruitment
The sampling frame comprised an eight-month period from August 2015 to April 2016. The researcher attended one outpatient clinic per week; a total of 22 clinics were attended. On average, 15 patients attended each clinic, roughly 8 of whom met the eligibility criteria for the current study. A total of 63 participants were approached to take part in the current study. Three patients declined to take part; two due to time constraints, the other did not wish to talk about the psychological impact of her condition due a recent bereavement. The final sample comprised 60 patients with complex COPD, as defined by referral criteria for the outpatient clinic (see Inclusion Criteria). Although 60 participants consented to participation, five declined to complete the trauma measure following completion of the health anxiety measure, three due to time constraints and two due to finding the content emotionally difficult. Sample characteristics are reported in Table 2.

3.2 Description of sample

3.2.1 Demographics
The sample had a mean age of 65.3 years and comprised 32 males and 28 females. The majority of participants identified as ‘White British’ (98%). The mean number of hospital admissions in the 12 months prior to assessment was one, and mean number of AEs in the same time period was four. The majority of participants were ex-smokers (n=50), nine were current smokers and one had never smoked before. Current smokers were smoking an average of 5 cigarettes per day (Range=1-10), those who were ex-smokers had on average stopped smoking 8.2 years ago (Range=1-35 years).
<table>
<thead>
<tr>
<th></th>
<th>All participants (n=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Age range (in years)</td>
<td>42.5 - 86.5</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>65.3 (9.0)</td>
</tr>
<tr>
<td><strong>Sex n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>32 (53.3%)</td>
</tr>
<tr>
<td>Female</td>
<td>28 (46.7%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>59</td>
</tr>
<tr>
<td>Other ethnic group – Chinese</td>
<td>1</td>
</tr>
<tr>
<td><strong>Number of hospital admissions (last 12 months)</strong></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0 - 9</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>1 (1.7)</td>
</tr>
<tr>
<td><strong>Number of acute exacerbations (last 12 months)</strong></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0 - 20</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>4 (4.0)</td>
</tr>
<tr>
<td><strong>Smoking status (n)</strong></td>
<td></td>
</tr>
<tr>
<td>(1) Current smoker</td>
<td>9</td>
</tr>
<tr>
<td>Mean number of cigarettes smoked per day (SD)</td>
<td>5 (2.8)</td>
</tr>
<tr>
<td>(2) Ex-smoker</td>
<td>50</td>
</tr>
<tr>
<td>Mean years since stopped smoking (SD)</td>
<td>8.2 (7.6)</td>
</tr>
<tr>
<td>(3) Never smoked</td>
<td>1</td>
</tr>
<tr>
<td><strong>Symptom severity n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>FEV1 predicted at &lt;50%</td>
<td>59 (98%)</td>
</tr>
<tr>
<td>MRC score ≥ 4</td>
<td>57 (95%)</td>
</tr>
<tr>
<td>CAT mean (SD)</td>
<td>25.6 (7.1)</td>
</tr>
</tbody>
</table>
3.2.2 Symptom severity

In accordance with the clinic referral criteria all participants had either reduced air flow (FEV1 predicted at <50%) and/or severe disability (MRC score ≥4). CAT scores assessing the impact of COPD on health status (Jones et al., 2009a) indicated a mean of 25.6 out of 40 (SD=7.1; Range 3-39). Guidelines note that CAT scores ≥20 are indicative of more severe COPD symptoms and impairment (CAT Development Steering Group, 2012).

3.3 Internal reliability of measures

Cronbach’s alpha was used to assess the reliability of the measures employed (HADS, SHAI and PDS). All yielded coefficients <.7, indicating adequate internal consistency (DeVellis, 2003) (See Appendix N, Cronbach alpha values).

3.4 Prevalence and comparison to population means

The first primary research question aimed to examine the prevalence of trauma symptoms and health anxiety in individuals with complex COPD. Means and standard deviations for the measures employed in the current study are reported in Table 3. Non-clinical, comparative (older adults), and clinical population data are reported where available. Clinical population data for COPD patients was reported preferentially; where data were not available for COPD, other health conditions are considered10. Details of the population characteristics from which data was drawn are noted within the references below the table. To test for significant differences z tests (two tailed) were carried out; results are reported by outcome measure.

10 Of note, data for chronic pain is reported as means and standard deviations were available in published articles, allowing for z tests to be conducted.
Table 3 EQ-5D, HADS anxiety and depression, SHAI and PDS sample and population means

<table>
<thead>
<tr>
<th>Measure</th>
<th>Sample Mean (SD)</th>
<th>Non-clinical Mean (SD)</th>
<th>Comparative Mean (SD)</th>
<th>Clinical Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>EQ-5D</td>
<td>52.89 (21.10)</td>
<td>86.2 (14.6)(^1)**</td>
<td>79.8 (17.5)(^1)**</td>
<td>42.7 (21.6)(^2)*</td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>8.23 (4.32)</td>
<td>6.14 (3.76)(^3)**</td>
<td>8.6 (2.1)(^4)</td>
<td>10.4 (3.1)(^4)**</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>7.95 (3.89)</td>
<td>3.68 (3.07)(^3)**</td>
<td>8.7 (2.7)(^4)</td>
<td>10.5 (3.6)(^4)**</td>
</tr>
<tr>
<td>SHAI (18-items)</td>
<td>17.55 (7.75)</td>
<td>12.2 (6.2)(^5)**</td>
<td>9.62 (5.95)(^6) **</td>
<td>-</td>
</tr>
<tr>
<td>SHAI (14-items)</td>
<td>13.90 (5.9)</td>
<td>-</td>
<td>-</td>
<td>16.3 (7.8)(^7)*</td>
</tr>
<tr>
<td>PDS (symptom severity score)</td>
<td>12.86 (8.4)</td>
<td>-</td>
<td>-</td>
<td>5.0 (7.6)(^8)**</td>
</tr>
</tbody>
</table>

\(^1\)Kind, Dolan & Gudex et al. (1998), data from normal population and older adults; \(^2\)Whynes, McCahon & Ravenscroft et al. (2013), data from chronic pain patients; \(^3\)Crawford, Henry & Crombie et al. (2001), data from a normal population; \(^4\)Lou, Zhu & Chen et al. (2012), data from COPD population and control group of older adults; \(^5\)Salkovskis, Rimes & Warwick (2002), data from a normal population; \(^6\)Boston & Merrick (2010), data from an older adult population (including community residents and retirement communities); \(^7\)Rode, Salkovskis & Dowd et al. (2006), data from chronic pain patients; \(^8\)Jones et al., (2009a) data from COPD population.

3.4.1. Health related quality of life

A total of 57 participants completed the EQ-5D (M=52.89). EQ-5D visual analogue scale captures overall health status, with higher scores indicating better overall health. The current sample had significantly higher scores than the non-clinical population (z=-11.688, p<.001) and comparative population (z=-9.257, p<.001) but lower scores than the clinical population (z=2.728, p<.05). Results suggested that participants in this study experienced worse overall health status compared to the general population and population of older adults, and better health status than individuals who experienced chronic pain.
3.4.2. Anxiety and depression

A total of 59 participants completed the HADS. The total mean for anxiety (M=8.23) fell below the cut-off indicating caseness for anxiety (cut-off ≥11). The mean anxiety score fell within the ‘mild’ range and despite total scores indicating subclinical levels of anxiety, 54% of participants reported anxiety scores within the clinical range (see Appendix O for a breakdown HADS scores by category). The current sample anxiety mean was significantly higher than the non-clinical population (z=3.671, p<.001), no different to a comparative population (z=-0.654, p>.05) and significantly lower than a COPD population (z=-3.806, p<.001). Results suggested that participants in this study experienced higher levels of anxiety symptoms than the general population, similar levels to older adults and lower levels of anxiety symptoms compared to other COPD populations.

The total mean for depression (M=7.95) fell below the cut-off indicating clinical caseness for depression (cut-off ≥11). Despite mean depression scores indicating subclinical levels of depression, individual case analysis indicated 54% of participants reported depression symptoms within the clinical range. The current sample depression mean was higher than the non-clinical population (z=8.346, p<.001); not significantly different to a comparative population (z=-1.462, p>.05) and significantly lower than a COPD population (z=-4.923, p<.001). Results suggested that participants in this study experienced higher levels of depression symptoms than the general population, similar levels to older adults, and lower levels of depression symptoms than other COPD populations.

3.4.3. Health anxiety

A total of 60 participants completed the SHAI, with a total mean score of 17.55, main scale score M=13.9 and a negative consequences score M=3.65. The clinical cut-offs for the SHAI are not consistent within the literature; some studies use a cut-off of 15 (Wright & Salkovskis, 2007), others report 18 to be indicative of clinically significant health anxiety difficulties (Rode et al., 2006). IAPT guidelines suggest a score of 15 indicates high health anxiety, whilst a score of 18 indicates clinically significant symptoms (IAPT, 2011). Under these guidelines the current sample total mean showed high, but not clinically significant health
anxiety symptoms to be present within the current sample. However, individual case analysis indicated 29 participants (48%) reported health anxiety symptoms within the clinical range.

It has been suggested that the 14-item main scale score should be reported preferentially in populations that examine medical conditions, as the negative consequences score (included in the total score) asks respondents to consider what it might be like to have a serious medical condition. As clinical populations generally have a serious illness, these questions may not be relevant (LeBouthillier et al., 2015). In the current study SHAI main scale scores (14 items) are preferentially reported, except where comparisons to non-clinical populations are made, or if otherwise indicated.

The total mean for SHAI (18 items) was higher than the non-clinical population ($z=4.799$, $p<.001$) and a comparison population of older adults ($z=7.107$, $p<.001$). SHAI main scale score (14 items) was significantly lower than population of chronic pain patients ($z=-2.452$, $p<.05$). The results suggested that participants in the current study experienced higher overall levels of health anxiety compared to the general population and populations of older adults, whilst results for the main scale scores indicated the current sample experienced lower levels of health anxiety compared to populations experiencing pain.

### 3.4.3. Trauma

A total of 55 participants completed the PDS of these, seven (13%) met the DSM-IV criteria for PTSD. Results are reported for each part of the measure:

**Part one**

Seven participants (12%) had not lived through/witnessed any traumatic event. The other respondents (88%) had lived through/witnessed traumatic events including: serious accident (45%), natural disaster (7%), assault by family member (20%), assault by stranger (24%), sexual assault by family member (11%), sexual assault by stranger (11%), military combat (9%), sexual contact prior to age of 18 with someone at least 5 years older (9%), imprisonment (11%),...
torture (7%) (respondents reported experiences related to domestic violence and sexual abuse) and life threatening illness (71%).

An open category ‘other traumatic event’ allowed respondents to comment on their experience of traumatic events not listed. Within this category, respondents were asked about events not listed, in addition to their experience of AEs. Participants most commonly reported experiences of bereavement (15%) within this category, and 55% (n=30) considered their previous experience of exacerbations to be traumatic.

Part two
Respondents who identified their AEs as traumatic (n=30) completed the full measure, answering questions in relation to their experience of their most traumatic AE. Most participants (43%) had experienced their ‘most traumatic AE’ 6 months to 3 years prior to participation in the study. During their exacerbation 83% reported thinking their life was in danger, 97% reported feeling helpless and 77% reported feeling terrified.

Part three
Part three assesses the presence and severity of 17 prominent symptoms of PTSD; these can be grouped by symptom cluster: re-experiencing, avoidance and hyperarousal. See Table 4 for means and standard deviations by symptom cluster and comparison data from Chung et al. (2015). The mean symptom severity score for the current study, 12.86 (SD=8.4), fell within the mild range (cut-offs: 1-10 ‘mild’; 11-20 ‘moderate’; 21-35 ‘moderate to severe’ and ≥36 ‘severe’; McCarthy, 2008). See Appendix P, for a breakdown of the sample by category.

Results from a z test indicated the current sample PDS symptom severity mean, was significantly higher than a population of COPD patients recruited through PR (z=5.762, p<.001). Other comparison data (general population and older adults) were not available.
Table 4 PDS cluster scores sample and population means

<table>
<thead>
<tr>
<th>Measure</th>
<th>Sample Mean (SD)</th>
<th>Chung et al. 2015, n=29 (Mean (SD))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-experiencing</td>
<td>3.13 (2.96)</td>
<td>3.96 (3.35)</td>
</tr>
<tr>
<td>Avoidance</td>
<td>4.90 (3.70)</td>
<td>3.41 (4.53)</td>
</tr>
<tr>
<td>Hyperarousal</td>
<td>4.83 (3.77)</td>
<td>2.93 (3.42)*</td>
</tr>
</tbody>
</table>

*Significance at .05 level *, significance at .01 level **

Cluster scores for re-experiencing and avoidance were not significantly different to the comparison sample (z=-1.007, p>.05; z=1.381, p>.05), and scores for hyperarousal were significantly higher in the current sample (z=2.029, p<.05). The results suggested that participants in this study experienced similar levels of re-experiencing and avoidance symptoms to the population in Chung et al.’s (2015) study and significantly higher hyperarousal symptoms compared to the population in Chung et al.’s (2015) study.

Part four

Part four examines whether PTSD symptoms interfered with various areas of life over the past month. Areas of impact and the percentage of participants endorsing each item included: work (30%), household chores (67%), relationships with friends (40%), fun and leisure activities (70%), relationships with family (30%), sex life (30%), general satisfaction with life (50%), overall functioning in all areas of life (60%). These results indicated that leisure activities and domestic activities were the areas of functioning most often impacted by PTSD symptoms.

3.5 Correlation analyses

The second primary research question sought to examine associations between trauma, health anxiety, psychological morbidity (anxiety and depression) and health related quality of life. Relationships were examined using Pearson product-moment correlation analyses (2-tailed); results are presented in Table 5.
Analyses suggested that there were some significant positive and negative relationships between trauma, health anxiety, anxiety, depression and health related quality of life. Cohen’s guidelines for interpreting effect size were used to determine the strength of these relationships (small $r=.10$ to .29; medium $r=.30$ to .49, large $r=.50$ to 1.0; Cohen 1988).

Table 5 Correlations for psychological morbidity (anxiety and depression), health related quality of life, health anxiety and trauma symptoms

<table>
<thead>
<tr>
<th></th>
<th>EQ-5D</th>
<th>HADS Anxiety</th>
<th>HADS Depression</th>
<th>SHAI (14-items)</th>
<th>PDS (total symptom score)</th>
</tr>
</thead>
<tbody>
<tr>
<td>EQ-5D</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>-.515**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADS Depression</td>
<td>-.514**</td>
<td>.586**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SHAI (14-items)</td>
<td>-.271*</td>
<td>.422**</td>
<td>.353**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>SHAI (18-items)</td>
<td>-.287*</td>
<td>.404**</td>
<td>.385**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>PDS (total</td>
<td>.014</td>
<td>.130</td>
<td>.034</td>
<td>.557**</td>
<td>-</td>
</tr>
</tbody>
</table>

Significance at .05 level *, significance at .01 level **

3.5.1. Health related quality of life

There was a large negative relationship between HRQL and anxiety and depression (anxiety $r=-.515$, $p<.01$; depression $r=-.514$, $p<.01$) and a small negative relationship between HRQL and health anxiety ($r=-.271$, $p<.05$). Findings suggested high levels of anxiety, depression and health anxiety are associated with poorer health related quality of life.
3.5.2. Psychological morbidity

There was a large positive relationship between anxiety and depression (r=.586, p<.01) and medium positive relationships between both anxiety and depression, and health anxiety (anxiety r=.422, p<.01; depression r=.353, p<.01). Findings suggested that high health anxiety was associated with higher levels of anxiety symptoms and depression symptoms.

3.5.3. Health anxiety

There was a large positive relationship between health anxiety and PTSD symptoms (r=.557, p<.01), other relationships have been outlined above. Findings suggested high levels of PTSD symptoms were associated with higher levels of health anxiety symptoms.

3.5.4. Trauma

Though a large positive relationship between PTSD symptoms and health anxiety was found, there were no other significant relationships between PTSD symptoms and other variables. Findings suggested trauma symptoms were unrelated to anxiety, depression and health related quality of life.

3.6 Regression analyses

The third part of this study aimed to examine the extent to which trauma and health anxiety predicted the variance in psychological morbidity and health related quality of life (HRQL), using regression analyses. This was considered an important research question as psychological morbidity (anxiety and depression) and HRQL are frequently assessed in COPD patients in clinical settings. HADS subscale scores for anxiety and depression and the EQ-5D were dependent variables (DV’s), while PDS total symptom scores and SHAI main scale scores were the intended independent variables (IV’s). Cases were excluded pairwise where data was missing for specific analyses. Prior to running the analyses, data was examined in line with the assumptions for multiple regression analyses.
3.6.1 Sample Size

For the multiple regression analyses to achieve a medium effect size (0.15; Cohen, 1992), the power analysis indicated 107 participants were required. Although the current sample was underpowered, there are differing guidelines on sample size requirements for conducting multiple regression analyses. The sample size did meet the requirements for social sciences research: 15 participants per predictor variable (Stevens, 1996) with the number of participants exceeding the number of predictors by at least 50, as recommended by Harris (1985). The current sample (n=60) for the SHAI was therefore considered adequate, while the sample size for those who completed the full PDS to obtain a symptom severity score (n=30) was questionable. To account for the small sample size, Adjusted R square values are reported, as recommended by Pallant (2007).

3.6.2 Preliminary data screening

Preliminary data screening was undertaken to ensure the assumptions required for regression analysis were met. Analyses checked for the presence of outliers and assessed: normality, linearity, homoscedasticity and multicollinearity/singularity. Inspection of the Boxplots indicated no extreme outliers and scatterplots indicated none of the standardised residuals were in excess of 3.29, therefore outliers were kept in the dataset (Tabachnick & Fidell, 1996). Histograms (displaying the normal curve), Normal Q-Q Plot, Detrended Normal Q-Q plots and 5% Trimmed Means indicated data was normally distributed and assumptions for homoscedasticity were met, for all variables except SHAI main scale score. Kolmogorov-Smirnov significance values were examined and indicated normality (p ≥.05; Pallant, 2007) for all variables except SHAI main score. See Appendix Q for significance values and Skewness and Kurtosis of the distributions. As the SHAI scale score variable did not meet the assumptions for normality, the same tests were carried out for SHAI total scores. This variable was found to meet all the assumptions for regression analysis. These scores were therefore included in the analysis in preference to the SHAI scale scores.

Inspection of the Normal P-P Plots indicated reasonably straight line relationships between the residuals and predicted DV scores. Multicollinearity was not present
within the independent variables (correlation coefficients ≤ .7; Pallant, 2007). See Table 5 for results of the correlation analyses. One IV (PDS symptom severity), showed an inadequate relationship (correlation coefficients ≥ .3) with all of the DV’s (Pallant, 2007). As no significant relationships were present for PDS symptom severity, and in consideration of the nature of analysis (pairwise exclusion) and significant disparity in the number of cases for the trauma variable (n=30) compared to the health anxiety variable (n=60), PDS total symptom scores were taken out of the regression model. Standard linear regression analyses were therefore conducted for SHAI total scores. Results are reported in Table 6 and Table 7.

### 3.6.3 Psychological Morbidity

Adjusted R Square scores indicated that health anxiety accounted for 15% of the variance in the HADS anxiety scores and 13% of the variance in the HADS depression scores. Health anxiety made a unique contribution to predicting HADS scores for anxiety and depression (p<.01).

#### Table 6 Regression analyses of relationships between health anxiety and psychological morbidity (anxiety and depression)

<table>
<thead>
<tr>
<th>Dependent Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS Anxiety</td>
</tr>
<tr>
<td>β¹, P, R², Adjusted R²</td>
</tr>
<tr>
<td>SHAI</td>
</tr>
<tr>
<td>.404, .001**, .163, .149</td>
</tr>
</tbody>
</table>

¹ β = Standardised coefficient/ Significance at .01 level **
3.6.4 Health related quality of life

The Adjusted R Square score indicated that health anxiety accounted for 25% of the variance in HRQL and made a significantly unique contribution to predicting HRQL (p<.001).

Table 7 Regression analysis of relationship between health anxiety and HRQL

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>EQ-5D VAS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>β</td>
<td>P</td>
<td>R²</td>
<td>Adjusted R²</td>
</tr>
<tr>
<td>SHAI</td>
<td>-.514</td>
<td>.000**</td>
<td>.264</td>
</tr>
</tbody>
</table>

1 β = Standardised coefficient/ Significance at .01 level **
4 Discussion

4.1 Overview of study aims

To date, limited research has examined PTSD symptoms in COPD, reporting on respondents with variable degrees of COPD symptom severity. The current study aimed to extend existing literature by examining the presence and extent of PTSD symptoms in a subset of individuals with complex COPD. As prior literature appeared to neglect the need to clarify the nature of the traumatic event during screening for PTSD, the current study aimed to examine PTSD symptoms specifically in relation to individual’s experiences of traumatic AEs. As no previous studies had assessed health anxiety in COPD populations, the current research aimed to examine the extent of health anxiety within COPD patients, to provide the first estimates of health anxiety within this population. The final study aim was to examine the extent to which PTSD symptoms and health anxiety were related to psychological morbidity and health related quality of life.

4.2 Summary and interpretation of study findings

4.2.1 Sample characteristics

The sample had a mean age of 65 years, lower than that of Jones et al., (2009a) M=68; Teixeira et al. (2015) M=72 and Chung et al. (2015) M=69. Gender proportions were fairly equal (53% males), the current sample comprised fewer males than Jones et al., (2009a) 65% and Chung et al. (2015) 72%, and differed significantly to Teixeira et al. (2015) who primarily recruited females (30% males). The sample comprised individuals with complex COPD such that patients had significantly compromised lung function (98% FEV1 predicted at <50%) and/or severe disability (95% MRC score ≥4). Spirometry data reported in Chung et al., (2015) and Teixeira et al. (2015) indicated sample means suggesting the majority of patients had FEV1 predicted at <50% (M=43.2% and M=37.7 respectively). Jones et al. (2009a) classified airflow obstruction in accordance with GOLD staging criteria. The majority of patients had FEV1 predicted at between 30 and 49%, though 32% had FEV1 predicted at between 50 and 79%. Although accurate comparison across studies is not possible, the inclusion of individuals with FEV1 between 50 and 79% in Jones et al. (2009a) is suggestive
of a more stable population than the current sample and the individuals in Teixeira et al., (2015) appeared to be the most acutely unwell. MRC scores were not reported in comparison studies.

The majority of patients had experienced a mean of four AEs in the 12 months prior to assessment; figures were based on self-report data obtained at assessment with the CNS. In Teixeira et al’s, (2015) study the majority (75%) had experienced ≥2 exacerbations per year; Chung et al. (2015) and Jones et al. (2009a) did not report number of AEs. Smoking status in the current sample indicated 50 participants were ex-smokers, nine were current smokers and one had never smoked, contrasting with comparison samples which reported a higher proportion of current smokers and individuals who had never previously smoked (Chung et al., 2015; Jones et al., 2009a).

4.2.2 Prevalence of health related quality of life, psychological morbidity (anxiety and depression), health anxiety and trauma

Participants in the current study experienced lowered HRQL than the general population, a population of older adults (Kind et al., 1998) and individuals with chronic pain (Whynes et al., 2013). No studies employing the same measure were found for COPD populations and the utility of the EQ-5D for the purpose of the current study was questioned (this is further considered within study limitations).

The current study revealed higher levels of anxiety and depression compared to the general population (Crawford et al., 2001), similar levels to an older adult population and lower levels of symptoms compared to a COPD population (Lou et al., 2012), though means were consonant with those reported by Jones et al. (2009a) and Chung et al. (2015). Despite mean depression scores indicating subclinical levels of depression, individual case analysis indicated 54% of participants reported depression symptoms within the clinical range. The mean score for anxiety fell within the ‘mild’ range and 54% of participants reported anxiety scores of clinical relevance.

Participants in the current study experienced higher levels of health anxiety than the general population (Salkovskis et al., 2002) and a population of older adults (Boston & Merrick, 2010), but lower levels than individuals with chronic pain.
(Rode et al., 2006). Total mean health anxiety scores showed high, but not clinically significant health anxiety symptoms to be present in the current sample. Whilst mean health anxiety scores were not in the clinical range, individual case analysis found that 29 participants (48%) reported health anxiety symptoms within the clinical range (scores ≤18).

Prevalence of clinically significant health anxiety was comparable to that seen in chronic pain patients (51%) (Rode, et al., 2006) and notably higher than other clinical populations: respiratory patients (20.9%), gastroenterology (19.5%), cardiology (19.1%), endocrinology (17.5%), breast cancer (23.4%) and diabetes (24.1%) (Tyrer et al., 2011; Jones, Hadjistavropoulous & Gullickson, 2014). These comparisons should be interpreted with caution due to the use of different clinical cut-offs (15/18) and inconsistent use of the SHAI (18-items/14-items).

In the current sample, 88% of participants had experienced traumatic events, which is comparable to other studies: 84% in Jones et al. (2009a) and 75% in Chung et al. (2015). The high prevalence of trauma experiences is not unexpected given the established links between childhood experience of adverse events and risk for impaired lung functioning (Spitzer, Koch & Grabe et al., 2011). The clinical implications of high levels of premorbid trauma within COPD populations is discussed later.

Of the 30 patients who experienced traumatic AEs, 13% met the DSM-IV criteria for PTSD. Symptom severity was significantly higher than a population of comparatively stable COPD patients recruited through PR (Jones et al., 2009a). Total symptom severity scores were not reported in Chung et al. (2015) and Teixeira et al. (2015) employed a different measure, therefore z tests were not permitted.

Prevalence of PTSD in the current study was higher than Chung et al. (2015), who reported 6% of participants met the full criteria for PTSD and 39% met partial criteria. It is also higher than the prevalence reported by Jones et al. (2009a), who reported prevalence of 8%, and lower compared to a population of COPD patients who were admitted to hospital for treatment associated with AEs, in which in 33.3% of participants met the criteria for PTSD (Teixeira et al., 2015). The variability in prevalence rates is most probably attributable to diverse recruitment
sources and resultant differences in sample characteristics across the studies. The study reporting the highest prevalence of PTSD recruited participants from an inpatient ward (Teixeira et al., 2015). It is of note that the timeframe for the completion of trauma screening was not made clear and for diagnosis of PTSD, symptoms are required to be present for at least one month following the traumatic event. If respondents in Teixeira et al’s (2015) study completed measures before this time had elapsed, this may have accounted for inflated scores. The lowest prevalence rates were reported in a study that recruited through PR programmes (Jones et al., 2009b). Though Chung et al. (2015) had a similar recruitment source to the current study differences in prevalence could be explained by differing sample characteristics.

Prevalence of PTSD is lower in older adults compared to the general population (DSM-V, 2013). Chung et al’s (2015) eligibility criteria excluded individuals under the age of 60 and the mean age in the current study was notably lower. Differences may also be attributable to symptoms severity; it was not clear in Chung et al’s (2015) study whether participants had experienced recurrent AEs, the comparatively elevated prevalence in the current study may be explained by the complex nature of COPD in the current sample and high frequency of AEs. Comparison of the cluster scores for re-experiencing and avoidance were similar to those reported by Chung et al. (2015) and symptoms of hyperarousal were significantly higher in the current sample, suggesting participants in the current sample were more hypervigilant.

Taken together the current study findings, consonant with the three studies noted above, suggest prevalence rates of PTSD among COPD patient between 6 and 33%. This range is in line with PTSD prevalence findings in burns patients, ranging between 8 and 31% (Bryant, 1996; Van Loey, Van Son & Van der Heijden et al., 2008); life threatening illnesses such as cancer between 0 and 35% (Kangas, Henry & Bryant, 2002) and acute medical events such as myocardial infarction between 5 and 42% (Chung, et al., 2008; O’Reilly, Grubb & O’Carrol, 2004; Wilder Schaaf, Artman & Peberdy et al., 2013); but notably lower than other chronic conditions such as multiple sclerosis, in which prevalence range between 16 and 75% (Chalfant, Byrant & Fulcher, 2004).
4.2.3 Association between variables and regression analysis

Analyses suggested that there were some significant positive and negative relationships between trauma, health anxiety, anxiety, depression and HRQL. Most notable however was the finding that trauma symptom severity was not significantly associated with anxiety, depression or health related quality of life. This is surprising as those with PTSD are much more likely (80%) to have psychological morbidities including anxiety, depression and bipolar disorder (DSM-V, 2013) and the link between PTSD and psychological morbidity is well established (Holman, Silver & Waitzkin, 2000). This finding also contradicted findings in Jones et al., (2009b) where PTSD was reportedly associated with anxiety (but not depression) and Teixeira et al. (2015) who found significant correlations between PTSD symptoms and both anxiety and depression. Of note, overall mean anxiety and depression scores indicated subclinical levels of anxiety and depression within the current sample.

The lack of significant relationships between trauma symptom severity and the other variables (excluding health anxiety) challenges the notion that PTSD is associated with other psychological morbidity. However, it is possible that this finding could be explained by the small sample size and data collection process. Trauma and health anxiety measures were administered at different time points and by a different clinician, to the HADS and EQ-5D. The latter were administered by the CNS generally (but not always) one week prior to recruitment, and patients were often noted to express a positive working relationship with this clinician. In the context of the established therapeutic relationship with the CNS, it could be that patients may have responded in a different way compared to when assessed by the CI, perhaps under-reporting symptoms with the CNS as a way of appearing stoic or not wanting to be perceived as burdensome (Spiers, 2006). Patients had no previous relationship with the CI, who was introduced to patients with a psychological orientation. It could be that this alternative frame may have encouraged more emotional expression. The face validity of the measures in relation to assessing the needs of those with chronic health conditions was also questioned; this is further discussed within the study limitations.
Findings from the regression analyses indicated health anxiety accounted for 15% of the variance in anxiety, 13% in depression scores and 25% of the variance in HRQL. These findings suggest that health anxiety may play a small role in explaining the variance in psychological morbidity and HRQL. Though much research has examined the associations between anxiety, depression and HRQL (Escobar, Billbao & Trancho et al., 2013; Hassel, Danner, Freier et al., 2012; Park, Kim & Jaing et al., 2014; Spiegel, Gerharz & Müller, et al., 2011), few studies have explored predictive links considering health anxiety within chronic disease populations. Evidence from one study indicated health anxiety predicted cancer related worry (Sweetman, Watson & Norman et al., 2006), though this study employed a cancer specific measure, rather than specifically examining anxiety or depression. Comparisons are therefore limited by the lack of available research.

4.3 Limitations

At the time the current study originated and indeed when the proposal was put forward, only one study (Jones et al., 2009b) had published data on trauma in COPD. This is suggestive of significant growth within the trauma literature over the past year. Current study aims were shaped by Jones et al. (2009b), with the intention to provide estimates of PTSD and health anxiety in a more acute subset of individuals with COPD. Reflections on the factors associated with increased trauma symptoms and health anxiety are limited by the cross sectional study design, which precluded causal examination, as well as the absence of between group comparisons. The current study did not seek to examine differences between those with clinically significant health anxiety and PTSD, and those with sub-clinical scores, these comparisons were however assessed in post hoc analyses and are reported in Appendix R.

The initial intention was to recruit in excess of 100 participants, which was not achieved; research involving more severely-affected COPD patients is time consuming and the intended sample size was not possible within the sampling frame. As the current study was significantly underpowered (n=60), caution should be exercised when interpreting the findings. Further limitations regarding
sample characteristics, measures employed, the data collection process and analysis are considered.

The sample was self-selected and issues of selection bias were not controlled for additionally, all of the measures relied on self-report. Issues related to influences of social desirability may have impacted the validity of findings (Clark-Carter, 2010), this has already been discussed in the context of interpreting research findings. It is of note that the current sample did not represent a discrete subset of individuals and influences related to intersectionality should have been given more consideration. For example, individuals with COPD tend to be older adults, though effects of age were not fully deliberated.

It may be that the subclinical levels of anxiety and depression reported here are reflective of employing measures that may not have accurately captured symptoms relevant to an older population, with specific and often co-morbid health needs. Geriatric assessments of anxiety and depression may have better accounted for issues specific to older adults, such as cognitive decline and inactivity. The Geriatric Depression Scale assesses ‘sense of purpose in life’ (Sheikh & Yesavage, 1986), which was reflected in the narratives individuals employed in describing their lives. To some extent this was captured in responses obtained on the trauma measure, in which individuals reported lack of satisfaction with regards to leisure activities. Similarly, the SHAI has been critiqued for not capturing age-related concerns, such as increased dependency on others and cognitive impairment (Boston & Merrick, 2010). The current findings highlight a need for more tailored outcome measures to be developed for use with clinical and older adult populations. Furthermore, adding to the current research using qualitative methodologies would help to capture the depths and idiosyncratic experiences of this population with complex needs and increase understanding of the subjective experience of recurrent traumatic events (AEs) in COPD.

Quality of life is a broad construct, in the current study EQ-5D was employed as the only measure of HRQL. This measure was selected for pragmatic reasons, due to its existing use within the host trust site and desire to ensure brevity. Whilst the EQ-5D is widely used, it is a simple generic health status measure that does not
capture the complete range or disease specific areas of life that are affected in COPD. Since only the visual analogue scale could be employed, these scores indicated health status at a particular single point in time, which may not be representative or comparable with how individuals were feeling generally over a more specific timeframe. Employing an alternative measure of health related quality of life, such as the Medical Outcomes Studies Health Survey (Ware et al., 1996), would have allowed for better estimates of HRQL across physical and mental health domains, and perhaps over a more representative period of time. The variable use of HAI clinical cut-offs has already been highlighted, along with the need to consider the use of 14-items rather than 18-items within in health populations, though in practice within research this is inconsistent. The current study may be limited due to having employed the 18-item SHAI within the regression analysis, and the presence of existing health conditions in the sample may have inflated the SHAI total scores.

The PDS is the only stand-alone instrument that assesses all the diagnostic criteria for PTSD (Foa, et al., 1997), although its administration is time consuming, the measure has a requirement for patient’s to establish a link between a single traumatic experience and resultant PTSD symptoms, thus allowing for causality to be implied. In the current study, links between AEs and PTSD could be examined however, there was no control for ascertaining if the experience of exacerbation was in fact the most traumatic/worst event individuals had experienced. The potential cumulative effects of the number of traumatic events experienced were not considered here and there is scope for future research to examine the recurrent nature of AEs and how repeated experiences of traumatic events may impact psychological morbidity.

In the current study, data related to AEs and hospital admissions relied on self-report and AEs were generally conceptualised according to Strauss, Corbin and Fagerhaugh’s et al.’s (1984) definition, being understood as ‘a medical crisis of a chronic illness’. This definition is broad and subjective, it would have been helpful to support self-report data with information pertaining to actual number of hospital admissions and requirement for steroids/antibiotics. More generally it would have been useful to collect detailed medical data, to examine differences
between patients in relation to severity of symptoms, studies assessing trauma in COPD have begun to make such comparisons (Chung et al., 2015; Teixeira et al., 2015). It would also be of interest to examine what the presence of trauma symptoms and health anxiety in individuals with COPD may predict. The current study is also limited by not having directly asked if patients had a previous diagnosis of PTSD, nor was it possible to determine pre-morbid mental health difficulties. Future research should explore historical and current psychological status more comprehensively, and consider the possible impact of co-morbid physical health problems. Other pre-trauma factors and factors unrelated to the traumatic event, such as perceived social support, also remain unexamined and would be of interest.

Lastly, it may be of note that there have been revisions in defining PTSD that are captured in the DSM-V. These revisions reflect the inclusion of negative cognitions and mood as characteristic of PTSD, and were not previously considered in the DSM-IV. As the PDS maps on to the DSM-IV which does not fully consider this new symptom cluster, estimates in the current study may not accurately reflect the current conceptualisation of PTSD. The DSM-V also notes perceived life threat and negative appraisal to be risk factor associated with developing PTSD. It would be of interest for future research to include appraisal measures in assessing the level of perceived threat associated with AEs and how this may relate to psychological morbidity.

4.4 Clinical implications and directions for future research

Despite the limitations outlined, the current study offers valuable contributions in further understanding the experience of PTSD following AEs and has provided the first estimates of health anxiety within this population. This study found PTSD to be present in COPD patients in excess of general population norms, and found clinical symptoms of health anxiety in nearly half of the sample. The current study was also the first to establish prevalence rates for PTSD, where AEs were the determinant factor for post-traumatic symptoms.

The global initiative for COPD (GOLD) outlines strategies for the diagnosis, management and treatment of COPD. Their strategy informs clinical practice in
COPD and has a number of objectives including: (1) assessing and monitoring COPD and its impact and (2) helping individuals who suffer from the disease (GOLD, 2015). The main clinical implication of the present study is advancement of a case for revising the routine psychological outcome measures administered as part of assessment of psychological well-being in COPD. Further implications regarding the development of targeted psychological interventions and healthcare utilisation associated with COPD are considered.

4.4.1 Assessment/psychological screening
At present within clinical practice, assessment of trauma symptoms and health anxiety are not generally undertaken, despite the suggestion that trauma symptoms may exacerbate COPD symptoms (Harrison et al., 2013) and anecdotal evidence that indicates high levels of illness preoccupation in individuals with existing medical conditions. Accurate screening and assessment of the psychological impact of COPD is key in adhering to GOLD objectives and in supporting individuals’ psychological needs, since if symptoms of psychological distress go undetected, they remain untreated. Within current clinical practice anxiety, depression and health related quality of life are routinely assessed (Yohannes et al., 2010). Given the prevalence rates herein of PTSD related to AEs, the levels of premorbid trauma and levels of health anxiety amongst individuals with complex COPD, the current study advances a case for direct screening for both health anxiety and PTSD within this client group.\textsuperscript{11}

4.4.2 Psychological interventions
The need to offer targeted interventions that reflect patient need is supported by the Outcomes Strategy for COPD in the UK (Department of Health, 2011). Recent research has suggested existing interventions for COPD, such as PR, may not be adequate in meeting patients’ psychological needs (Harrison et al., 2013; Jones et al., 2009b; Mannino et al., 2010). Further research is recommended to support investment in the development of interventions that better reflect the psychological status of individuals with COPD. The current study findings suggest that there may be benefit in drawing on the already established treatments for PTSD and health anxiety in the development of more targeted psychological

\textsuperscript{11} Direct screening is considered important as Solomon and Davidson (1997) found trauma symptoms can be underestimated if individuals are not explicitly asked about their experience of the ‘traumatic event’.
interventions for COPD populations. The finding of high levels of pre-morbid trauma amongst COPD patients may be of particular interest in informing interventions related to smoking behaviour. This finding is supported in Jones et al., (2009a) and Chung et al., (2015) and suggests there is a call for future research to further examine the relationship between earlier experiences of traumatic events, impaired lung functioning and smoking behaviour (since smoking is often used as a form of self-soothing). It would also be of interest to compare levels of premorbid trauma in COPD to other health conditions and consider what factors may mediate the relationship between the experience of multiple adversities and health outcomes.

4.4.3 Healthcare utilisation
Research in COPD to date has not considered how health anxiety might be implicated in patients accessing healthcare. Understanding the extent to which health anxiety is present in chronic health conditions is of interest as a number of studies have examined the relationship between health anxiety and health care utilisation, with compelling findings in which health anxiety predicts healthcare use (Boston & Merrick, 2010; Tomenson, McBeth & Chew-Graham, 2012). In COPD, it could be that high levels of health anxiety may lead to increased monitoring of health parameters (e.g. oxygen saturation levels) or scanning the body for changes (e.g. hypervigilantly observing breathing rate), which could result in increased symptom detection, increased threat appraisal (i.e. thinking that an AE might occur) and increased healthcare use. Individuals with COPD who experience repeated AEs have high hospital readmission rates and there is increased rate of re-hospitalisation for individuals with mental health difficulties (Baker, Zou & Su, 2013; Damiani & Dixon, 2001). Further examination of health anxiety in individuals with COPD may shed light on some of the precipitating factors that lead to repeat admissions within this population, and could again inform the development of targeted interventions for individuals with COPD.
References


Bailey, P.H. (2004). The dyspnea-anxiety-dyspnea cycle-COPD patients' stories of breathlessness: "It's scary /when you can't breathe". *Qualitative Health Research, 14*(6), 760-778.


PART 3: Critical Appraisal
1 Introduction

The aim of this section is to offer critical reflections on the research process. Throughout completion of the project, I used both formal and informal means to facilitate critical thinking. For example, a research diary was kept and research supervision was attended regularly, along with a peer support group. I draw on these means, in addition to informal discussions held with staff, in considering my decision to explore the chosen research topic. I also discuss the challenges faced during the research process, focusing in particular on obstacles associated with conducting research within a clinical setting and finally consider how involvement in this research project has influenced my personal and professional development.

1.1 Research process

1.1.1 The decision to explore trauma and health anxiety in lung disease

My professional and academic background greatly influenced my desire to undertake this project. Coming into training I had a longstanding interest in health psychology, having previously completed post-graduate studies within this field. My interests in working psychologically with individuals with chronic disease were supported during training, through undertaking placements in within various Medical Psychology settings. For my first clinical placement, I was based in a general hospital where I worked with inpatients and outpatients with a range of physical health difficulties. Within this work, I was particularly moved by a couple of individual accounts of traumatic experiences whilst in intensive care. During this clinical work, I became aware of how individual narratives about difficult hospital stays are not often shared with healthcare professionals. I became curious about how patients made sense of traumatic experiences
associated with their care and conditions and about how such experiences may shape future health behaviour? These questions directed my reading to models of trauma, Acute Stress Disorder and Disorders of Extreme Stress. When staff presented their research interests to trainees, an idea was put forward to consider trauma in individuals with Chronic Obstructive Pulmonary Disease (COPD). This project stood out as an exciting opportunity and seemed to me, a way to merge my interest in trauma with my passion for health psychology.

Reading through the literature examining trauma in different populations (e.g. burns victims and birth trauma) I also become interested in the distinction between ‘flashforwards’, intrusions associated with future events and ‘flashbacks’, intrusions associated with the already experienced traumatic event (Mundy & Baum; 2004). Quantitatively operationalising the concept of ‘flashforwards’ proved challenging, however following discussions with my supervisor, it was felt that examining health anxiety could be a useful way of trying to capture anxious cognitions associated with future outcomes. After a meeting with staff at the COPD outpatient clinic and discussions at the meeting regarding exacting challenges associated with COPD, such as acute exacerbations, I was further convinced that examining trauma and health anxiety within a COPD population would be worthy of investigation.

1.1.2 Choice of methodology

Acknowledging the lack of extant literature on the lived experience of trauma in lung disease, my initial interest was in using a mixed methods approach, to explore the experience of trauma symptoms in individuals who had acute exacerbations of COPD. It was hoped that a mixed methods approach would
support the exploration of the subjective experience of trauma symptoms in individuals with COPD, alongside examining the extent of health anxiety and posttraumatic stress disorder (PTSD) within this population. A proposal outlining this intention was compiled and ethical approval for a mixed methods study was gained. However, once recruitment was underway, it became evident that using a mixed methods approach was not feasible within the given timeframe for conducting the research and also given that screening for PTSD was required in order to identify candidates eligible for interview.

It was decided that conducting a mixed methods project was not viable due to time restrictions associated with completing research in the context of Clinical Psychology doctoral training, delays encountered in gaining ethical approval which meant that recruitment started later than intended, and not having realised the ambitious nature of the scale of the initial proposal. Consequently, the focus of the research was narrowed to just the quantitative research questions.

1.2 Ethical approval and ethical considerations

Navigating through the ethical approval process was both challenging and time consuming. The Research and Development (R&D) application for the local trust site could not be processed in parallel with the Integrated Research Application System (IRAS) as Research Ethics Committee (REC) approval was required before the R&D application could be considered. On the whole, I experienced the IRAS form as repetitive and confusing; the lack of clarity in parts meant that I made simple errors which had unfortunate consequences, such entering the current date when uploading documents rather than date of document creation, which proved to be problematic later on. Due to the requirements for R&D
approval, such as having to wait to attend Consent Training, it took around eight months to obtain full ethical approval. I felt frustrated at having to wait to this length of time to start recruitment and some of the requirements for gaining ethical approval did always seem sensible to me. For example, having to attend two training courses (Good Clinical Practice and Consent Training), with overlapping content. Despite the associated challenges, the process of applying for ethical approval taught me the importance of allowing excess time when applying for ethical approval, in order to account for unexpected obstacles. The process also highlighted the benefits of having prior experience of using the complex online systems involved.

Ethical considerations in the current study primarily related to the potential for some of the participants to be considered vulnerable adults i.e. individuals often had co-morbid physical difficulties and the majority of whom were older adults. It was important to hold potential vulnerabilities in mind during recruitment; there were also associated practical and emotional considerations that are further discussed within the recruitment and data collection section.

Age associated cognitive decline was examined in relation to capacity to consent and the decision to recruit particular patients was carefully considered on an individual basis, by consulting with clinical staff. I was pleased to have the support from the clinical team in screening patients for eligibility and liaising with multi-disciplinary staff acted as a safeguard to prevent recruiting individuals who would not have been appropriate to include in the sample, both in terms of their own vulnerability and in relation to study eligibility criteria. I did however
wonder whether relying on clinical judgement in this way, may have introduced sampling bias.

1.3 Recruitment and data collection

Utilising strengths within the therapeutic relationship between the Clinical Nurse Specialist (CNS) and patients, proved to be vital in recruitment. I feel that having the CNS introduced me to the patients, rather than independently approaching patients, accounted for the small number of participants who declined to take part in the study (n=3). I was however aware of social desirability effects and wondered whether the representation within the sample would have been different had alternative recruitment methods been employed.

The duration of completion time anticipated to be 20 minutes for the two measures, was vastly underestimated and overall participants required more support than was initially accounted for. Uptake of support in reading questionnaire items and recording responses was high, notably because a number of patients either did not feel comfortable to read the small font or had not brought their reading glasses with them to the appointment. It may have been helpful to have had a prompt related to glasses on the information sheet and to have enlarged the measures to support with this. More generally, it would have been useful to have conducted a pilot study, which would have flagged these areas of difficulty sooner and allowed for modifications to be made.

Difficulties associated with understanding some of the concepts on the measures were also noted. For example, whilst completing the health anxiety measure patients frequently asked what ‘bodily sensations and changes’ meant. So as not to offer my own interpretation, which may have biased the results, I asked
participants what they thought this meant. Responses were generally relatable to the concept, however if patients struggled generate ideas, I would consistently state that these questions were referring to ‘anything that changes physically in the body’. I was mindful not to give examples that could have cued patients into particular bodily sensations such as; breathing rate, heart rate etc., as this could have altered their responses.

Throughout the data collection process, I was aware of the potential emotional impact of talking about difficult and traumatic experiences and was mindful of the well documented link between anxiety, depression, and COPD (Hynnine, Breitve, Wiborg, et al., 2004). It was important for me to acknowledge that some individuals may become upset when talking about content evoked by the measures. Indeed, high emotionality was occasionally evident, particularly when individuals were describing details of traumatic events or talking about anxiety provoking issues. I was aware during these times of the ethical obligation to signpost to services if needed, and to seek permission from patients to continue with the measures. Of note, care was taken during the consent process to make sure patients understood that they could terminate their participation in the research at their request, without the need to give a reason and without any consequences to their clinical care. No participants asked to withdraw and I observed that I was often met with relief from participants after moments of observable upset. On the whole, patients tended to report a positive or cathartic experience of having some of their experiences validated through their inclusion on standardised measures.
As indicated, despite observable emotionality, no participants requested to terminate their participation, though two individuals did not wish to complete the trauma measure following the health anxiety measure, due to finding the content of the questionnaires emotionally difficult. The item on the health anxiety measure that most consistently evoked an emotional response was a question regarding ‘loss of dignity’, which often sparked conversation about loss of independence. During these and other conversations, I was struck by the sense of empathy elicited in me, in relation to patient’s accounts of not wanting to burden others and in relation to the terror reported during times when individuals had not been able to breathe. I wondered what outlets patients did have to discuss their emotions and was also disappointed that the nuances and richness of these conversations were not captured by the quantitative approach.

I was mindful of the need for self-care following these more emotive sessions, and the potential personal impact of hearing about accounts of traumatic experiences. I used my reflective diary and supervision to discuss my reactions to this content and also observed my reactions to contrasting experiences, where individuals talked about post-traumatic growth, most commonly framed as experiences that ‘made me stronger’. As a training clinician it was at times difficult for me to avoid using clinical skills during interactions with patients, particularly in response to indicators of distress. It was evident to me that recruitment sessions could at times bear similar features to assessment sessions I was conducting within my clinical role (in cancer care) and it was important for me to acknowledge the distinctions. I managed this by being aware of the tension created by being both a researcher and a clinician, and consciously tried to maintain my stance as a researcher.
Through the process of data collection I was aware of recruitment being placed in the context of patients medical appointments. Asking for participant’s time before or after their attendance at appointments with the Respiratory Consultant was not ideal for a number of reasons; (1) time pressures, (2) patients may have been fatigued, (3) some patients were required to undertake spirometry testing before their consultation. Although this is a simple procedure, due to the nature of their condition many individuals with COPD can find breathing tests distressing and screening patients after a distressing experience, could have inflated patients scores on the health anxiety and trauma measures. There were also practical difficulties associated with conducting research in a clinical setting, for example I did not have an allocated room and often ended up carrying out screening within the ECG room, which was fairly small and unexpectedly contained medical equipment, which may have altered the frame of the session. There were also frequent disruptions during screening and it was difficult manoeuvre wheelchairs within this room. Due to the lack of an alternative, accessibility, comfort and issues related to the frame of the session could not be given adequate consideration.

2 Personal and professional development

I initially felt overwhelmed by the complexity of COPD and associated clinical procedures. In attempt to manage my own anxiety, I sought to familiarise myself with commonly encountered medical terms and treatment procedures. I noticed that as my familiarity with the condition and clinical setting increased, I was able to engage more actively with the research process. Early on within the research process, I also found that I was distracted by novel information such as learning
about Cumulative Trauma Disorder and phenomena like ‘flashforwards’, which I had previously not encountered. I was required move past a desire to focus on the minutiae of novel information and had to be mindful of the need to redirect my attention and reading endeavours to the task and research questions at hand. This was a useful realisation which awareness of, encouraged me not to lose sight of the overall research aims.

Loosening my attachment to the intended qualitative component of the research proved challenging. I had not previously had experience of conducting qualitative research and was excited by the prospect of developing my skills in a methodology new to me, Interpretive Phenomenological Analysis (IPA). I was drawn to IPA’s focus on privileging the individual and allowing idiosyncratic experiences to be better understood. I was conscious of my lack of experience in conducting qualitative research and as a result attended an IPA workshop. Following investment in IPA skills development and indeed having enjoyed the training, I was disappointed not to be able to use these skills. That said I am keen to explore future research opportunities that lend to this method post training.

I completed the current research alongside various clinical placements, one of which was in a psychodynamic setting. Experiencing this placement in parallel to conducting the research, I was curious about psychoanalytic views on physical conditions. I came across one paper that reviewed 50 years of respiratory research, which commented on the exclusion of COPD from psychoanalytical theorising in contrast to other respiratory conditions, due to stigma associated with the development of COPD, notably smoking, and due to smoking be conceptualised as a non-psychological determinant of the disease (Kaptien, Scharloo & Fischer,
I found this exclusion unjust and the conceptualisation of smoking as a definitively ‘non-psychological’ deterrent seemed to me to be lacking complexity and consideration for the psychological factors associated with sustaining health behaviours. I also wondered more broadly about staff’s perception of their work and the individuals they care for. One interesting discussion with staff members illuminated what are probably some widely shared attitudes of COPD/respiratory medicine not being viewed as ‘sexy medicine’, in contrast to other disciplines, such as cardiac medicine. This echoed my experience of discussing my chosen research topic with friends and family members and my experience of recruiting in a shared clinic environment, where much proportional material for other chronic conditions was on display. Despite such perceptions being evident, my observation was that staff working within respiratory medicine appeared to value and enjoy their roles, and the individuals I encountered and observed recognised the complexity and uniqueness of working with COPD patients in contrast to other patients.

Kaptein et al’s (2009) review paper noted distinctive groupings of patients; those described as having HOUND characteristics (perceived as being humble, old, unattractive, non-verbal and dull) and those described as having YAVIS characteristics (perceived as being young, attractive, verbal intelligent and successful) (Kaptein et al., 2009), I wondered how these archetypes fitted with staff and wider public perceptions of COPD patients and how they contrasted to other patients with chronic diseases. I felt that there were perhaps some interesting research questions around perception and staff satisfaction using these archetypes, which would be interesting areas for future research.
Overall, I was impressed by the research ethos within the outpatient department and dedicated on site research team. Being part of a nationally recognised research team within a clinical setting, made me aware of research being something that I value within a working environment. I reflected on the current socio-political climate and how there are many settings in which psychologists work that are unable to promote protected time for research. This has encouraged me to consider settings research agenda’s when applying for jobs and if possible, I would like to be able to pursue research interests within a supportive and research active environment.

3 Dissemination

Due to continuing recruitment into April (in attempt to increase the sample size), the write up of this research has been both demanding and time pressured. I have reflected on the need to be realistic about the quality of work produced under such time constraints and have wondered more generally about the publish-ability of an underpowered study. Whilst the initial intention was to put forward both the literature review and the empirical research report for publication, I feel the empirical piece requires additional data, in order to support its clinical utility and offer a significant contribution to existing literature.

4 Final reflections

My interest in undertaking this project stemmed from my vocational training and personal interest in working with individuals with chronic health conditions, which I remain passionate about. The research process provided the opportunity for me to experience the reality of conducting research within a clinical setting,
which I feel has taught me a great deal about the need to compromise and work within the limits of complex and ever changing systems, where clinical work understandably has to take priority.

Throughout the research process, I was fortunate to have support from the hospital staff at the outpatient clinic, who greatly contributed to sustaining my motivation and enthusiasm for this project, and without whom, this research would not have come to fruition. I shall continue to remain sincerely grateful to them and to all the participants who gave their time to participate in this research. Reflecting on the research process more generally, the recurrent theme for me was about learning to reign in ambitious plans. I found holding in mind Voltaire’s notion of “the best being the enemy of the good”, helpful in reminding me to draw a line under things and accept good enough qualities of the work produced. On that note, I have not been able to find a reference for this quote but acknowledging the author and stopping here is good enough for me!
**References**


PART 4: Appendices
Appendix A: Databases selected and associated rationale

<table>
<thead>
<tr>
<th>Database</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINHAL</td>
<td>CINHAL was selected in order to ensure coverage of nursing research and research conducted by other allied health professionals.</td>
</tr>
<tr>
<td>Medline</td>
<td>Medline was selected in order to ensure comprehensive coverage of biomedical literature.</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>PsycINFO was selected as it provides comprehensive coverage of psychology and mental health related articles.</td>
</tr>
<tr>
<td>Scopus</td>
<td>Scopus was selected as it is an expansive database that provides articles from a number of social science related disciplines including, medicine and humanities related subjects.</td>
</tr>
</tbody>
</table>
Appendix B: Search strategy applied to the database searches and number of articles yielded

<table>
<thead>
<tr>
<th>Database</th>
<th>Search Terms</th>
<th>Number of Articles</th>
</tr>
</thead>
</table>
| PsycInfo | 1) psychologic* OR morbidity OR distress OR anxiety OR depression OR trauma OR mood OR burden OR impact OR need*  
2) carer OR care giv* OR caregive* OR spous* OR wife OR husband OR partner*  
3) COPD OR COAD OR chronic obstructive pulmonary disease OR chronic obstructive airways disease OR respiratory disease OR lung disease | 1,518,661            |
|          | Combined                                                                                                                                                                                                    | 167                |
|          | Combined with limits (English language and peer reviewed)                                                                                                                                                   | 140                |
| Scopus   | 1) psychologic* OR morbidity OR distress OR anxiety OR depression OR trauma OR mood OR burden OR impact OR need*  
2) carer OR care giv* OR caregive* OR spous* OR wife OR husband OR partner*  
3) COPD OR COAD OR chronic obstructive pulmonary disease OR chronic obstructive airways disease OR respiratory disease OR lung disease | 7,008,934           |
<p>|          | Combined                                                                                                                                                                                                    | 73                 |
|          | Combined with limits (English language and journal articles)                                                                                                                                                 | 63                 |
| Medline  | 1) psychologic* OR morbidity OR distress OR anxiety OR depression OR trauma                                                                                                                                 | 2976010            |</p>
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<td>OR mood OR burden OR impact OR need*</td>
<td>201064</td>
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<tr>
<td>2) carer OR care giv* OR caregive* OR spous* OR wife OR husband OR partner*</td>
<td></td>
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<tr>
<td>3) COPD OR COAD OR chronic obstructive pulmonary disease OR chronic obstructive airways disease OR respiratory disease OR lung disease</td>
<td>81535</td>
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<td><strong>Combined</strong></td>
<td><strong>396</strong></td>
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<td><strong>Combined with limits (English language and human studies)</strong></td>
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**CINAHL**

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<td>2) carer OR care giv* OR caregive* OR spous* OR wife OR husband OR partner*</td>
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<td>3) COPD OR COAD OR chronic obstructive pulmonary disease OR chronic obstructive airways disease OR respiratory disease OR lung disease</td>
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**Total combined**

<table>
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<td>737</td>
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</table>

**Total combined with duplicates removed**

<table>
<thead>
<tr>
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**Total identified through other sources**

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</table>

**Total Shortlisted**

<table>
<thead>
<tr>
<th>Count</th>
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<tbody>
<tr>
<td>51</td>
</tr>
</tbody>
</table>
Appendix C: Review Profile

Records identified through database searches (PsychINFO, Scopus, Medline and CINAHL from inception to April 2016)  
\[ n = 737 \]

Records after duplicates removed  
\[ n = 576 \]

Records identified through additional sources  
\[ n = 1 \]

Records screened (titles assessed for eligibility)  
\[ n = 577 \]

Records excluded  
\[ n = 526 \]

Full text articles assess for eligibility (abstracts/articles reviewed)  
\[ n = 51 \]

Articles excluded  
\[ n = 39 \]

Studies included in quantitative synthesis  
\[ n = 12 \]

Full text articles excluded with reasons:
- Study aim not relevant to current review  
  \[ n = 21 \]
- Qualitative research  
  \[ n = 9 \]
- Review or systematic overview of literature  
  \[ n = 6 \]
- No English translation available  
  \[ n = 1 \]
- COPD data not discernible  
  \[ n = 2 \]
## Appendix D: Data extraction form

<table>
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<th>Author(s):</th>
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<tbody>
<tr>
<td>Title:</td>
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<tr>
<td>Publication date:</td>
</tr>
<tr>
<td>Journal:</td>
</tr>
<tr>
<td>Volume:</td>
</tr>
<tr>
<td>Keywords / Definitions:</td>
</tr>
<tr>
<td>Study aims and objectives:</td>
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<tr>
<td>Study type /design:</td>
</tr>
<tr>
<td><strong>Participants:</strong> <em>(Recruitment source and method, sample size, mean age, gender composition, other carer attributes)</em></td>
</tr>
<tr>
<td><strong>Patient characteristics:</strong> <em>(Severity of COPD symptoms, duration of diagnosis)</em></td>
</tr>
<tr>
<td><strong>Outcomes:</strong> <em>(Measurements used, were they validated, did they use sample appropriate norms, self-report or clinician-assessed)</em></td>
</tr>
<tr>
<td><strong>Analysis:</strong> <em>(Power calculations, statistical method employed)</em></td>
</tr>
<tr>
<td>Key findings:</td>
</tr>
<tr>
<td><strong>Conclusions:</strong> <em>(What do the findings mean, considerations related to generalisablility, implications and limitations)</em></td>
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<tr>
<td>Controls/Validity/Reliability:</td>
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<td>Additional Comments:</td>
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<tbody>
<tr>
<td>1. Is the hypothesis/aim of the study clearly described?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<tr>
<td>3. Are the characteristics of the participants clearly described?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
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</tr>
<tr>
<td>4. Are the main findings of the study clearly described?</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
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<tr>
<td>5. Does the study provide estimates of the random variability in the data for the main outcomes?</td>
<td>x</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>6. Have actual probability values been reported (e.g., 0.035 rather than &lt;0.05) for the main outcomes except where the probability value is less than 0.001?</td>
<td>x</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
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</tr>
<tr>
<td><strong>External Validity</strong></td>
<td>7. Were the participants asked to participate in the study representative of the entire population from which they were recruited?</td>
<td>✓</td>
<td>?</td>
<td>?</td>
<td>✓</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>?</td>
<td>?</td>
<td>?</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>8. Were subjects who were prepared to participate representative of the entire population from which they were recruited?</td>
<td>✓</td>
<td>?</td>
<td>?</td>
<td>✓</td>
<td>✗</td>
<td>✗</td>
<td>✗</td>
<td>?</td>
<td>?</td>
<td>?</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>9. If any of the results of the study were based on ‘data dredging’ was this made clear?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>?</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>10. Were the statistical tests used to assess outcomes appropriate?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
</tr>
<tr>
<td></td>
<td>11. Were the main outcome measures used accurate (valid and reliable)?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✗</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td><strong>Power</strong></td>
<td>12. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?</td>
<td>✓</td>
<td>?</td>
<td>?</td>
<td>✓</td>
<td>✗</td>
<td>✗</td>
<td>?</td>
<td>✗</td>
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</table>

**Total Quality Score**

10  5  9  10  7  5  6  8  7  4  5  8

*Note: ✓ = Yes; ✗ = No; ? = unable to rate*
### Appendix F: Papers shortlisted for inclusion/exclusion

<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Title</th>
<th>Inclusion/Exclusion</th>
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<tbody>
<tr>
<td>Al-Gamal (2014)</td>
<td>Quality of life, anxiety and depression among patients with chronic obstructive pulmonary disease and their spouses</td>
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<tr>
<td>Arpita et al. (2009)</td>
<td>Relationship among differentiation of self, relationship satisfaction, partner support, and depression in patients with Chronic Lung Disease and their partners</td>
<td>Excluded – Examined patient’s differentiation of self</td>
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<tr>
<td>Burton et al. (2012)</td>
<td>Burden and well-being among a diverse sample of cancer, congestive heart failure, and Chronic Obstructive Pulmonary Disease caregivers</td>
<td>Excluded – Considered correlates of caregiver burden in patient-carer dyads</td>
</tr>
<tr>
<td>Cain (2000)</td>
<td>Caregiving attributes as correlates of burden in family caregivers coping with Chronic Obstructive Pulmonary Disease</td>
<td>Excluded – Study aim was to determine correlates of caregiver burden</td>
</tr>
<tr>
<td>Caress et al. (2009)</td>
<td>A review of the information and support needs of family carers of patients with chronic obstructive pulmonary disease</td>
<td>Excluded – Narrative Review</td>
</tr>
<tr>
<td>Cedano et al. (2013)</td>
<td>Quality of life and burden in carers for persons with COPD receiving oxygen therapy</td>
<td>Included</td>
</tr>
<tr>
<td>Authors</td>
<td>Study Description</td>
<td>Included/Excluded</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
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<tr>
<td>Cossette et al. (1993)</td>
<td>Caregiving tasks as predictors of mental health of wife caregivers of men with Chronic Obstructive Pulmonary Disease</td>
<td>Excluded – Examined predictors of mental health outcomes, focusing on task specific disturbance and support needs</td>
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<tr>
<td>Currow et al. (2008)</td>
<td>Caregivers for people with end-stage lung disease: characteristics and unmet needs in the whole population</td>
<td>Excluded – Described demographic characteristics of caregivers (using a survey), not psychological morbidity</td>
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<tr>
<td>de Miranda et al. (2011)</td>
<td>Postintensive care unit psychological burden in patients with chronic obstructive pulmonary disease and informal caregivers: A multicenter study</td>
<td>Excluded – Psychological morbidity considered in relation to postintensive care stay, not in relation to role as a caregiver</td>
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<tr>
<td>Ek, (2011)</td>
<td>Shifting life rhythms: Couples’ stories about living together when one spouse has advanced chronic obstructive pulmonary disease</td>
<td>Excluded – Phenomenological study</td>
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<tr>
<td>Farquhar et al. (2010)</td>
<td>Diversity of experiences and impacts of caring for a patient with breathlessness in advanced COPD</td>
<td>Excluded – Qualitative (interview study)</td>
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<tr>
<td>Figueiredo et al. (2014)</td>
<td>Caring for relatives with chronic obstructive pulmonary disease how does the disease severity impact on family carers?</td>
<td>Included</td>
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<tr>
<td>Fried et al. (2005)</td>
<td>Unmet desire for caregiver-patient communication and increased caregiver burden</td>
<td>Excluded – Examined adequacy of communication in caregiver relationship and how this related to caregiver burden</td>
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<td>Fried et al. (2012)</td>
<td>Caring for the older person with chronic obstructive pulmonary disease</td>
<td>Excluded – Qualitative study, patient accounts regarding management of dyspnoea</td>
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<tr>
<td>Study</td>
<td>Title</td>
<td>Included/Excluded</td>
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<tr>
<td>------------------------------</td>
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<tr>
<td>Grant et al. (2012)</td>
<td>The impact of caring for those with chronic obstructive pulmonary disease (COPD) on carers' psychological well-being: a narrative review</td>
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<td>Garlo et al. (2010)</td>
<td>Burden in caregivers of older adults with advanced illness</td>
<td>Excluded – COPD data not discernible</td>
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<td>Gysels et al. (2009)</td>
<td>Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources</td>
<td>Excluded – Qualitative study, semi-structured interviews analysed using Grounded Theory</td>
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<td>Hasson et al. (2009)</td>
<td>Experiences and needs of bereaved carers during palliative and end-of-life care for people with chronic obstructive pulmonary disease</td>
<td>Excluded - explored experiences of palliative care that bereaved carers had while providing care using semi-structured interviews</td>
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<td>Jácome et al. (2014)</td>
<td>Predicting anxiety and depression among family carers of people with Chronic Obstructive Pulmonary Disease</td>
<td>Included</td>
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<td>Kanervisto et al. (2007)</td>
<td>Family dynamics in families of severe COPD patients</td>
<td>Excluded – Described family dynamics in COPD using a framework for healthy family systems</td>
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<td>Kanervisto et al. (2007)</td>
<td>Severe chronic obstructive pulmonary disease in a family's everyday life in Finland: Perceptions of people with chronic obstructive pulmonary disease and their spouses</td>
<td>Excluded – Described the experience of living with COPD</td>
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<tr>
<td>Kara et al. (2004)</td>
<td>Loneliness, depression, and social support of Turkish patients with Chronic Obstructive Pulmonary Disease and their spouses</td>
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<tr>
<td>Keele-Card et al. (1993)</td>
<td>Loneliness, depression, and social support of patients with Chronic Obstructive Pulmonary Disease and their spouses</td>
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<tr>
<td>Kim et al. (2010)</td>
<td>Burden of COPD among Family</td>
<td>Excluded – No English</td>
</tr>
<tr>
<td>Study Reference</td>
<td>Title of Study</td>
<td>Exclusion Reason</td>
</tr>
<tr>
<td>-----------------</td>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Kühl et al. (2008)</td>
<td>Mental disorders and quality of life in COPD patients and their spouses</td>
<td>Excluded – Study aims not relevant to current review/combined patient and spouse data in multiple regression analysis</td>
</tr>
<tr>
<td>Langa et al. (2002)</td>
<td>Informal caregiving for chronic lung disease among older Americans</td>
<td>Excluded – Multivariable regression analysis to obtain national estimates of factors associated with caregiving</td>
</tr>
<tr>
<td>Lee et al. (2010)</td>
<td>Psychosocial condition of family caregivers of patients with chronic obstructive pulmonary disease in Hong Kong</td>
<td>Included</td>
</tr>
<tr>
<td>Meier et al. (2011)</td>
<td>Dyadic coping, quality of life, and psychological distress among chronic obstructive pulmonary disease patients and their partners</td>
<td>Excluded – Considered relationship between coping and wellbeing</td>
</tr>
<tr>
<td>Miravitlles et al. (2015)</td>
<td>Caregivers' burden in patients with COPD</td>
<td>Excluded – Considered impact of level of dependence on caregivers health, leisure and profession related problems</td>
</tr>
<tr>
<td>Nienke et al. (2015)</td>
<td>Informal caregivers of patients with COPD: Home sweet home?</td>
<td>Excluded – Review article considering the shift from home to hospital care and complex relationship between patient and carer</td>
</tr>
<tr>
<td>Nordtug et al. (2011)</td>
<td>Similarities and differences in caring burden of home dwellers with partners suffering from chronic obstructive pulmonary disease or dementia</td>
<td>Excluded – Examined interplay between personality and mental health</td>
</tr>
<tr>
<td>Nordtug et al. (2011)</td>
<td>Personality features, caring burden and mental health of cohabitants of partners with chronic obstructive pulmonary disease or dementia</td>
<td>Excluded – Examined interplay between personality and mental health</td>
</tr>
<tr>
<td>Parnell (2010)</td>
<td>Caring for the carers of chronic lung disease sufferers in the community</td>
<td>Excluded – Descriptive overview</td>
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<tr>
<td>Pinto et al. (2007)</td>
<td>Assessment of the burden of caregiving for patients with chronic</td>
<td>Included</td>
</tr>
<tr>
<td>Study Reference</td>
<td>Title</td>
<td>Included/Excluded</td>
</tr>
<tr>
<td>-----------------</td>
<td>-------</td>
<td>------------------</td>
</tr>
<tr>
<td>Ross <em>et al.</em> (1997)</td>
<td>The impact on the wife of caring for a physically ill spouse</td>
<td>Included</td>
</tr>
<tr>
<td>Sautter <em>et al.</em> (2014)</td>
<td>Caregiver experience during advanced chronic illness and last year of life</td>
<td>Excluded – Mixed sample (multiple chronic illnesses) and considered predictors of caregiver esteem and burden</td>
</tr>
<tr>
<td>Schreiner <em>et al.</em> (2006)</td>
<td>Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview</td>
<td>Excluded – Study aim was to determine a statistically valid cut-off score for a particular measure</td>
</tr>
<tr>
<td>Sexton <em>et al.</em> (2015)</td>
<td>Impact of a husband's chronic illness (COPD) on the spouse's life</td>
<td>Included</td>
</tr>
<tr>
<td>Simpson <em>et al.</em> (2010)</td>
<td>A day at a time: caregiving on the edge in advanced COPD</td>
<td>Excluded – Qualitative study, ‘interpretative description’</td>
</tr>
<tr>
<td>Spence <em>et al.</em> (2008)</td>
<td>Active carers: living with chronic obstructive pulmonary disease</td>
<td>Excluded – Qualitative study using interviews</td>
</tr>
<tr>
<td>Takata <em>et al.</em> (2008)</td>
<td>Burden among caregivers of patients with chronic obstructive pulmonary disease with long-term oxygen therapy</td>
<td>Included</td>
</tr>
<tr>
<td>Utens <em>et al.</em> (2014)</td>
<td>Informal caregiver strain, preference and satisfaction in hospital-at-home and usual hospital care for COPD exacerbations: Results of a randomised controlled trial</td>
<td>Excluded – Difference in caregiver strain between hospital care and home care</td>
</tr>
<tr>
<td>Vaske <em>et al.</em> (2015)</td>
<td>For better or for worse: A longitudinal study on dyadic coping and quality of life among couples with a partner suffering from COPD</td>
<td>Excluded – Correlation analysis exploring the long-term effects of dyadic coping</td>
</tr>
<tr>
<td>Vincent (2014)</td>
<td>Carers’ experience of looking after a person with chronic obstructive respiratory disease</td>
<td>Excluded – Qualitative, narrative commentary/descriptive overview</td>
</tr>
<tr>
<td>Washio <em>et al.</em> (2003)</td>
<td>Depression among caregivers of patients with Chronic Obstructive Pulmonary Disease</td>
<td>Included</td>
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</tbody>
</table>
## Pulmonary Disease

### Appendix G: GOLD staging criteria

<table>
<thead>
<tr>
<th>GOLD STAGE</th>
<th>COPD Severity</th>
<th>FEV1 Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Mild COPD</td>
<td>$\geq 80%$ of normal</td>
</tr>
<tr>
<td>II</td>
<td>Moderate COPD</td>
<td>50-79% of normal</td>
</tr>
<tr>
<td>III</td>
<td>Severe COPD</td>
<td>30-49% of normal</td>
</tr>
<tr>
<td>IV</td>
<td>Very Severe COPD</td>
<td>$&lt;30%$ of normal, or $&lt;50%$ normal with chronic respiratory failure present</td>
</tr>
</tbody>
</table>
Appendix H: Research Ethics Committee approval letter

31 March 2015

Miss Lorraine Craig
Trainee Clinical Psychologist
Leicestershire Partnership NHS Trust
School of Psychology, University of Leicester
104 Regent Road,
Leicester
LE1 7LT

Dear Miss Craig

Study title: The experience of trauma symptomatology in individuals with Chronic Obstructive Pulmonary Disease: A mixed methods approach

REC reference: 15/EM/0116
Protocol number: 5
IRAS project ID: 169130

The Research Ethics Committee reviewed the above application at the meeting held on 23 March 2015. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Assistant.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Amend the participant information sheet and/or consent form to allow
participants the opportunity to request feedback of study results.

2. Amend the participant information sheet with information explaining that interviews will be audio recorded.

3. Confirm that all transcription of interviews would be undertaken by the applicant.

4. Confirm that participants will have at least 24 hours to consider taking part in the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission (“R&D approval”) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the integrated Research Application System or at [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk).

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (“participant identification centre”), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [admin@hra.nhs.uk](mailto:admin@hra.nhs.uk). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.
Appendix I: Research and Development approval letter

DIRECTORATE OF RESEARCH & INNOVATION

Director:

Assistant Director:

Head of Research Operations:

Direct Dial: (0116) 258 8381
Fax No: (0116) 258 4226

4th August 2015

Lorraine Craig
University of Leicester
104 Regents Road
Leicester
LE1 7LT

Dear Lorraine,

Letter of access for research.

RE: UHL 11417 - Trauma symptoms in acute exacerbations of COPD.

As you have an existing NHS Contract you do not require an additional contract with this NHS organisation. We are satisfied that such checks as are necessary have been carried out by your employer and that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. This letter confirms your right of access to conduct research through the University of Leicester premises for the purpose and on the terms and conditions set out below. This right of access commences on 4th August 2015 and ends on 29th April 2016 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to University Hospitals of Leicester NHS Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise
the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely,

[Redacted]

Head of Research Operations

cc: [Redacted]
[Redacted]
Appendix J: Participant information sheet

Participant Information Sheet - Questionnaire Study

The experience of trauma symptomatology in individuals with Chronic Obstructive Pulmonary Disease: A mixed methods approach

Chief Investigator: Lorraine Craig

Supervised by: [Redacted]

You are invited to take part in a research study. Before deciding whether or not you would like to take part, we would like to give you some information on why the research is being carried out and what taking part will involve. Please read through this information sheet carefully and complete the participant consent form. Feel free to speak to your assessor or contact one of the researchers (details provided at the end of the information sheet), if you have any questions, or if anything about the research process is unclear.

Why is the research being carried out?

There has been limited research carried out on exploring some of the possible psychological implications of having a condition like Chronic Obstructive Pulmonary Disease (COPD). As well as exploring the impact of COPD symptoms, this study aims to see if there are links between acute exacerbations of COPD symptoms and the experience of trauma symptoms and health anxiety. It is suggested that a small number of people with COPD may be likely to experience the symptoms of their condition as traumatic but this is not something that is routinely considered at assessment. This study is also being carried out in partial fulfilment of the Chief Investigator’s (Lorraine Craig) completion of a Doctorate in Clinical Psychology.

Why are you been invited to take part?

You have been invited to join this study because the service involved in your care is committed to carrying out research. It is up to you to decide whether to join the study
or not. If you do decide to take part, you will be asked to sign a consent form saying that you would like to participate in this research.

Even if you agree to take part, it is important that you understand that you are free to withdraw from the research at any time, without giving a reason. It is also important to understand that a decision to withdraw from this research, will not affect the standard of the care you receive from your clinical team.

**What will happen if you decide to take part in the research?**

If you are happy to consent to taking part in the research, could you please complete the trauma questionnaire and health anxiety questionnaire given to you by the researcher. Please return these along with your completed consent form. It is thought that these questionnaires will take up to 20 minutes to complete.

A small number of people will be invited to take part in an interview with the Chief Investigator after completing the screening questionnaires enclosed. It could also be that once you have completed the questionnaires; that will be the end of your participation in this study.

If you are invited to take part in the interview, the interview process will be explained to you before you are asked to make a decision about whether or not you would like to be interviewed. Interviews will be audio recorded using a discrete audio recording device.

All information collected about you as part of this study, including the audio recordings, will be kept confidential. All data will be anonymised and held on an encrypted memory stick which will be stored securely in a locked filing cabinet at the [Biomedical Research Unit]. Only the Chief Investigator will have access to the passwords and data.

**Potential benefits of taking part in this research**

The information gathered from this study will help to inform healthcare professionals about the needs of people with COPD and may lead to developments or improvements in treatment options that could be made available to people with COPD.

We cannot promise that the study will directly help you, but the information we get from this study will contribute to the growing literature on COPD, and participation is greatly valued.
What happens if you don’t want to carry on participating in the study?

You have the right to withdraw from participation in the study at any time. If you chose to withdraw after your data has been returned to the researchers, your data will be identified using your unique participation number and appropriately destroyed.

What if I would like to make a complaint about the research?

Please note that this research has been reviewed by a group of people called a Research Ethics Committee within the NHS. This happens in order to protect participant’s interests. This study has also been reviewed and received permission to be carried out by the University of Leicester.

If you have any concerns about any aspects of this study, you can speak to one of the researchers directly on the contact details below. If you remain unsatisfied after our attempts to answer your questions, and wish to complain formally you can do this by contacting the Independent Complaints Advocacy Service (ICAS) on 0808 8023000.

What if I have more questions?

If you have any questions about the study or if you would like to request feedback of the study results, please contact:

Miss Lorraine Craig
Trainee Clinical Psychologist
Leicester Doctoral Course in Clinical Psychology
104 Regent Road
Leicester
LE1 7LT
Tel. 0116 2231639

Dr Noelle Robertson
Course Director – Doctorate in Clinical Psychology
Leicester Doctoral Course in Clinical Psychology
104 Regent Road
Leicester
LE1 7LT
Tel. 0116 2231617
Dear <Insert name>

Re: Study on the experience of trauma in COPD

You are invited to take part in a research study exploring the psychological impact of living with COPD. Participation is voluntary and will involve completion of two questionnaires at your next outpatient appointment.

Enclosed is an information sheet that outlines further details of the study and may answer some of the questions you might have. If you have questions that remain unanswered, please feel free to contact the researcher using the contact details provided in the information sheet.

Thank you for taking the time to read this.

Yours sincerely,
Appendix L: Consent form

The experience of trauma symptomatology in individuals with Chronic Obstructive Pulmonary Disease: A mixed methods approach.

Chief Investigator: Lorraine Craig
Supervised by: [Redacted]

Please initial the boxes below to indicate consent:

1. Details of the research project have been explained to me and I am aware of what my participation in the study will involve.

2. I have been provided with a participant information sheet, which I have read and understood.

3. I have been given the opportunity to ask questions and have received satisfactory answers to any questions asked.

4. I understand that my questionnaire data will be kept confidentially in line with research ethics regulations.

5. I understand that my participation in the research is voluntary and I can withdraw from the research at any point without giving a reason.

6. If I decide to withdraw from the study I understand that my data will be appropriately destroyed and my care will not be affected in any way.

I consent and agree to all statements detailed above.

Participant Signature __________________________
Assignment Number __________________________
Researcher Signature __________________________
Thank you for your participation. If you have any questions about the study, or if you would like to request feedback of the study results, please contact:

Miss Lorraine Craig (Trainee Clinical Psychologist)

e-mail: lcc27@le.ac.uk
Contact number: 01162231639
## Appendix M: Medical Research Council Dyspnoea Scale

<table>
<thead>
<tr>
<th>Grade</th>
<th>Degree of breathlessness related to activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not troubled by breathlessness except on strenuous exercise</td>
</tr>
<tr>
<td>2</td>
<td>Short of breath when hurrying or walking up a slight hill</td>
</tr>
<tr>
<td>3</td>
<td>Walks slower than people of the same age on the level ground because of breathlessness or has to stop for breath when walking at own pace</td>
</tr>
<tr>
<td>4</td>
<td>Stops for breath after walking about 100m or after a few minutes on level ground</td>
</tr>
<tr>
<td>5</td>
<td>Too breathless to leave the house, or breathless when dressing or undressing</td>
</tr>
</tbody>
</table>
### Appendix N: Cronbach’s alpha

<table>
<thead>
<tr>
<th>Measure</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
<td>.736</td>
</tr>
<tr>
<td>Health Anxiety Inventory (SHAI)</td>
<td>.841</td>
</tr>
<tr>
<td>Posttraumatic Stress Diagnostic Scale (PDS)</td>
<td>.790</td>
</tr>
</tbody>
</table>
### Appendix O: Number of participants and percentage per clinical category for anxiety and depression scores

#### Anxiety

<table>
<thead>
<tr>
<th>Clinical category (score range)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal (0-7)</td>
<td>27</td>
<td>46</td>
</tr>
<tr>
<td>Mild (8-11)</td>
<td>17</td>
<td>29</td>
</tr>
<tr>
<td>Moderate (12-14)</td>
<td>11</td>
<td>19</td>
</tr>
<tr>
<td>Severe (≥15)</td>
<td>4</td>
<td>7</td>
</tr>
</tbody>
</table>

#### Depression

<table>
<thead>
<tr>
<th>Clinical category (score range)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal (0-7)</td>
<td>27</td>
<td>46</td>
</tr>
<tr>
<td>Mild (8-11)</td>
<td>20</td>
<td>34</td>
</tr>
<tr>
<td>Moderate (12-14)</td>
<td>11</td>
<td>19</td>
</tr>
<tr>
<td>Severe (≥15)</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
Appendix P: Number of participants and percentage per clinical category for PDS symptom score

<table>
<thead>
<tr>
<th>Clinical category (score range)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild (0-10)</td>
<td>14</td>
<td>47</td>
</tr>
<tr>
<td>Moderate (11-20)</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td>Moderate to severe (21-35)</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Severe (≥36)</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>
### Appendix Q: Normality testing

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Error</th>
<th>5% Trimmed</th>
<th>Kolmogorov-Smirnov</th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Std. Error</td>
<td></td>
<td>Statistic</td>
<td>Df</td>
<td>Sig. Statistic</td>
</tr>
<tr>
<td>EQ-5D VAS</td>
<td>52.895</td>
<td>2.795</td>
<td>52.661</td>
<td>.115</td>
<td>57</td>
<td>.57*</td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>8.288</td>
<td>.562</td>
<td>8.246</td>
<td>.075</td>
<td>59</td>
<td>.200*</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>7.949</td>
<td>.507</td>
<td>7.999</td>
<td>.91</td>
<td>59</td>
<td>.200*</td>
</tr>
<tr>
<td>SHAI (14-items)</td>
<td>13.900</td>
<td>.766</td>
<td>13.815</td>
<td>.144</td>
<td>60</td>
<td>.004</td>
</tr>
<tr>
<td>SHAI (18-items)</td>
<td>17.550</td>
<td>1.000</td>
<td>17.444</td>
<td>.079</td>
<td>60</td>
<td>.200*</td>
</tr>
<tr>
<td>PDS (symptom severity)</td>
<td>12.867</td>
<td>1.542</td>
<td>12.519</td>
<td>.099</td>
<td>30</td>
<td>.200*</td>
</tr>
</tbody>
</table>

Significance at .05 level *
Appendix R: Additional analyses (results reported pages 138 to 142)

Table 1 Summary of comparison groups including clinical cut offs and total number of participants in each category

<table>
<thead>
<tr>
<th>Measure and associated variable</th>
<th>Clinical cut off/criteria</th>
<th>n and % per category</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAI - Health Anxiety</td>
<td>Total score ≥18</td>
<td>No health anxiety = 31 (52)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health anxiety = 29 (48)</td>
</tr>
<tr>
<td>HADS - Anxiety</td>
<td>Anxiety subscale total ≥11</td>
<td>No anxiety= 41 (69)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anxiety = 18 (31)</td>
</tr>
<tr>
<td>HADS - Depression</td>
<td>Depression subscale ≥11</td>
<td>No Depression = 41 (69)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Depression = 18 (31)</td>
</tr>
<tr>
<td>PDS - PTSD</td>
<td>Fulfilment of DSM-IV criteria*</td>
<td>No traumatic acute exacerbations = 30 (50)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No PTSD = 23 (38)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PTSD = 7 (12)</td>
</tr>
</tbody>
</table>

Note total n for HAI and PDS =60, HADS n=59/ * See page 53 for DSM-IV criteria for PTSD
Table 2 Number and percentage of participants for each categorical variable and means/standard deviations for continuous variables

<table>
<thead>
<tr>
<th>Categorical variables</th>
<th>No health anxiety</th>
<th>Health anxiety</th>
<th>No anxiety</th>
<th>Anxiety</th>
<th>No Depression</th>
<th>Depression</th>
<th>No traumatic AEs</th>
<th>No PTSD</th>
<th>PTSD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17 (55)</td>
<td>15 (52)</td>
<td>22 (54)</td>
<td>9 (50)</td>
<td>23 (56)</td>
<td>8 (44)</td>
<td>21 (70)</td>
<td>9 (39)</td>
<td>2 (29)</td>
</tr>
<tr>
<td>Female</td>
<td>14 (45)</td>
<td>14 (48)</td>
<td>19 (46)</td>
<td>9 (50)</td>
<td>18 (44)</td>
<td>10 (56)</td>
<td>9 (30)</td>
<td>14 (31)</td>
<td>5 (71)</td>
</tr>
<tr>
<td><strong>Smoking status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current smoker</td>
<td>8 (26)</td>
<td>1 (3)</td>
<td>36 (88)</td>
<td>14 (78)</td>
<td>34 (83)</td>
<td>16 (89)</td>
<td>28 (93)</td>
<td>6 (74)</td>
<td>6 (86)</td>
</tr>
<tr>
<td>Non-smoker</td>
<td>23 (74)</td>
<td>28 (97)</td>
<td>5 (12)</td>
<td>4 (22)</td>
<td>7 (17)</td>
<td>2 (11)</td>
<td>2 (7)</td>
<td>1 (26)</td>
<td>1 (14)</td>
</tr>
<tr>
<td><strong>Continuous variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>65.9 (9.7)</td>
<td>64.6 (8.2)</td>
<td>65.2 (9.1)</td>
<td>64.8</td>
<td>6.5 (8.5)</td>
<td>64.3 (8.8)</td>
<td>66.9 (8.9)</td>
<td>66.4 (9.5)</td>
<td>65.7 (7.8)</td>
</tr>
<tr>
<td>No. of hospital admissions</td>
<td>1 (1.3)</td>
<td>1 (2.1)</td>
<td>1 (1.7)</td>
<td>1 (1.8)</td>
<td>1 (1.9)</td>
<td>1 (1.1)</td>
<td>1 (1.2)</td>
<td>1 (2.1)</td>
<td>1 (2.3)</td>
</tr>
<tr>
<td>No. of acute exacerbations</td>
<td>4 (2.7)</td>
<td>5 (5)</td>
<td>5 (5)</td>
<td>4.4 (3.3)</td>
<td>4 (4.2)</td>
<td>5 (3.6)</td>
<td>5 (4.5)</td>
<td>4 (3.2)</td>
<td>4 (4.4)</td>
</tr>
</tbody>
</table>
| CAT scores            | 24 (7)           | 27 (7)        | 23 (7)     | 30 (4)  | 23 (7)       | 31 (4)     | 26 (8)          | 25 (8)  | 27 (6)| 139
<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Error</th>
<th>5% Trimmed</th>
<th>Kolmogorov-Smirnov</th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>65.307</td>
<td>1.157</td>
<td>65.335</td>
<td>.061</td>
<td>.200*</td>
<td>-.127</td>
</tr>
<tr>
<td><strong>No. of hospital admissions</strong></td>
<td>1.033</td>
<td>.224</td>
<td>.794</td>
<td>.302</td>
<td>.000</td>
<td>2.463</td>
</tr>
<tr>
<td><strong>No. of AEs</strong></td>
<td>4.441</td>
<td>.525</td>
<td>4.117</td>
<td>.185</td>
<td>.000</td>
<td>1.268</td>
</tr>
<tr>
<td><strong>CAT scores</strong></td>
<td>25.560</td>
<td>.930</td>
<td>25.939</td>
<td>.181</td>
<td>.000</td>
<td>-1.034</td>
</tr>
</tbody>
</table>

Significance at .05 level *
Results

Chi-square tests, independent-samples t-tests (Mann-Whitney U test where data were not normally distributed) and one-way analysis of variance (ANOVA) (Kruskal-Wallis test where data were not normally distributed) were used to assess clinical groups with regards to demographic variables (age, gender and smoking status) and clinical characteristics (number of hospital admissions, number of acute exacerbations and self-rated COPD symptom severity, as measured using CAT scores). For categorical variables, where assumptions for the chi-square tests were violated (i.e. where cells had expected counts that did not meet the requirement for the minimum expected cell frequency) either Fisher’s exact probability test, or Likelihood ratios are reported.

1. Health Anxiety

In order to assess whether the presence of health anxiety was associated with demographic variables or clinical characteristics, participants were categorised as ‘no health anxiety’ (total HAI score ≤17) or ‘health anxiety’ (total HAI score ≥18). There were no significant differences between groups in gender [χ²(1)=.06, p=.81], age [t(58)=.53, p=.594], number of hospital admissions [U=414.5, z=-.33, p=.74] and number of acute exacerbations [U=362, z=-1.10, p=.27].

There were significant differences between groups in smoking status [Fisher’s exact probability p=.03, phi= -.31] and self-rated COPD severity [U=292, z=-2.16, p=.03, r=0.28]. Current smokers were more likely to have ‘no health anxiety’ than non-smokers. Those with ‘no health anxiety’ reported lower CAT scores (indicating less severe COPD symptomatology) than those with ‘health anxiety’.

2. Anxiety

In order to assess whether the presence of anxiety was associated with demographic variables or clinical characteristics, participants were categorised as ‘no anxiety’ (HADS anxiety score ≤10) or ‘anxiety’ (HADS anxiety score ≥11). There were no significant differences between groups in gender [χ²(1)=.07, p=.80], smoking status [Fisher’s exact probability p=.43], age [t(58)=.14, p=.89], number of hospital admissions [U=291, z=-1.09, p=.28] and number of acute exacerbations [U=320.5, z=-.48, p=.63]. There was a significant difference between groups in self-rated COPD severity [U=137, z=-3.83, p < 0.01, r=0.50]. Those with ‘no anxiety’ reported lower CAT scores (indicating less severe COPD symptomatology) than those with ‘anxiety’.

141
3. Depression

In order to assess whether the presence of depression was associated with demographic variables or clinical characteristics, participants were categorised as ‘no depression’ (HADS depression score ≤10) or ‘depression’ (HADS depression score ≥11). There were no significant differences between groups in gender [$\chi^2(1)=.69$, $p=.41$], smoking status [Fisher’s exact probability $p=.71$], age [$t(57)=1.01$, $p=.886$], number of hospital admissions [$U=328.5$, $z=-.38$, $p=.7$] and number of acute exacerbations [$U=312.5$, $z=-.62$, $p=.54$]. There was a significant difference between groups in self-rated COPD severity [$U=131.5$, $z=-3.92$, $p<0.01, r=0.51$]. Those with ‘no depression’ reported lower CAT scores (indicating less severe COPD symptomatology) than those with ‘depression’.

4. Trauma

In order to assess whether the presence of trauma and trauma symptomatology was associated with demographic variables or clinical characteristics, participants were categorised as ‘no traumatic acute exacerbation’ (these participants did not experience acute exacerbations of their COPD symptoms as traumatic), ‘no PTSD’ (did not fulfil DSM-IV criteria for PTSD as assessed using the PDS) or ‘PTSD’ (met DSM-IV criteria for PTSD as assessed using the PDS). Due to the small number of participants scoring for PTSD (n=7), it was not possible to meet the requirement for the minimum expected cell frequency for 2x3 chi-square analyses, nor was it possible to meaningfully collapse categories in attempt to inflate the sample size for the ‘PTSD’ category.

Likelihood ratios are reported in the absence of a non-parametric equivalent test/absence of Fisher’s exact probability. Given that the data did not meet the assumptions for chi-square testing, it is acknowledge that the test statistics reported for the chi-square test (indicated by Likelihood ratio $\chi^2$) are not reliable. These data are provided here for interest only and conclusions should not be drawn from these data. Results from the ANOVA and Kruskal-Wallis test were interpretable and are reported along with the Likelihood ratio $\chi^2$ data.

There were no significant differences between groups in age [$F(2,57) = 1.8, p = .18$] smoking status [Likelihood ratio$\chi^2(2)=3.89$, $p=.14$], number of hospital admissions [Kruskal-Wallis $\chi^2(2)=1.16$, $p=.56$], number of acute exacerbations [Kruskal-Wallis $\chi^2(2)=.396$, $p=.82$] and self-rated COPD severity [Kruskal-Wallis $\chi^2(2)=1.26$, $p=.53$]. There was a significant differences between groups in gender [Likelihood ratio $\chi^2(2)=7.09$, $p=.03$, Cramer’s V=.34]. Women were more likely to present with trauma symptoms than men.
Appendix S: Epistemological position

The researcher adopted a critical realist epistemological stance, which makes assumptions that reality is observable and causal language can be applied in describing the world. This seemed to me a pragmatic approach that both considered the initial intent of conducting a mixed methods study and was aligned with the aims of examining the presence and clinical features of a defined psychological disorder, as well as broader psychological constructs such as quality of life.
Appendix T: Chronology of research process

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thesis proposal peer reviewed</td>
<td>10\textsuperscript{th} June 2014</td>
</tr>
<tr>
<td>Integrated Research Application System (IRAS) submitted</td>
<td>23\textsuperscript{rd} February 2015</td>
</tr>
<tr>
<td>Research Ethics Committee (REC) panel meeting</td>
<td>23\textsuperscript{rd} March 2015</td>
</tr>
<tr>
<td>REC approval gained</td>
<td>31\textsuperscript{st} March 2015</td>
</tr>
<tr>
<td>Research and Development application initiated</td>
<td>13\textsuperscript{th} April 2015</td>
</tr>
<tr>
<td>Research and Development approval gained</td>
<td>4\textsuperscript{th} August 2015</td>
</tr>
<tr>
<td>Recruitment and data collection</td>
<td>August 2015 - April 2016</td>
</tr>
<tr>
<td>Literature review database searches and write up</td>
<td>October 2015 - April 2016</td>
</tr>
<tr>
<td>Data analysis for thesis</td>
<td>April 2016</td>
</tr>
<tr>
<td>Write-up and submission of draft thesis and literature review</td>
<td>February - May 2016</td>
</tr>
<tr>
<td>Thesis Submitted</td>
<td>May 2016</td>
</tr>
<tr>
<td>Research Viva</td>
<td>1\textsuperscript{st} July 2016</td>
</tr>
<tr>
<td>Preparation for publication and dissemination of research/trainee research conference</td>
<td>July - September 2016</td>
</tr>
</tbody>
</table>
Appendix U: Guidelines for target journal for Literature Review

Guidelines for Chronic Respiratory Disease accessed 1st May 2016 from:

https://uk.sagepub.com/en-gb/eur/journal/chronic-respiratory-disease#submission-guidelines

1. Article types

Manuscripts are considered for publication with the understanding that they have not been published previously and are not under consideration by another publication.

The journal publishes original papers, reviews and correspondence.

Summary of manuscript structure:

Please double-space the text and references and leave generous margins at head, foot and left- and right-hand margins. All pages must be numbered. Do not paste figures and tables into the text - they should appear at the end of the paper.

Headings: In dividing articles under headings, please grade the headings by writing A, B, or C in the margin:
A - subheading
B - subsubheading
C - subsubsubheading

Manuscripts should be approximately as follows:

Review articles, 4000-5000 words plus references;
Original papers, 2000-3000 words plus references, with up to six tables or figures;
Editorials, up to 800 words plus references;
Pro/con debates, up to 500 words plus references;
What the papers say, 500-1000 words plus references;
Review of the guidelines, 500-1000 words plus references;
Hot topic, up to 1000 words plus references;
Technical notes, 500-1000 words plus references;
Letters, including Research Letters, up to 600 words plus 2/3 references and 2/3 illustrations/tables;
Book reviews, 300-500 words plus references;
Web reviews, 300-500 words plus references

Scientific papers should be divided into a structured abstract that uses the headings 'Background, Methods, Results, Conclusions', introduction, methods, results, discussion, acknowledgements, and references. Authors bear sole responsibility for the accuracy of such abstracts.
Original papers
Should include:

- **Title page:** (1) title of the article; (2) first name(s) or initial(s) and surname of each author; (3) address of the department or institution to which the work should be attributed; (4) full postal address of each author; (5) name, telephone, email address and fax number of the author responsible for correspondence and to whom requests for offprints should be sent. (This is particularly important where the corresponding author is not the first named author.)

- **Abstract (<200 words):** a short inclusive statement suitable for direct electronic abstracting identifying the purpose of the study, key methods, the main results and the main conclusion. Structured abstracts are essential for research and review papers, and should be submitted under the headings: objectives, methods, results, and discussion.

- **Key words:** maximum of 6 key words for indexing.

- **Introduction:** concise description of background, sufficient for the non-specialist to appreciate the context of the work. Clear statement of the purpose of the study. Authors should avoid obviously partisan selection and quotation of literature.

- **Methods:** should demonstrate a clear and documented design or strategy directed towards a specific research question. The study design should be appropriate to the aims of the study and be clearly described. The criteria for selecting the sample should be clearly described and justified. A clear description of sampling, recruitment to the study, data collection, and data analysis should be provided. Full details of interventions should be given for intervention studies. This section should also include details of approval from a named Research Ethics Committee, and any arrangements for data oversight.

- **Results:** should contain all the information required by referees and readers to assess the validity of the conclusions. The characteristics of the sample included in the study should be clearly described. For quantitative studies, the section should include details of the response rates and numbers lost to follow-up. The analysis should be clear and systematic. Results of statistical tests should be reported with confidence intervals in order to provide an estimate of precision. No more than six tables should be included.

- **Discussion:** an interpretation of the study placed within the context of current knowledge leading to specific conclusions where possible. We recommend that this covers the following sections, using sub-headings: summary of main findings; the strengths and the limitations of this study; how and why it agrees or disagrees with the existing literature, in particular including any papers published since the study was designed and carried out; the implications for future research or clinical practice.

- Each of the above sections should use subheadings as appropriate
- **Acknowledgements.**
- **References (ideally max. 25),** figures and tables (see 4.5 for more details).
Style
Generic names should be used for drugs. Authors should be aware of different drug names and availability in the UK, North America and Australia, and give alternative names or drugs in the text.
(ii) Scientific measurements should be given in SI units, but blood pressure should be expressed in mmHg and haemoglobin as g/dl.
(iii) For numbers, adopt a rule that all numbers under 10 should be written as words, except when attached to a unit of quantity (e.g. 1 mm or 3 kg), and that numbers of 10 or more should be written as digits, except at the beginning of a sentence.
(iv) Abbreviations should be kept to a minimum and must be clearly defined when used for the first time. Abbreviations should be typed with no full point.
(v) Avoid excessive capitalization. For the titles of books and articles, capitals should be used for the initial letter of the first word only. However, for the titles of journals and series, the initial letter of all principal words should be capitalized.
(vi) Use italics for emphasis only very sparingly.

Tables
Tables should be typed on separate sheets. Indicate in the margin of the text where tables should be positioned. Each table should have an explanatory caption, and be clearly numbered.

Statistics
Numbers of patients or subjects should be given, with percentages in brackets. Means should be expressed as the mean with standard deviation of the mean: where appropriate, authors should also consider supplying the median. Care should be taken that all statistical methods are appropriate and that it is clear which methods were used for which analyses. Any statistical methods not in common use should be supported by references or described in detail. Results of statistical tests should be reported as well as the p values; where possible, confidence intervals should also be reported.

2. Editorial policies

2.1 Peer review policy
The journal's policy is to obtain at least two independent reviews of each article. It operates a double-blind reviewing policy in which the reviewer's name is always concealed from the submitting author; authors may choose to reveal their name but the journal otherwise leaves the article anonymous. Referees will be encouraged to provide substantive, constructive reviews that provide suggestions for improving the work and distinguish between mandatory and non-mandatory recommendations.

All manuscripts accepted for publication are subject to editing for presentation, style and grammar. Any major redrafting is agreed with the author but the Editor's decision on the text is final.
As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers
should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors. The list of authors should include all those who can legitimately claim authorship. This is all those who:

1. Made a substantial contribution to the concept and design, acquisition of data or analysis and interpretation of data,
2. Drafted the article or revised it critically for important intellectual content,
3. Approved the version to be published.

Authors should meet the conditions of all of the points above. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include
a person who provided purely technical help, or a department chair who provided only general support.

2.3.1 Writing Assistance

Individuals who provided writing assistance, e.g. from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgements section. Authors must disclose any writing assistance – including the individual’s name, company and level of input – and identify the entity that paid for this assistance.

It is not necessary to disclose use of language polishing services.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.4 Funding

Chronic Respiratory Disease requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Chronic Respiratory Disease to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a ‘Declaration of Conflicting Interests’ statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that ‘The Author(s) declare(s) that there is no conflict of interest.’

For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods
section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

All research involving animals submitted for publication must be approved by an ethics committee with oversight of the facility in which the studies were conducted.

2.7 Clinical trials

Chronic Respiratory Disease conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart as a cited figure, and a completed CONSORT checklist as a supplementary file.

Other resources can be found at NLM’s Research Reporting Guidelines and Initiatives

2.9 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

Chronic Respiratory Disease requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data
repositories or detailed contact information for third-party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal’s platform or a third-party platform to ensure continuing accessibility. Examples of data types include but are not limited to statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. The editor may consider limited embargoes on proprietary data. The editor can also grant exceptions for data that cannot legally or ethically be released. All data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office at jovie.mcmillan@sagepub.co.uk

3. Publishing policies

3.1 Publication ethics

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4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE’s Manuscript Submission Guidelines. Images should be supplied as bitmap based files (i.e. with .tiff or .jpeg extension) with a resolution of at least _300 dpi_ (dots per inch). Line art should be supplied as vector-based, separate .eps files (not as .tiff files, and not only inserted in the Word or pdf file), with a resolution of _600 dpi_. Images should be clear, in focus, free of pixilation and not too light or dark.

If, together with your accepted article, you submit usable colour figures, these figures will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the possible costs from SAGE after receipt of your accepted article. In text: tables and figures are either inserted as part of a sentence, for example table 1 or in parentheses for example (figure 1). Each table should carry a descriptive heading. Each figure should be submitted electronically.
4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our Manuscript Submission Guidelines page.

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IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne [Online Help](#).

5.2 Title, keywords and abstracts

Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online.
through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting the SAGE Journal Author Gateway for guidelines on How to Help Readers Find Your Article Online

5.3 Corresponding author contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article’s progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly.

6.2 Access to your published article

SAGE provides authors with online access to their final article.

6.3 Online First publication

Online First allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be published online prior to their inclusion in a final journal issue which significantly reduces the lead time between submission and publication. For more information please visit our Online First Fact Sheet
Appendix V: The COPD Assessment Test (CAT)

How is your COPD? Take the COPD Assessment Test™ (CAT)

This questionnaire will help you and your healthcare professional measure the impact COPD (Chronic Obstructive Pulmonary Disease) is having on your wellbeing and daily life. Your answers, and test score, can be used by you and your healthcare professional to help improve the management of your COPD and get the greatest benefit from treatment.

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example: I am very happy 0 1 2 3 4 5 I am very sad

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I never cough</td>
<td>0 1 2 3 4 5</td>
<td>I cough all the time</td>
</tr>
<tr>
<td>I have no phlegm (mucus) in my chest at all</td>
<td>0 1 2 3 4 5</td>
<td>My chest is completely full of phlegm (mucus)</td>
</tr>
<tr>
<td>My chest does not feel tight at all</td>
<td>0 1 2 3 4 5</td>
<td>My chest feels very tight</td>
</tr>
<tr>
<td>When I walk up a hill or one flight of stairs I am not breathless</td>
<td>0 1 2 3 4 5</td>
<td>When I walk up a hill or one flight of stairs I am very breathless</td>
</tr>
<tr>
<td>I am not limited doing any activities at home</td>
<td>0 1 2 3 4 5</td>
<td>I am very limited doing activities at home</td>
</tr>
<tr>
<td>I am confident leaving my home despite my lung condition</td>
<td>0 1 2 3 4 5</td>
<td>I am not at all confident leaving my home because of my lung condition</td>
</tr>
<tr>
<td>I sleep soundly</td>
<td>0 1 2 3 4 5</td>
<td>I don't sleep soundly because of my lung condition</td>
</tr>
<tr>
<td>I have lots of energy</td>
<td>0 1 2 3 4 5</td>
<td>I have no energy at all</td>
</tr>
</tbody>
</table>

COPD Assessment Test and the CAT logo is a trade mark of the GlaxoSmithKline group of companies. © 2009 GlaxoSmithKline group of companies. All rights reserved. Last Updated: February 24, 2012
Appendix W: EQ-5D, measure of health related quality of life

N.B. For copyright reasons the questionnaire is not included
Appendix X: Health Anxiety Inventory short form (SHAI)

N.B. For copyright reasons the questionnaire is not included
Appendix Y: Hospital Anxiety and Depression Scale (HADS)

**Hospital Anxiety and Depression Score (HADS)**

This questionnaire helps your physician to know how you are feeling. Read every sentence. Place an “X” on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important.

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>I feel tense or 'wound up':</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most of the time</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A lot of the time</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>From time to time (occ.)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>I still enjoy the things I used to enjoy:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Definitely as much</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not quite as much</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Only a little</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hardly at all</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>I get a sort of frightened feeling as if something awful is about to happen:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very definitely and quite badly</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes, but not too badly</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A little, but it doesn’t worry me</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>I can laugh and see the funny side of things:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>As much as I always could</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not quite so much now</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Definitely not so much now</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>Worrying thoughts go through my mind:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A great deal of the time</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A lot of the time</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>From time to time, but not often</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Only occasionally</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>I feel cheerful:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not often</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most of the time</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>I can sit at ease and feel relaxed:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Definitely</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not often</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>I feel as if I am slowed down:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nearly all the time</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very often</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>I get a sort of frightened feeling like &quot;butterflies&quot; in the stomach:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Occasionally</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quite often</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very often</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>I have lost interest in my appearance:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Definitely</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I don’t take as much care as I should</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I may not take quite as much care</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I take just as much care</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>I feel restless as I have to be on the move:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very much indeed</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quite a bit</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not very much</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>I look forward with enjoyment to things:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>As much as I ever did</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rather less than I used to</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Definitely less than I used to</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hardly at all</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>I get sudden feelings of panic:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very often indeed</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quite often</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not very often</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>I can enjoy a good book or radio/TV program:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not often</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very seldom</td>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix Z: Posttraumatic Stress Disorder Scale (PDS)

N.B. For copyright reasons the questionnaire is not included