

The roles of Illness Beliefs, Illness Behaviours, and Self-Compassion in adjustment to  
Chronic Obstructive Pulmonary Disease (COPD)

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June, 2016

*Submitted in partial fulfillment of the requirements for the degree of Doctor in  
Clinical Psychology (DCLinPsy), Royal Holloway, University of London.*

## **Acknowledgements**

This research would not have been possible without the help of the kind participants.

I am also grateful to the staff of the pulmonary rehabilitation groups in London and Berkshire, who offered their time and facilities, and above all, their interest.

I am so grateful to my supervisor, Dr. Abigail Wroe, for all of her time, guidance and responses to late-night emails over the last two years.

Finally, all my love to my wonderful friends in London and elsewhere- especially Sarah- who supported every pizza order in the final stages!

## **Abstract**

Illness beliefs, illness behaviours and self-compassion have been associated with adjustment outcomes in illness. This cross-sectional study investigates the roles of illness beliefs, illness behaviours and self-compassion in adjustment to COPD, and explores possible relationships between these variables. To carry out these aims, COPD patients (n= 26) were recruited from NHS services to complete questionnaires regarding adjustment to illness, illness beliefs, self-compassion, and specific illness behaviours- limiting and all-or-nothing behaviour patterns.

Contrary to hypotheses and previous research, illness beliefs did not account for a significant amount of variance in adjustment to COPD. However, illness behaviours and self-compassion were found to be associated with adjustment. Findings demonstrated the role of limiting behaviour patterns as a key variable in explaining adjustment in terms of depression, and as a mediating variable in the relationship between self-compassion and depression; higher self-compassion was associated with lower levels of limiting behaviour patterns, and in turn with lower depression. All-or-nothing behaviour patterns were found to be a key variable in explaining adjustment in terms of anxiety, and as a mediating variable in the relationship between self-compassion and anxiety; higher self-compassion was associated with lower levels of all-or-nothing behaviour patterns, and in turn with lower anxiety.

In exploratory analyses, the relationship between self-compassion and quality of life (emotional functioning) was serially mediated by limiting behaviour patterns and depression, such that higher self-compassion was associated with lower levels of limiting behaviour patterns, and in turn, lower depression, and thus better quality of life (emotional functioning).

It was concluded that illness behaviours and self-compassion should be considered in psychological interventions around adjustment to COPD. It is suggested that enhancing self-compassion might help patients to avoid limiting or all-or-nothing behaviour patterns, which might have a positive effect on mood and anxiety, and in turn on quality of life.

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## **Introduction**

This chapter includes a description of Chronic Obstructive Pulmonary Disease (COPD) as a chronic physical illness or long-term condition (LTC), followed by a discussion of research around the psychological impact of COPD on patients. The concept of *adjustment to illness* is defined in the context of physical illnesses generally, before the focus is narrowed to examine adjustment to COPD in particular. This narrowed focus includes a review of existing research exploring the factors that have been shown to be associated with adjustment to living with COPD, after which the gaps in this knowledge are highlighted. Based on these gaps, two broad research questions are presented, from which more specific hypotheses are posed.

### **Chronic Obstructive Pulmonary Disease (COPD)**

COPD is described as a disease of the lungs that is characterised by irreversible airflow obstruction or limitation. ‘COPD’ is now the most widely used term for conditions of airflow obstruction, which were previously diagnosed as chronic bronchitis, emphysema or chronic unremitting asthma (Department of Health, 2012b). This airflow obstruction is described as progressive, and not fully reversible (Department of Health, 2012b). Importantly, in the context of the present focus on long-term chronic physical illness, COPD is described as treatable, but not curable, in that early diagnosis and treatment are reported to markedly slow decline in lung function (Department of Health, 2012b). The disease is reportedly the world’s fourth leading cause of combined mortality and morbidity, and is projected to climb to third rank by 2030 (World Health Organisation, 2008). COPD therefore commands the

attention of health authorities- both medically and financially- and individuals with this disease comprise the focus group in the context of the current study.

Individuals with COPD experience severe breathlessness (or dyspnea) and fatigue, and thus limited capacity for physical exertion (Pauwels et al., 2001). Deteriorating capacity for exercise or exertion may often lead to a decline in everyday physical, social and occupational functioning, and thus in an individual's overall quality of life (Zoeckler, Kenn, Kuehl, Stenzel, & Rief, 2014). COPD is therefore unsurprisingly associated with psychological consequences, including symptoms of anxiety and depression (e.g., Hill, Gesit, Goldstein, & Lacasse, 2008; Kuehl, Schurmann, & Rief, 2008). COPD may also result in fear of breathlessness, panic, reduced confidence, and social isolation (Zoeckler et al., 2014). Naturally, fear related to breathlessness can lead to avoidance of physical activity (Zoeckler et al., 2014). The illness develops most commonly following a history of smoking or passive smoking. However, its onset is also related to air pollution or fumes, and it can, in some cases, be hereditary (Department of Health, 2012b).

### **Adjustment to Chronic Illness: An Overview**

COPD is considered to be a chronic physical illness, or a long-term condition (LTC). Chronic physical illnesses or LTC's are diseases that endure over time, and profoundly impact upon people's day-to-day lives (Moss-Morris, 2013). As well as COPD, such illnesses include cancer, coronary heart disease, hypertension, multiple sclerosis (MS), chronic kidney disease, and diabetes. In the physical sense, chronic illnesses are typically prolonged- that is, they do not resolve spontaneously, and are rarely completely cured (Centres for Disease Control and Prevention; CDC, 2003).

These conditions involve irreversible changes in the patient's life, threaten physical health status and, in some cases, present threats of long-term disability (Goodheart & Lansing, 1997; Pinto-Gouveia, Duarte, Matos, & Fraguas, 2014). Such threats would challenge even the most psychologically resilient patient (Goodheart & Lansing, 1997). LTC's carry important psychological and social consequences that demand significant psychological adjustment (Stanton, Revenson, & Tennen, 2007). Psychologically therefore, the definition of chronic disease could be more complex than the physical description (Stanton et al., 2007).

Around 15 million people in England have a long-term physical health condition (Department of Health, 2012a). Alongside COPD, hypertension, diabetes, and coronary heart disease are among the most common diagnoses in the UK. American figures project that as populations age, increasing numbers of people will live with at least one LTC (Stanton et al., 2007). Considering this growing prevalence, *adjustment to chronic illness or LTC's* is an idea that has unsurprisingly received a lot of research attention in both medicine and health psychology (Moss-Morris, 2013; Stanton et al., 2007). In fact, Stanton et al.'s review identified 200 longitudinal reports on 'adjustment' to different cancers alone in 2007. There have likely been more since.

Unfortunately however, as Moss-Morris (2013) points out, researchers do not have a consistent definition of adjustment to chronic illness, or an agreed way of measuring this construct. This, Moss-Morris proposes, is symptomatic of the various theories that researchers use to understand variation in adjustment across patients even with the same illness. Adjustment to chronic illness has therefore been operationalised in various ways throughout the literature (see Dennison, Moss-Morris, & Chalder, 2009; Stanton et al., 2007). For instance, mental health or psychiatric approaches have

traditionally defined adjustment in terms of the presence or absence of psychopathologies- such as depression or anxiety- or symptoms indicative of these disorders (Moss-Morris, 2013). This approach is simple, and therefore popular from an operational point of view, but has its limitations, as Moss-Morris (2013) notes. For instance, this approach assumes that poor adjustment is reflected purely in mood or anxiety levels. This assumption fails to take into account that poor adjustment may reflect in other adjustment outcomes beyond mood, such as impact on life roles, occupational status or relationships (see Moss-Morris, 2013). Furthermore, this mental health approach has implications for treatment, in that poor adjustment is assumed to be a mental health problem. Traditional mental health treatments are then applied, which are not effective, as they tackle mood and anxiety in isolation, and fail to help the patient to manage more effectively in the specific context of their health condition (see Moss-Morris, 2013).

In contrast to mental health or psychiatric approaches, health psychology approaches have typically defined adjustment to illness in terms of outcomes such as preserving functional status, perceived generic quality of life, or mastery of disease-related adaptive tasks (Moss-Morris, 2013; Stanton, Collins, & Sworowski, 2001; Stanton et al., 2007). However, there are also limitations associated with these definitions. For instance, Moss-Morris (2013) cautions that preserving functional status in the face of progressive loss of physical function may not always be realistic. Additionally, different illnesses carry unique challenges, and therefore, unique disease-related adaptive tasks. As such, relevant adaptive outcomes will be disease-specific, and may vary considerably across conditions. Similarly, low negative affect may not always be obtainable, or indeed desirable, in the trajectory of a particular illness.

On the other hand, Stanton et al. (2007) highlight a more symptom-focused approach to adjustment to illness. They note that popular adjustment outcomes across the literature often include objective measures of pain, physical disability, illness symptoms, physiological measures, medical test scores, hospitalisation frequency, as well as self-reported measures of health-related quality of life. Researchers vary of course in their choice of outcomes even across the same conditions- some choosing generic measures, and others preferring those that are condition-specific. Moss-Morris (2013) suggests that we carefully consider the unique challenges of the particular illness under study with regard to successful or poor adjustment. This may explain the great variation in adjustment outcome measures in use across the literature.

However, despite inconsistency across definitions of the construct of *adjustment to illness*, research demonstrates considerable variability in adjustment across individuals even with the same illness (Stanton et al., 2007). Decline in activities, vitality and relationships with others vary among people with the same condition and even those with similar objective parameters of illness (Stanton et al., 2007). In fact, illness severity has been shown to be a poor predictor of adjustment outcomes. For instance, objective disease-severity has been shown to be unrelated to quality of life in COPD (Bonsaksen et al., 2014), whilst research in rheumatic disease has revealed differences in pain, disability and fatigue among populations with comparable levels of arthritic illness severity (Stanton et al., 2007; Stone, Broderick, Porter, & Kaell, 1997). Put simply, some people adjust better than others to living with the same condition, and illness severity does not always explain these differences. As such, the major goal of much research into living with a chronic illness is to establish the risk

and protective factors for favourable adjustment outcomes that might account for such variation (Stanton et al., 2007).

### **The Role of Illness Beliefs in Adjustment to COPD**

In approaching this research into living with a chronic illness, authors tend to draw on a variety of theoretical models. Of such models, the Common Sense Model of Illness Representations (Dennison et al., 2009; Moss-Morris, 2013) is dominant in the literature, and has addressed how cognitive factors influence illness coping behaviours and outcomes (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984). Known varyingly as the Illness Beliefs Model, the Illness Perceptions Model, the Illness Representations Model, the Self-Regulatory Model, the Common Sense Model of Self-Regulation of Health and Illness, and the Common Sense Model of Illness Representations (see Hale, Treharne, & Kitas, 2007), it shall be referred to going forward as the Common Sense Model or CSM. Elsewhere in the literature, the model is simply known as Leventhal's model, after the author who led its development (see Leventhal et al., 1997; Leventhal, Brissette, and Leventhal, 2003; Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984).

The CSM proposes that when faced with health threats, individuals will construct their own beliefs about their illness and the symptoms (Kaptein et al., 2008; Leventhal, Brissette, & Leventhal, 2003; Petrie & Weinman, 2006; Weinman & Petrie, 1997). These beliefs about illness- also referred to as *illness beliefs*, *illness representations* or *illness perceptions* (Hale et al., 2007)- are idiosyncratic and formed on the basis of encounters with illness, as well as information from medical sources or other people (Kaptein et al., 2008). Illness beliefs are not always medically accurate-

but they shape the responses and coping behaviours of patients, and as such, have been shown to shape different adjustment outcomes across a range of different conditions (Kaptein et al, 2008). These illness beliefs integrate with existing schemata, enabling patients to make sense of health threats and guide their subsequent coping actions (Hagger & Orbell, 2003; Hale et al., 2007; Zoeckler et al., 2014). These responses are often in the aim of returning to *equilibrium*, which Moss-Morris (2013, p. 684) has defined as successful adjustment to illness.

Leventhal and his colleagues originally described five main components of these illness beliefs. These include the *identity* of the illness (beliefs about the illness label and knowledge about its symptoms), the *cause* of the illness (beliefs regarding the factors that are responsible for causing the illness), the *timeline* of the illness (predictive beliefs about the course of the illness and time scale of illness symptoms; i.e., acute or chronic), the *consequences* of the illness (beliefs regarding the effects and likely impact of the illness), and *cure/control* (beliefs about how one controls or may recover from the illness) (see Leventhal et al., 1997; Leventhal, Brissette, and Leventhal, 2003; Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984). Beliefs about causes are not always accurate, and typically reflect issues such as stress, environmental pollution, pathogens or lifestyle choices- for example, smoking, lack of exercise, poor diet, and so forth (Hale et al., 2007).

The CSM has inspired the development of instruments to measure illness beliefs (Hagger & Orbell, 2003). Firstly, the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996) was developed to address the five aforementioned dimensions of beliefs about illness. Through the use of the IPQ, the utility of the CSM has been investigated across multiple chronic illnesses. Later, the

IPQ was revised (the Revised Illness Perception Questionnaire; IPQ-R, Moss-Morris et al., 2002), with additional subscales added to assess *emotional representations* of the illness and *illness coherence* (understanding of the illness). Furthermore, the timeline and cure/control dimensions were further developed in the IPQ-R. In the case of the timeline dimension, a new subscale was developed to assess beliefs in the improve-relapse nature of an illness- *timeline (cyclical)*. In the case of the cure/control dimension, another subscale was included to differentiate beliefs in personal control (or self-efficacy) from beliefs about the effectiveness of the treatment or recommended medical advice, creating two distinct cure/control subscales- *personal control* and *treatment control*.

Studies using the IPQ or IPQ-R have consistently shown that adjustment outcomes are significantly influenced by a patient's individual beliefs about their illness (Hagger & Orbell, 2003). In fact, the relationship between illness beliefs and a variety of outcomes across several chronic illnesses has been highlighted (Petrie & Weinman, 2006; Scharloo et al., 2007; Schiaffino, Shawaryn & Blum, 1998; Weinman & Petrie, 1997). For instance, research has shown that illness beliefs were predictive of multiple adjustment outcomes in several illnesses, including rheumatoid arthritis and psoriasis (Scharloo et al., 1998), coronary heart disease (Byrne, Walsh & Murphy, 2005; Foxwell, Morley, & Frizelle, 2013), multiple sclerosis (Schiaffino, Shawaryn & Blum, 1998), Chronic Fatigue Syndrome (CFS; Moss-Morris & Chalder, 2003; Moss-Morris, Petrie, & Weinman, 1996) and Addison's Disease (Heijamns & de Ridder, 1998). Across this literature, these adjustment outcomes have included psychological measures such as illness-specific health-related quality of life, illness-specific and generic measures of coping or functional adaptation, and the presence or absence of

psychopathology or distress (symptoms of depression and anxiety). Other health-related outcomes have included physical markers of adjustment, such as disease state or illness severity, medication or treatment adherence, frequency of use of healthcare services, and measures of daily activity or physical functioning.

The role of illness beliefs in COPD has also been explored- however much less plentifully (Kaptein et al., 2008; Scharloo et al., 2007; Zoeckler et al., 2014).

Nonetheless, the literature would suggest that illness beliefs- anchored in the Common Sense Model- influence social, medical, behavioural and psychological outcomes in COPD patients (Zoeckler et al., 2014). For instance, research has shown that more pessimistic beliefs about treatment control and negative beliefs about illness consequences were associated with quality of life and general functioning in COPD patients (Scharloo et al., 1998, 2007). It has also been demonstrated that illness beliefs are associated with hospitalisation frequency and medication use in COPD patients, after controlling for duration of diagnosis and objective severity of COPD (Scharloo et al., 1998, 2007; Scharloo, Kaptein, Weinman, Willems, & Rooijmans, 2000).

Similarly, Kaptein et al.'s (2008) review showed that illness beliefs in COPD are associated with disability and psychological outcomes including depression and anxiety. The same review also suggested that the severity of COPD (as measured by pulmonary function) often fails to predict quality of life and general functioning.

Overall therefore, it can be seen that illness beliefs in COPD patients have been shown to be important for various outcomes above and beyond objective physical measures of disease severity. These results are consistent with those of Hagger and Orbell (2003), whose meta-analysis on illness beliefs in patients with various illnesses also illustrated these effects.

However, some limitations of the above studies that explore the role of illness beliefs in COPD are noted, which would suggest that the results should be interpreted cautiously. For one, most variables in these studies are patient self-reported, which introduces some potential bias. Additionally, there are often multiple analyses performed across these studies in order to identify influential variables, wherein the possibility of a Type 1 error increases (see Scharloo et al., 2007). Finally, with the exception of Scharloo et al. (2000), the above studies tend to be predominantly cross-sectional in nature, and as such, hypotheses about causation between independent and dependent variables cannot be inferred.

However, Zoeckler et al. (2014) recently demonstrated in a longitudinal study, that COPD patients' illness beliefs before an outpatient pulmonary rehabilitation programme were predictive of psychological wellbeing after rehabilitation (as measured by perceived health-related quality of life). Zoeckler et al.'s sample consisted of a total of 96 COPD participants attending a German centre for outpatient pulmonary rehabilitation. Exclusion criteria for these patients included serious illness exacerbation or another severe or acute illness (e.g. myocardial infarction, tumor, or other comorbid physical diagnosis). Eighty-one percent of this German sample used long-term oxygen treatment, and 27.1% of them were listed for lung transplantation.

Unfortunately, the high rate of long-term oxygen therapy use among the sample may limit the generalisability of their findings- given the sample consisted of predominantly very severe COPD patients, and was not therefore representative of COPD patients across the spectrum of disability. The authors suggest their methodology be replicated in less disabled samples- possibly including a larger cohort of those not using long-term oxygen treatment. Additionally, whilst the longitudinal

data reported may provide stronger evidence of possible causal relations, alternative causal models cannot be ruled out. Despite these limitations however, the reported contribution of variance made by illness beliefs was just 21% for health-related quality of life. These figures indicate that beyond the influence of beliefs about illness, there may be other variables that are likely contributing to patients' quality of life. As such, further exploration is required in order to achieve a more comprehensive understanding of the variables that predict better adjustment to living with COPD in the long term.

### **The Potential Role of Illness Behaviours in Adjustment to COPD**

What other factors therefore might explain more of the variance in quality of life in Zoeckler's study? A recent study by Terry, Leary, Mehta, & Henderson (2013) would suggest that we look beyond beliefs, and towards behaviour. The authors suggest that beyond cognitive factors like illness beliefs, how people approach health and illness depends also on how people manage their emotional reactions to health problems, and crucially, how they enact behaviours to avoid, treat, or cope with illness or injury. Reflecting this, Moss-Morris' (2013) model of adapting to chronic illness is equally multi-factorial. Aside from the role of cognitive factors (including beliefs about illness), Moss-Morris (2013) suggests that adjusting to chronic illness is equally associated with behavioural factors. Specifically, Moss-Morris proposes that poor adjustment to illness might be related to unhelpful behaviour patterns, such as coping through avoidance, unhelpful responses to symptoms (consistently reducing activity/resting, focusing on symptoms), and venting, denying or repressing emotional responses (Moss-Morris, 2013). On the other hand, successful adjustment might be

related to more helpful behaviour patterns, such as coping using problem-focused strategies, planning, seeking social support, engaging in good health behaviours (diet, exercise), adherence to medical and self-management regimes, maintaining activity levels despite illness, and appropriate emotional expression (Moss-Morris, 2013). These more positive behaviours may better reduce health threats, and thus facilitate a return to *equilibrium*.

Supporting this further, literature surrounding medically unexplained syndromes like chronic fatigue syndrome (CFS), irritable bowel syndrome (IBS) and chronic pain also suggests that cognitive and behavioural factors are both relevant in predicting outcomes related to adjustment to illness. For example, Deale, Chalder and Wessely (1998) demonstrated that beliefs about the harmful effects of physical activity were related to poorer outcomes in patients with CFS in terms of functional impairment, fatigue and mood. This implies, Deary, Chalder, & Sharpe (2007) suggest, that the beliefs about the harmful effects of activity inform behaviour- or in this case, behaviour avoidance, or a pattern of *limiting behaviour*. Activity is perceived as threatening as it leads to increased fatigue, and as such, coping behaviours include activity avoidance. This belief-behaviour link echoes the CSM, where beliefs about illness are seen to inform coping behaviours. This link is also consistent with a cognitive-behavioural approach to the development of medically unexplained conditions, including IBS (Spence & Moss-Morris, 2007), as well as CFS and chronic pain (Deary et al., 2007).

These limiting behaviour patterns in response to threatening interpretations of illness symptoms have been demonstrated to be unhelpful in CFS, where empirical research showed that longer convalescence (or excessive bed rest) was associated with poorer

physical recovery outcomes (Sharpe & Wessely, 1998). Hotopf, Noah and Wessely (1996) also found that the onset of chronic fatigue symptoms was predicted by lengthy convalescence following initial viral infection. Though with this latter study, findings are interpreted with care, as now 20 years old, it is uncertain whether these findings apply as relevantly. Hotopf et al.'s (1996) study also included a postal survey, which leaves the results open to response bias. Nonetheless, limiting behaviour patterns have also been strongly associated with fatigue and social impairment in multiple sclerosis (MS; Skerrett & Moss-Morris, 2006).

Supporting this trend further, Candy, Chalder, Cleare, Wessely, & Hotopf (2004) found that a graded return to activity following infection with glandular fever/infectious mononucleosis-often considered to precipitate development of CFS (see Candy et al., 2002; 2004)- predicted a lower chance of developing CFS when compared with resting behaviour. Candy et al.'s (2002) review also reported that the risk factor most consistently reported as predictive of ongoing fatigue is reduced or limited physical activity during the acute infection and recovery phases of infectious mononucleosis. Despite its longitudinal design, Candy et al.'s (2004) trial was blighted by attrition and incomplete follow-up data, particularly for the control group. Nonetheless, it would seem that limiting behaviour patterns might be related to poorer outcomes. Parallels can be drawn with COPD, in that this relationship might also be relevant in a COPD population, where individuals report avoiding physical activity in response to threatening interpretations of bodily symptoms, i.e. fear of breathlessness (Lindgren, Storli, & Wiklund-Gustin, 2014), and this in turn has a counterproductive effect on future activity capacity in terms of deconditioning and therefore increased breathlessness (Almagro & Castro, 2013).

Linked with this, Spence, Moss-Morris, and Chalder (2005) highlighted a different behavioural response to illness and symptoms. The response in question takes the form of *all-or-nothing behaviour patterns*- where people move between extreme activity and complete rest in response to oscillating severities of symptoms. All-or-nothing behaviour patterns are described as ‘patterns of alternating extremes of behaviour, characterized by a cyclical response of pushing oneself to keep going until it no longer feels physically possible’ (Spence et al., 2005, p. 590). Responding with this behavioural pattern at the time of acute food poisoning appeared to be a risk factor for the onset of chronic symptoms, and the subsequent development of IBS (Spence et al., 2005). This trend recurred in Spence and Moss-Morris’ (2007) study, where patients who developed IBS following gastroenteritis infection were significantly more likely to display all-or-nothing behaviour patterns. Spence et al. (2005) and Surawy, Hackmann, Hawton, & Sharpe (1995) note how CFS patients can also behave in much the same way. An all-or-nothing response to symptoms was also strongly associated with fatigue (a symptom also common in COPD) in multiple sclerosis (MS; Skerrett & Moss-Morris, 2006). As with all cross-sectional studies, Skerrett and Moss-Morris’ study is interpreted with caution, as the direction of the relationships cannot be inferred. Nonetheless, parallels can be drawn again with COPD, in which moving between complete rest and over-exertion (all-or-nothing behaviour patterns) might also lead to deconditioning and increases in symptoms in COPD patients.

In the case of Skerrett and Moss-Morris’ (2006) MS study however, the harmful effects of limiting and all-or-nothing behaviour patterns on adjustment are presented in terms of increased symptomology or disease progression. This is also the case in

the studies of Candy et al. (2002, 2004), Hotopf et al. (1996), Spence et al. (2005), and Sharpe and Wessely (1998). In contrast, there is little research on the role of behavioural patterns in response to illness on the outcomes of *quality of life* and *psychological distress* (anxiety and depression)- more typical psychological markers of adjustment to illness as Moss-Morris (2013) suggests. Therefore, this section has necessarily drawn upon research considering symptoms as an outcome.

However, Kindermans et al. (2011) showed that limiting and all-or-nothing behaviour patterns were *both* related to higher levels of depressive symptomatology in people who identified with having chronic pain. When controlling for pain, and other types of activity patterns, limiting and all-or-nothing behaviour patterns were the most detrimental in terms of relationships with depressed mood. Some limitations with regard to Kindermans et al.'s study are noted. For one, their sample of only Dutch participants was relatively small, and also non-clinical, comprising patients who were recruited from the community rather than a healthcare setting. It is therefore unclear how representative of chronic pain patients Kindermans et al.'s sample may be.

Despite these criticisms, their findings would suggest a relationship between limiting and all-or-nothing behaviour patterns and the adjustment outcome of distress (depressive symptomatology). What is not clear is whether these two behavioural patterns are associated with other adjustment outcomes, such as anxious symptomatology and health-related quality of life, or in particular, whether these behaviour patterns are relevant to adjustment in COPD.

Recent research in COPD would suggest that they are- in that COPD patients are often reported to manage symptoms of fatigue, breathlessness, and fear of same, by avoiding physical activity altogether (Arne, Emtner, Janson, & Wilde-Larsson, 2007;

Habraken, Pols, Bindels, & Willems, 2008; Lindgren et al., 2014; Zoeckler et al., 2014). As such, the adoption of limiting behaviour patterns in particular in order to cope with symptoms is likely to be common in COPD. And equally, like chronic pain, MS, CFS, and IBS patients, COPD patients may also cope with symptoms using all-or-nothing behaviour patterns.

As such, the first aim of the present study is to build on previous illness beliefs research in COPD populations, and to explore the extent to which, in addition to illness beliefs, the behavioural responses of people with COPD (in terms of the two behavioural responses to illness above: limiting and all-or-nothing behaviour patterns) might be associated with their adjustment to their condition in terms of quality of life and distress (anxiety and depression). Based on the above review of previous research, significant relationships are predicted. The first general research question therefore asks *what are the roles of illness beliefs and illness behaviours in COPD?*

### **The Potential Role of Self-Compassion in Adjustment to COPD**

Empirical research has therefore revealed a relationship between illness beliefs and adjustment outcomes in COPD (Zoeckler et al., 2014). Furthermore, theoretical research in adjusting to illness (Moss-Morris, 2013), and empirical research in behavioural responses to illness (Spence et al., 2005), alongside reports of activity avoidance amongst COPD patients in an effort to manage breathlessness (Lindgren et al., 2014), suggest a possible relationship between patients' behavioural responses to COPD and adjustment outcomes. However, in addition to illness beliefs and illness behaviours, recent research in adjusting to chronic illness suggests an important role

for the positive psychological construct of self-compassion (Neff, 2003a, 2003b; Pinto-Gouveia et al., 2014; Przedziecki et al., 2013).

There are several conceptualisations of self-compassion (see for example, Gilbert & Procter, 2006). However, Neff's view of self-compassion is rooted in social psychology and the Buddhist tradition (Costa & Pinto-Gouveia, 2011; see Neff 2003a, 2003b). According to Neff, self-compassion is a positive construct that involves *being touched by and open to one's own suffering, not avoiding or disconnecting from it, generating the desire to alleviate one's suffering and to heal oneself with kindness. Self-compassion also involves offering nonjudgmental understanding to one's pain... so that one's own experience is seen as part of the larger human experience* (Neff, 2003b, p. 87). Self-compassion is described as an adaptive way of relating to oneself when considering one's inadequacies or difficult life circumstances (Neff & McGehee, 2010, p. 225). More simply, *self-compassion is compassion turned inward*, and refers to the ability to hold one's own feelings of suffering with a sense of warmth, connection, and concern (Neff & McGehee, 2010, p. 226). Neff (2003a, 2003b, 2009; Neff & McGehee, 2010) conceptualises self-compassion to comprise three components: self-kindness (as opposed to self-judgment), common humanity (as opposed to isolation), and mindfulness (as opposed to over-identification). Self-kindness refers to the ability to extend kindness and understanding to oneself, rather than self-criticism and judgment. Common humanity is seeing one's experiences as part of the larger human experience, rather than feeling separated and isolated by one's failures.

Neff (2003a) has transferred these components of self-compassion (above) into a six-subscale measure- the Self-Compassion Scale (SCS). Using the SCS, a considerable

body of research has indicated that self-compassion is related to psychological well-being- including increased happiness, optimism, personal initiative, and connectedness, as well as decreased anxiety, depression, neurotic perfectionism, and rumination (see Neff & McGehee, 2010). Pinto-Gouveia et al. (2014) highlighted research indicating that self-compassion has been strongly associated with increased psychological wellbeing, with less depression and anxiety (see Neff, 2009; Neff, Hsieh, & Dejitterat, 2005; Van Dam, Sheppard, Forsyth, & Earleywine, 2011).

Self-compassion has also been recently highlighted as relevant in relation to the experience of chronic and long-term physical illness- particularly in the context of chronic pain (Wren et al., 2011). Wren et al. (2011) showed that self-compassion might be important in explaining the variability in adjustment to pain among obese patients with persistent musculoskeletal pain. In Wren et al.'s study, patients who reported higher levels of self-compassion had lower levels of negative affect, pain catastrophising, and pain disability, and higher levels of positive affect and pain self-efficacy. A most interesting finding of Wren et al.'s study was that higher levels of self-compassion were seen to be associated with better psychological functioning, specifically lower levels of negative affect and higher levels of positive affect.

However, there are limitations associated with Wren et al.'s study. For instance, given the cross-sectional nature of the design, it is unclear whether self-compassion leads to better adjustment to pain or vice versa. Additionally, the chronic pain patients in the study were also obese, of which the majority were female. The authors highlight that pain patients who are also obese may face additional challenges such as body image problems and increased psychological distress. These additional challenges may have influenced the findings, and it is unclear whether these findings would be reproduced

in a sample of participants who were not obese or where there was a more equal gender ratio.

Nonetheless, building on Wren et al.'s work, Pinto-Gouveia et al. (2014) demonstrated that self-compassion is associated with decreased psychopathological symptoms of stress and depression, and better quality of life in patients with several chronic illnesses including congestive cardiac failure and rheumatoid arthritis, and especially in patients with cancer. Thus, it was concluded that self-compassion plays a protective role by diminishing psychological distress and enhancing perceived quality of life- as mentioned, common measures of adjustment (Pinto-Gouveia et al., 2014). From these results, we could interpret self-compassion as having the power to help patients with long-term conditions to adjust to their condition better. As Pinto-Gouveia et al. (2014) highlight, their findings are in line with Wren et al.'s (2011) study in suggesting that self-compassion might be a predictor of increased psychological adjustment in patients with chronic medical conditions.

Extending this exploration of the role of self-compassion in health populations, Przedziecki et al. (2013) showed that self-compassion might help to protect against psychological distress in breast cancer survivors who experience dramatic changes to their bodies following cancer treatments. These treatments- which include excisional surgery, unilateral/bilateral mastectomy, chemotherapy, radiation therapy, hormonal treatment, and so forth- produce a number of side effects including partial or complete loss of the breast(s), breast asymmetry, scarring, loss of nipple sensation, hair loss, skin changes, weight fluctuation and hot flashes related to early-onset menopause (Przedziecki et al., 2013). Przedziecki et al. (2013) report evidence that a woman who endures such adverse effects may experience psychological distress- particularly

in relation to adverse changes in her body image. Basing their definition of self-compassion in Neff's (2003a, 2003b) conceptualisation as above, the authors suggested that women who are more self-compassionate would be more likely to react with tolerance to physical changes in their body, and with awareness, understanding and self-kindness when experiencing distress. Thus, Przewdziecki et al. reasoned, self-compassion might mediate the negative effects of disturbance to body image on distress in breast cancer patients. Their subsequent results provided preliminary evidence for the mediating role of self-compassion in the relationship between body image disturbance and psychological distress, suggesting the potentially protective effect of higher levels of self-compassion for women at risk of experiencing body image disturbance.

Again, there are limitations associated with this study with regard to the use of self-report measures only and limited generalisability of the sample (exclusively female). Additionally, given the cross-sectional design, the findings are interpreted cautiously, and longitudinal research would further reveal the potential mediating role of self-compassion upon distress, and establish whether these findings are robust across age, gender, and disease types. Nonetheless, Przewdziecki's results suggest that self-compassion could be seen to enhance adjustment to physical changes and losses in breast cancer. Similarly, Brion, Leary, & Drabkin (2014) showed that HIV patients reported less negative affect the higher they scored in self-compassion. In this study, higher self-compassion was associated with lower general negative affect (including lower levels of stress, anxiety, self-pity, and shame), and therefore lower psychological distress.

Given its protective role in cancer, chronic pain, and HIV- particularly with regard to

distress- self-compassion might therefore predict more favourable adjustment outcomes in COPD also. Terry and Leary's (2011) work points to some mechanisms by which this might happen. Beyond being protective against psychological distress in illness, self-compassion is also associated with other outcomes, including the adoption of health-promoting behaviours (Terry & Leary, 2011). Self-compassion has been proposed as an emotional regulation strategy that may enhance self-regulation to promote health, wellbeing and adaptive behavioural reactions to illness (Pinto-Gouveia et al., 2014; Terry & Leary, 2011). Specifically, Terry and Leary (2011, p. 359) suggest that *self-compassion may facilitate healthy adaptive behaviours by helping people to monitor their health goals with less distraction and defensiveness, consider their situation with equanimity, disengage from goals that are not in their best interests, seek medical help when needed, adhere to treatment recommendations, and regulate their negative affect*. The authors theorize therefore, that people who are higher in self-compassion should treat themselves with concern when unwell, and that such compassionate reactions should enhance their ability to self-regulate in ways that promote physical and psychological wellbeing- including the adoption of adaptive behavioural responses to their symptoms and illness (see also Pinto-Gouveia et al., 2014).

Terry and Leary's (2011) self-compassion → health behaviour theory has been applied to recent empirical studies, the first of which showed that self-compassion has important implications for health-promoting behaviours and reactions to illness threats in terms of more immediate treatment-seeking behaviours (Terry et al., 2013). This research, whilst promising, was conducted with non-clinical samples in the context of both actual and hypothetical illnesses. However, the theory was also

applied to HIV populations, where Brion et al. (2014) showed that higher self-compassion was not only associated with favourable adjustment outcomes (including lower stress and lower anxiety, as mentioned), but it was also related to engaging in adaptive behaviours, including disclosing HIV status to sexual partners and family members, obtaining medical information, seeking medical care, and adhering to medical treatment. In fact, not only were self-compassionate individuals more likely to engage in these helpful behaviours, but participants who were *lower* in self-compassion indicated that shame related to the diagnosis interfered more with their willingness to seek HIV information and care, and adhere to their treatment (Brion et al., 2014). Brion et al.'s findings are particularly noteworthy, given maladaptive health behaviours, such as treatment avoidance, might be particularly common in conditions for which patients feel responsible, or that are particularly stigmatized in society, such as HIV (Brion et al., 2014).

On this note, though HIV and COPD are not typically comparable, patients of the two conditions share some common ground. For instance, Lindgren, et al.'s (2014) qualitative data revealed that COPD patients experience self-judgment and shame in relation to a disease that they may perceive to be 'self-inflicted' through smoking (pp. 441, 444). Patients may feel responsible for their illness and report experiencing stigmatizing attitudes in the healthcare system. In addition, Lindgren et al.'s study highlighted the behavioural impact of this self-judgment and shame- including participants' efforts to isolate themselves, hide the diagnosis, and avoidance of pursuing further information on the condition. Lindgren et al. also showed that feelings of self-judgment and shame were reported to delay the help-seeking process and contribute to poor self-management in COPD (see also Arne, Emtner, Janson, &

Wilde-Larsson, 2007; Sheridan et al., 2011). This self-judgment and shame in COPD patients may correspond to low levels of self-compassion, in the context of Neff's (2003a, 2003b) definition of self-compassion above.

For this reason, self-compassion may be particularly relevant in the experience of COPD - as it is for HIV patients, who also experience shame, self-judgment, and stigma. Given the links (highlighted above) between self-compassion and wellbeing in both illness and healthy samples, higher levels of self-compassion might be associated with better adjustment outcomes in COPD populations too. For instance, as in the aforementioned cancer, pain, and HIV studies, self-compassion may be protective in COPD also. It is posited that this is likely in light of the shame and self-judgment experienced by COPD patients who may attribute their disease to smoking- which may erode self-compassion and therefore predict a whole range of poorer adjustment outcomes.

Furthermore, given higher self-compassion can promote the adoption of adaptive health behaviours in HIV (Brion et al., 2014), higher self-compassion might also promote the adoption of adaptive health behaviours in COPD, with those higher in self-compassion more likely to engage in helpful behavioural responses to their illness. In contrast, it is possible that COPD patients who are low in self-compassion are more likely to engage in unhelpful or maladaptive health behaviours. Such unhelpful behaviours may include limiting or all-or-nothing behaviour patterns (as above), which have been associated with poor outcomes in other illnesses (IBS, CFS, pain, MS). As such, it is possible that lower levels of self-compassion in COPD patients are associated with unhelpful behavioural responses, such as higher levels of limiting and all-or-nothing behaviour patterns, which in turn, might be associated with

poorer adjustment outcomes in COPD. That is, it may be via illness-related behaviours, that self-compassion exerts an influence on adjustment outcomes in illness.

The second aim of the present study is therefore to explore the potential role of self-compassion in adjustment to living with COPD. Specifically, this aim includes assessing the possible relationships, if any, between self-compassion, illness beliefs, and specific illness behaviour patterns in COPD patients. A second general research question therefore asks; *what can self-compassion add to our understanding of responses to illness in COPD?*

### **Hypotheses**

In the context of the two broad research questions above, a number of specific hypotheses are posed in relation to each;

#### **Research question 1: What are the roles of illness beliefs and illness behaviours in COPD?**

##### ***Hypothesis 1.***

Beliefs about illness and specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) will be associated with adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD. This will also be the case when controlling for illness severity.

***Hypothesis 2 (part i).***

After accounting for variance explained by illness severity, beliefs about illness and specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) will statistically predict adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD.

***Hypothesis 2 (part ii).***

Specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) will predict a significant proportion of variance over and above beliefs about illness, and illness severity.

**Research question 2: What can self-compassion add to our understanding of responses to illness in COPD?**

***Hypothesis 3.***

Self-compassion will explain a significant proportion of variance in adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression), after accounting for variance explained by illness severity, beliefs about illness, and behavioural responses to illness (limiting and all-or-nothing behaviour patterns) in people with COPD.

***Hypothesis 4.***

Behaviours in response to illness (limiting and all-or-nothing behaviour patterns) will mediate the relationship between self-compassion and adjustment to illness in terms

of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD.

In order to test these hypotheses, individuals with a diagnosis of COPD were recruited from three separate NHS pulmonary rehabilitation services, and asked to complete a range of measures assessing their beliefs about their illness, self-compassion, illness severity, specific behavioural responses to illness in terms of limiting and all-or-nothing behaviour patterns, and adjustment to illness in terms of quality of life and distress. In obtaining COPD patients' scores on these variables, it was intended that the relationships between the variables, if any, could be explored, and therefore the above hypotheses tested.

### **Clinical Relevance.**

Considering the common experience of depression, anxiety, fear, and isolation amongst COPD patients, a more comprehensive understanding of the factors associated with adjustment to living with COPD is warranted. Such an understanding could benefit the way healthcare teams help COPD patients to adapt to their condition and maintain favourable adjustment outcomes across the trajectory of this particular illness. Clarifying the roles of illness beliefs, illness behaviours and self-compassion in adjustment to COPD may have important implications with regard to the psychological factors that should be targeted in order to improve wellbeing in living with the condition.

Furthermore, understanding both the psychological risk and protective factors for adaptive outcomes in illness more generally could be translated into targeted

psychological interventions that could bolster adjustment and ameliorate the impact of illness across many LTC's (Stanton et al., 2007). This is necessary, because as Moss-Morris (2013) highlights, psychiatric approaches to adjustment to illness are problematic. In these approaches, difficulties with adjustment are conceptualised as mental health problems. This has implications for psychological treatment in these populations, where routine interventions for depression and anxiety are ineffective, given they do not target the impact of the illness on quality of life for the patient. Routine approaches to treating depression and anxiety will need to be adapted for work with LTC populations. This has already begun where Acceptance and Commitment Therapy (ACT; Hayes, 2004; Hayes, Luoma, Bond, Masuda, & Lillis, 2006), Cognitive Behavioural Therapy (CBT; Westbrook, Kennerley, & Kirk, 2011) and Compassion Focused Therapy (CFT; Gilbert, 2009) protocols have been adapted for treatment in CFS, IBS, chronic pain, stroke, and brain injury populations (see Deary et al., 2007; Shields & Ownsworth, 2013; Vowles et al., 2007). This is timely considering that psychological input will be offered routinely for a range of LTC's as part of the Improving Access to Psychological Therapies programme (IAPT; Department of Health, 2011).

## **Method**

### **Ethical Approval**

The method described to follow received full ethical approval from the Wales REC 6 (NHS Research Ethics Committee). REC approval was granted for the study protocol at the original site (Appendix A), before a slightly adapted protocol for two additional sites was approved as an amendment (Appendix B). The University Ethics Department also approved the study. Again, the protocol was approved at the original site (Appendix C), before the slightly adapted protocol at the two additional sites was approved as an amendment (Appendix D). The study also received approval from the Research and Development (R&D) departments of the three NHS Trusts from where participants were recruited (see Appendices E, F, & G for R&D permission letters). The three Trusts were separate and not linked in any way.

Following a discussion of power, the sample is described in terms of the information collected about participants, before a description of the procedures used at all sites. In describing these procedures, each of the measures used in the study will be outlined.

### **Power Analysis**

In examining whether illness beliefs before pulmonary rehabilitation predicted quality of life after rehabilitation, Zoeckler et al. (2014) performed hierarchical multiple regression analyses. In predicting quality of life, Zoeckler et al. reported that illness beliefs, measured by sum scores of the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002), explained an additional 21% of the variance and reported an adjusted  $R^2$  difference of .22. To detect an effect size of this magnitude

(medium effect size) in regression analyses with up to four predictor variables (independent variables), a significance level of .05 and power of .80, between 67 and 84 participants are recommended (Cohen, 1992). This estimated effect size was based on Zoeckler et al.'s study, as their methodology and predictions reflected the hypotheses relevant to both general research questions in the current study.

### **Participants**

The final sample consisted of 26 outpatients with a diagnosis of chronic obstructive pulmonary disease (COPD), who attended one of three outpatient pulmonary rehabilitation group programmes in Central London and Berkshire. To be eligible for inclusion, patients had to be diagnosed as suffering from emphysema and/or chronic bronchitis, or have been given a diagnosis of COPD by a respiratory physician, be participating in an outpatient pulmonary rehabilitation group programme, and capable of understanding and completing the questionnaires in English.

A total of 38 individuals with COPD across 3 pulmonary rehabilitation services were approached about the study. Five individuals were not interested and declined to participate, whilst 33 consented to participate and completed informed consent procedures. These 33 patients were given a battery of questionnaires to complete and return to the researcher by post. A total of 26 patients returned completed questionnaires as requested, and thus as stated above, the final sample consisted of 26 participants. It is noteworthy that this sample does not meet even the minimum sample suggested by the original power analysis above (this will be considered further in the Discussion chapter). Out of the 26 participants, 18 (69.23%) rated smoking as a

primary cause of their condition (see ‘Measures’ section below, p. 45). Table 1 below shows the relevant demographic and clinical characteristics of the final sample.

Table 1

*Demographic and clinical characteristics of the study sample*

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<u>Age</u>	<u>years</u>
Mean	70.31
Standard deviation	9.37
<u>Gender</u>	<u>n</u>
F:M	15:11 (57.69%: 42.31%)
<u>Illness duration</u>	<u>years</u>
Mean	9.69
Standard deviation	13.07
<u>Participant ethnicity</u>	<u>n</u>
White British	20
White Irish	4
Black/Black British- Caribbean	1
Asian/Asian British- Indian	1

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A total of 7 participants reported no additional physical illnesses or health problems at the time of recruitment. The remainder (n= 19) reported a number of other current physical diagnoses in addition to their respiratory diagnosis. Most commonly, these included Type 2 diabetes, cardiac health problems (including angina, heart stent, atrial

fibrillation), arthritis, pain, hypertension, osteoporosis, and kidney disease. None of the sample was dependent on oxygen therapy.

In terms of mental health difficulties, 19 participants reported no current mental health difficulties at recruitment. The remainder (n= 7) described a number of current mental health difficulties for which they reported that were receiving ongoing treatment (medication or psychological therapy). These difficulties are listed below in Table 2.

Table 2

*Current mental health problems reported and number of participants reporting each*

Current mental health problem	n
Depression	4
Anxiety disorders	4
Stress	1

16 participants reported no previous mental health difficulties. The remainder (n= 10) described a number of previous mental health difficulties for which they received some form of treatment in the past, with some reporting comorbid diagnoses. Those difficulties reported are listed in Table 3.

Table 3

*Previous mental health problems reported and number of participants reporting each*

Previous mental health problems	n
Depression	9
Anxious Disorders	3

### **Setting**

Participants were recruited from three separate outpatient pulmonary rehabilitation services. Two of these were based in Central London hospitals; the Royal Free Hospital, Hampstead (Royal Free London NHS Foundation Trust) and the Whittington Hospital, London (Whittington Hospital NHS Trust). The third was based in a community pulmonary rehabilitation site in Berkshire (Berkshire Health NHS Foundation Trust). The rehabilitation programmes, in each case, were facilitated by a physiotherapy team, and ran for 1-2 hours, twice weekly, over six to eight weeks. Each of the three programmes ran in an almost identical format. Each session consisted of supervised physical activity in an outpatient gym setting. One of the two sessions per week was extended to facilitate an educational discussion after the exercise. These discussions covered such topics as breathlessness, chest infections, medication/inhalers, oxygen therapy, anxiety/depression, and smoking cessation, and were run by different members of the multi-disciplinary respiratory team; respiratory nurses, dieticians, and pharmacists. In one of the Trusts (the Whittington Hospital),

this also included a clinical psychologist, though only a very small number of participants ( $n = 4$ ) were recruited from this site.

Pulmonary rehabilitation is a broad concept that includes exercise, education to improve medication compliance, smoking cessation, nutrition, and where possible, psychological support (see Almagro & Castro, 2013). It is designed to reduce symptoms, optimise functional status, improve activity and daily function, and restore the highest level of independent physical function in patients with COPD (Almagro & Castro, 2013). Two of the pulmonary rehabilitation groups were rotational 8-week groups (Royal Free Hospital and Berkshire sites), whilst the other was of a stop-start format (Whittington Hospital site).

## **Procedure**

### **The Royal Free Hospital and Berkshire sites.**

In the case of the Royal Free Hospital (RFH) and Berkshire sites, the researcher attended rehabilitation sessions to speak to the patients. The research was presented to the group. Patients who were interested in participating could approach the researcher at any point during or after the rehabilitation session to discuss the research further. Participant information sheets (see Appendix H) were provided to those who were interested, and there was an immediate opportunity to discuss the study and to ask questions.

With those who were interested in participating, informed consent procedures were completed. In this case, a consent form (Appendix I) was administered and signed, and these patients were given the battery of questionnaires to take home to complete.

This battery included all standardised questionnaires discussed in the ‘Measures’ section to follow (p. 44), as well as a participant demographic form collecting socio-demographic data (age, gender, ethnicity, length of diagnosis, physical and mental health history; see Appendix J). These patients were also given a pre-paid addressed envelope so that they could return the completed questionnaires to the researcher. The patients had the researcher and academic supervisor’s contact details, whereby they could contact them with questions as they considered their participation at home. The majority of participants were recruited from these two sites over a two-month period.

### **The Whittington Hospital site.**

Procedures at the Whittington Hospital site differed slightly. The study was originally developed as a longitudinal design, in conjunction with the pulmonary rehabilitation staff of this site, and with this particular site in mind. The study then began at this site with the intention of collecting longitudinal data. The research was introduced to patients by the pulmonary rehabilitation staff. The rehabilitation staff provided participant information sheets and consent forms for the patients to take home to read (see Appendix K; note that these particular documents relate to the original longitudinal design). Interested participants who consented to having their contact details passed to the researcher were then contacted by telephone following this assessment. The research was discussed further over the telephone.

To those who were interested in participating, a battery of questionnaires was sent by post to an address they provided, along with another consent form (Appendix K) if necessary, and a pre-paid envelope. Patients who participated were asked to return the completed battery and consent form via post using this envelope. This battery

included a participant demographic form (as per the other sites above), but with different Trust logos as relevant (see Appendix L). The battery also included all standardised questionnaires discussed in the ‘Measures’ section to follow (p. 44), with two exceptions. The Chronic Respiratory Questionnaire (CRQ) and the Medical Research Council (MRC) Breathlessness Scale (discussed in the ‘Measures’ section to follow) were not included in the battery as these measures were administered routinely as part of this particular pulmonary rehabilitation programme. Responses for these measures were forwarded to the researcher by the pulmonary rehabilitation staff at this site after signed consent forms and completed questionnaire packs were received by the researcher for the relevant participants. Participants consented to this procedure.

Recruitment rates were low at this Whittington Hospital site, and the site could not support recruitment for long. Although the study was originally developed with a longitudinal design in mind, ultimately only cross-sectional data was collected from a small number of participants (n= 4) at this site over a 1-month period. Recruitment then ceased here, and the study was amended such that a cross-sectional design was taken forward to the additional two sites (Royal Free Hospital and Berkshire sites), where recruitment began later. This amendment was more in line with the available time frame in which to complete the research. The amendment was reviewed and approved by the Wales REC 6 (see Appendix B for approval form), as well as Royal Holloway, University of London (Appendix D).

## Measures

In order to address the hypotheses described, the following measures were used.

### Illness beliefs.

The Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002) was used to measure participants' beliefs about their illness. The IPQ-R (Appendix M) is a revision of the Illness Perception Questionnaire (IPQ; Weinman et al., 1996)- a scale used to assess patients' representations of illness, as noted earlier. It was developed from Leventhal et al.'s Common Sense Model (CSM) of illness representations or perceptions (beliefs about illness).

The first part of the IPQ-R measures the *Identity* dimension with a list of commonly occurring physical symptoms. Responders are asked to indicate, by circling 'yes' or 'no', which of these symptoms they experience, and which of those experienced, they consider to be related to their illness (COPD).

The second part of the questionnaire consists of 38 statements, which participants rate on a 5-point Likert scale (range; 'strongly disagree' to 'strongly agree'). These 38 items provide separate scores for the *Consequences* subscale (for example- 'My illness is a serious condition'), *Timeline* (divided into the subscales: *acute/chronic*, and *cyclical*, for example- 'My illness will last a short time' or 'My symptoms come and go in cycles'), *Cure/Control* (divided into the subscales: *Personal Control*, and *Treatment Control*, for example- 'My treatment can control my illness' or 'There is a lot which I can do to control my symptoms'), *Emotional Representations* (for

example- My illness makes me feel afraid’) and *Illness Coherence* (for example- I don’t understand my illness’) subscales.

Finally, the third part of the IPQ-R measures the *Cause* dimension, and consists of 18 items relating to causal attributions, where responders are asked to indicate the extent to which they believe their illness was caused by a number of factors. The developers do not recommend that these items be used as a scale. With sufficient sample sizes, factor analysis is recommended to identify groups of causal beliefs, which can then be used as subscales.

However, in line with Zoeckler et al.’s (2014) study, only the 38 items of the second part of the IPQ-R measured on the 5-point Likert scale were included in the current study’s analysis. The first part (*Identity* subscale) and third part (*Cause* subscale) of the measure (described above) were not included (though participants completed them). This is due to the different ways in which responses on these two subscales are scored and interpreted, as above. However, to describe the sample, the number of participants who rated smoking as an important factor in causing their COPD on the *Cause* subscale was noted (see ‘Participants’ section above, p. 37- 38).

Generally, the IPQ-R has strengthened the psychometric properties of the original IPQ by improving subscale reliability (see Moss-Morris et al. 2002). The IPQ-R is a widely used quantitative measure, which has been applied to several illnesses (Zoeckler et al., 2014). The IPQ-R has demonstrated internal reliability, retest reliability, and predictive validity (Moss-Morris et al., 2002; Scharloo et al., 2007; Zoeckler et al., 2014).

The developers suggest that scores for each item in each subscale are summed to produce a subscale score. Higher subscale scores on the *Consequences*, *Timeline (acute/chronic)* and *Timeline (cyclical)* subscales indicate stronger negative beliefs in serious negative consequences of the illness, a chronic long-term non-improving disease, and the illness and/or symptoms as cyclical in nature. Higher scores on the *Emotional Representations* subscale indicate a stronger negative emotional response to illness. On the other hand, higher scores on the *Illness Coherence* subscale indicate stronger positive beliefs in the patient's understanding of the illness. High scores on the *Personal Control* and *Treatment Control* dimensions represent stronger positive beliefs about the patients' own ability to control symptoms, and the effectiveness of treatment in controlling the illness.

The purpose of the present study was to explore the effect of illness beliefs in general, rather than the relative roles of each of the dimensions (as is more common in other studies; see Hagger & Orbell, 2003). Participants' IPQ-R full-scale scores were therefore computed. To do this, scores on the positive subscales (*Personal Control*, *Treatment Control* and *Illness Representations*) were reversed- as in Zoenckler et al.'s (2014) study- as high scores on these positive dimensions would indicate more positive illness beliefs in these particular domains. The full-scale score for each participant was then computed by obtaining a mean score for each of the seven subscales (*Timeline (acute/chronic)*, *Consequences*, *Personal Control*, *Treatment Control*, *Illness Coherence*, *Timeline (cyclical)*, and *Emotional Representations*). A full-scale score was then obtained by summing all seven subscale mean scores for each participant. Higher full-scale scores indicated more negative beliefs overall

about the illness. The full-scale score was chosen due to the high collinearity between the subscales, as also applied by Zoeckler et al. (2014).

In the present study, internal reliability of the subscales used as measured by Cronbach's alpha was .79 (timeline; acute/chronic items), .68 (consequences items), .78 (personal control items), .71 (treatment control items), .81 (illness coherence items), .85 (timeline; cyclical items), and .88 (emotional representations items), and .96 for overall scores across the 7 subscales used.

### **Limiting and all-or-nothing behaviour patterns.**

Limiting and all-or-nothing behaviour patterns were assessed in participants by administering the *limiting behaviour* and *all-or-nothing behaviour* subscales of Spence et al.'s (2005) Behavioural Responses to Illness Questionnaire (BRIQ; Appendix N). Kindermans et al. (2011) measured these behaviour patterns using the same instrument. The BRIQ is a 21-item self-report questionnaire developed to measure behavioural responses of patients in an acute phase of illness. Besides the all-or-nothing behaviour (6 items) and limiting behaviour (7 items) subscales, the measure also includes an emotional support seeking subscale (4 items), and a practical support seeking subscale (4 items). All items are answered on a 5-point scale ranging from 1 (not at all) to 5 (every day), indicating the frequency of the stated behaviour for the participant. However, personal communication with the developer suggested that the two support seeking subscales had not been found to be significant in previous research, and that the all-or-nothing behaviour and limiting behaviour subscales could be used on their own. As only these two latter subscales were relevant to the current hypotheses, only these two subscales were used. Total scores are

obtained by summing the scores on the items for each subscale separately. Total scores range from 6 to 30 (all-or-nothing behaviour) and 7 to 35 (limiting behaviour).

Although the BRIQ was originally developed for patients in an acute phase of illness, inspection of the items indicated that the questionnaire was also suitable for administration in a COPD or respiratory illness population without modification- where the constructs of interest are all-or-nothing and limiting behaviour patterns. In the past, the all-or-nothing and limiting behaviour scales have been considered appropriate for administration to a chronic pain population (Kindermans et al., 2011), an irritable bowel syndrome (IBS) sample (Spence & Moss-Morris, 2007), and a multiple sclerosis (MS) sample (Skerrett & Moss-Morris, 2006).

Psychometric properties of the BRIQ are satisfactory (see Spence et al., 2005). In the validation study of the final scales, Spence et al. (2005) reported that the internal reliability of the subscales as measured by Cronbach's alpha ranged between .81 (for all-or-nothing behaviour) and .89 (for limiting behaviour; see Spence et al., 2005). In the present study, internal reliability of the subscales as measured by Cronbach's alpha was .80 (limiting behaviour) and .80 (all-or-nothing behaviour).

The limiting behaviour scale measures the extent to which patients rest and reduce activity in response to illness, and includes items such as 'I have avoided my usual activities' and 'I have gone to bed during the day'. The all-or-nothing behaviour scale measures a pattern of over-activity and then rest, and includes items such as 'I have overdone things, then needed to rest up for a while' and 'I have pushed myself as hard as ever until I cannot push myself any more'.

## **Adjustment to illness.**

*Adjustment to illness* was assessed by two separate outcome measures; quality of life, which comprised two separate components of physical functioning and emotional functioning, and distress, which comprised measures of anxiety and depression.

### ***1. Quality of life.***

As noted, Moss-Morris (2013) highlighted the common use of quality of life measures as outcomes in studies of adjustment to illness. Generic quality of life tools are common, as are health-related quality of life measures, and even those that are specifically designed for particular illness populations (Moss-Morris, 2013). Generic quality of life can be defined as how a person generally functions day-to-day, whilst health-related quality of life can be defined as the way a person feels, and how he or she functions in day-to-day activities specifically in the context of living with an illness (Guyatt, Feeny, & Patrick, 1993). In general, measures of health-related quality of life, that are also disease-specific, are reported to be more responsive than generic quality of life tools, and may have more face validity for both the patient and the clinician (Chauvin, Rupley, Meyers, Johnson, & Eason, 2008; Guyatt, Feeny, & Patrick, 1993; Singh, Sodergren, Hyland, Williams, & Morgan, 2001). For this reason, the Chronic Respiratory Questionnaire (CRQ; Guyatt, Townsend, Keller, Singer, & Nogradi, 1989), a measure of health-related quality of life specific to respiratory disease, was chosen as an adjustment outcome for the current study.

The CRQ is reported to be the most commonly used disease-specific tool to assess health-related quality of life in patients with chronic respiratory disease (Chauvin et al., 2008; Guyatt, Berman, Townsend, Pugsley, & Chambers, 1987). The CRQ has

been rigorously tested to ensure that it is reproducible, that it is valid, and that it is responsive to change (Guyatt et al., 1987; Guyatt et al., 1989). The CRQ evaluates 20 items relating to four aspects of health-related quality of life specific to respiratory illness, including dyspnea or breathlessness (5 items), fatigue (4 items), emotional function (7 items), and mastery (4 items). Patients rate their experience on a 7-point Likert scale ranging from 1 (maximum impairment) to 7 (no impairment). In the first section (the dyspnea domain), the patient chooses the 5 most important activities during which they have experienced shortness of breath in the past 2 weeks. The patient is prompted with a list of 25 common activities. As such, the dyspnea domain is individualised to each participant. The remaining items across the 3 other domains are all standardised.

In clinical use, a mean score is typically computed for each of the four domains based upon responses to items within each (range 1-7). For research use however, the developers recommend computing a mean *physical functioning* score across the items of the two physical domains (that is, the mean score across the dyspnea and fatigue items), and a mean *emotional functioning* score across the items of the two emotional domains (that is, the mean score across the emotional function and mastery items) (Department of Clinical Epidemiology and Biostatistics, McMaster University, 2005). Therefore, in the present study, the adjustment outcome of illness-specific health-related quality of life comprise two separate components, which are referred to going forward as simply- quality of life (physical functioning) and quality of life (emotional functioning). This scoring procedure has been carried out in previous research also (e.g., Schunemann, Guyatt, Griffith, Stubbing, & Goldstein, 2002). Higher mean

scores in physical and emotional functioning indicate better health-related quality of life.

The original CRQ is interviewer-administered, and therefore in the present study, the self-administered version (the CRQ-self-administered individualised; CRQ-SAI) was used. The CRQ-SAI does not require the presence of an interviewer to complete, but is otherwise unchanged in content and order from the original CRQ (Department of Clinical Epidemiology and Biostatistics, McMaster University, 2005). The CRQ-SAI was compared with the original CRQ in two randomised trials, the results of which would suggest that the self-administered version has excellent measurement properties (see Puhan et al., 2004). In the present study, internal reliability of the subscales as measured by Cronbach's alpha was .85 (dyspnea items), .90 (fatigue items), .93 (emotional functioning items), .80 (mastery items), .88 (physical functioning; dyspnea and fatigue items combined), and finally .93 (emotional functioning; emotional function and mastery items combined).

In the current study, the CRQ-SAI baseline version was administered only, as given the cross-sectional nature of the study, there was no requirement for the follow-up version. Due to copyright restrictions, the CRQ-SAI could not be included in the current report's appendices with the other measures (see Appendix O).

## ***2. Distress.***

The second adjustment outcome comprised distress, which also included two components- depression and anxiety. Depression and anxiety were assessed using the Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1986; see

Appendix P). The HADS is a validated 14-item rating scale designed to screen for clinically significant levels of depression and generalised anxiety in medical outpatients. All items are scored on a scale ranging from 0 to 3. Both the depression and anxiety scales are scored separately by summing the responses- the scores in both cases can range from 0 to 21. Higher scores reflect more symptoms of depression and anxiety- where scores of 7 or below reflect clinically insignificant levels of symptoms, scores between 8-10 reflect borderline abnormal levels, and scores of 11-21 reflect abnormal levels. The HADS was developed to measure mood and anxiety disorders in a hospital outpatient population, and therefore the HADS excludes confounding somatic symptoms (Snaith & Zigmund, 1986; Zockler et al., 2014). The HADS is a well-validated measure, and has often been used in studies to assess levels of anxiety and depression in respiratory illness patients (see Dahlén & Janson, 2002; Janson, Bjornsson, Hetta, & Boman, 1994).

### **Self-compassion.**

Levels of self-compassion in participants were measured by the aforementioned Self-Compassion Scale (SCS) developed by Neff (2003a). The SCS is available in Appendix Q. The SCS is a self-report tool measuring compassion towards the self, and assesses the extent to which participants treat themselves with self-compassion during times of difficulty. The SCS includes 26 items across six subscales, three of which comprise a positive component that includes the self-kindness (5 items, e.g., ‘I try to be understanding and patient towards those aspects of my personality I don’t like’), Common Humanity (4 items, e.g., ‘I try to see my failings as part of the human condition’) and Mindfulness (4 items, e.g., ‘When something painful happens I try to

take a balanced view of the situation’) subscales; and three of which comprise a negative component including the Self-Judgement (5 items, e.g., ‘I’m disapproving and judgemental about my own flaws and inadequacies’), Isolation (4 items, e.g., ‘When I think about my inadequacies it tends to make me feel more separate and cut off from the rest of the world’) and Over-Identification (4 items, e.g., ‘When I’m feeling down I tend to obsess and fixate on everything that’s wrong’) subscales.

Responses on the SCS are given on a 5-point scale ranging from 1 (almost never) to 5 (almost always)- higher scores representing greater self-compassion. Neff (2003a) highlights that it is possible to examine the six subscales separately, or as an overall self-compassion score. In the current study, a grand mean self-compassion score was obtained for each participant (range 1-5) in accordance with scoring and interpretation guidelines from the developer (see Appendix Q). That is, scores for the negative subscale items (self-judgment, isolation and over-identification) were reversed, before calculating subscale means for all subscales, and computing a grand mean of all six subscale means.

Research indicates that the SCS has an appropriate factor structure, and that a single factor of ‘self-compassion’ can explain the inter-correlations among the six facets (see Neff, 2003a; Neff, et al., 2005; Wren et al., 2012). Neff & McGehee (2010) highlight that research has indicated that the SCS demonstrates concurrent validity (correlates negatively with self-criticism), convergent validity (significantly correlates with therapist ratings of self-compassion), discriminant validity (no correlation with social desirability or narcissism), and test–retest reliability (0.93; Neff, 2003a; Neff & McGehee, 2010; Przedziecki et al., 2013). Past research with American samples has also demonstrated good internal consistency for the SCS (.90 - .95 for overall self-

compassion scores, and .75 - .86 for individual subscale scores; Neff & McGehee, 2010). Costa and Pinto-Gouveia (2011) and Wren et al. (2011) also highlight the adequate psychometric properties of the scale. In the present study, internal reliability of the subscales as measured by Cronbach's alpha was .73 (self-kindness subscale), .86 (self-judgement subscale), .75 (common humanity subscale), .94 (isolation subscale), .79 (mindfulness subscale), .86 (over-identification subscale) and for overall scores (.93).

### **Illness severity.**

Illness severity was also measured so that it could be controlled for in statistical analyses- such that the association between illness beliefs/ behaviours and adjustment to illness beyond the influence of illness severity could be established. Illness severity was operationalised as patients' self-reported scores on the Medical Research Council (MRC; see Appendix R) Breathlessness Scale (Fletcher, Elmes, Fairbairn, & Wood, 1959). The MRC Scale has been used for many decades to provide a simple and valid method of categorising patients in terms of respiratory illness severity (Bestall et al., 1999). Researchers vary in how they refer to the scale. Across the literature, it is known varyingly as the MRC Breathlessness Scale, Dyspnea Scale, or Dyspnoea Scale.

The scale comprises five statements that describe a range of respiratory disability from none (Grade 1) to almost complete incapacity (Grade 5); Grade 1, 'Not troubled by breathlessness except on strenuous exercise'; Grade 2, 'Short of breath when hurrying on the level or walking up a slight hill'; Grade 3, "Walks slower than most people on the level, stops after a mile or so, or stops after 15 minutes walking at own

pace'; Grade 4, 'Stops for breath after walking about 100 yards or after a few minutes on level ground'; Grade 5, 'Too breathless to leave the house, or breathless when undressing'. The scale can be self-administered, in that the patient indicates the extent to which their breathlessness affects their mobility (Bestall et al., 1999) by choosing the grade that they perceive to describe their current condition (Grade 1 -5). A patient's score is the grade that they choose.

Whilst the MRC Scale does not quantify breathlessness itself (other tools such as the Borg Scale do so; see American Thoracic Society, 1999), it quantifies the disability associated with breathlessness by identifying whether breathlessness occurs when it should not (Grade 1-2), or by quantifying the associated exercise limitation (Grade 3-5; Stenton, 2008). The scale is typically recommended to complement objective pulmonary-function tests (forced expiratory volume in one second; FEV1; used by Zoeckler et al., 2014) in the classification of illness severity in COPD (Bestall et al., 1999; Stenton, 2008). However, where pulmonary-function tests are not carried out, the MRC scale is used instead to categorise illness severity (Stenton, 2008). It has been used as a measure of functional breathlessness in order to supplement FEV1 measures of pulmonary function in classifying COPD patients in terms of severity in several previously mentioned studies (for example, Scharloo et al., 2007).

The scale is widely used to describe patient cohorts and stratify them for interventions such as pulmonary rehabilitation programmes (Stenton, 2008; Wedzicha et al., 1998). Patients typically must score MRC grade 3 or above to meet entry criteria for any of the three pulmonary rehabilitation services that supported this study's recruitment. The scale's great strength is that a score can be obtained in seconds (Stenton, 2008), and all grades relate to everyday activities, which are easily understood by the patient.

The MRC Scale is not subject to copyright and is widely available for research and clinical work (Stenton, 2008).

### **Service-User Involvement and Dissemination**

Participants were not involved in the design of the research, nor were they involved in the analysis of the results. However, participants who indicated on the consent forms (Appendices I & K) that they would like to receive a summary of the study's findings in accessible terms, or would like to be involved in the development of such a summary, will be contacted on the telephone number or email address that they provided on their form. Additionally, the staff of the pulmonary rehabilitation service at the Berkshire site requested that the study's results be presented at one of their respiratory multi-disciplinary meetings. A presentation will be made following the viva examination.

### **Analyses**

#### **Preliminary data analyses.**

Data were analysed using the Statistical Package for the Social Science (SPSS; version 21). Data were inspected for missing items. For the Self-Compassion Scale, 3.8% of items were missing from two of the subscales (Self-kindness and Mindfulness). For the Self-Kindness items, a non-significant Little's MCAR test ( $\chi^2(4) = 3.165, p = .53$ ), revealed that the data were missing completely at random (Little, 1988). Similarly, for the Mindfulness items, a non-significant Little's MCAR test ( $\chi^2(3) = .382, p = .53, .94$ ) also revealed that the data were missing completely at

random. When data are missing completely at random, and only a very small portion of data are missing (less than 5% overall), a single imputation using the expectation maximization algorithm provides unbiased parameter estimates and improves statistical power of analyses (Enders, 2001; Scheffer, 2002). Missing data were imputed using Missing Values Analysis and the Expectation-Maximization (EM) technique within the Statistical Package for the Social Sciences (SPSS, version 21).

In tests of normality, it was found that none of the variables exhibited significant skewness or kurtosis. Scores on each of the standardized measures used were normally distributed, with all values of skewness and kurtosis  $< 2.58$  ( $p < .01$ ).

Analysis of outliers was conducted, aided by the inspection of box plots. This indicated 2 extreme values for anxiety (anxiety subscale of the HADS), 1 for illness beliefs (IPQ-R), and 1 for the all-or-nothing behaviour subscale of the BRIQ. These extreme values were inspected further and ultimately retained, as they did not meet criteria for being an outlier, leaving all 26 cases for further analysis.

### **Statistical analyses.**

*Research question 1: What are the roles of illness beliefs and illness behaviours in COPD?*

In order to address hypothesis 1 of this general research question- *beliefs about illness and specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) will be associated with adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD. This will also be the case when controlling for illness severity-* Pearson's

bivariate correlations and partial correlations were used to identify the association between variables.

In order to address Hypothesis 2 (*part i*)- *after accounting for variance explained by illness severity, beliefs about illness and specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) will statistically predict adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD*- a series of hierarchical multiple linear regression analyses were conducted in order to assess the extent to which, when controlling for illness severity, illness beliefs, limiting behaviour patterns, and all-or-nothing behaviour patterns were associated with quality of life (physical and emotional functioning) and distress (depression and anxiety).

In total, four regression analyses were conducted- one for each of the four adjustment outcomes (quality of life (physical and emotional functioning) and distress (anxiety and depression)). For each of these four regression analyses, variables were entered in two steps. In the first step, the potentially confounding variable (illness severity) was entered. Illness beliefs, limiting behaviour patterns and all-or-nothing behaviour patterns were entered at step 2 to determine whether these variables contributed a significant increase in variance explained beyond the contribution of illness severity.

In order to address hypothesis 2 (*part ii*)- *specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) will predict a significant proportion of variance over and above beliefs about illness and illness severity*- a second series of hierarchical multiple linear regression analyses were conducted in order to assess the extent to which, when controlling for both illness severity and illness beliefs,

illness behaviours (in terms of limiting and all-or-nothing behaviour patterns) were associated with quality of life (physical and emotional functioning) and distress (depression and anxiety).

Again, four regression analyses were conducted in total - one for each of the four adjustment outcomes (quality of life (physical and emotional functioning) and distress (anxiety and depression)). For each of these four regression analyses, variables were entered in three steps. In the first step, the first potentially confounding variable- illness severity- was entered. In the second step, the other potentially confounding variable- illness beliefs- was entered. Illness behaviours (in terms of limiting and all-or-nothing behaviour patterns) were then entered at step 3 in order to determine whether these behavioural variables contributed a significant increase in variance explained beyond the contribution of illness severity and illness beliefs.

*Research question 2: What can self-compassion add to our understanding of responses to illness in COPD?*

In order to address hypothesis 3- *self-compassion will explain a significant proportion of variance in adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression), after accounting for variance explained by illness severity, beliefs about illness, and behavioural responses to illness (limiting and all-or-nothing behaviour patterns) in people with COPD-* a third series of hierarchical multiple linear regression analyses were conducted in order to assess the extent to which, when controlling for illness severity, illness beliefs and illness behaviours (in terms of limiting and all-or-nothing behaviour patterns), self-

compassion was associated with quality of life (physical and emotional functioning) and distress (depression and anxiety).

Again, four regression analyses were conducted in total - one for each of the four adjustment outcomes (quality of life (physical and emotional functioning) and distress (anxiety and depression)). For each of these four regression analyses, variables were entered in three steps. In the first step, the first potentially confounding variable- illness severity- was entered. In the second step, the other potentially confounding variables- illness beliefs, limiting, and all-or-nothing behaviour patterns- were entered. Self-compassion was then entered at step 3 in order to determine whether this variable contributed a significant increase in variance explained beyond the contribution of illness severity, illness beliefs and illness behaviours (limiting and all-or-nothing behaviour patterns).

Hypothesis 4 - *behaviours in response to illness (limiting and all-or-nothing behaviour patterns) will mediate the relationship between self-compassion and adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD-* was separated into three mediation models; models *i* to *iii*. A series of three mediation analyses were conducted to test all three mediation models.

These three mediation analyses were carried out according to the Preacher and Hayes (2004, 2008) bootstrapping method. This method was conducted using the INDIRECT script by Preacher and Hayes (2008), which was downloaded as a custom dialog file for SPSS (version 21) from the author's website (Hayes, 2016).

INDIRECT is a computational procedure for SPSS that estimates the path coefficients

in single and multiple mediator models, and generates bootstrap confidence intervals (percentile, bias-corrected, and bias-corrected and accelerated) for total and indirect effects of X (independent variable) on Y (dependent variable) through one or more mediator variable(s) (M). This custom dialog allows for more than one mediator variable, and adjusts all paths for the potential influence of covariates not proposed to be mediators in the model.

In assessing mediation using the INDIRECT computational procedure for SPSS, Krieger, Altenstein, Baettig, Doerig, and Holtforth (2013) highlight the importance of making clear distinctions between several different effects, which are presented here for the sake of clarity:

The total effect ( $c$ ) of an independent variable (IV) or predictor variable on a dependent variable (DV) is composed of a direct effect ( $c'$ ) of the IV on the DV, and an indirect of the IV on the DV through a proposed mediator (M). Path  $a$  typically represents the effect of the IV on the M, whilst path  $b$  is typically the effect of the M on the DV, partialing out the effect of the IV. The indirect effect is traditionally computed by multiplying the regression coefficients of  $a$  and  $b$  ( $a \times b$ , or just  $ab$ ) as per Baron and Kenny's (1986) traditional causal-steps approach to assessing mediation. However, using INDIRECT, a bootstrapping resampling method with 5000 resamples is used to estimate, and test the significance of, the indirect effect (Preacher & Hayes, 2008).

Preacher and Hayes (2008) describe bootstrapping as a computationally intensive method that involves repeatedly sampling from a dataset and estimating the indirect effect in each resampled dataset. By repeating this process thousands of times, an

empirical approximation of the sampling distribution of  $ab$  (the indirect effect) is built, and this is used to construct confidence intervals for the indirect effect (Preacher & Hayes, 2008, p. 880). As described by Przedziecki et al. (2013), rather than providing a p-value for the obtained estimate of the indirect effect, the Preacher and Hayes (2004, 2008) bootstrapping approach gives confidence intervals based on the bootstrap distribution. The general rule follows that if the confidence interval does not contain zero, the indirect effect is said to be significant at a level corresponding to the confidence interval specified (95% in the present study). Przedziecki et al. (2013) report that bootstrapping is considered to be superior to other tests of the indirect effect (see also MacKinnon, Fairchild, & Fritz, 2007). Especially in the case of smaller samples (relevant in the present case), the bootstrapping method is reportedly more likely to provide unbiased estimates of the standard error of the indirect effect than other approaches, including, as Przedziecki et al. (2013) note, the asymptotic method described by Sobel (1982; see also MacKinnon et al., 2007).

Following the analysis of models *i* to *iii*, further exploratory analyses were then conducted, where an additional exploratory mediation model was proposed and tested (model *iv*). Model *iv* comprised a serial multiple mediation model including two mediator variables. Therefore, in order to conduct this particular mediation analysis, PROCESS (Hayes, 2012) was used. PROCESS is a more recently developed computational procedure for SPSS. PROCESS implements mediation analysis and provides many of the same capabilities of INDIRECT, while also expanding the number and complexity of mediation models that can be estimated. For instance, like INDIRECT, PROCESS can construct bias corrected and percentile based bootstrap confidence intervals for indirect effects in mediation models, including the simple and

multiple mediation models estimated by INDIRECT and described by Preacher and Hayes (2004, 2008), as above. However, using PROCESS, multiple mediator variables can be specified to operate in parallel or in sequence (serially), and thus PROCESS was chosen to analyse the additional exploratory mediation model (model *iv*). PROCESS was downloaded as a custom dialog file for SPSS (version 21) from the author's website (Hayes, 2016).

## Results

Results of the statistical analyses that were carried out are described to follow and relevant statistics are reported. Each hypothesis is repeated to aid clarity. To sum up the findings, each hypothesis was partially supported by the analyses conducted.

### **Research Question 1: What are the Roles of Illness Beliefs and Illness Behaviours in COPD?**

#### **Hypothesis 1.**

Hypothesis 1 stated that *beliefs about illness and specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) would be associated with adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD, and that this would also be the case when controlling for illness severity.* The results show that illness beliefs correlated negatively with quality of life (emotional functioning), such that greater negative beliefs about illness were associated with poorer self-reported quality of life (emotional functioning). However, the association was not significant in the case of quality of life (physical functioning) (see Table 4). Illness beliefs were positively correlated with depression, such that greater negative beliefs about their illness among participants were associated with greater levels of depression. This association was not found for anxiety. Bivariate correlations among the variables used to test Hypothesis 1 are presented in Table 4.

Table 4

*Bivariate correlations between variables of interest (Hypothesis 1)*

Variables	<u>Quality of life</u>				<u>Distress</u>			
	Physical		Emotional		Anxiety		Depression	
	r	p	r	p	r	p	r	p
Illness beliefs	-.10	.62	-.42*	.04	.28	.17	.40*	.04
Limiting behaviour	-.37	.06	-.43*	.03	.34	.09	.73**	.000
All-or-nothing behaviour	-.10	.62	-.21	.31	.57**	.002	.29	.16

*N* = 26

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

Limiting behaviour patterns correlated negatively with quality of life (emotional functioning), such that limiting behaviour patterns were associated with poorer quality of life (emotional functioning) in participants. Limiting behaviour patterns were positively correlated with depression, such that limiting behaviour patterns were associated with higher levels of depression. Limiting behaviour patterns did not correlate significantly with quality of life (physical functioning) or with anxiety (see Table 4).

In terms of other behavioural patterns, all-or-nothing behaviour patterns correlated positively with anxiety. However, all-or-nothing behaviour patterns among individuals with COPD did not correlate significantly with depression or quality of life (physical or emotional functioning).

Furthermore, when controlling for illness severity, the number of significant correlations between illness beliefs/behaviour variables and outcomes reduced. In the context of this control, there remained a significant positive correlation between limiting behaviour patterns and depression, and all-or-nothing behaviour patterns and anxiety. These correlations remained significant when using Bonferroni adjustments, such that a p value of ( $p = 0.05/12$ ) 0.004 was required. Bivariate correlations between variables of interest, when controlling for illness severity, are presented in Table 5.

Table 5

*Partial correlations between variables of interest, controlling for illness severity (Hypothesis 1)*

	<u>Quality of life</u>				<u>Distress</u>			
	Physical		Emotional		Anxiety		Depression	
	r	p	r	p	r	p	r	p
1. Illness beliefs	.18	.39	-.23	.27	.14	.52	.21	.31
2. Limiting behaviour	.02	.92	-.05	.83	.11	.59	.57*	.003
3. All-or-nothing behaviour	-.06	.78	-.19	.37	.58*	.002	.28	.17

$N = 26$

\*Correlation is significant at the 0.004 level (2-tailed).

These findings above therefore partially support Hypothesis 1, in that a portion, but not all, of the bivariate and partial correlations were significant.

## **Hypothesis 2 (part i).**

Hypothesis 2 (part i) stated that *after accounting for variance explained by illness severity, beliefs about illness and specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) would statistically predict adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD.* In order to address hypothesis 2 (part i), a series of hierarchical multiple regression analyses were conducted. The aim was to test the predictive power of illness beliefs and behavioural responses to illness, and to determine the extent to which illness beliefs and behavioural responses to illness (in terms of limiting and all-or-nothing behaviour patterns) accounted for variance in quality of life and distress after accounting for the effects of illness severity.

1. The first analysis was carried out with quality of life (physical functioning) as the dependent variable. Therefore, illness severity was entered as a first step in a hierarchical multiple regression in order to partial out any contribution to quality of life (physical functioning).

Illness severity explained a significant amount of the variance in quality of life (physical functioning) ( $R^2 = .32$ , adjusted  $R^2 = .29$ ;  $F(1, 24) = 11.12$ ,  $p = .003$ ). Illness beliefs, limiting behaviour and all-or-nothing behaviour patterns entered at step 2 did not contribute a significant increase in variance explained (from 31.7% to 34.3%, adjusted  $R^2 = .28$ ), a change that was not significant ( $F(3, 21) = .28$ ,  $p = .84$ ).

In the final equation, illness severity made a significant unique contribution to explaining quality of life (physical functioning) ( $B = -.63$ ,  $\beta = -.64$ ,  $t(21) = -2.53$ ,  $p =$

.02), whilst illness beliefs did not make a significant unique contribution to explaining this outcome ( $B = .06$ ,  $\beta = .17$ ,  $t(21) = .86$ ,  $p = .40$ ), nor did limiting behaviour patterns ( $B = .002$ ,  $\beta = .01$ ,  $t(21) = .04$ ,  $p = .97$ ), nor all-or-nothing behaviour patterns ( $B = -.01$ ,  $\beta = -.06$ ,  $t(21) = -.34$ ,  $p = .74$ ). The overall proposed model therefore did not show a significant relationship to the dependent variable.

2. The same analyses were carried out with quality of life (emotional functioning) as the dependent variable. In this case, illness severity was entered as a first step in a hierarchical multiple regression in order to partial out any contribution to quality of life (emotional functioning).

Illness severity explained a significant amount of the variance in quality of life (emotional functioning) ( $R^2 = .34$ , adjusted  $R^2 = .31$ :  $F(1, 24) = 12.25$ ,  $p = .002$ ). However, illness beliefs, limiting behaviour and all-or-nothing behaviour patterns entered at step 2 did not contribute a significant increase in variance explained (from 33.8% to 39.2%, adjusted  $R^2 = .28$ ), a change that was not significant ( $F(3, 21) = .62$ ,  $p = .61$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining quality of life (emotional functioning) ( $B = -.56$ ,  $\beta = -.48$ ,  $t(21) = -2.00$ ,  $p = .06$ ), nor did illness beliefs ( $B = -.08$ ,  $\beta = -.19$ ,  $t(21) = -1.02$ ,  $p = .32$ ), nor limiting behaviour patterns ( $B = -.001$ ,  $\beta = -.002$ ,  $t(21) = -.01$ ,  $p = .99$ ), nor all-or-nothing behaviour patterns ( $B = -.04$ ,  $\beta = -.14$ ,  $t(21) = -.81$ ,  $p = .43$ ). Therefore the proposed model did appear to show a significant relationship to the outcome of quality of life (emotional functioning) but it did not appear to be carried by any one variable.

Though illness severity was approaching significance so illness severity likely carried the significance.

3. The same analyses were carried out with anxiety as the dependent variable. In this case, illness severity was entered as a first step in a hierarchical multiple regression in order to partial out any contribution to anxiety.

Illness severity did not explain a significant amount of the variance in anxiety ( $R^2 = .14$ , adjusted  $R^2 = .11$ ;  $F(1, 24) = 4.03$ ,  $p = .056$ ). However it was approaching significance. Illness beliefs, limiting behaviour and all-or-nothing behaviour patterns entered at step 2 contributed a significant increase in variance explained (from 14.4% to 44.3%, adjusted  $R^2 = .34$ ), a change that was significant ( $F(3, 21) = 3.77$ ,  $p = .03$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining anxiety ( $B = 1.18$ ,  $\beta = .25$ ,  $t(21) = 1.1$ ,  $p = .28$ ), nor did illness beliefs ( $B = .15$ ,  $\beta = .09$ ,  $t(21) = .52$ ,  $p = .61$ ), nor limiting behaviour patterns ( $B = .04$ ,  $\beta = .05$ ,  $t(21) = .21$ ,  $p = .83$ ). However, all-or-nothing behaviour patterns did make a significant unique contribution to explaining anxiety ( $B = .56$ ,  $\beta = .17$ ,  $t(21) = 3.22$ ,  $p = .004$ ). Therefore, the model showed a significant relationship to the outcome of anxiety, which was carried by all-or-nothing behaviour patterns only.

4. Finally, the same analyses were carried out with depression as the dependent variable. In this case, illness severity was entered as a first step in a hierarchical multiple regression in order to partial out any contribution to depression. Illness severity explained a significant amount of the variance in depression ( $R^2 = .32$ , adjusted  $R^2 = .29$ ;  $F(1, 24) = 11.42$ ,  $p = .002$ ).

Illness beliefs, limiting behaviour and all-or-nothing behaviour patterns entered at step 2 contributed a significant increase in variance explained (from 32.2% to 58.5%, adjusted  $R^2 = .51$ ), a change that was significant ( $F(3, 21) = 4.44, p = .01$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining depression ( $B = .43, \beta = .09, t(21) = .45, p = .66$ ), nor did illness beliefs ( $B = .20, \beta = .13, t(21) = .80, p = .43$ ), nor did all-or-nothing behaviour patterns ( $B = .19, \beta = .18, t(21) = 1.23, p = .23$ ). However, limiting behaviour patterns did make a significant unique contribution to explaining depression ( $B = .54, \beta = .60, t(21) = 3.06, p = .01$ ). Therefore the model showed a significant relationship to the outcome of depression, which was carried by limiting behaviour patterns only.

Based on the above findings therefore, this part *i* of hypothesis 2 is partially supported. The proposed model did not show a significant relationship to the outcome of quality of life (physical functioning). However, the model did appear to show a significant relationship to the outcome of quality of life (emotional functioning)- though this significance did not appear to be carried by any one variable in particular in the model. However, from the figures above, illness severity was approaching significance. The model did show a significant relationship to the outcome of anxiety, which was carried by all-or-nothing behaviour patterns only. And finally, the model also showed a significant relationship to the outcome of depression, which was carried by limiting behaviour patterns only. Links are therefore emerging between all-or-nothing behaviour patterns and anxiety, and between limiting behaviour patterns and depression.

## Hypothesis 2 (part ii).

Hypothesis 2 (part ii) stated that *specific behavioural responses to illness (limiting and all-or-nothing behaviour patterns) would predict a significant proportion of variance over and above beliefs about illness, and illness severity*. In order to test this, a second set of hierarchical multiple regression analyses was carried out. In these analyses, illness severity was entered at step 1, followed by illness beliefs at step 2, and behavioural responses to illness (limiting and all-or-nothing behaviour patterns) at step 3. The analyses using quality of life as outcome variables were completed for completeness, although given the previous findings, no significant contributions of any of the variables were expected.

1. The first of this set was carried out with quality of life (physical functioning) as the dependent variable. Illness severity explained a significant amount of the variance in quality of life (physical functioning) ( $R^2 = .32$ , adjusted  $R^2 = .29$ ;  $F(1, 24) = 11.12$ ,  $p = .003$ ). Illness beliefs entered at step 2 did not contribute to any significant increase in variance explained (31.7% to 33.9%, adjusted  $R^2 = .28$ ), a change that was not significant ( $F(1, 23) = .78$ ,  $p = .39$ ). Limiting and all-or-nothing behaviour patterns entered at step 3 did not contribute any significant increase in variance explained (33.9 % to 34.3%, adjusted  $R^2 = .22$ ), a change that was not significant ( $F(2, 21) = .06$ ,  $p = .95$ ).

In the final equation, illness severity made a significant unique contribution to explaining quality of life (physical functioning) ( $B = -.63$ ,  $\beta = -.64$ ,  $t(21) = -2.53$ ,  $p = .02$ ), however illness beliefs did not ( $B = .06$ ,  $\beta = .17$ ,  $t(21) = .86$ ,  $p = .40$ ), nor did

limiting behaviour patterns ( $B = .002$ ,  $\beta = .01$ ,  $t(21) = .04$ ,  $p = .97$ ), nor did all-or-nothing behaviour patterns ( $B = -.01$ ,  $\beta = -.06$ ,  $t(21) = -.34$ ,  $p = .74$ ).

Therefore the model did not show a significant relationship to the dependent variable. Though the model was approaching significance and this significance was likely carried by illness severity.

2. The same analyses were carried out with quality of life (emotional functioning) as the dependent variable. In this case, illness severity was again entered as a first step in a hierarchical multiple regression in order to partial out any contribution to quality of life (emotional functioning). Illness severity explained a significant amount of the variance in quality of life (emotional functioning) ( $R^2 = .34$ , adjusted  $R^2 = .31$ ;  $F(1, 24) = 12.25$ ,  $p = .002$ ). However, illness beliefs entered at step 2 did not contribute a significant increase in variance explained (33.8% to 37.2%, adjusted  $R^2 = .32$ ), a change that was not significant ( $F(1, 23) = 1.26$ ,  $p = .27$ ). Limiting and all-or-nothing behaviour patterns entered at step 3 did not contribute a significant increase in variance explained (37.2% to 39.2%, adjusted  $R^2 = .28$ ), a change that was not significant ( $F(2, 21) = .34$ ,  $p = .72$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining quality of life (emotional functioning) ( $B = -.56$ ,  $\beta = -.48$ ,  $t(21) = -2.00$ ,  $p = .06$ ), nor did illness beliefs ( $B = -.08$ ,  $\beta = -.19$ ,  $t(21) = -1.02$ ,  $p = .32$ ), nor limiting behaviour patterns ( $B = -.001$ ,  $\beta = -.002$ ,  $t(21) = -.01$ ,  $p = .99$ ), nor all-or-nothing behaviour patterns ( $B = -.04$ ,  $\beta = -.14$ ,  $t(21) = -.81$ ,  $p = .43$ ).

Therefore the model showed a significant relationship to this dependent variable (quality of life (emotional functioning)), which did not appear to be carried by any of the variables in particular- though it was likely to be carried by illness severity (approaching significance).

3. The same analyses were carried out with anxiety as the dependent variable. In this case, illness severity was again entered as a first step in a hierarchical multiple regression in order to partial out any contribution to anxiety. Illness severity did not explain a significant amount of the variance in anxiety ( $R^2 = .14$ , adjusted  $R^2 = .11$ ;  $F(1, 24) = 4.03$ ,  $p = .056$ ). However, it was approaching significance.

Illness beliefs entered at step 2 did not contribute a significant increase in variance explained (from 14.4% to 16.0%, adjusted  $R^2 = .09$ ), a change that was not significant ( $F(1, 23) = .43$ ,  $p = .52$ ). However, limiting and all-or-nothing behaviour patterns entered at step 3 did contribute a significant increase in variance explained (from 16.0% to 43.3%, adjusted  $R^2 = .34$ ), a change that was significant ( $F(2, 21) = 5.35$ ,  $p = .01$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining anxiety ( $B = 1.18$ ,  $\beta = .25$ ,  $t(21) = 1.1$ ,  $p = .28$ ), nor did illness beliefs ( $B = .15$ ,  $\beta = .09$ ,  $t(21) = .52$ ,  $p = .61$ ), nor did limiting behaviour patterns ( $B = .04$ ,  $\beta = .05$ ,  $t(21) = .21$ ,  $p = .83$ ).

However, all-or-nothing behaviour patterns ( $B = .56$ ,  $\beta = .53$ ,  $t(21) = 3.22$ ,  $p = .004$ ) did make a significant unique contribution to explaining this outcome (anxiety).

Therefore the model did show a significant relationship to the dependent variable, which appeared to be carried by all-or-nothing behaviours.

4. Finally, the analyses were repeated with depression as the dependent variable.

Again, illness severity was entered as a first step in a hierarchical multiple regression in order to partial out any contribution to depression. Illness severity explained a significant amount of the variance in depression ( $R^2 = .32$ , adjusted  $R^2 = .29$ ;  $F(1, 24) = 11.42$ ,  $p = .002$ ).

However, illness beliefs entered at step 2 did not contribute a significant increase in variance explained (from 32.2% to 35.3%, adjusted  $R^2 = .30$ ), a change that was not significant ( $F(1, 23) = 1.07$ ,  $p = .31$ ). On the other hand, limiting and all-or-nothing behaviour patterns entered at step 3 did contribute a significant increase in variance explained (from 35.3% to 58.5%, adjusted  $R^2 = .23$ ), a change that was significant ( $F(2, 21) = 5.90$ ,  $p = .01$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining depression ( $B = .43$ ,  $\beta = .09$ ,  $t(21) = .45$ ,  $p = .66$ ), nor did illness beliefs ( $B = .20$ ,  $\beta = .13$ ,  $t(21) = .80$ ,  $p = .43$ ), nor did all-or-nothing behaviour patterns ( $B = .19$ ,  $\beta = .18$ ,  $t(21) = 1.23$ ,  $p = .23$ ). However, limiting behaviour patterns ( $B = .54$ ,  $\beta = .60$ ,  $t(21) = 3.06$ ,  $p = .01$ ) did make a significant unique contribution to explaining this outcome. Therefore the model showed a significant relationship to depression, which was carried by limiting behaviour patterns only.

To summarise the above findings, the support for hypothesis 2 (part *ii*) is again partial. Results are consistent with those from part *i* above. The findings did not show a significant relationship to the outcome of quality of life (physical functioning).

However, the model was approaching significance and this was likely carried by illness severity based on the figures in the results above. The model did show a significant relationship to the outcome of quality of life (emotional functioning), which did not appear to be carried by any of the variables in particular- though illness severity was approaching significance. The findings demonstrated a significant relationship with the outcome of anxiety, which appeared to be carried by all-or-nothing behaviour patterns. And finally, the proposed model also showed a significant relationship to depression, which was carried by limiting behaviour patterns only. Again, the findings suggest links between all-or-nothing behaviour patterns and anxiety, and between limiting behaviour patterns and depression.

**Research Question 2: What can Self-Compassion add to our Understanding of Responses to Illness in COPD?**

**Hypothesis 3.**

Hypothesis 3 stated that *self-compassion would explain a significant proportion of variance in adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression), after accounting for variance explained by illness severity, beliefs about illness, and behavioural responses to illness (limiting and all-or-nothing behaviour patterns) in people with COPD.* In order to address this hypothesis, a series of hierarchical multiple regression analyses were conducted. These analyses were in order to explore the relationship between self-compassion and the adjustment to illness outcomes of quality of life (physical and emotional functioning), and distress (anxiety and depression), whilst controlling

for illness severity, behavioural responses to illness (limiting and all-or-nothing behaviour patterns) and illness beliefs.

This series of regression analyses was carried out with self-compassion as the predictor variable, and with each of the adjustment to illness outcomes as the dependent variable. The aim was to evaluate the predictive power of self-compassion, and to determine the extent to which self-compassion accounted for variance in the four outcome variables, after accounting for the effects of illness severity, behavioural responses to illness (limiting and all-or-nothing behaviour patterns), and illness beliefs.

1. The first analysis was carried out with quality of life (physical functioning) as the dependent variable. Therefore, illness severity was entered as a first step in a hierarchical multiple regression in order to account for contribution to quality of life (physical functioning). Illness severity explained a significant amount of the variance in quality of life (physical functioning) ( $R^2 = .32$ , adjusted  $R^2 = .29$ ;  $F(1, 24) = 11.12$ ,  $p = .003$ ).

Behavioural responses to illness (limiting and all-or-nothing behaviour patterns) and illness beliefs entered at step 2 did not contribute a significant increase in variance explained (from 31.7% to 34.3%, adjusted  $R^2 = .22$ ), a change that was not significant ( $F(3,21) = .28$ ,  $p = .841$ ).

Self-compassion entered at step 3 did not contribute a significant increase in variance explained (from 34.3% to 40.7%, adjusted  $R^2 = .26$ ), a change that was not significant ( $F(1, 20) = 2.17$ ,  $p = .156$ ). Therefore the model showed a significant relationship to

the dependent variable of quality of life (physical functioning), which was carried by illness severity only.

2. The second analysis was carried out with quality of life (emotional functioning) as the dependent variable. Therefore, illness severity was entered as a first step in a hierarchical multiple regression in order to partial out any contribution to quality of life (emotional functioning). Illness severity explained a significant amount of the variance in quality of life (emotional functioning) ( $R^2 = .58$ , adjusted  $R^2 = .31$ ;  $F(1, 24) = 12.52$ ,  $p = .002$ ).

Behavioural responses to illness (limiting and all-or-nothing behaviour patterns) and illness beliefs entered at step 2 did not contribute a significant increase in variance explained (from 33.8% to 39.2%, adjusted  $R^2 = .31$ ), a change that was not significant ( $F(3,21) = .62$ ,  $p = .611$ ). Self-compassion entered at step 3 contributed a significant increase in variance explained (from 39.2% to 51.7%, adjusted  $R^2 = .40$ ), a change that was significant ( $F(1, 20) = 5.18$ ,  $p = .034$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining quality of life (emotional functioning) ( $B = -.52$ ,  $\beta = -.45$ ,  $t(20) = -2.04$ ,  $p = .055$ ), nor did limiting behaviour (patterns  $B = .03$ ,  $\beta = .14$ ,  $t(20) = .61$ ,  $p = .547$ ), nor did all-or-nothing behaviour patterns ( $B = .001$ ,  $\beta = .003$ ,  $t(20) = .02$ ,  $p = .988$ ), nor did illness beliefs ( $B = -.06$ ,  $\beta = -.16$ ,  $t(20) = -.92$ ,  $p = .368$ ). However, self-compassion did make a significant unique contribution to explaining this outcome ( $B = .65$ ,  $\beta = .43$ ,  $t(20) = 2.28$ ,  $p = .034$ ). Therefore the model showed a significant relationship to the outcome of quality of life (emotional functioning), which was carried by self-compassion only.

3. The third analysis was carried out with anxiety as the dependent variable.

Therefore, illness severity was entered as a first step in a hierarchical multiple regression in order to partial out any contribution to anxiety. Illness severity did not explain a significant amount of the variance in anxiety ( $R^2 = .14$ , adjusted  $R^2 = .11$ ;  $F(1, 24) = 4.03$ ,  $p = .056$ ). However it was approaching significance.

Behavioural responses to illness (limiting and all-or-nothing behaviour patterns) and illness beliefs entered at step 2 contributed a significant increase in variance explained (from 14.4% to 44.3%, adjusted  $R^2 = .34$ ), a change that was significant ( $F(3,21) = 3.77$ ,  $p = .026$ ). Self-compassion entered at step 3 also contributed a significant increase in variance explained (from 44.3% to 61.7%, adjusted  $R^2 = .52$ ), a change that was significant ( $F(1, 20) = 9.08$ ,  $p = .007$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining anxiety ( $B = 1.0$ ,  $\beta = .22$ ,  $t(20) = 1.1$ ,  $p = .286$ ), nor did limiting behaviour patterns ( $B = -.10$ ,  $\beta = -.12$ ,  $t(20) = -.59$ ,  $p = .565$ ), nor did illness beliefs ( $B = .09$ ,  $\beta = .06$ ,  $t(20) = .35$ ,  $p = .727$ ). However, all-or-nothing behaviour patterns ( $B = .38$ ,  $\beta = .36$ ,  $t(20) = 2.41$ ,  $p = .026$ ) and self-compassion did make a significant unique contribution to explaining this outcome ( $B = -3.06$ ,  $\beta = -.51$ ,  $t(20) = -3.01$ ,  $p = .007$ ). Therefore the model showed a significant relationship to the outcome of anxiety, which was carried by both all-or-nothing behaviour patterns and self-compassion.

4. The fourth and final analysis was carried out with depression as the dependent variable. Therefore, illness severity was entered as a first step in a hierarchical multiple regression in order to partial out any contribution to depression. Illness

severity explained a significant amount of the variance in depression ( $R^2 = .32$ , adjusted  $R^2 = .29$ ;  $F(1, 24) = 11.42$ ,  $p = .002$ ).

Behavioural responses to illness (limiting and all-or-nothing behaviour patterns) and illness beliefs entered at step 2 contributed a significant increase in variance explained (from 32.2% to 58.5%, adjusted  $R^2 = .51$ ), a change that was significant ( $F(3,21) = 4.44$ ,  $p = .014$ ). Self-compassion entered at step 3 did not contribute a significant increase in variance explained (from 58.5% to 61.3%, adjusted  $R^2 = .52$ ), a change that was not significant ( $F(1, 20) = 1.40$ ,  $p = .25$ ).

In the final equation, illness severity did not make a significant unique contribution to explaining anxiety ( $B = .35$ ,  $\beta = .07$ ,  $t(20) = .37$ ,  $p = .712$ ), nor did all-or-nothing behaviour patterns ( $B = .12$ ,  $\beta = .11$ ,  $t(20) = .71$ ,  $p = .485$ ) nor did illness beliefs ( $B = .18$ ,  $\beta = .11$ ,  $t(20) = .70$ ,  $p = .490$ ), nor did self-compassion ( $B = -1.25$ ,  $\beta = -.20$ ,  $t(20) = -1.18$ ,  $p = .250$ ). However, limiting behaviour patterns ( $B = .48$ ,  $\beta = .53$ ,  $t(20) = 2.64$ ,  $p = .016$ ) did make a significant unique contribution to explaining this outcome. Therefore the model showed a significant relationship to the dependent variable, which was carried by limiting behaviour patterns.

To summarise the findings from analyses with regard to this particular hypothesis; the proposed model showed a significant relationship to the outcome of quality of life (physical functioning), which appeared to be carried by illness severity only. The model showed a significant relationship to the outcome of quality of life (emotional functioning), which appeared to be carried by self-compassion only. The model showed a significant relationship to the outcome of anxiety, which was carried by both all-or-nothing behaviour patterns and self-compassion. Finally, the model

showed a significant relationship to depression, which was carried by limiting behaviour patterns only. These findings partially support the hypothesis, and suggest that self-compassion contributes to the variance in adjustment outcomes, when considering quality of life (emotional functioning) and anxiety.

#### **Hypothesis 4.**

Hypothesis 4 stated that *behaviours in response to illness (limiting and all-or-nothing behaviour patterns) would mediate the relationship between self-compassion and adjustment to illness in terms of quality of life (physical and emotional functioning) and distress (anxiety and depression) in people with COPD.* Testing of Hypothesis 4 was separated initially into three parts for analysis (models *i* to *iii*). The traditional causal-steps approach to assessing mediation (Baron & Kenny, 1986) requires that each pair of the three variables to be investigated in a proposed mediation model be significantly correlated (Baron & Kenny, 1986; Raque-Bogdan et al., 2011). In keeping with these requirements, three particular mediation models relevant to Hypothesis 4 were tested. This is because it was found that in only three possible mediation models (models *i* to *iii*), did each pair of relevant variables significantly correlate. The results of testing models *i* to *iii* are described to follow, after which the results of testing the additional exploratory mediation model (model *iv*) are presented as exploratory analyses.

#### ***Model i.***

The first relationship to be tested for mediation was the relationship between self-compassion and depression (Figure 1A below), with limiting behaviour patterns as the

mediator variable. This mediation model is illustrated below in Figure 1B. The bivariate correlations for each pair of variables in the mediation model are shown in Table 6 below. In terms of this mediation model, it was hypothesised that *limiting behaviour patterns would mediate the relationship between self-compassion and depression*, such that higher levels of self-compassion would be associated with lower levels of limiting behaviour patterns, and in turn, lower levels of depression.

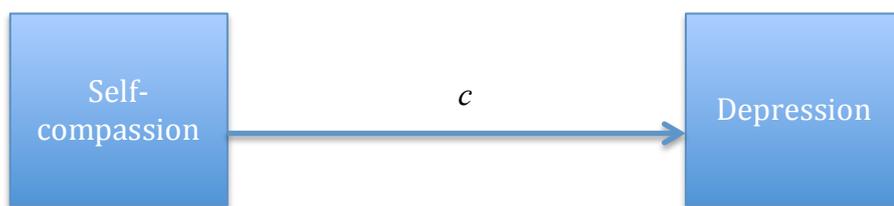


Figure 1A. Direct relationship between self-compassion and depression.

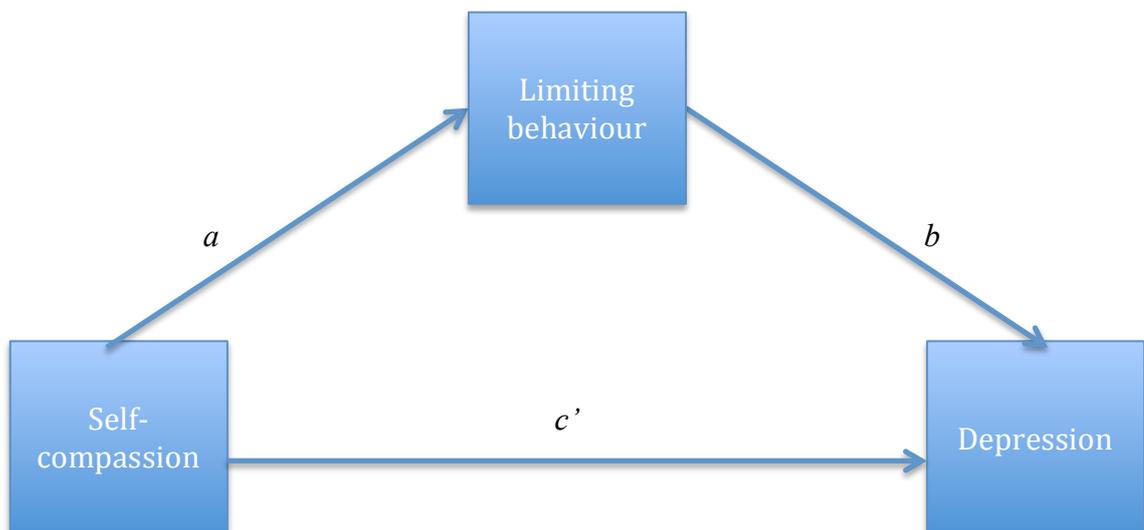


Figure 1B. Relationship between self-compassion and depression mediated by limiting behaviour patterns.

Table 6

*Bivariate correlations between variables of interest (Hypothesis 4, model i)*

	Limiting behaviours		Depression	
	r	p	r	p
Self-compassion	-.46*	.02	-.54**	.004
Depression			.73**	.004

*N* = 26

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

Findings suggest that the relationship between self-compassion and depression was mediated by limiting behaviour patterns, such that higher levels of self-compassion were associated with lower levels of limiting behaviour patterns, and in turn, lower levels of depression. Bootstrapping procedures were used to test the significance of this indirect effect (indirect effect = -1.74, 95% CI [-3.62, -.29]). The unstandardised indirect effect was found to be significant (see Table 7), and therefore mediation criteria are satisfied according to Preacher and Hayes (2004, 2008). Unstandardised coefficients are the preferred metric in causal modeling, and are therefore reported for the indirect effect figure in Table 7 below (Hayes, 2016).

Table 7

*Tests of the potential mediating effect of limiting behaviour patterns on the relationship between self-compassion and depression (Hypothesis 4, model i)*

a path		b path		c' path		total effect c path		indirect effect (a path x b path)		indirect effect (a path x b path)	
B	p	B	p	B	p	B	p	B	SE	95% CI Lower Higher	
-3.15	.02*	.55	.001**	-1.64	.09	-3.36	.004**	-1.74	.83	-3.62	-.29

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

B = unstandardised coefficient.

SE = standard error.

CI = confidence interval.

### ***Model ii.***

The second relationship to be tested for mediation was the relationship between self-compassion and anxiety (Figure 2A below), with all-or-nothing behaviour patterns as the mediator variable. This mediation model is illustrated below in Figure 2B. The bivariate correlations for each pair of variables in the mediation model are shown in Table 8 below. In terms of this mediation model, it was hypothesised that *all-or-nothing behaviour patterns would mediate the relationship between self-compassion and anxiety*, such that higher levels of self-compassion would be associated with lower levels of all-or-nothing behaviours patterns, and in turn, lower levels of anxiety.

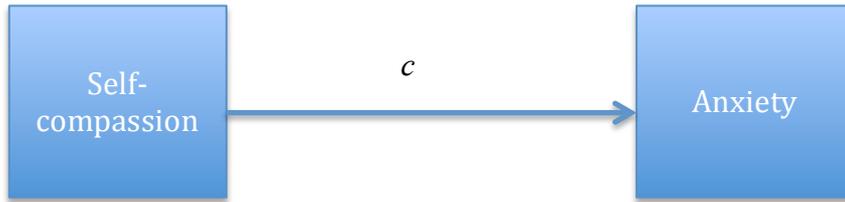


Figure 2A. Direct relationship between self-compassion and anxiety.

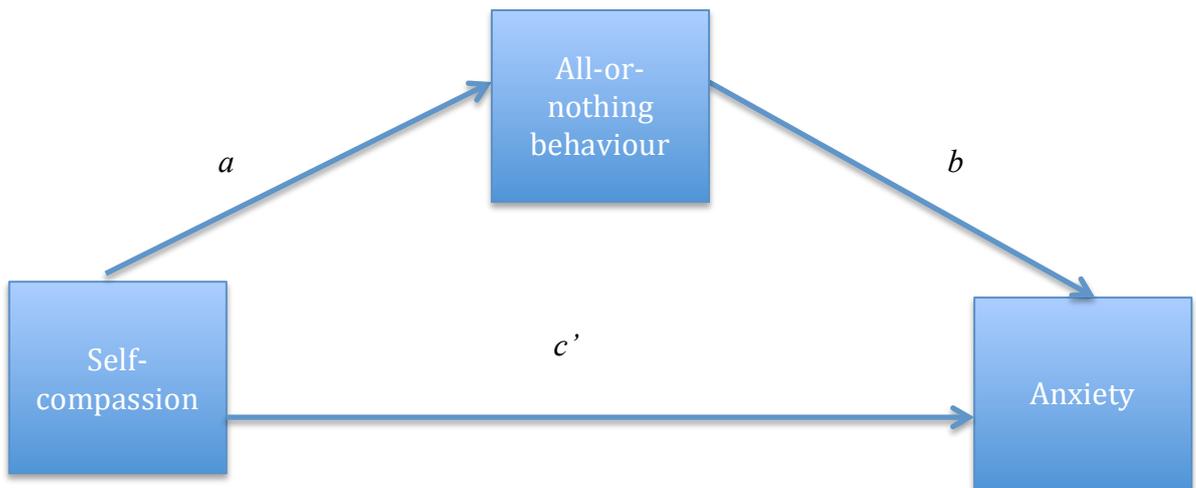


Figure 2B. Relationship between self-compassion and anxiety mediated by all-or-nothing behaviour patterns.

Table 8

*Bivariate correlations between variables of interest (Hypothesis 4, model ii)*

	All-or-nothing behaviours		Anxiety	
	r	p	r	p
Self-compassion	-.40*	.046	-.70**	.000
Anxiety	.57**	.002		

*N* = 26

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

Findings suggest that the relationship between self-compassion and anxiety was mediated by all-or-nothing behaviour patterns, such that higher levels of self-compassion were associated with lower levels of all-or-nothing behaviour patterns, and in turn, lower levels of anxiety. Bootstrapping procedures were used to test the significance of this indirect effect (indirect effect= -.86, 95% CI [-3.07, -.01]). The unstandardised indirect effect was found to be significant (see Table 9), and therefore mediation criteria are satisfied according to Preacher and Hayes (2004, 2008). Unstandardised coefficients are the preferred metric in causal modeling, and are therefore reported for the indirect effect figure in Table 9 below (Hayes, 2016).

Table 9

*Tests of the potential mediating effect of all-or-nothing behaviour patterns on the relationship between self-compassion and anxiety (Hypothesis 4, model ii)*

<i>a</i> path		<i>b</i> path		<i>c</i> ' path		total effect <i>c</i> path		indirect effect ( <i>a</i> path x <i>b</i> path)		indirect effect ( <i>a</i> path x <i>b</i> path)	
B	p	B	p	B	p	B	p	B	SE	95% CI	
										Lower	Higher
-2.28	.046*	.37	.02*	-3.32	.001**	-4.16	.0001**	-.86	.73	-3.07	-.01

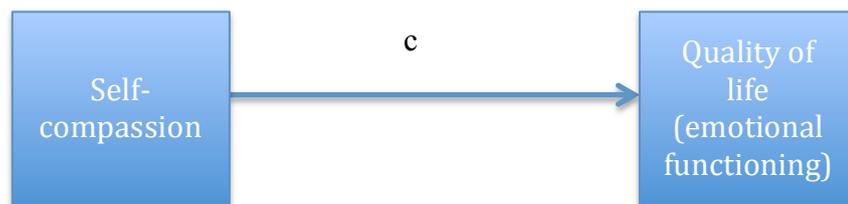
\*Correlation is significant at the 0.05 level (2-tailed).  
 \*\*Correlation is significant at the 0.01 level (2-tailed).  
 B = unstandardised coefficient.  
 SE = standard error.  
 CI = confidence interval.

Based on the first two mediation models above (Figures 1B & 2B), findings suggest that self-compassion works via the way in which people behave in response to their

illness, such that greater self-compassion is associated with lower limiting and all or nothing behaviour patterns, and in turn, improved outcomes.

***Model iii.***

The third relationship to be tested for mediation was the relationship between self-compassion and quality of Life (emotional functioning; Figure 3A below), with limiting behaviour patterns as the mediator variable. This mediation model is illustrated below in Figure 3B. The bivariate correlations for each pair of variables in the mediation model are shown in Table 10 below. In terms of this mediation model, it was hypothesised that *limiting behaviour patterns would mediate the relationship between self-compassion and quality of life (emotional functioning)*, such that higher levels of self-compassion would be associated with lower levels of limiting behaviour patterns and in turn, higher levels of quality of life (emotional functioning).



*Figure 3A.* Direct relationship between self-compassion and quality of life (emotional functioning).

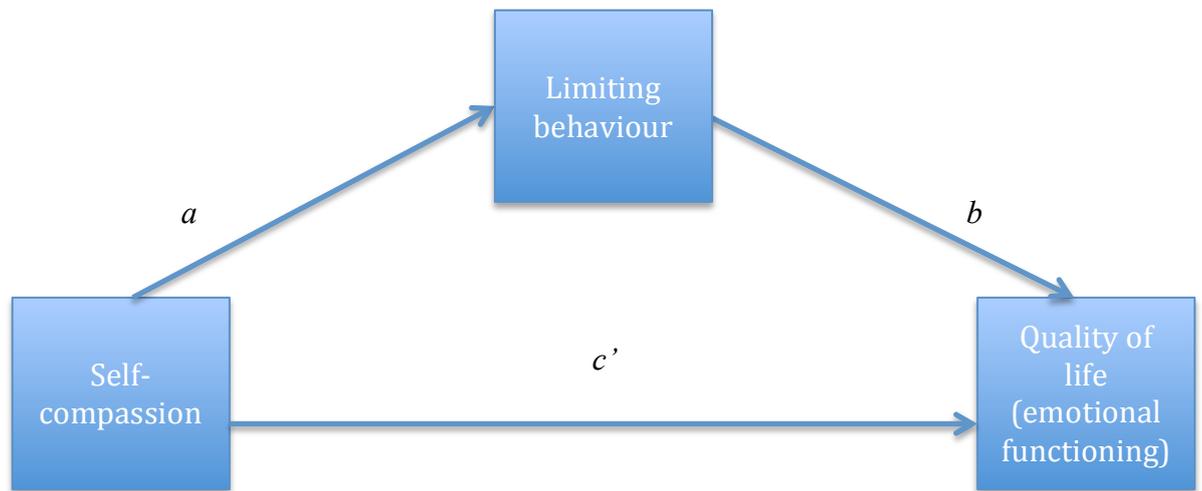


Table 10

*Bivariate correlations between variables of interest (Hypothesis 4, model iii)*

	Limiting behaviours		Quality of life (emotional function)	
	r	p	r	p
Self-compassion	-.46*	.02	.57**	.002
Quality of life (emotional function)			-.43**	.03

*N* = 26

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

Findings suggest that the relationship between self-compassion and quality of life (emotional functioning) was not mediated by limiting behaviour patterns, such that higher levels of self-compassion were not associated with lower levels of limiting

behaviour patterns, or in turn, higher levels of quality of life (emotional functioning). Bootstrapping procedures were used to test the significance of this indirect effect (indirect effect= .11, 95% CI [-.11, .59]). The unstandardised indirect effect was not found to be significant (see Table 11), and therefore mediation criteria are not satisfied according to Preacher and Hayes (2004, 2008). Unstandardised coefficients are the preferred metric in causal modeling, and are therefore reported for the indirect effect figure in Table 11 below (Hayes, 2016).

Table 11

*Tests of the potential mediating effect of limiting behaviour patterns on the relationship between self-compassion and quality of life (emotional functioning) (Hypothesis 4, model iii)*

<i>a</i> path		<i>b</i> path		<i>c</i> ' path		total effect <i>c</i> path		indirect effect ( <i>a</i> path x <i>b</i> path)		indirect effect ( <i>a</i> path x <i>b</i> path)	
B	p	B	p	B	p	B	p	B	SE	95% CI Lower Higher	
-3.15	.02*	-.05	.28	.72	.02*	.86	.002**	.11	.17	-.11	.59

\*Correlation is significant at the 0.05 level (2-tailed).  
 \*\*Correlation is significant at the 0.01 level (2-tailed).  
 B = unstandardised coefficient.  
 SE = standard error.  
 CI = confidence interval.

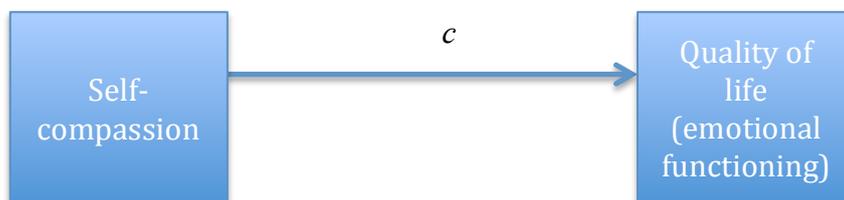
### ***Exploratory analyses: Model iv.***

Due to the above findings, which suggest the role of self-compassion in the way that people behaviourally respond to their illness (limiting and all-or-nothing behaviour patterns), further exploration of this relationship was considered worthy. Recent unpublished research (Bowers, Wroe, & Pincus, in press) has found that quality of life in people with fibromyalgia is associated with belief patterns, and that this relationship is serially mediated by illness behaviours, and in turn by depression. However, this mediation model was not significant when depression was not included. Bowers et al.'s research therefore suggested a key role for depression in the relationship between specific illness-related beliefs, illness behaviours, and illness-related quality of life. This relationship was therefore tested in people with COPD as an exploratory mediation analysis.

Therefore, the fourth and final relationship to be tested for mediation was an exploratory mediation model of the relationship between self-compassion and quality of life (emotional functioning; Figure 4A below), this time with limiting behaviour patterns and depression as two potential serial mediator variables. This exploratory mediation model is illustrated below in Figure 4B. The bivariate correlations for each pair of variables in the mediation model are shown in Table 12. In terms of this particular mediation model, it was hypothesised that *limiting behaviour patterns and depression would serially mediate the relationship between self-compassion and quality of life (emotional functioning)*, such that higher levels of self-compassion would be associated with lower levels of limiting behaviour patterns, and in turn, lower levels of depression, and therefore higher levels of quality of life (emotional functioning).

In a simple mediation model (as above in models *i* to *iii*), the total effect (*c*) of an independent variable (IV) on a dependent variable (DV) is composed of a direct effect (*c'*) of the IV on the DV, and an indirect effect of the IV on the DV through a proposed mediator (M). In the cases of the previous models *i* to *iii*, path *a* has represented the effect of the IV on the M, whilst path *b* has represented the effect of the M on the DV, partialing out the effect of the IV. For each of these three models (*i* to *iii*), the indirect effect was estimated as  $ab$  (Baron & Kenny, 1986), and the significance of which was assessed using a bootstrapping resampling method with 5000 resamples via INDIRECT with SPSS (Preacher & Hayes, 2008) (as described in the Analyses section above, pp. 60 – 62).

However in the case of this multiple serial mediation model (model *iv*), where there are two proposed mediator variables, the indirect effect can now be estimated as  $a_1a_2b$  ( $a_1 \times a_2 \times b$ ; illustrated in Figure 4B below). In this case, via PROCESS with SPSS (as described in Analyses section above, pp. 62 -63), a bootstrapping resampling method with 5000 resamples was used to assess the significance of the indirect effect (again see Hayes, 2012).



*Figure 4A.* Direct relationship between self-compassion and quality of life (emotional functioning).

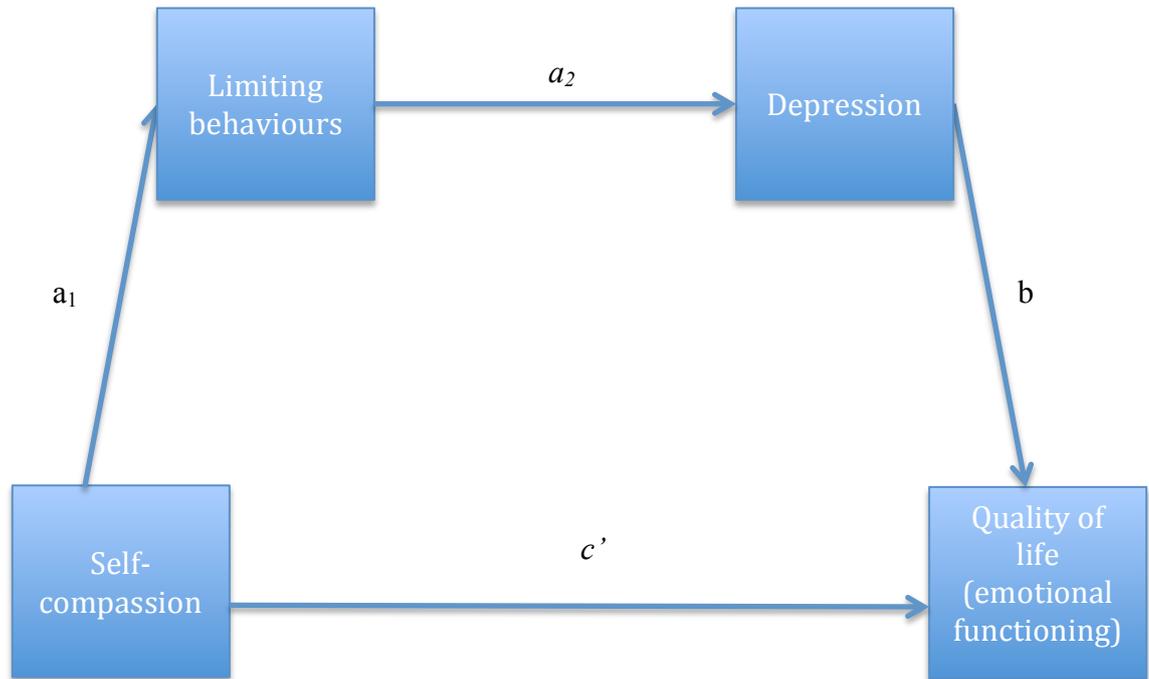


Figure 4B. Relationship between self-compassion and quality of life (emotional functioning) serially mediated by limiting behaviour patterns and depression.

Table 12

*Bivariate correlations between variables of interest (exploratory analyses: model iv)*

	Limiting behaviours		Depression		Quality of life (emotional function)	
	r	p	r	p	r	p
Self-compassion	-.46*	.02	-.54**	.004	.57**	.002
Quality of life (emotional function)	-.43*	.03	-.68**	.000		
Depression			.73**	.000		

N = 26

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

Findings (Table 13 below) suggest that the relationship between self-compassion and quality of life (emotional functioning) was serially mediated by limiting behaviour patterns and depression, such that higher levels of self-compassion were associated with lower levels of limiting behaviour patterns, and in turn, lower levels of depression, and therefore higher levels of quality of life (emotional functioning). Bootstrapping procedures were used to test the significance of this indirect effect (indirect effect= .27, 95% CI [.06, .72]). The unstandardised indirect effect was found to be significant (see Table 13), and therefore mediation criteria are satisfied according to Preacher and Hayes (2004, 2008) and Hayes (2012). Unstandardised coefficients are the preferred metric in causal modeling, and are therefore reported for the indirect effect figure in Table 13 (Hayes, 2016). These results can be inferred on the basis that bias-corrected confidence intervals relevant to the indirect effect  $a_1a_2b$  for the model [self-compassion → limiting behaviour patterns → depression → quality of life (emotional functioning)] do not include zero.

Table 13

*Tests of the potential serial mediating effect of limiting behaviour patterns and depression on the relationship between self-compassion and quality of life (emotional functioning)(exploratory analyses: model iv)*

$a_1$ path		$a_2$ path		$b$ path		$c'$ path		total effect $c$ path		indirect effect ( $a_1a_2b$ )		indirect effect ( $a_1a_2b$ )	
B	p	B	p	B	p	B	p	B	p	B	SE	95% CI Lower Higher	
-3.15	.02*	.55	.001**	-.16	.01**	.46	.09	.86	.002**	.27	.16	.06	.72

\*Correlation is significant at the 0.05 level (2-tailed).  
 \*\*Correlation is significant at the 0.01 level (2-tailed).  
 B = unstandardised coefficient.  
 SE = standard error.  
 CI = confidence interval.

## **Discussion**

The main findings of the current research are summarised below. The most notable findings are discussed along with both their theoretical and clinical implications. This is followed by a presentation of the limitations of the current study, and finally, some suggested directions for future research. It is concluded that, although it is likely a more complicated picture than the original hypotheses would suggest, there is a role for both self-compassion and illness behaviours in adjustment to COPD. Future longitudinal research, and importantly, larger sample sizes, would illuminate the relationships between illness beliefs, illness behaviours, and self-compassion further.

### **Summary of the Main Findings**

#### **Research question 1: The roles of illness beliefs and illness behaviours in COPD.**

In terms of illness beliefs, the findings from the correlation analyses (Hypothesis 1) showed that greater negative beliefs about illness were associated with poorer self-reported quality of life (emotional functioning). However, the association was not significant in the case of quality of life (physical functioning). Greater negative beliefs about COPD among participants were associated with higher levels of depression, but this association was not found for anxiety. However, when controlling for self-reported levels of illness severity, the above associations did not remain.

In terms of illness behaviours, the findings from the correlation analyses (Hypothesis 1) showed that limiting behaviour patterns were associated with poorer quality of life (emotional functioning), and also with higher levels of depression. Higher levels of

all-or-nothing behaviour patterns were shown to be associated with higher levels of anxiety. When controlling for illness severity, the associations between limiting behaviour patterns and depression, and all-or-nothing behaviour patterns and anxiety remained- indicating the strength of these relationships beyond illness severity. However, the significant relationship between limiting behaviour patterns and quality of life (emotional functioning) did not remain in the context of this control. As such, the data initially revealed a relationship between illness behaviours and outcomes beyond the influence of illness severity; where limiting behaviour patterns were associated with depression, and all-or-nothing behaviour patterns were associated with anxiety.

The findings from the regression analyses (Hypothesis 2 parts *i* & *ii*) reflected the patterns found in the results of the initial correlations. Most interestingly, the regression models showed a significant relationship to the outcome of anxiety, which was carried by all-or-nothing behaviour patterns; and a significant relationship to the outcome of depression, which was carried by limiting behaviour patterns. These results supported the emerging relationships between all-or-nothing behaviour patterns and anxiety, and between limiting behaviour patterns and depression- beyond the contributions of illness severity and illness beliefs.

### **Research question 2: The role of self-compassion in COPD.**

The second general research question explored the role of self-compassion, and how this positive psychological construct might add to our understanding of responses to illness in COPD. The regression analyses (Hypothesis 3) showed a significant

relationship to the outcome of quality of life (emotional functioning), which was carried by self-compassion only; a significant relationship to the outcome of anxiety, which was carried by both all-or-nothing behaviour patterns and self-compassion; and a significant relationship to the outcome of depression, which was carried by limiting behaviour patterns only. These findings therefore partially supported Hypothesis 3, in that self-compassion explained a significant proportion of variance in adjustment to illness in terms of quality of life (emotional functioning) and anxiety, after accounting for variance explained by illness severity, beliefs about illness, and behavioural responses to illness (limiting and all-or-nothing behaviour patterns) in people with COPD.

Furthermore, mediation analyses (Hypothesis 4) suggested that the relationship between self-compassion and depression was mediated by limiting behaviour patterns, such that higher levels of self-compassion were associated with lower levels of limiting behaviours patterns, and in turn, lower levels of depression. Findings also suggested that the relationship between self-compassion and anxiety was mediated by all-or-nothing behaviour patterns, such that higher levels of self-compassion were associated with lower levels of all-or-nothing behaviours patterns, and in turn, lower levels of anxiety. These two mediation models suggest that self-compassion may work via the patterns in which people may behave in response to their illness, such that higher levels of self-compassion might be associated with lower limiting and all-or-nothing behaviour patterns, which in turn might be associated with improved outcomes.

Further exploratory mediation analysis found that the relationship between self-compassion and quality of life (emotional functioning) was serially mediated by

limiting behaviour patterns and depression, such that higher levels of self-compassion were associated with lower levels of limiting behaviour patterns, and in turn, lower levels of depression, and again in turn, higher levels of quality of life (emotional functioning). Notably, the quality of life measure was health-related and COPD-specific.

## **Theoretical Implications**

### **The roles of Illness beliefs and illness behaviours.**

The findings that illness beliefs did not predict distress or quality of life in COPD, when accounting for the influence of illness severity, were not expected. These findings are inconsistent with previous COPD-focused studies (Kaptein et al., 2008; Scharloo et al., 1998, 2000, 2007; Zoeckler et al., 2014), which showed that illness beliefs can determine a variety of outcomes such as symptoms of psychopathology, health-related quality of life, exercise capacity, and prescribed medication use, after controlling for objective measures of severity of COPD (for example, pulmonary function). These findings are also inconsistent with studies across other illnesses, in which a relationship has been demonstrated between illness beliefs and numerous outcomes (see Hagger & Orbell, 2003). A number of reasons for these results are suggested in the 'Limitations' section below (p. 106).

Other findings however, were more consistent with previous research trends, including the emerging relationships between limiting behaviour patterns and the outcome of depression, and all-or-nothing behaviour patterns and the outcome of anxiety. These relationships have been shown elsewhere. For instance, in her working

model of adjustment to chronic illness, Moss-Morris' (2013) highlighted the contribution of such unhelpful behavioural responses towards adjustment difficulties. In terms of the former relationship specifically (limiting behaviour patterns and depression), research in depression has consistently made links between low activity levels (limiting behaviour patterns) and low mood (Ekers, Richards, & Gilbody, 2008). This relationship might be apparent in COPD populations due to the fear of breathlessness that has been consistently related to avoidance of physical activity in COPD (Lindgren et al., 2014; Zoeckler et al., 2014). In terms of the latter relationship specifically (all-or-nothing behaviour patterns and anxiety), Spence and Moss-Morris (2007) reported that alongside gender, a cluster of anxiety related variables and all-or-nothing behaviours predicted the development of irritable bowel syndrome (IBS) following gastroenteritis. Thus, all-or-nothing behaviour patterns and anxiety have been linked in the past.

These relationships are also reflected in the cognitive behavioural approach to medically unexplained syndromes (Deary et al., 2007), including CFS (Deale et al., 1998; Surawy et al., 1995) and IBS (Spence & Moss-Morris, 2007). The cognitive behavioural approach highlights the contributions of both of these specific behaviour patterns in maintaining low mood and anxiety, as well as physical symptoms in these medically unexplained syndromes- particularly in CFS (see Surawy et al., 1995). For instance, as earlier noted, Deale et al. (1998) demonstrated that beliefs about the harmful effects of physical activity were related to poorer outcomes in patients with CFS in terms of both fatigue (most prominent physical symptom) and mood (distress). Following this, Deary et al. (2007) ventured that theoretically, these beliefs about the harmful effects of activity inform CFS patients' behaviour- leading to behaviour

avoidance (limiting behaviour patterns). It is therefore possible that beliefs about the harmfulness of exercise lead to higher levels of activity avoidance, and culminate in persistent limiting behaviour patterns. Equally, this could be the case in COPD, where fears related to breathlessness (see Lindgren et al., 2014; Zoeckler et al., 2014) may play into beliefs about the potential damage of exertion, which may lead to activity avoidance.

Avoidance of activity, as well as being associated with low mood, can lead to deconditioning and increased breathlessness in COPD (Almagro & Castro, 2013)- that is, greater severity of symptoms. Although severity of symptoms is used as an outcome when considering medically unexplained conditions such as CFS, IBS and pain, in the current study, as in much of the research into psychological adjustment in COPD (see Kaptein et al., 2008; Scharloo et al., 1998, 2000, 2007; Zoeckler et al., 2014) and other long-term conditions (see Hagger & Orbell, 2003), illness severity was considered an independent variable. It was beyond the scope of the current study, but it would be interesting to consider the role of illness beliefs and illness behaviours with medical symptoms (such as fatigue and breathlessness) as outcomes in conditions that are *not* medically unexplained (see 'Future Research' section below). It may be expected that illness beliefs, illness behaviours, mood, and severity of symptoms work in a maintaining cycle- consistent with the cognitive behavioural model of medically unexplained symptoms (see Deale et al., 1998; Deary et al., 2007; Surawy et al., 1995). Further research is needed to identify the exact nature of the illness-related beliefs in operation, and how these are related to illness behaviours. Nonetheless, in response to the current study's first research question, the findings suggest relationships between limiting behaviour patterns and depression; and

between all-or-nothing behaviour patterns and anxiety, and that these relationships are not specific to, but important when considering COPD.

### **The protective role of self-compassion.**

The second research question addressed a novel area; that is, the role of self-compassion in living with COPD. The findings are consistent with the proposal that self-compassion plays a protective role against distress, and in turn protects quality of life in people with COPD. These findings support previous research by Pinto-Gouveia et al. (2014), who demonstrated the role of self-compassion in protecting against stress and depression, and improving quality of life in cancer patients (Pinto-Gouveia et al., 2014). The findings are also consistent with Przewdziecki et al.'s (2013) study, in which it was shown that self-compassion protected breast cancer survivors from psychological distress (depression, anxiety and stress) as a result of body image disturbance following breast cancer treatment.

However, the current study went beyond Pinto-Gouveia et al.'s (2014) remit, and explored the possible processes through which the relationship between self-compassion, distress and quality of life exists. Firstly, the results suggested that greater self-compassion was associated with lower levels of limiting behaviour patterns, and in turn, lower levels of depression. As such, self-compassion appears to operate via the way in which people behave in response to their illness. This particular finding carries theoretical implications for many illnesses. For instance, limiting behaviour patterns have been shown to be associated with poorer outcomes in terms of symptoms in CFS (Candy et al., 2002, 2004; Hotopf et al. 1996; Sharpe & Wessely, 1998), and several other physical health conditions (Allen, Glasziou, & Del Mar,

1999), where bed rest has been described as an unhelpful- even harmful- approach that impedes recovery. The current findings suggest that self-compassion may protect against unhelpful limiting behaviour patterns, and therefore possibly improve physical symptoms in CFS and other illnesses. Further research would be required in order to determine whether this would be the case in COPD also. However, the current findings suggest that in a COPD population, self-compassion, in protecting against limiting behaviour patterns, may possibly improve adjustment-related outcomes, including depression. These results therefore reflect the findings of Kindermans et al. (2011), who showed that limiting behaviour patterns were associated with depressed mood in chronic pain.

With regard to all-or-nothing behaviour patterns, the current study suggests that self-compassion was also associated with lower all-or-nothing behaviour patterns, and in turn, lower levels of anxiety. Again, self-compassion appears to be operating via the way in which patients behave in response to their illness. As described, the ability of higher all-or-nothing behaviour patterns to predict poorer outcomes in terms of illness symptoms is consistent across research in IBS, CFS, chronic pain and MS (Kindermans et al., 2011; Spence et al., 2005; Spence & Moss-Morris, 2007; Surawy et al., 1995; Skerrett & Moss-Morris, 2006). From the current findings, it now appears as though this particular behavioural pattern in response to illness is possibly also related to higher levels of anxiety in COPD patients.

On the other hand, it is interesting to note that limiting behaviour patterns did not appear to mediate the relationship between self-compassion and quality of life (emotional functioning), unless depression was included in a serial mediation model. That is, in further exploratory mediation analyses (exploratory analyses; model *iv*

above), higher levels of self-compassion were shown to be associated with lower levels of limiting behaviour patterns, and in turn, lower levels of depression, and again in turn, higher levels of quality of life (emotional functioning). Notably, the quality of life measure was a COPD-specific measure of health-related quality of life. This exploratory finding, whilst not originally hypothesised, suggests the potential importance of psychological distress (namely depression) in understanding the roles of self-compassion and behavioural responses in adjustment to illness. These findings are consistent with recent research by Bowers et al. (in prep), which suggests that illness-related behaviours and depression serially mediate the relationship between beliefs and quality of life in fibromyalgia.

Cumulatively, on the basis of all of the above self-compassion based mediation analyses (models *i* to *iv*), it is concluded that low self-compassion might be a risk factor for counterproductive behavioural responses in COPD patients, such as limiting and all-or-nothing behaviour patterns, which are in turn, a potential risk factor for poorer adjustment outcomes of psychological distress and health-related quality of life. That is, COPD patients who are higher in self-compassion might engage less in these unhelpful behaviour patterns. This conclusion is consistent with previous research in COPD, as well as other illnesses. Firstly, this conclusion is reflective of Terry and Leary's (2011) suggestion that people who are higher in self-compassion would treat themselves with care, and that their self-compassion should enhance their ability to engage in more helpful behavioural patterns that promote their physical and psychological wellbeing. Secondly, this conclusion is also consistent with Brion et al.'s (2014) results, which showed that HIV patients who were higher in self-compassion behaved in healthier, more adaptive ways. Brion et al. concluded that

people who are high in self-compassion manage their illness more successfully than people who are low in self-compassion- specifically in terms of their health-related behaviours. Finally, in relation to COPD patients specifically, this conclusion also mirrors Lindgren et al. (2014), who highlighted the behavioural impact of self-judgment and shame (or low self-compassion) on COPD patients, examples of which included maladaptive behaviours such as hiding the diagnosis and avoiding treatment.

### **Clinical Implications**

The current findings also have implications for helping patients to cope with long-term physical illness. Given the co-morbidity of the current sample (see ‘Participants’ section, pp. 38- 39), these implications cannot be applied exclusively to COPD patients, but rather to physical illnesses more broadly. For one, as noted earlier, adjustment to illness is often conceptualised in terms of the presence or absence of psychopathology, including the symptoms of depression and anxiety. This mental health approach (Moss-Morris, 2013) has implications for treatment, in that traditional mental health interventions are likely to be applied- resulting in therapeutic approaches that tackle the psychopathology in isolation, rather than in the context of a physical illness. As Moss-Morris (2013) notes, patients with long-term health conditions may not always find this approach particularly effective (see Hind et al., 2010).

To address this, the current findings suggest that psychotherapeutic approaches should tackle anxiety and depression in the specific context of physical illness. Based on previous research, and in conjunction with current findings, this might mean

addressing any unhelpful illness-related beliefs (such as catastrophic or negative beliefs about illness), or maladaptive illness-related behaviours (e.g. limiting or all-or-nothing behaviour patterns). Typical mental health interventions, such as CBT protocols for depression and anxiety, may be helpful, but only if targeted at the level of illness-related beliefs and behaviours. This has been demonstrated in diabetes by Wroe, Rennie, Gibbons, Hassy, and Chapman (2015), who showed that a psychological intervention focusing on depression is only effective if the intervention is adapted such that the beliefs about the illness, and any related behaviours, are considered. The current findings suggest that limiting and all-or-nothing behaviour patterns are key behaviours, and could be targeted in interventions for patients with COPD and other physical illnesses.

In addition to addressing unhelpful illness-related beliefs and behaviours, the findings would also suggest addressing patients' levels of self-compassion in chronic physical illness. COPD patients were considered likely to be a particularly at-risk group for low self-compassion due to the self-judgment and shame associated with what patients consider to be a 'self-inflicted' illness, derived from a history of smoking (Lindgren et al., 2014). The majority of participants (69.23%) in the current sample attributed their condition to smoking at least in part (from IPQ-R *Cause* subscale; Appendix M). Following Lindgren et al.'s (2014) findings, this would imply feelings of shame related to a self-inflicted disease, which could be interpreted as low levels of self-compassion as per Neff's (2003a, 2003b) definition. As noted, like COPD patients, HIV patients are also considered to be at risk of low self-compassion due to the way in which they might feel at fault for acquiring the disease through their own behaviour (Brion et al., 2014). On the basis of their findings, Brion et al. (2014)

concluded that psycho-educational interventions that teach people to approach their illness with self-compassion could produce more adaptive emotional and behavioral reactions in HIV populations. Patients could be taught to respond more self-compassionately, they suggested, and enhancing self-compassion might lower illness-related shame and maladaptive behavioural responses in HIV patients (Brion et al., 2014),

On this basis, and on the basis of the current research, it is possible that compassion-enhancing work could also reduce shame and maladaptive behavioural responses in individuals with COPD. Furthermore, given the physical co-morbidity of the current sample, such self-compassion interventions may be beneficial for individuals with a range of other physical conditions also. Specifically, the current findings suggest that self-compassion interventions may be effective in terms of the suggested association with increased helpful illness behaviours, and thus reduced anxiety and depression. Previous research supports these results, in that brief experimental interventions that lead people to reframe problems in a self-compassionate manner have previously been seen to lower negative emotions and reduce maladaptive behaviours in non-illness groups (see Brion et al., 2014). Furthermore, interventions that promote self-compassion have been shown to reduce self-criticism and shame, and ameliorate the maladaptive reactions that often accompany self-blame (see Gilbert & Procter, 2006; Leary, Tate, Adams, Batts Allen, & Hancock, 2007). However, as Brion et al. noted, more research is needed to examine the impact of self-compassion interventions on behavioural and emotional responses in HIV and in other long-term physical conditions.

Some of this work has already begun, with feelings of self-criticism in stroke patients being targeted using Compassion Focused Therapy (CFT; see Gilbert, 2009; Shields & O'Connell, 2013). CFT is a psychological treatment approach that was specifically designed for individuals with high levels of self-criticism and shame (see Gilbert & Procter, 2006). Within CFT, enhancing the individual's capacity for compassion and self-compassion is achieved through compassionate mind training- a range of exercises that focus on developing compassionate skills. These exercises may include compassionate attention, compassionate thinking, and compassionate imagery (see Gilbert, 2009). There is also some evidence for the effectiveness of CFT for individuals with psychological difficulties following acquired brain injury (ABI), in which CFT has been associated with a reduction in symptoms of anxiety, depression, and self-criticism (Ashworth, Gracey, & Gilbert, 2011). In particular, ABI participants in Ashworth, Clarke, Jones, Jennings, and Longworth's (2015) study reported that CFT provided them with tools to manage psychological difficulties.

Therefore, Ashworth et al. (2015) concluded that CFT appears to be an effective intervention for psychological problems after ABI. In the same way, CFT may also be effective in supporting patients with COPD or other physical conditions. The formal application of CFT to COPD populations as well as other illness groups, is a promising suggestion for future trials. In the meantime, at a more basic level, Terry and Leary (2011) suggested that enhancing self-compassion in long-term condition patients could be achieved by encouraging healthcare personnel to frame explanations in ways that encourage self-kindness, a sense of common humanity with regard to physical illness, and a mindful and non-judgmental way of approaching illness-related problems.

Irrespective however, of the therapeutic model employed, enhancing self-compassion in COPD and other physical illnesses might help patients to avoid unhelpful limiting or all-or-nothing behaviour patterns, and promote the choice of more adaptive healthy behaviours, such as regular and paced activity- which might have a positive effect on mood and anxiety, and in turn on quality of life. Paced activity patterns are consistent with the current advice of pulmonary healthcare teams, who recommend regular exercise to improve lung capacity and prevent deconditioning, which promotes the management of breathlessness in the long term (Almagro & Castro, 2013).

### **Limitations**

Despite the promising potential clinical applications above, some limitations are noted with regard to the current study. In particular, as mentioned, the current findings that illness beliefs did not predict distress or quality of life in COPD, when controlling for illness severity, was not expected. Again, this is contrary to previous research findings across a range of chronic illnesses, including COPD. A number of reasons for these results are suggested.

Firstly, some concerns are noted with regard to the usefulness of the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002) (see Appendix M). As previously explained, the IPQ-R was used to measure participants' beliefs about their illness. This is a relatively long measure. The items are listed in order of the subscales, rather than in a randomised order. A number of negatively worded items are scattered throughout the subscales. The items therefore read as clusters of consecutive repetitive statements, punctuated by a number of randomly placed reverse items. This structure could introduce confusion for the responder. Completion of the

measure requires much concentration, and in the context of the research battery at large, elderly or unwell participants (of whom the current sample largely consisted) may have struggled. In reviewing the raw data and responses to the items on this measure, there appeared a significant amount of inconsistency between items across the same subscales. This inconsistency suggests that participants may have indeed struggled, which would affect the accuracy of the responses, and therefore the reliability of the measure.

Furthermore, as described earlier in the Method chapter, the IPQ-R sum score was chosen due to the high collinearity between the subscales, reflecting previous research by Zoeckler et al. (2014). In line also with Zoeckler's study, the Identity and Cause subscales were not included in the current analysis. This is due to the different ways in which responses on these two particular subscales are scored, which are inconsistent with computing a full-scale IPQ-R score based on summing the mean scores of each subscale (as in the current study). However, the collinearity between the IPQ-R subscales reported by Zoeckler et al. (among others) was not upheld in the current study, in which few significant correlations between the subscales were found. These correlations are presented in Appendix S. This low number of correlations may be the result of participants' difficulty in completing the measure. It is also possible that all subscales should have been included in the analyses in the present study, however this would have been difficult given, as mentioned, the different ways in which the Identity and Cause subscales are scored and interpreted. The results of the current study are certainly inconsistent with a large body of psychological research across several different chronic illnesses- a body of research that repeatedly

demonstrates a relationship between illness beliefs and many different adjustment outcomes. Possibly, a larger sample would have produced different IPQ-R results.

Beyond the IPQ-R, concerns are noted also with regard to the usefulness of other measures. For instance, the MRC Breathlessness Scale (Appendix R) was used to capture a self-reported measure of illness severity. The MRC Scale is recommended to complement pulmonary-function tests (forced expiratory volume in one second; FEV1; see Zoeckler et al., 2014) in the classification of illness severity in COPD (Bestall et al., 1999; Stenton, 2008). However, where pulmonary-function tests are not carried out, the MRC scale is used instead to categorise illness severity in respiratory conditions. Ideally, subjective illness severity measures should be reinforced with some objective physiological measures such as pulmonary function tests (FEV1). Unfortunately, this was not possible in the current study's design. This is acknowledged as a limitation of the current study, particularly because self-reported illness severity is not an objective measure, and may itself be a reflection of more catastrophic beliefs about illness, or a more negative interpretation of the illness. This will therefore affect adjustment to illness more acutely.

However it is noteworthy, that the MRC Scale was used routinely, as mentioned, as part of referral and assessment criteria at each of the pulmonary rehabilitation services that supported recruitment for the current study. The scale was therefore in line with the routine processes of these pulmonary rehabilitation teams. This is the reason that the measure was retained and used to track illness severity amongst participants.

Some authors also criticise the use of the Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmund, 1986). In terms of a generic psychological distress

measure for a COPD population that can capture clinically significant levels of anxiety and depression simultaneously, the HADS adequately met the requirements of the current study. Alternative generic distress measures include the robust combination of the PHQ-9 and GAD-7 (Kroenke, Spitzer, Williams, & Löwe, 2010), however it was felt that these tools are overly symptom-focused in a way that overlaps with symptoms of COPD. Another alternative is the Structured Clinical Interview (SCID; First, 2002; Spitzer, Williams, Gibbon, & First, 1992). However, this lengthy interview is not feasible for conducting studies with multiple participants. More recently, a COPD-specific measure of anxiety has been developed. However, the COPD Specific Anxiety Questionnaire (CAF; Kuhl, Kuhn, Kenn, & Rief, 2011) does not capture a level of depressive symptomatology, and is difficult to obtain for research or clinical use due to strict copyright restriction. Zoeckler et al. (2014) used the CAF, but the authors had to also include the depression subscale of the HADS in order to measure depression.

In addition to concerns over the usefulness of the measures employed, further limitations of the study are also noted. The power of the study, for instance, was not sufficient- as noted in the Method chapter. Unfortunately, the sample size did not meet even the minimum requirements ( $n = 30$ ) for detecting an effect of any size using multiple regression analyses with up to, and including, four predictor (independent) variables, as per Cohen's (1992) guidelines.

Additionally, according to the mediation sample size guidelines of Fritz and MacKinnon (2007), the current study also lacked a sufficient sample size in order to detect a mediation effect with the bias-corrected bootstrapping procedures that were used (Hayes, 2012; Preacher & Hayes, 2004, 2008). Particularly, based upon the size

of the *a* and *b* paths found across the three simple mediation models (models *i* to *iii*) explored in this study, the sample sizes deemed necessary for power of .80 ranged from a minimum of  $n = 34$  up to  $n = 396$  (Fritz & MacKinnon, 2007). Clearly, the study's sample did not match even this minimum figure.

Beyond limited power, the sample size brings other limitations to the study. Findings should be interpreted cautiously for several reasons. For one, the current study employed a cross-sectional design and as such, the direction of the relationships between the variables cannot be determined. As always, these results should be interpreted with caution. The findings do not imply causality. This criticism reflects similar limitations with aforementioned studies- including those by Przewdziecki et al. (2013), Skerrett and Moss-Morris (2006), Wren et al. (2011), and Scharloo et al., (1998, 2007), as well as a lot of the studies reviewed by Hagger and Orbell (2003).

Secondly, in designing the study, patients were originally to be excluded from participation if they reported to suffer from any other physical illness or condition, separate to, and in addition to their respiratory condition. Scharloo et al. (1998, 2000, 2007) and Zoeckler et al. (2014) applied similar exclusion criteria to their samples, as did the authors of many of the studies reviewed by Hagger and Orbell (2003) that explored the role of illness beliefs in a range of other conditions. It was thought that any comorbid physical diagnoses, acute or chronic, would influence self-reported illness beliefs and behaviours, as well as self-compassion scores, and in particular, influence the outcome of self-reported health-related quality of life.

However, owing to recruitment difficulties that transpired during the study, and the small sample that was ultimately recruited, it was decided that excluding participants

who reported additional physical illnesses beyond their respiratory diagnosis would have left an entirely insufficient sample, and data that would not justify statistical analysis. Several participants reported to experience comorbid physical illnesses- some up to four additional diagnoses. These statistics are summarised in the ‘Participants’ section of the Method chapter (pp. 38- 39). As such, the current sample is not a ‘pure COPD’ sample. It is highly likely that the experience of multiple physical health conditions affected participant responses, particularly in terms of illness-related beliefs and behaviours, which will be influenced by all relevant diagnoses, rather than COPD alone. Indeed, this may also somewhat account for why the current findings with regard to the role of illness beliefs in COPD (as measured by the IPQ-R) are inconsistent with the findings of previous studies in COPD (e.g. Zoeckler et al, 2014) and in a range of other chronic conditions (see Hagger & Orbell, 2003). Ideally, with larger samples like that of Zoeckler et al. (2014), those with other physical diagnoses, in addition to their COPD, would be excluded, however this was not possible in the current study.

It is also noteworthy that the sampling procedure may have introduced bias, in that it could be hypothesised that individuals with COPD attending pulmonary rehabilitation programmes are potentially *less* likely to display limiting behaviour patterns, or potentially *more* likely to display all-or-nothing behaviour patterns- given their potential motivation to attend for supervised exercise.

Additionally, as noted in the Method chapter, two of the pulmonary rehabilitation services ran rotational 8-week programmes (Royal Free Hospital and Berkshire sites), whilst the third ran a stop-start programme (Whittington Hospital site). The different service models did not impact upon the study’s cross-sectional methodology, though

this would have been problematic for a longitudinal design. Nonetheless, it is worth noting that participants recruited from the two rotational programmes (the majority of the sample) were all at different stages of rehabilitation when recruited. Additionally, there may have been participants across the sample at large who had previously completed programmes of rehabilitation in the past, depending on the duration of their COPD. As such, some participants may have benefited from multiple rehabilitation interventions, and demonstrated comparatively more motivation to exercise. This may have influenced responses to measures of illness beliefs and illness behaviours across the sample. The study did not collect information on individuals' stage of rehabilitation or participation in previous rehabilitation programmes, which represents another weakness of the current study.

### **Future Research**

Further research may address some of the above limitations- both with regard to the study's cross-sectional design and choice of measures. In terms of research design, longitudinal research with larger sample sizes would improve power, and help to elucidate the direction of the relationships between the predictors and outcomes.

With regard to predictor measures, the Brief Illness Perception Questionnaire (Brief IPQ; Broadbent, Petrie, Main, & Weinman, 2006) is a plausible substitute for the IPQ-R, and might address some of the above limitations with regard to the usefulness of the IPQ-R in the current study. For instance, the Brief IPQ retains adequate levels of validity and reliability, but is a shorter measure which participants may find more user-friendly.

With regard to outcome measures, the current findings focus largely on psychological distress (anxiety and depression). As noted, this reflects the psychiatric or mental health approach to adjustment to illness (Moss-Morris, 2013). As Moss-Morris notes, there are shortcomings associated with this approach. If we define adjustment in terms of the presence or absence of psychopathologies, such as clinical depression and anxiety, we might fail to acknowledge the fact that the presence of psychopathology may not always be a consequence of illness. For instance, research with diabetes patients has shown that depression can precede diabetes, develop as a consequence of the diagnosis, or co-exist as a separate condition (McSharry, Bishop, Moss-Morris, & Kendrick, 2013). In light of this diabetes research, it might not always be adequate, in every case, to define poor adjustment as the mere presence of psychopathology (Moss-Morris, 2013).

As well as more varied measures of adjustment, theoretical models of persistent/chronic physical symptoms (Deary et al., 2007) suggest that we might use COPD symptoms, such as breathlessness and fatigue, as outcomes in future COPD studies. This is often the case in research in MS, CFS, and IBS, but in the current study, illness symptoms were considered to be an independent variable (MRC Scale scores). Further longitudinal research would be required to explore the associations between illness beliefs, illness behaviours, and adjustment outcomes around quality of life/distress *and* symptom severity.

Finally, at a more applied level, suggestions for future therapy studies include evaluation of the application of Compassion Focused Therapy (CFT) to COPD patients in order to enhance levels of self-compassion. It would also be worth evaluating the extent to which a compassion-focused intervention encourages helpful

behavioural responses (or discourages counterproductive ones), and whether it is ultimately protective against poorer adjustment outcomes in terms of quality of life and distress.

### **Conclusion**

Despite the limitations discussed above, the present research provides evidence suggesting a relationship between self-compassion and adjustment outcomes (particularly distress), and that illness-related behaviours may play a mediating role in this relationship.

In managing COPD populations, the findings suggest that patients should be supported in adopting more helpful behaviours in response to their illness and symptoms. In particular, this means avoiding limiting and all-or-nothing behaviour patterns, and this in turn, should improve mood and reduce anxiety levels. The findings also suggest that supporting people in being more self-compassionate might be an effective way in which to achieve this. That is, enhancing self-compassion amongst patients can aid them in making behavioural changes, which in turn can result in a positive effect on mood, and in turn, on quality of life in living with COPD.

These findings provide a solid grounding for further exploration of the relationships between illness-related beliefs, illness-related behaviours, and self-compassion among patients with long-term physical conditions. These findings are important given the recognised emotional impact of chronic disease (Stanton et al., 2007).

## References

- Allen, C., Glasziou, P., & Del Mar, C. (1999). Bed rest: A potentially harmful treatment needing more careful evaluation. *The Lancet*, *354*(9186), 1229-1233.
- Almagro, P., & Castro, A. (2013). Helping COPD patients change health behavior in order to improve their quality of life. *International Journal of Chronic Obstructive Pulmonary Disease*, *8*, 335-345.
- American Thoracic Society. (1999). Dyspnea. Mechanisms, assessment, and management: a consensus statement. *American Journal of Respiratory and Critical Care Medicine*, *159*, 321–340.
- Arne, M., Emtner, M., Janson, S., & Wilde-Larsson, B. (2007). COPD patients' perspectives at the time of diagnosis: A qualitative study. *Primary Care Respiratory Journal*, *16*(4), 215-221.
- Ashworth, F., Clarke, A., Jones, L., Jennings, C., & Longworth, C. (2015). An exploration of compassion focused therapy following acquired brain injury. *Psychology and Psychotherapy: Theory, Research and Practice*, *88*(2), 143-162.
- Ashworth, F., Gracey, F., & Gilbert, P. (2011). Compassion focused therapy after traumatic brain injury: Theoretical foundations and a case illustration. *Brain Impairment*, *12*(02), 128-139.
- Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*(6), 1173.

- Bestall, J. C., Paul, E. A., Garrod, R., Garnham, R., Jones, P. W., & Wedzicha, J. A. (1999). Usefulness of the medical research council (MRC) dyspnoea scale as a measure of disability in patients with chronic obstructive pulmonary disease. *Thorax*, *54*(7), 581-586.
- Bowers, H.M., Wroe, A.L., & Pincus, T. (in prep). Beliefs about emotions, emotional suppression, support- seeking and distress in fibromyalgia: A mediation analysis of cross sectional data.
- Brion, J. M., Leary, M. R., & Drabkin, A. S. (2014). Self-compassion and reactions to serious illness: The case of HIV. *Journal of Health Psychology*, *19*(2), 218-229.
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, *60*(6), 631-637.
- Byrne, M., Walsh, J., & Murphy, A. W. (2005). Secondary prevention of coronary heart disease: Patient beliefs and health-related behaviour. *Journal of Psychosomatic Research*, *58*(5), 403-415.
- Candy, B., Chalder, T., Cleare, A. J., Wessely, S., White, P. D., & Hotopf, M. (2002). Recovery from infectious mononucleosis: A case for more than symptomatic therapy? A systematic review. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners*, *52*(483), 844-851.
- Candy, B., Chalder, T., Cleare, A. J., Wessely, S., & Hotopf, M. (2004). A randomised controlled trial of a psycho-educational intervention to aid recovery in infectious mononucleosis. *Journal of Psychosomatic Research*, *57*(1), 89-94.

- Centres for Disease Control and Prevention, U.S. Department of Health and Human Services. (2003). *About chronic disease*. Washington DC, USA: U.S. Department of Health and Human Services.
- Chauvin, A., Rupley, L., Meyers, K., Johnson, K., & Eason, J. (2008). Research corner outcomes in cardiopulmonary physical therapy: Chronic respiratory disease questionnaire (CRQ). *Cardiopulmonary Physical Therapy Journal*, *19*(2), 61-67.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*(1), 155.
- Costa, J., & Pinto-Gouveia, J. (2011). Acceptance of pain, self-compassion and psychopathology: Using the chronic pain acceptance questionnaire to identify patients' subgroups. *Clinical Psychology & Psychotherapy*, *18*(4), 292-302.
- Deale, A., Chalder, T., & Wessely, S. (1998). Illness beliefs and treatment outcome in chronic fatigue syndrome. *Journal of Psychosomatic Research*, *45*(1), 77-83.
- Deary, V., Chalder, T., & Sharpe, M. (2007). The cognitive behavioural model of medically unexplained symptoms: A theoretical and empirical review. *Clinical Psychology Review*, *27*(7), 781-797.
- Dennison, L., Moss-Morris, R., & Chalder, T. (2009). A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clinical Psychology Review*, *29*(2), 141-153.
- Department of Clinical Epidemiology and Biostatistics, McMaster University. (2005). The self-administered chronic respiratory questionnaire standardized (CRQ-

SAS) and individualized version (CRQ-SAI): Background information and suggestions for application. Hamilton, Ontario: McMaster University.

Department of Health. (2011). *Talking therapies: A four-year plan of action*. London, UK: Department of Health.

Department of Health (2012a). *Long-term conditions compendium of information* (3<sup>rd</sup> ed.). London, UK: Department of Health.

Department of Health (2012b). *An outcomes strategy for COPD and asthma: NHS companion document- Impact Report*. London, UK: Department of Health.

Ekers, D., Richards, D., & Gilbody, S. (2008). A meta-analysis of randomized trials of behavioural treatment of depression. *Psychological Medicine*, 38(05), 611-623.

Enders, C. K. (2001). A primer on maximum likelihood algorithms available for use with missing data. *Structural Equation Modeling*, 8(1), 128-141.

First, M. B. (2002). *User's guide for the structured clinical interview for DSM-IV-TR axis I disorders: SCID-I*. New York, NY: Biometrics Research Department, New York State Psychiatric Institute.

Fletcher, C. M., Elmes, P. C., Fairbairn, A. S., & Wood, C. H. (1959). The significance of respiratory symptoms and the diagnosis of chronic bronchitis in a working population. *British Medical Journal*, 2(5147), 257-266.

Fritz, M. S., & Mackinnon, D. P. (2007). Required sample size to detect the mediated effect. *Psychological Science*, 18(3), 233-239.

- Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in Psychiatric Treatment, 15*(3), 199-208.
- Gilbert, P., & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: Overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy, 13*(6), 353-379.
- Goodheart, C. D., & Lansing, M. H. (1997). *Treating people with chronic disease: A psychological guide*. American Psychological Association.
- Guyatt, G., Townsend, M., Keller, J., Singer, J., & Nogradi, S. (1989). Measuring functional status in chronic lung disease: Conclusions from a randomized control trial. *Respiratory Medicine, 83*(4), 293-297.
- Guyatt, G. H., Feeny, D. H., & Patrick, D. L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine, 118*(8), 622-629.
- Guyatt, G. H., Berman, L. B., Townsend, M., Pugsley, S. O., & Chambers, L. W. (1987). A measure of quality of life for clinical trials in chronic lung disease. *Thorax, 42*(10), 773-778.
- Habraken, J. M., Pols, J., Bindels, P. J., & Willems, D. L. (2008). The silence of patients with end-stage COPD: A qualitative study. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners, 58*(557), 844-849.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health, 18*(2), 141-184.

- Hale, E. D., Treharne, G. J., & Kitas, G. D. (2007). The common-sense model of self-regulation of health and illness: How can we use it to understand and respond to our patients' needs? *Rheumatology*, *46*(6), 904-906.
- Hayes, A. F. (2012). PROCESS: A versatile computational tool for observed variable mediation, moderation, and conditional process modeling [White paper]. Retrieved from <http://www.afhayes.com/public/process2012.pdf>
- Hayes, A.F. (2016). <http://afhayes.com/spss-sas-and-mplus-macros-and-code.html>
- Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behaviour Therapy*, *35*(4), 639-665.
- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, *44*(1), 1-25.
- Hill, K., Geist, R., Goldstein, R. S., & Lacasse, Y. (2008). Anxiety and depression in end-stage COPD. *The European Respiratory Journal*, *31*(3), 667-677.
- Hind, D., O’Cathain, A., Cooper, C. L., Parry, G. D., Isaac, C. L., Rose, A., ... Sharrack, B. (2010). The acceptability of computerised cognitive behavioural therapy for the treatment of depression in people with chronic physical disease: A qualitative study of people with multiple sclerosis. *Psychology and Health*, *25*(6), 699-712.

- Hotopf, M., Noah, N., & Wessely, S. (1996). Chronic fatigue and minor psychiatric morbidity after viral meningitis: A controlled study. *Journal of Neurology, Neurosurgery, and Psychiatry*, *60*(5), 504-509.
- Janson, C., Bjornsson, E., Hetta, J., & Boman, G. (1994). Anxiety and depression in relation to respiratory symptoms and asthma. *American Journal of Respiratory and Critical Care Medicine*, *149*(4), 930-934.
- Kaptein, A. A., Scharloo, M., Fischer, M. J., Snoei, L., Cameron, L. D., Sont, J. K., ... Weinman, J. (2008). Illness perceptions and COPD: An emerging field for COPD patient management. *Journal of Asthma*, *45*(8), 625-629.
- Kindermans, H. P., Roelofs, J., Goossens, M. E., Huijnen, I. P., Verbunt, J. A., & Vlaeyen, J. W. (2011). Activity patterns in chronic pain: Underlying dimensions and associations with disability and depressed mood. *The Journal of Pain*, *12*(10), 1049-1058.
- Krieger, T., Altenstein, D., Baettig, I., Doerig, N., & Holtforth, M. G. (2013). Self-compassion in depression: Associations with depressive symptoms, rumination, and avoidance in depressed outpatients. *Behavior Therapy*, *44*(3), 501-513.
- Kroenke, K., Spitzer, R. L., Williams, J. B., & Löwe, B. (2010). The patient health questionnaire somatic, anxiety, and depressive symptom scales: A systematic review. *General Hospital Psychiatry*, *32*(4), 345-359.
- Kuhl, K., Kuhn, C., Kenn, K., & Rief, W. (2011). The COPD-anxiety-questionnaire (CAF): A new instrument to assess illness specific anxiety in COPD patients. *Psychotherapie, Psychosomatik, Medizinische Psychologie*, *61*(1), 1-9.

- Leary, M. R., Tate, E. B., Adams, C. E., Batts Allen, A., & Hancock, J. (2007). Self-compassion and reactions to unpleasant self-relevant events: The implications of treating oneself kindly. *Journal of Personality and Social Psychology, 92*(5), 887.
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E. L., Patrick-Miller, L., & Robitaille, C. (1997). Illness representations: Theoretical foundations. In K.J. Petrie, & J.A. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 19-45). Amsterdam: Harwood Academic Publishers.
- Leventhal, H.L., Brissette, I., & Leventhal, E.A. (2003). The common-sense model of self-regulation of health and illness. In L.D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 42- 65). London: Routledge.
- Leventhal, H., Nerenz, D. R., & Steel, D.S. (1984). Illness representations and coping with health threats. In A. Baum, S.E. Taylor, & J.E. Singer (Eds.), *Handbook of psychology and health* (pp. 219- 252). Hillsdale, NJ: Erlbaum.
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. *Contributions to Medical Psychology, 2*, 7-30.
- Lindgren, S., Storli, S. L., & Wiklund-Gustin, L. (2014). Living in negotiation: Patients' experiences of being in the diagnostic process of COPD. *International Journal of Chronic Obstructive Pulmonary Disease, 9*, 441-451.
- MacKinnon, D., Fairchild, A., & Fritz, M. (2007). Mediation analysis. *Annual Review of Psychology, 58*, 593–614.

- McSharry, J., Bishop, F., Moss-Morris, R., & Kendrick, T. (2013). Diabetes management in the context of multiple illnesses: A qualitative analysis. *Psychology & Health, 28*, 9-10.
- Moss-Morris, R. (2013). Adjusting to chronic illness: Time for a unified theory. *British Journal of Health Psychology, 18*(4), 681-686.
- Moss-Morris, R., & Chalder, T. (2003). Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *Journal of Psychosomatic Research, 55*(4), 305-308.
- Moss-Morris, R., Petrie, K. J., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? *British Journal of Health Psychology, 1*(1), 15-25.
- Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health, 17*(1), 1-16.
- Neff, K. D. (2003a). The development and validation of a scale to measure self-compassion. *Self and Identity, 2*(3), 223-250.
- Neff, K. (2003b). Self-compassion: An alternative conceptualization of a healthy attitude toward oneself. *Self and Identity, 2*(2), 85-101.
- Neff, K. D., Hsieh, Y., & DeJitterat, K. (2005). Self-compassion, achievement goals, and coping with academic failure. *Self and Identity, 4*(3), 263-287.

- Neff, K. D., & McGehee, P. (2010). Self-compassion and psychological resilience among adolescents and young adults. *Self and Identity, 9*(3), 225-240.
- Neff, K. D. (2009). The role of self-compassion in development: A healthier way to relate to oneself. *Human Development, 52*(4), 211-214.
- Pauwels, R. A., Buist, A. S., Ma, P., Jenkins, C. R., Hurd, S. S., & GOLD Scientific Committee. (2001). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: National heart, lung, and blood institute and world health organization global initiative for chronic obstructive lung disease (GOLD): Executive summary. *Respiratory Care, 46*(8), 798-825.
- Petrie, K. J., & Weinman, J. (2006). Why illness perceptions matter. *Clinical Medicine (London, England), 6*(6), 536-539.
- Pinto-Gouveia, J., Duarte, C., Matos, M., & Fráguas, S. (2014). The protective role of self-compassion in relation to psychopathology symptoms and quality of life in chronic and in cancer patients. *Clinical Psychology & Psychotherapy, 21*(4), 311-323.
- Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behaviour Research Methods, Instruments, & Computers, 36*(4), 717-731.
- Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behaviour Research Methods, 40*(3), 879-891.

- Przezdziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: Breast cancer, body image, distress and self-compassion. *Psycho-Oncology*, 22(8), 1872-1879.
- Puhan, M. A., Behnke, M., Laschke, M., Lichtenschopf, A., Brändli, O., Guyatt, G. H., et al. (2004). Self-administration and standardisation of the chronic respiratory questionnaire: A randomised trial in three German-speaking countries. *Respiratory Medicine*, 98(4), 342-350.
- Scharloo, M., Kaptein, A., Weinman, J., Willems, L., & Rooijmans, H. (2000). Physical and psychological correlates of functioning in patients with chronic obstructive pulmonary disease. *Journal of Asthma*, 37(1), 17-29.
- Scharloo, M., Kaptein, A. A., Schlösser, M., Pouwels, H., Bel, E. H., Rabe, K. F., & Wouters, E.F.M. (2007). Illness perceptions and quality of life in patients with chronic obstructive pulmonary disease. *Journal of Asthma*, 44(7), 575-581.
- Scharloo, M., Kaptein, A. A., Weinman, J., Hazes, J. M., Willems, L. N. A., Bergman, W., & Rooijmans, H.G.M. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research*, 44(5), 573-585.
- Scheffer, J. (2002). *Dealing with Missing Data: Research Letters in the Information and Mathematical Sciences*, 3, 153-160.
- Schiaffino, K. M., Shawaryn, M. A., & Blum, D. (1998). Examining the impact of illness representations on psychological adjustment to chronic illnesses. *Health Psychology*, 17(3), 262.

Schunemann, H. J., Guyatt, G. H., Griffith, L., Stbbing, D., & Goldstein, R. (2002).

A randomized controlled trial to evaluate the effect of informing patients about their pretreatment responses to two respiratory questionnaires. *CHEST Journal*, 122(5), 1701-1708.

Schunemann, H. J., Goldstein, R., Mador, M. J., McKim, D., Stahl, E., Puhan, M., ...

Guyatt, G.H. (2005). A randomised trial to evaluate the self-administered standardised chronic respiratory questionnaire. *The European Respiratory Journal*, 25(1), 31-40.

Sharpe, M., & Wessely, S. (1998). Putting the rest cure to rest-again: Rest has no place in treating chronic fatigue. *BMJ: British Medical Journal*, 316(7134), 796-796.

Sheridan, N., Kenealy, T., Salmon, E., Rea, H., Raphael, D., & Schmidt-Busby, J.

(2011). Helplessness, self blame and faith may impact on self management in COPD: A qualitative study. *Primary Care Respiratory Journal: Journal of the General Practice Airways Group*, 20(3), 307-314.

Shields, C., & Ownsworth, T. (2013). An integration of third wave cognitive

behavioural interventions following stroke: A case study. *Neuro-Disability and Psychotherapy*, 1(1), 39-69.

Singh, S., Sodergren, S., Hyland, M., Williams, J., & Morgan, M. (2001). A

comparison of three disease-specific and two generic health-status measures to evaluate the outcome of pulmonary rehabilitation in COPD. *Respiratory Medicine*, 95(1), 71-77.

- Skerrett, T. N., & Moss-Morris, R. (2006). Fatigue and social impairment in multiple sclerosis: The role of patients' cognitive and behavioral responses to their symptoms. *Journal of Psychosomatic Research, 61*(5), 587-593.
- Snaith, R. P., & Zigmond, A. S. (1986). The hospital anxiety and depression scale. *British Medical Journal (Clinical Research Ed.), 292*(6516), 344.
- Sobel, M. E. (1982). Asymptotic confidence intervals for indirect effects in structural equation models. *Sociological Methodology, 13*(1982), 290-312.
- Spence, M., Moss-Morris, R., & Chalder, T. (2005). The behavioural responses to illness questionnaire (BRIQ): A new predictive measure of medically unexplained symptoms following acute infection. *Psychological Medicine, 35*(04), 583-593.
- Spence, M. J., & Moss-Morris, R. (2007). The cognitive behavioural model of irritable bowel syndrome: A prospective investigation of patients with gastroenteritis. *Gut, 56*(8), 1066-1071.
- Spitzer, R. L., Williams, J. B., Gibbon, M., & First, M. B. (1992). The structured clinical interview for DSM-III-R (SCID). I: History, rationale, and description. *Archives of General Psychiatry, 49*(8), 624-629.
- Stanton, A.L., Collins, C.A., & Sworowski, L.A. (2001). Adjustment to chronic illness: Theory and research. In A. Baum, T.A. Revenson, & J.E. Singer (Eds.), *Handbook of Health Psychology* (pp. 387- 403). Mahwah, NJ: Erlbaum.

- Stanton, A. L., Revenson, T. A., & Tennen, H. (2007). Health psychology: Psychological adjustment to chronic disease. *Annu.Rev.Psychol.*, 58, 565-592.
- Stenton, C. (2008). The MRC breathlessness scale. *Occupational Medicine (Oxford, England)*, 58(3), 226-227.
- Stone, A. A., Broderick, J. E., Porter, L. S., & Kaell, A. T. (1997). The experience of rheumatoid arthritis pain and fatigue: Examining momentary reports and correlates over one week. *Arthritis & Rheumatism*, 10(3), 185-193.
- Surawy, C., Hackmann, A., Hawton, K., & Sharpe, M. (1995). Chronic fatigue syndrome: A cognitive approach. *Behaviour Research and Therapy*, 33(5), 535-544.
- Terry, M. L., & Leary, M. R. (2011). Self-compassion, self-regulation, and health. *Self and Identity*, 10(3), 352-362.
- Terry, M. L., Leary, M. R., Mehta, S., & Henderson, K. (2013). Self-compassionate reactions to health threats. *Personality & Social Psychology Bulletin*, 39(7), 911-926.
- Van Dam, N. T., Sheppard, S. C., Forsyth, J. P., & Earleywine, M. (2011). Self-compassion is a better predictor than mindfulness of symptom severity and quality of life in mixed anxiety and depression. *Journal of Anxiety Disorders*, 25(1), 123-130.
- Vowles, K. E., McNeil, D. W., Gross, R. T., McDaniel, M. L., Mouse, A., Bates, M., ... McCall, C. (2007). Effects of pain acceptance and pain control strategies on

- physical impairment in individuals with chronic low back pain. *Behavior Therapy*, 38(4), 412-425.
- Wedzicha, J. A., Bestall, J. C., Garrod, R., Garnham, R., Paul, E. A., & Jones, P. W. (1998). Randomized controlled trial of pulmonary rehabilitation in severe chronic obstructive pulmonary disease patients, stratified with the MRC dyspnoea scale. *The European Respiratory Journal*, 12(2), 363-369.
- Weinman, J., & Petrie, K. J. (1997). Illness perceptions: A new paradigm for psychosomatics? *Journal of Psychosomatic Research*, 42(2), 113-116.
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11(3), 431-446.
- Westbrook, D., Kennerley, H., & Kirk, J. (2011). *An introduction to cognitive behavior therapy: Skills and applications* (2<sup>nd</sup> ed.). London: Sage.
- World Health Organisation (WHO; 2008). World Health Statistics. Geneva.
- Wren, A. A., Somers, T. J., Wright, M. A., Goetz, M. C., Leary, M. R., Fras, A. M., ... Keefe, F.J. (2012). Self-compassion in patients with persistent musculoskeletal pain: Relationship of self-compassion to adjustment to persistent pain. *Journal of Pain and Symptom Management*, 43(4), 759-770.
- Wroe, A. L., Rennie, E. W., Gibbons, S., Hassy, A., & Chapman, J. E. (2015). IAPT and long term medical conditions: What can we offer? *Behavioural and Cognitive Psychotherapy*, 43(04), 412-425.

Zoeckler, N., Kenn, K., Kuehl, K., Stenzel, N., & Rief, W. (2014). Illness perceptions predict exercise capacity and psychological well-being after pulmonary rehabilitation in COPD patients. *Journal of Psychosomatic Research*, 76(2), 146-151.

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