

Understanding COPD Patients' Barriers to Behavioural and Lifestyle Changes Using a Resilience, Readiness to Change, and Self-Management Model

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Statement of Originality

This work has not previously been submitted for a degree or diploma at any university. To the best of my knowledge and belief, this thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Danielle Cannon

Dedication

This thesis is dedicated to my boys, Riley and Aiden, and my Mother Dawn. Your love and support is unconditional and unwavering. A dream was made and became a reality because of you.

Abstract

Chronic obstructive pulmonary disease is a preventative degenerative illness of the lungs characterised by persistent airflow limitation. Currently chronic obstructive pulmonary disease is the fourth leading cause of death worldwide, with predictions that it will increase to become the third leading cause of death by 2030. Australian treatment recommendations, based upon the global treatment strategy, suggest a five-step plan for chronic obstructive pulmonary disease patients to manage their disease and its disturbances. Within these recommendations is a set of behavioural and lifestyle changes that includes adopting a self-management approach, undertaking pulmonary rehabilitation, and adhering to medication regimens. Unfortunately, research has identified that adherence to these behavioural and lifestyle changes is low, which can impact upon chronic obstructive pulmonary disease patients' health outcomes and quality of life.

Studies on the barriers for adherence to these recommendations have found a diverse range of reasons that patients report for not undertaking or continuing with these behavioural and lifestyle changes. These barriers include not feeling ready, poor self-efficacy, and lack of support. Although various psychological, physiological, and social factors have been identified, these barriers are yet to be quantitatively examined. This thesis aimed to examine Australian chronic obstructive pulmonary disease patients' barriers to behavioural and lifestyle changes via a resilience, readiness to change, and self-management model. The studies investigated: (1) the effect of self-management programs on chronic obstructive disease patients' health-related quality of life via a meta-analysis; (2) the relationships between chronic obstructive disease patients' levels of resilience and their health-related quality of life; (3) the association between patients' levels of resilience and their adherence to pulmonary rehabilitation programs; (4) the relationships between chronic obstructive disease patients' levels of resilience and

readiness to change and their adherence to medication regimens; (5) the validity and reliability of the St George's Respiratory Questionnaire on Australian chronic obstructive disease patients.

One hundred and fifty-nine chronic obstructive pulmonary disease patients were recruited from the Gold Coast University and Robina hospitals, and through education seminars with the Lung Foundation Australia held in Brisbane, and Gold Coast community health centres (Helensvale and Robina). These participants completed a questionnaire enquiring into their individual and contextual resilience, readiness to change, health-related quality of life, and various demographic variables. Resilience was examined via three measures: a disease specific grief questionnaire (Acceptance of Disease and Impairments questionnaire) which analysed defensive coping and disease specific self-esteem; the Connor-Davidson Resilience scale; and the Pulmonary Rehabilitation Benefits and Consequences Scale (professional support; developed for this study). Patients' readiness to change was assessed via a modified version of the Readiness to Change questionnaire (originally devised in relation to alcohol consumption). Health-related quality of life was measured by the St George's Respiratory Questionnaire. All measures were refactored, validated, and assessed for reliability in this study. Associations between the variables were examined via bivariate and decision tree analyses.

The results identified that: (1) self-management interventions significantly improved chronic obstructive disease patients' health-related quality of life, especially when disease specific education, exercise information, and an exacerbation action plan were included in the program; (2) all individual and contextual resilience factors were important for chronic obstructive pulmonary disease patients' health-related quality of life (breathlessness, symptoms, and cough domains); (3) chronic obstructive disease patients' levels of resilience (self-efficacy, self-esteem, decision making, coping,

defensive coping, relationships, and professional support) were important for their referral to and completion of pulmonary rehabilitation programs; (4) chronic obstructive pulmonary disease patients' trust, coping, self-esteem, decision making abilities, level of support and readiness to change were important for their adherence to medications; (5) the St George's Respiratory Questionnaire, once refactored, was a valid and reliable measure for Australian chronic obstructive pulmonary disease patients.

Combined, the results of this thesis identify that low levels of individual and contextual resilience, and poor readiness to change are barriers to chronic obstructive pulmonary disease patients' adherence to behavioural and lifestyle changes. It was also identified that undertaking a self-management approach can improve patients' health-related quality of life, and that health-related quality of life is important for chronic obstructive pulmonary disease patients' resilience. In all, it was found that a patient's relationships and their sense of self, in particular their self-esteem and self-efficacy, were highly important for their adherence to these behavioural and lifestyle changes.

Thus, this thesis has established that chronic obstructive pulmonary disease patients' individual and contextual resilience factors were related to their health-related quality of life and pulmonary rehabilitation referral and completion. Further to this, it was identified that patients' medication adherence was associated with their resilience and readiness to change. Given that these relationships have been identified, strategies need to be implemented in clinical settings to provide chronic obstructive pulmonary disease patients with additional support that focuses on increasing patient empowerment and collaboration within the patient—clinician relationship. Finally, these research topics need to be undertaken in an experimental context so that causal relationships can be identified between resilience, readiness to change, and the behavioural and lifestyle changes that are recommended to chronic obstructive pulmonary disease patients.

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Publications in Support of this Thesis

Five manuscripts have been prepared for publication by the PhD candidate. These manuscripts are presented in the results chapter (chapter 4). The first publication, a meta-analysis has been published in *Respiratory Medicine*. The second publication has been published in Respiratory Care. The remaining three publications have been submitted to *Physiotherapy, Annals of Medicine, and Thorax* and are currently under review. The five manuscripts presented in this thesis are listed in below:

- Cannon D, Buys N, Sriram KB, Sharma S, Morris N, Sun J, The effects of chronic obstructive pulmonary disease self-management interventions on improvement of quality of life in COPD patients: A meta-analysis, Respiratory Medicine (2016), doi: 10.1016/j.rmed.2016.11.005.
- Cannon D, Sriram KB, Liew A, Sun J, Resilience factors important in Chronic Obstructive Pulmonary Disease subjects' health-related quality of life,
 Respiratory Care (2018), Accepted for publication.
- Cannon D, Sharma S, Sun J, A machine learning analysis on the association between resilience factors and completion of pulmonary rehabilitation programs, Physiotherapy (2018), Submitted for publication.
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- Cannon D, Buys N, Sun J, Validation and normalisation of the of the St
 George's Respiratory Questionnaire in chronic obstructive pulmonary disease
 patients in Australia, Thorax (2018) Submitted for publication.

A part of this research has been presented at a national and an international conference:

• Cannon D, Buys N, Sriram KB, Sharma S, Sun J, Readiness to follow

clinicians' recommendations and quality of life in Chronic Obstructive

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and Medical Research Conference, Gold Coast, Australia.

Cannon D, Buys N, Sriram KB, Sharma S, Sun J, The impact of grief and

resilience on Chronic Obstructive Pulmonary Disease patients' quality of life.

Abstract presentation at 2016 Chinese Association of Scientists and Engineers

Inc, Queensland Australia.

Acknowledgment of Papers Included in this Thesis

Included in this thesis are papers and manuscripts in the Results Chapter (Chapter Four)

which are co-authored with other researchers. My contribution to each co-authored

paper is outlined at the front of the relevant sections. Appropriate acknowledgments of

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Danielle Cannon (26/03/2018)

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Chapter 1: Introduction

1.1. Aims and context

Chronic obstructive pulmonary disease (COPD) is a serious and incurable degenerative illness of the lungs which is characterised by persistent airflow limitation (Australian Institute of Health and Welfare, 2016), leading to feelings of dyspnoea which intensify as the disease progresses (Martinez, Donohue, & Rennard, 2011). COPD risk factors include both genetic and environmental influences (Eisner et al., 2010; GOLD, 2017b). The environmental influences stretch across the lifespan and can include factors from childhood development, cigarette smoking, or from working conditions later in life (GOLD, 2017b; Yang et al., 2017). In 2014 the prevalence of COPD in Australia was 7.5%, with 7,025 COPD recorded deaths (Australian Institute of Health and Welfare, 2017a), an increase of 1,147 deaths from 2011 (Australian Institute of Health and Welfare, 2013). Global COPD prevalence estimates are reported to be 7–12% (2012 to 2013; Landis et al., 2014), with three million COPD deaths being recorded globally in 2015 (World Health Organisation, 2016a). Worldwide death estimates in 2015 identified COPD as the fourth leading cause of death, marginally behind lower respiratory infections (World Health Organisation, 2014). As the incidence of COPD has more than doubled since the 1970s (Decramer, Janssens, & Miravitlles, 2012), it is predicted that COPD will become the third leading cause of death in the next few years (World Health Organisation, 2017). The burden of COPD on the Australian economy was just under one billion dollars in 2008-2009, with the primary expense resulting from hospitalisations (Australian Institute of Health and Welfare, 2013a). An investigation by Wouters (2003) identified poor symptom control

as the principal determinant for the extensive number of COPD patient hospital admissions.

The current COPD-X plan recommendations for the management of COPD and its disturbances suggest a five step process in maintaining COPD patients' health and well-being (Yang et al., 2017). These recommendations are proposed for primary care clinicians to utilise with their patients (Lung Foundation Australia, 2016e). The five steps advocated for the management of COPD involve confirming that the patient has COPD, which is completed via a comprehensive medical history and a spirometry; the optimisation of the patient's current lung functioning through increasing exercise and medication adherence; preventing further lung deterioration by adhering to behavioural and lifestyle changes recommended by their clinician and reducing risk factors by means such as smoking cessation; developing a care plan, which can be achieved through utilising a multidisciplinary health care team and undertaking a self-management approach; and managing exacerbations through early detection and treatment (Yang et al., 2017).

The recommendations above identify that successful management of COPD is best achieved through adhering to behavioural and lifestyle changes (Australian Institute of Health and Welfare, 2017b). However, research has found that COPD patients' adherence to medications is substandard (Make, 2003; Sriram & Percival, 2016), and this is especially so for younger COPD patients (Sriram & Percival, 2016). Investigations into why COPD patients' medication adherence is substandard have revealed a number of common themes, including avoiding side-effects, feeling well, and forgetting to take medications (Agh, Inotai, & Meszaros, 2011; Bourbeau & Bartlett, 2008). Other factors which have been identified in patients' adherence to recommended behavioural and lifestyle changes include having depression (Albrecht et al., 2016;

Cassidy, Turnbull, Gardani, & Kirkwood, 2014; Khdour, Hawwa, Kidney, Smyth, & McElnay, 2012), social stigma (Goldbart, Yohannes, Woolrych, & Caton, 2013), lack of self-care, forgetfulness, and reduced motivation (Restrepo et al., 2008).

Another of the behavioural and lifestyle recommendations provided by the COPD guidelines – cessation of smoking – provides the largest improvement for patients, yet tends to have the lowest initial adherence (Mehuys et al., 2010; Tøttenborg, Thomsen, Johnsen, Nielsen, & Lange, 2016). Investigations have found that patients frequently feel that they are not ready to quit smoking (Wilson, Elborn, & Fitzsimons, 2011). However, a factor that has been found to promote successful behaviour change in individuals undertaking smoking cessation is social support (Wagner, Burg, & Sirois, 2004). Specifically, social support is found to be the most beneficial when it is both positive and strong at the commencement of a smoking cessation attempt (Lawhon, Humfleet, Hall, Reus, & Muñoz, 2009). Social support has also been found to be an influential factor in other COPD guideline recommendations, such as pulmonary rehabilitation (Sohanpal, Seale, & Taylor, 2012; Zaidi et al., 2015).

Pulmonary rehabilitation is an important recommendation for COPD patients (Queensland Health and Lung Foundation of Australia, 2012). The aim of pulmonary rehabilitation is to improve patients' lung capacity and strength by implementing a program which incorporates both breathing exercises and weight training (Lung Foundation Australia, 2016f). Studies examining adherence to pulmonary rehabilitation programs have found that patients' completion of these programs is extremely low, with one study reporting that only 20% of COPD patients completed pulmonary rehabilitation (Hayton et al., 2013). Factors which have been found to influence COPD patients' completion include both individual and contextual factors (Cassidy et al., 2014; Hayton et al., 2013; Johnston, Young, Grimmer, Antic, & Frith, 2013; Thorpe,

Kumar, & Johnston, 2014). Some of the contextual factors involve the patients' situation, for example, living alone decreases their motivation (Hayton et al., 2013) and contributes to transportation issues, as they are unable to find others to assist them with travel to the rehabilitation site (Sohanpal et al., 2012). Individual factors associated with non-completion of pulmonary rehabilitation programs include increasing dyspnoea (Harris, Hayter, & Allender, 2008b); patients not feeling well enough to complete (Thorpe et al., 2014), and having poor psychological well-being, all of which can reduce motivation and confidence (Cassidy et al., 2014). These individual factors have also been found to be influenced by another feature which is frequently incorporated into pulmonary rehabilitation programs: self-management.

The recommendation for undertaking a self-management approach toward better health outcomes involves the COPD patient becoming more involved with their illness management and treatment, reducing the risk factors which may exacerbate their condition, and initiating treatment earlier (Bischoff et al., 2012; Kara & AŞTi, 2004; Wadell et al., 2013). One method of improving COPD patients' self-management abilities is to have them undertake self-management training on various aspects of illness management, including disease education, management of stress and anxiety, medication, exercise, and nutritional information, in addition to providing them with an individualised exacerbation action plan to reduce the likelihood of hospitalisation (Bischoff et al., 2012; Gadoury et al., 2005; Koff, Jones, Cashman, Voelkel, & Vandivier, 2009). Past research on self-management interventions has found that the inclusion of these programs leads to improvements in COPD patients' clinical outcomes, including their health-related quality of life (HRQoL), exercise capacity, self-efficacy, hospitalisations, and anxiety (Apps et al., 2009; Wang et al., 2013).

The literature on recommended behavioural and lifestyle changes for COPD patients and the currently identified barriers signify that both individual and contextual factors are important for patients' adherence to rehabilitation programs and overall well-being (Albrecht et al., 2016; Goldbart et al., 2013; Katsenos & Constantopoulos, 2011; Khdour et al., 2012). Although it has been found that psychological, physiological, and social factors are important for behavioural and lifestyle changes, other potential influencing factors such as grief, readiness to change, resilience, and HRQoL are yet to be quantitatively investigated.

Patients' grief regarding their illness has been studied for decades; however, the focus has been on the grieving process from palliative care until death (Jacobsen, Zhang, Block, Maciejewski, & Prigerson, 2010; Kübler-Ross, 1973; Kübler-Ross, Kessler, & Shriver, 2014; Kübler-Ross, Wessler, & Avioli, 1972). More recent research on grief regarding chronic illness has primarily focused on that of family or caregiver grief, both before and after death (Guldin, Vedsted, Zachariae, Olesen, & Jensen, 2012; Simpson, Young, Donahue, & Rocker, 2010). However, the recent development and validation of a COPD grief scale by Boer et al. (2014) has identified that COPD patients experience feelings of grief regarding their diagnosis. This research began to consider patients' emotions regarding their illness, including the denial of their illness, their levels of anger and depression, and acceptance of their illness; all of which have been found to be cognitive, affective, or behavioural responses to fluctuations in the patients' self-esteem (Baumeister, 2013). These feelings are thought to influence COPD patients' disease management abilities, including their self-management, readiness to change, and acceptance of recommendations (Boer et al., 2014).

A qualitative study by Harrison et al. (2015) examined some of the psychological barriers experienced by COPD patients who rejected pulmonary rehabilitation. In this

study, forms of grief were frequently identified, where COPD patients often had feelings of denial, anger, and depression. During these interviews COPD patients described isolating themselves or denying the severity of their illness in order to avoid scrutiny. They also expressed feelings of internalised and externalised anger, where they either blamed themselves for their current predicament or defended themselves and their current capabilities, stating that their diminished abilities were caused by external factors. In addition to this, Harrison et al. (2015) found that COPD patients reported extensive feelings of depression and guilt over how their illness was impacting upon their families, where they often felt like a burden both financially and emotionally. Other recent research has investigated patient grief over the loss of future plans, their current functioning and relationship with hospitalisations, finding that feelings of grief were associated with increased hospitalisations (Holland, Graves, Klingspon, & Rozalski, 2016). Holland et al. (2016) also found that patients' grief was identified as a disrupting component to their adherence to the recommended behavioural and lifestyle changes that could enhance their health outcomes (Holland et al., 2016).

The behavioural and lifestyle changes that are recommended following a COPD diagnosis are implemented immediately by some patients, while others appear to place these recommendations as a low priority, with no intention of undertaking these changes in the short or long-term (Prochaska, DiClemente, & Norcross, 1992). A process which explains differences in motivation is termed readiness to change and considers an individual's progression through a series of stages (Emdadi, Nilsaze, Hosseini, & Sohrabi, 2007). These stages consider the patient's initial reluctance to consider the need for change, through to actively partaking in and maintaining the changes they have implemented (Prochaska, Redding, & Evers, 2008). The concept of readiness to change in pulmonary rehabilitation completion was identified in a study by Harrison et al.

(2015), where they found that COPD patients who refused a referral to pulmonary rehabilitation often rejected the notion that their illness was a problem. They disputed the idea that they were experiencing functional limitations and minimised the impact of their disease, implying their difficulties were the result of other issues. Furthermore, the patients would distance themselves from their illness, frequently discussing it and its complications as a communal issue rather than a personal one. This rejection of their disease is an indicator that the patient is in pre-contemplation; that is, they are not yet ready to identify that they have an issue that requires action (DiClemente, Schlundt, & Gemmell, 2004). Other research has identified that patients' behaviour change is driven by their efficacy (Emdadi et al., 2007), the number of changes required, and personal priority (Prochaska, Redding, et al., 2008). Efficacy, in particular self-efficacy, is highly influential for COPD patients when they begin to consider whether or not they will undertake a particular activity (Bourbeau, Nault, & Dang-Tan, 2004).

Self-efficacy has long been considered an important personal characteristic for growth and change, and is a fundamental factor of resilience, as it considers the individual's belief in their own ability to manage a task or situation successfully (Bandura, 1982; Davis, Carrieri-Kohlman, Janson, Gold, & Stulbarg, 2006). The concept of resilience consists of various individual and contextual factors which interact to assist in the maintenance of psychological and physical well-being, in addition to providing opportunities for growth following an adverse experience (Black & Dorstyn, 2013; Bonanno, 2004; Reich, Zautra, & Hall, 2010).

The individual resilience factors in this paper include the COPD patients' self-efficacy; level of self-esteem; coping, problem solving and decision making abilities; with contextual resilience factors incorporating the patients' relationships and professional support. The qualitative study by Harrison et al. (2015) examined the

influence of two resilience factors on pulmonary rehabilitation completion: self-esteem and support. In their study, COPD patients reported feelings of low self-worth (indicating that they believed that they were not worthy of care), which could decrease their likelihood of accepting a referral. Lack of social and family support provided through their relationships was also a factor within Harrison and colleagues study, as patients often chose to isolate themselves. This self-imposed isolation greatly reduced their ability to encounter the love and support of friends and family; aspects which can promote the maintenance and growth of physical and psychological well-being (Reich et al., 2010). One potential reason given for their isolation is that the patients reported feeling threatened by external support, believing that accepting help would mean that they were relinquishing their right to make decisions (Harrison et al., 2015).

The defensive position that COPD patients may take by rejecting aspects such as support in order to maintain their independence involves their ability to maintain the quality of life that they have achieved over their adult years. The concept of HRQoL reflects the disparity between a COPD patient's desired and actual mental, physical, and social capabilities (Almagro & Castro, 2013; Centers for Disease Control and Prevention, 2017). COPD patients frequently report low HRQoL (Ioanna, Kocks, Tzanakis, Siafakas, & van der Molen, 2011). This reduction in HRQoL is identified as an outcome of the constant declines and functional limitations that patients experience as a result of their disease (Cully et al., 2006b). Nevertheless, COPD patients' HRQoL has been found to improve with the implementation of the behavioural and lifestyle changes recommended by Lung Foundation Australia (Ágh et al., 2015; Bulley et al., 2009; Turnock, Walters, Walters, & Wood-Baker, 2005; Yang et al., 2017). Studies have found a positive relationships between HRQoL and medication adherence, where low HRQoL improves adherence (Ágh et al., 2015), and HRQoL was improved

following adherence to medication regimens (Restrepo et al., 2008). However, it has also been found that patients who already have a high HRQoL are less likely to adhere to medication regimes (Ágh et al., 2015).

When considering the influence of self-management on COPD patients' HRQoL, it was found that HRQoL is significantly improved through self-management interventions, with some HRQoL domains reaching a clinically important difference (Zwerink et al., 2014). During these self-management interventions, COPD patient disease specific self-efficacy was also examined for its relationship with HRQoL. These studies found that increases in COPD patients' self-efficacy significantly improved their HRQoL (Kara & AŞTi, 2004; Wang, Liu, & Zhao, 2014). Finally, similar results have also been found for pulmonary rehabilitation and HRQoL, where patients who completed pulmonary rehabilitation experienced improvements in their HRQoL (Haave & Hyland, 2008; Puhan & Lareau, 2014). Although these improvements were not sustained at the six-month follow-up, other research has found that COPD patients who undertake independent moderate to high physical activity are able to increase and better maintain their HRQoL over a longer time period (Esteban et al., 2010).

1.2. Research rationale

The incidence of COPD is increasing significantly, with predictions that it will become the third leading cause of death worldwide by 2030 (World Health Organisation, 2016b). In Australia COPD is the fifth leading cause of death, with COPD deaths being higher among Indigenous Australians and those in lower socio-economic and remote areas (Australian Institute of Health and Welfare, 2017a). In order to improve COPD patients' HRQoL and health outcomes the Australian and New Zealand guidelines recommend a five-step plan which involves early diagnosis followed by the

optimisation of lung functioning via pharmacological and non-pharmacological interventions including pulmonary rehabilitation (Yang et al., 2017). The guidelines also suggest the prevention of future deterioration through the cessation of smoking and regular immunisations to reduce exposure to lung irritants and exacerbations (Yang et al., 2017). It is also recommended that COPD patients undertake a self-management approach, adhering to medications and establishing therapeutic partnerships to appropriately manage the disease limitations, reduce the occurrence of exacerbations, and promote stable health outcomes (Yang et al., 2017).

Past research has identified that COPD patients who undertake the behavioural and lifestyle recommendations provided in the guidelines can experience improvements in their self-efficacy, exercise capacity, dyspnoea, anxiety, and overall HRQoL (Kara & AŞTi, 2004; Keating, Lee, & Holland, 2011b; Papadopoulos et al., 2011; Wang et al., 2013). In particular, COPD patients who completed pulmonary rehabilitation and self-management experienced improvements in self-efficacy (Wang et al., 2013), as well as reductions in anxiety, dyspnoea (Cassidy et al., 2014), exacerbations, and hospitalisations (Selzler, Simmonds, Rodgers, Wong, & Stickland, 2012). Other research has found that successful smoking cessation has improved COPD patients' self-efficacy and HRQoL (Papadopoulos et al., 2011). Poor adherence to medications has been found to be associated with increased levels of depression (Albrecht et al., 2016), and good adherence is associated with increased social activity, self-management abilities, and perceived health status (Goldbart et al., 2013). These improvements to patients' general health and well-being can be extensive (Keating et al., 2011b) and provide the primary reason for the current guidelines.

The behavioural and lifestyle changes recommended by the Lung Foundation

Australia and the Thoracic Society of Australia and New Zealand are implemented to

reduce the risks and promote a better HRQoL; however, these recommendations are not always undertaken by COPD patients. The barriers for undertaking these behavioural and lifestyle changes have been found to be diverse, with one of the main reasons involving COPD patients failing to perceive the benefits of change (Fischer et al., 2007; Guo & Bruce, 2014; Harris et al., 2008b; Keating, Lee, & Holland, 2011a; Vercoulen, 2012), including not feeling ready to undertake the changes (Wilson et al., 2011), or fearing increasing dyspnoea as a result of a pulmonary rehabilitation program (Harris, Hayter, & Allender, 2008a).

Patients' perception of the benefits of change has been identified as a large motivator for undertaking the recommended behavioural and lifestyle changes (Vercoulen, 2012). An inability to be motivated due to a perceived lack of benefits reduces patients' sense of control and increases helplessness, all of which can impact upon their HRQoL (Sheridan et al., 2011). Although patients' perceptions are no doubt important for adherence, other research has revealed that successful behaviour change goes beyond patients' perceptions and includes individual and contextual factors such as efficacy, emotions (Harrison et al., 2015), comfort (Hansen, Walters, & Wood Baker, 2007), support, and situational issues (Keating et al., 2011a).

The influence of COPD patients' aforementioned individual and contextual factors on behavioural and lifestyle changes has been found to impact patients' sense of control over their illness (Harrison et al., 2015). These feelings can be further exacerbated when COPD patients are feeling as though they lack the appropriate support to achieve the desired changes (Albrecht et al., 2008). Patients have also expressed the need to feel competent and confident in their ability to undertake the recommended changes, otherwise they can experience anxiety which can further reduce their ability to cope and their likelihood of undertaking these changes (Harrison et al.,

2015; Hill, Geist, Goldstein, & Lacasse, 2008). A feeling of depression is another important factor which can interfere with undertaking the recommended behavioural and lifestyle changes, with COPD patients frequently expressing their lack of motivation and self-worth as well as a poor HRQoL (Hill et al., 2008).

Although there is extensive research into various aspects of patients' barriers towards behavioural and lifestyle changes, no studies have yet quantitatively examined the barriers that occur following a COPD diagnosis, using either grief, readiness to change, resilience, or HRQoL as influential factors. Understanding COPD patients' disease specific grief in the subsequent months or years following their diagnosis could provide insight into their feelings of self-worth regarding the limitations they are experiencing and, further to this, how their self-worth is influencing their adherence to the recommended behavioural and lifestyle changes. Investigating COPD patients' readiness to change will provide insight into their motivational processes and whether a patient's motivation affects their adherence to the recommendations which are advised to assist patients to maintain optimum lung health.

Understanding the impact of a COPD diagnosis on patients' resilience levels is especially important, as having good resilience assists individuals to regain much of their psychological and physical well-being following the confrontation of the diagnosis (Black & Dorstyn, 2013; Bonanno, 2004). It is believed that patient resilience could either assist or hinder patients' adherence to the recommended behavioural and lifestyle changes. A recent study identified that total resilience is related to COPD and arthritis patients' HRQoL; although this study did not examine which resilience factors contribute to these associations (Sanyal, Fernandes, Fathi, & Khatoon, 2017). It is believed that low levels of resilience could influence COPD patients' HRQoL, impacting how they perceive their illness intrusions and their functional capacity. Thus,

this thesis aims to investigate these gaps through identifying the relationships between these psychological processes and patients' adherence to the recommended behavioural and lifestyle changes; specifically, pulmonary rehabilitation and medication adherence. The relationships identified by this research can assist in the development of future interventions to improve COPD patients' psychological well-being in addition to their adherence to the recommendations.

1.3. Statement of the problem

The Global Initiative for Chronic Lung Disease (GOLD) presented its first report on a global strategy for the diagnosis, management and prevention of COPD in 2001 (GOLD, 2017a). Three revisions have since been published globally to update recommendations for COPD management. The GOLD report suggests improvements to the ABCD diagnostic tool, inhaler technique guidance, self-management, pulmonary rehabilitation, as well as other non-pharmacological interventions (GOLD, 2017a). The GOLD report also recommends an approach to pharmacological treatment which is based upon the individual's symptoms, exacerbation risks and their other comorbidities, concluding with new hospital discharge and follow-up procedures (GOLD, 2017a). The GOLD recommendations form the basis for the Australian and New Zealand COPD-X plan guidelines (Yang et al., 2017) with both initiatives focusing primarily on management of the disease.

Although illness management is vital, reduction of the risk factors that cause or exacerbate the disease are also of significant importance. The GOLD guidelines specify that resources should be directed at promoting smoking cessation, as eradicating cigarette consumption will have the largest impact on the development and progression of COPD; this measure is closely followed by the appropriate safe management of

causative occupational chemicals, dusts, and pollutants (GOLD, 2017a). Due to the risk factors associated with smoking, the Australian government ran a national campaign to promote smoking cessation from 1972 to 1975 (Carroll, Cotter, & Purcell, 2017). Further developments for reducing the risks of smoking in Australia saw, for example, the Government introduce a ban on smoking in enclosed premises in 2002, which was amended in 2005 to include building entrances, stadiums and other outdoor public areas such as children's playgrounds (Grace, 2016). In addition to this, extensive television advertising campaigns were launched with a focus on the negative health effects of smoking, support available and graphic representations of health outcomes (Carroll et al., 2017). Although the number of Australians smoking has decreased by 10% during the past 20 years (ABS, 2017), for some individuals adverse health outcomes in the future will be unavoidable as some lung damage has already been done (Kenfield, Stampfer, Rosner, & Colditz, 2008; Lee, 2013).

Although COPD is primarily caused by cigarette smoking, other factors such as occupational chemicals, dusts and pollutants are strong risk factors for disease development (Yang et al., 2017). The premise of delayed onset for smoking-related disease development is also consistent with the risks associated with those from occupational chemicals and dusts, where it can take years to decades for the disease to present (Jamrozik, de Klerk, & Musk, 2011). Thus, although workplace health and safety regulations have been improved to limit workplace risks and exposure (WorkCover Queensland, 2017), the potential remains for the disease to develop in older individuals who were exposed to potentially harmful chemicals prior to the tightening of workplace regulations. This delay highlights that the burden of the disease, both individual and economic, will continue for many decades, and that treatment currently and in subsequent decades will remain a priority.

As discussed previously, the burden of COPD presents problems both economically and individually. The total economic burden of COPD on the Australian economy was estimated at \$98 billion in 2008, with this figure including health care expenditure, loss of productivity and deadweight loss, and represented more of a burden to the economy than cardiovascular disease (Lung Foundation Australia, 2017). The burden of COPD on the individual includes aspects such as morbidity, mortality and reduced HRQoL, aspects which contribute to the patient's ability to live a fulfilling and sociable life (Yang et al., 2017). Treatment recommendations that aim to reduce the disease burden on COPD patients are individualised, based upon the patient's current symptoms and future risks, and may include adhering to medications and completing pulmonary rehabilitation (GOLD, 2017a).

Although COPD patients are provided with treatment recommendations on the premise that their disease will be more appropriately managed, leading to a better HRQoL, patients often do not adhere to the recommendations (Hayton et al., 2013; Sriram & Percival, 2016; Wilson et al., 2011). Research to date has identified some of the reasons expressed by COPD patients as to why they fail to adhere to treatment recommendations (Agh et al., 2011; Cassidy et al., 2014; Sohanpal et al., 2012). However, studies examining adherence factors have found that although interventions improve COPD patients' adherence, the improvements can be short lived, with some decreasing to insignificant levels within 12 months of the intervention (Bjoernshave, Korsgaard, Jensen, & Vinther Nielsen, 2011; Bryant et al., 2013; Hayton et al., 2013; Lawhon et al., 2009). This relapse could indicate that other unexplored factors such as the patients' resilience may be influencing the adherence declines seen in many COPD studies.

1.4. Significance of the research

Considering that adherence to behavioural and lifestyle recommendations remains an issue for many COPD patients despite the current interventions, further investigation is warranted. This thesis will provide additional understanding as to the relationships which exist between COPD patients' willingness to undertake behavioural and lifestyle changes and the psychological processes that result following a COPD diagnosis. The impact of a COPD diagnosis can have either a short or long-term effect on the psychological outcomes of the patient. Thus, this thesis will examine the concepts of resilience, readiness to change, and HRQoL on the recommended behavioural and lifestyle changes: self-management, pulmonary rehabilitation completion and medication adherence.

An extensive examination of the relationship between COPD patients' HRQoL and self-management interventions via a meta-analysis will identify whether self-management interventions provide improvements to COPD patients' HRQoL. In addition to this, subgroup analyses will be conducted to examine which educational components of the self-management program should be included in the intervention. This examination will assist in providing guidance for the development of a standardised self-management intervention that health care professionals can implement to improve the health and well-being of their patients.

As there is a distinct lack of knowledge regarding the relationship between COPD patients' resilience and their health outcomes, this thesis will examine the association between their levels of resilience and their HRQoL and completion of pulmonary rehabilitation programs. Understanding the relationships that resilience shares with the recommended behavioural and lifestyle changes and COPD patients' HRQoL will

provide insight into the impact that the disease and its disturbances have on patients' adherence to clinicians' recommendations, and on their overall well-being. Once understanding of the importance of resilience for COPD patients' adherence and well-being is gained, clinicians and researchers can incorporate this knowledge into future treatments and intervention programs.

Finally, questions remain about why COPD patients fail to adhere to medication regimes. Although psychological processes such as resilience may be of importance, the patients' readiness to change may also influence their adherence to their clinicians' treatment recommendations. Past research has found that a positive patient-clinician relationship is important for their adherence (Halding, Wahl, & Heggdal, 2010; Hogg, Grant, Garrod, & Fiddler, 2012; Marshall, Medvedev, & Antonov, 2008; Wilson, O'Neill, Reilly, MacMahon, & Bradley, 2007), in addition to their self-efficacy regarding their ability to manage their illness (Luszczynska, Sarkar, & Knoll, 2007; Maeda, Shen, Schwarz, Farrell, & Mallon, 2013). It has also been identified that patients' readiness to change and take action can lead to increases in adherence behaviours (DiClemente, Nidecker, & Bellack, 2008; Piatt & Chiasson, 2016), and that possible links exist between individual and contextual resilience factors and readiness to change (DiClemente et al., 2008; Prochaska, Redding, et al., 2008). Through investigating COPD patients' readiness to change and their levels of resilience, clinicians and researchers will gain an understanding of the motivational barriers that COPD patients encounter and how best to work with these barriers to promote adherence to the recommended behavioural and lifestyle changes.

1.5. Study aims and objectives

This research aims to investigate COPD patients' barriers to treatment recommendations; these barriers involve their resilience, readiness to change, and HRQoL. Firstly, it will examine the effects of self-management interventions on COPD patients' HRQoL. Secondly, this thesis will investigate the association between HRQoL and resilience in COPD patients. It will also examine the relationship between COPD patients' levels of resilience and their completion of pulmonary rehabilitation. The fourth aim is to examine the relationship between resilience and readiness to change, and medication adherence in COPD patients. Finally, this thesis will also investigate the validity of the HRQoL measure St George's Respiratory Questionnaire (SGRQ) for the current Australian COPD sample.

Thus, this thesis will answer the following research questions:

- 1) Do self-management programs have positive effects on COPD patients' HRQoL?
- 2) Is there a relationship between COPD patients' levels of resilience and their HRQoL?
- 3) Are COPD patients' levels of resilience associated with their completion of pulmonary rehabilitation programs?
- 4) Is resilience and readiness to change associated with COPD patients' adherence to the medication regimens prescribed by their clinicians?
- 5) Is the SGRQ a reliable and valid measure in the current Australian COPD sample?

Hypotheses

Hypothesis 1: COPD patients who undertake self-management interventions will experience greater increases in HRQoL when compared with patients who continue treatment as usual.

Hypothesis 2: High levels of resilience is associated with a better HRQoL in an Australian COPD sample.

Hypothesis 3: Low levels of resilience is related to poor completion rates of pulmonary rehabilitation programs in Australian COPD patients.

Hypothesis 4: Australian COPD patients with high levels of resilience and readiness to change will display higher adherence to the medication regimens prescribed by their clinicians.

Hypothesis 5: The SGRQ will be a valid and reliable measure of Australian COPD patients' HRQoL.

Chapter 2: Literature review

2.1. Chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is a serious degenerative illness of the lungs for which there is no known cure (Australian Institute of Health and Welfare, 2016). COPD is characterised by persistent airflow limitation, dyspnoea, abnormal gas exchange, an increased inflammatory response, hyperinflation, mucus hypersecretion, pulmonary hypertension, exacerbations and other systemic problems such as cardiac issues (Abramson et al., 2015a; GOLD, 2017b). The risk factors of COPD involve a gene-environment interaction (Eisner et al., 2010; GOLD, 2017b). The genetic influences that contribute to declines in lung functioning include alpha-1 antitrypsin or the gene encoding matrix metalloproteinase 12 (GOLD, 2017b). Numerous environmental factors can contribute to the development of COPD, including the patient's age, gender, lung development and socio-economic status (GOLD, 2017b). In addition to this, the individual's health, working conditions and lifestyle choices can present a risk if they involve factors such as being asthmatic, having bronchial hyperreactivity, chronic bronchitis, lung infections, being exposed to occupational chemicals and dusts, and being a smoker, which has been found to be the largest risk factor (GOLD, 2017b; Yang et al., 2017). Emphysema and chronic bronchitis are the most common pulmonary health issues associated with COPD; both are primarily caused by cigarette smoking (Stellefson, Chaney, & Chaney, 2009). Although COPD is a serious debilitating condition, individuals with this condition frequently experience other comorbidities including hypertension, gastroesophageal reflux disease, depression, anxiety (Mehuys et al., 2010), diabetes, heart disease, and lung cancer (Yang et al., 2017). Many of these comorbidities are thought to frequently occur in

COPD patients as they share 'common risk factors or mechanistic pathways' (Decramer et al., 2012, p. 1344).

Symptoms and diagnosis

The primary symptom of COPD characteristically involves severe breathlessness or dyspnoea that progressively intensifies with disease severity (Martinez, Donohue, & Rennard, 2011). A recent study of COPD patients' symptomatic experiences found that almost all (94%) participants reported suffering from dyspnoea. This was followed by other symptoms such as fatigue (71%), dry mouth (60%), coughing (56%), anxiety (51%), drowsiness (47%), irritability (42%), nervousness (40%), and wheezing (40%; Blinderman, Homel, Billings, Tennstedt, & Portenoy, 2009). Weight loss, chest tightness, sputum production, a poor appetite, and exacerbations often caused by bacterial or viral lung infections are also common in sufferers (Decramer et al., 2012; Yang et al., 2017). As consequence of these symptoms, COPD patients frequently decrease their levels of physical activity or the number of household duties they undertake in order to avoid experiencing dyspnoea and/or other adverse symptoms (Reishtein, 2005). However, the reduction of physical activity can increase the likelihood of future deterioration and the number of exacerbations experienced (Seymour et al., 2010). This gradual deterioration in physical and lung capacity reduces patients' sense of control, increases their levels of anxiety and depression, and reduces confidence in their ability to manage their illness, leading to poor quality of life (Yang et al., 2017).

The principal method of diagnosing COPD is via spirometry, primarily the 'forced expiratory volume in one second' test (FEV₁; Lung Foundation Australia, 2016b). In order for a diagnosis of COPD to be confirmed the patient must exhibit two similar

FEV₁ results, one at baseline and the other following the administration of a bronchodilator (Lung Foundation Australia, 2016b); thus, the airflow limitation is not fully reversible (Yang et al., 2017). Current guidelines for COPD severity are listed in Table 1 and are categorised as mild, moderate, or severe (Yang et al., 2017). In addition to the FEV₁, formal diagnosis of COPD also involves a comprehensive medical history, especially the consideration of whether the patient is a smoker or ex-smoker and is aged over 35 years (Lung Foundation Australia, 2016b). Another measure that facilitates the diagnosis is the COPD assessment test (Jones et al., 2009). This test provides clinicians with quantifiable information about the patients' well-being and the impact that COPD is having on their daily life (Yang et al., 2017). This standardised diagnostic tool further facilitates the dialogue between patient and clinician during collection of information at diagnosis (Lung Foundation Australia, 2016b).

Table 1. Diagnostic guidelines for COPD

Disease severity	FEV ₁ % predicted	Typical symptoms
Mild COPD	60% to 80%	Few symptoms, moderate breathlessness, little to no impact on activities of daily living, recurrent chest infections
Moderate COPD	40% to 59%	Dyspnoea on minimal exertion, severe impact on activities of daily living, chronic cough, regular sputum production
Severe COPD	<40%	Increasing dyspnoea, breathlessness walking on level ground, infections requiring steroids, increasing limitations on daily activities, cough, and sputum

Adapted from Yang et al. (2017)

Prevalence

In 2014, 7,025 Australians (3,911 males and 3,114 females) died as a result of COPD, making it the fifth leading cause of death in Australia for that year (Australian Institute of Health and Welfare, 2017a). This constituted an increase of 1,147 deaths from those recorded in 2011 (Australian Institute of Health and Welfare, 2013). The World Health Organisation estimated that in 2015 the number of COPD deaths globally was 5% or three million deaths (World Health Organisation, 2016a). The worldwide prevalence estimates for people aged over 40 with COPD ranged from 7% to 12% in 2012 to 2013, with rates being higher in men (6% to 14%) than in women (5% to 11%; Landis et al., 2014). In 2013 the Australian prevalence for COPD in individuals aged 40 and over was 7.5%, with the prevalence increasing to 29.2% for individuals aged 75 and over (Toelle et al., 2013), results which indicate that an individual's risk of developing COPD greatly increases with age. In 2015 COPD was the fourth leading cause of death worldwide, just behind lower respiratory infections, and with ischaemic heart disease and stroke being the most common causes of death (World Health Organisation, 2014). The incidence of COPD has more than doubled since the 1970s (Decramer et al., 2012) and the World Health Organisation has predicted that COPD deaths will further increase by 30% during the next 10 years if drastic action is not undertaken to reduce individuals' exposure to the COPD risks factors (World Health Organisation, 2017).

Economic and health care burden of COPD

The burden of COPD has grown steadily during the past few decades. This increase is primarily due to our ageing population and the uptake and continuation of cigarette smoking (Buist et al., 2007). The burdens associated with this disease are vast and range from morbidity and mortality, to social and economic (Chapman et al., 2006).

The primary cause of these burdens results from frequent lung infections and the chronic exacerbations that are characteristic of COPD (Wedzicha & Seemungal, 2007). As exacerbation frequency increases with disease severity (Hoogendoorn, Feenstra, Hoogenveen, Al, & Rutten-van Mölken, 2010) and prevalence increases with age, it is hardly surprising that COPD was named as the third highest health burden in Australasia in 2010 (Australian Institute of Health and Welfare, 2014).

In 2008–2009 the burden of COPD on the Australian economy was \$929 million, with hospital admissions being the primary expense, followed by prescribed pharmaceuticals and out-of-hospital services (Australian Institute of Health and Welfare, 2013a). Poor symptom control has been named as one of the principal reasons for the large number of hospitalisations and extensive use of out-of-hospital services (Wouters, 2003). A report into the economic impact of COPD found that the disease was more expensive per case than other significant health issues such as arthritis, cardiovascular disease, or osteoporosis (Access Economics, 2008). The report identified that in 2008, the total financial cost of COPD to the Australian economy was \$8.8 billion, with lost productivity being the major cost at \$6.8 billion (Access Economics, 2008). A study by Toy et al. (2011) examined the relationship between treatment adherence and cost and found that increasing treatment adherence by 5% led to a 2.2% reduction in health care costs and utilisation. One particular program which aims to improve treatment adherence through better management of symptoms is selfmanagement (Bourbeau & Bartlett, 2008), which is a core component of the current COPD guidelines.

COPD guidelines – management of COPD

The current Australian and New Zealand guidelines for managing COPD have been developed via a joint venture between the Thoracic Society of Australia and New Zealand and Lung Foundation Australia (Lung Foundation Australia, 2016e). These guidelines are based on the Global Initiative for Chronic Obstructive Lung Disease or GOLD recommendations (Yang et al., 2017). The COPDX guidelines suggest five key steps in the identification and management of COPD. Firstly, the guidelines suggest case finding and confirming the diagnosis for patients; a step which generally begins with patients' general practitioners conducting patient histories to identify smokers or ex-smokers 35 years and older (Yang et al., 2017). The second step involves optimising the lung functioning of COPD patients. Optimisation of the lung involves several primary goals: the cessation of smoking, adherence to medication to reduce and manage the symptoms of the disease, undertaking pulmonary rehabilitation to improve aerobic capacity and quality of life, and to actively identify and manage factors that can aggravate the symptoms of COPD (Lung Foundation Australia, 2016d).

Step three involves preventing deterioration. In order to achieve this, patients are advised to reduce the risk factors associated with the disease by quitting smoking, obtaining annual immunisations, using mucolytics to reduce the frequency and duration of exacerbations, and increasing the use of oxygen therapy (Yang et al., 2017). The fourth step recommends that patients develop a plan for their care. The development of a care plan assists patients to better manage their health outcomes, improve their quality of life and support networks, reduce adverse mental health effects, and assist in the development of an end-of-life plan (Lung Foundation Australia, 2016a). Self-management is a key component of this care plan and has been shown to greatly improve patient health outcomes (Lung Foundation Australia, 2016a) and increase patient self-efficacy (Kara & AŞTi, 2004; Stellefson et al., 2009). The final guideline suggests the prompt management of exacerbations. Exacerbation management, through assessment of the severity of the exacerbation, can assist in identifying whether the

exacerbation can be managed at home with the assistance of a multidisciplinary team, if it requires a referral to a specialist, or if hospitalisation is recommended (Yang et al., 2017). Appropriate exacerbation management can assist patient recovery and reduce the demands placed on hospitals, especially if home care is possible (Lung Foundation Australia, 2016c). It is hoped that by following these guidelines patients will experience a shift in treatment from solely pharmacological to a combination of therapies that target their overall well-being (Lung Foundation Australia, 2016e).

2.2. Treatment adherence, behavioural, and lifestyle changes

The Australian Institute of Health and Welfare's (2017b) goals for managing COPD suggest modifications to the patient's lifestyle as well as ongoing drug and oxygen therapy for severe sufferers. Successful management of COPD relies upon adherence to the institute's recommendations to ensure that the patient's health is maintained. The World Health Organisation (2003) defines treatment adherence as the individual's level of behavioural compliance towards recommendations made by their health professional. Investigations into COPD patients' treatment adherence have found that compliance rates can vary greatly. For instance, a comprehensive review which investigated the therapeutic adherence of COPD patients found that adherence to medication regimes ranged between 30.8% to 70% (Make, 2003). This result was confirmed in a recent investigation into adherence to inhaled medications, where 58% of patients reported suboptimal adherence (Sriram & Percival, 2016). This study also found that high adherers were on average five years older than patients who were low in adherence. On investigating the reasons for non-adherence it was revealed that patients were either avoiding side-effects, missing doses when feeling well, overusing their medications, or having difficulty adhering due to complicated dosing regimens (Bourbeau & Bartlett, 2008).

Analysis of the psychological aspects of COPD patients' non-adherence to treatment recommendations has revealed depression as a major contributing factor (Albrecht et al., 2016; Khdour et al., 2012). Depressed COPD patients may be less adherent to their treatment regimens as their condition can lead to forgetfulness or reduced motivation, either toward caring for themselves or following their treatment recommendations (Restrepo et al., 2008). Recent research on medication adherence found that COPD patients who were newly diagnosed with depression were more likely to score lower on their adherence to maintenance medications (Albrecht et al., 2016). This adverse impact of depression was also evident in a study by Cassidy et al. (2014), where COPD patients with higher levels of depression were less likely to complete pulmonary rehabilitation programs. Conversely, other research has identified that completion of pulmonary rehabilitation can significantly improve COPD patients' levels of depression (Hogg, Garrod, et al., 2012), though it is not yet clear which aspects of the programs contribute the most to these improvements (Cassidy et al., 2014).

Patient adherence to long-term oxygen therapy has also proven to meet with various barriers. Patients prescribed long-term oxygen therapy have identified that the use of oxygen for 15 or more hours limits their ability to perform activities of daily living (Earnest, 2002). In addition to this, the use of oxygen via nasal cannulae can deliver various side effects such as nasal bleeding and/or dryness, bouts of dizziness, a loss of taste and/or smell, as well as an impact to their cosmetic appearance (Katsenos & Constantopoulos, 2011). The effect of dependency and the social stigma of long-term oxygen therapy were found to be stronger negative influences for adherence. For instance, patients expressed feeling too embarrassed to take their oxygen with them on outings or preferred to leave their oxygen at home when getting out and about due to the inconvenience of the tank (Goldbart et al., 2013). Feelings of embarrassment were

frequently surrounded by the social stigma of a primarily smoking related illness (Katsenos & Constantopoulos, 2011) and were further compounded by the possibility of dependency on oxygen therapy, where patients and carers believe that the use of oxygen therapy reduces their ability to perform activities without being provided with additional oxygen (Goldbart et al., 2013).

Smoking cessation is another core component of the COPD guidelines and can provide the biggest benefit for COPD sufferers (Mehuys et al., 2010); however, cessation is rarely achieved by newly diagnosed COPD patients (<20%; Bourbeau & Bartlett, 2008; Tøttenborg et al., 2016). Reasons for this include timing, readiness to change, guilt, bargaining, and attachment, where giving up was akin to losing a friend (Wilson et al., 2011). Thus, it could be said that smoking is seen as a form of support: a relationship which could increase the difficulties associated with smoking cessation. A finding by Wagner et al. (2004) has identified that social support is strongly associated with the behavioural processes of change. That is, smokers with good social support are more likely to apply various behavioural techniques in order to achieve their goal of quitting. The challenge here is that if smokers are emotionally attached to their cigarettes, the external support required for change may be greater than that available to the individual, essentially reducing their likelihood of successful smoking cessation.

Another lifestyle change that is recommended for the management of COPD involves pulmonary rehabilitation programs. These programs have a low referral rate (Johnston et al., 2013), a low uptake (approximately 50%), and lower non-completion rates (Hayton et al., 2013). These figures were confirmed in a hospital referral study where only 9.6% of patients admitted for an acute exacerbation of COPD undertook and completed the pulmonary rehabilitation program (Jones et al., 2013). Current research into why COPD patients fail to undertake or complete pulmonary rehabilitation

programs has primarily investigated the external factors associated with non-attendance. Such external factors include the influence of the referring clinician (Arnold, Bruton, & Ellis-Hill, 2006; Bulley et al., 2009; Hogg, Garrod, et al., 2012), smoking, living alone (Hayton et al., 2013), lack of support, transportation issues (Sohanpal et al., 2012; Zaidi et al., 2015), and the ability of patients to see the benefits of the program (Bulley et al., 2009; Keating et al., 2011a).

A few papers have also investigated some of the internal factors for non-attendance. These often involve feeling unwell (Thorpe et al., 2014), denial of their illness severity (Sohanpal et al., 2012), and poor psychological well-being (Cassidy et al., 2014). Although these papers identify which internal factors contribute to the poor uptake of pulmonary rehabilitation, they fail to comprehensively examine the underlying characteristics promoting these factors. This includes whether or not these factors are influenced by an individual's level of social support or belief in their own ability to achieve positive health outcomes. If these underlying characteristics are identified, programs such as pulmonary rehabilitation may incorporate ways to strengthen these characteristics into the program and thus increase adherence.

2.3. Pulmonary rehabilitation

Pulmonary rehabilitation programs are highly recommended for individuals with chronic lung diseases (Queensland Health and Lung Foundation of Australia, 2012), yet these programs are significantly underutilised by clinicians and COPD patients (Cox, Oliveira, Lahham, & Holland, 2017; Johnston et al., 2013). Recent research into pulmonary rehabilitation completion rates have identified that only 9.6% of COPD patients undertake and fully complete these programs (Jones et al., 2013). Pulmonary rehabilitation is a goals-based intervention, incorporating education, aerobic, strength,

and flexibility training, as well as breathing exercises in order to improve patients' social and physical well-being (Lung Foundation Australia, 2016f). Although these programs provide significant benefits, COPD patients often acknowledge that various barriers inhibit their ability to attend or complete pulmonary rehabilitation. It has also been identified that some clinicians note that knowledge regarding the program and the referral process can act as a barrier to providing referrals (Johnston, Grimmer-Somers, Young, Antic, & Frith, 2012).

In Australia and New Zealand pulmonary rehabilitation is recommended for all COPD patients regardless of their disease severity (Lung Foundation Australia, 2016f). However, entry requirements for these programs can differ; some programs require a doctor's referral, while others allow patients to self-refer (Queensland Health and Lung Foundation of Australia, 2012). Once successfully enrolled, Queensland patients undertake a bi-weekly eight-week program consisting of group education and exercise classes. The education component involves multidisciplinary care and the enhancement of the patient's self-management of the disease (Queensland Health and Lung Foundation of Australia, 2012), a topic that will be discussed in detail in the next section. The exercise component of pulmonary rehabilitation involves strength and endurance training, consisting of repetitive arm and leg exercises such as cycling and weight training (Hayton et al., 2013).

The aim of pulmonary rehabilitation is to increase an individual's level of physical functioning, peer support, independence, exercise capacity, and quality of life (Bulley et al., 2009), in addition to improving patient mental health and reducing hospital admissions (Lung Foundation Australia, 2016f). Recent studies have found that pulmonary rehabilitation has significantly reduced hospitalisations, including the length of stay, exacerbations (Selzler et al., 2012), social isolation (Sohanpal et al., 2012),

dyspnoea, and patients' levels of depression and anxiety (Paz-Díaz, De Oca, López, & Celli, 2007). Common goals of COPD patients who undertake pulmonary rehabilitation include improvements in weight, breathing ability, or psychosocial health (Fischer et al., 2007), in addition to improving fitness to resume recreational activities (Thorpe et al., 2014). Although some patients can recognise the benefits of pulmonary rehabilitation, attitudes towards these programs are frequently negative (Fischer et al., 2007).

A study by Bulley et al. (2009) found that patients' attitudes towards pulmonary rehabilitation were influenced by the referring clinician and the information they were given at the point of referral. In addition to this, Bulley and colleagues also found that patients were influenced by current and previous interactions with their health care professionals, where positive and informative interactions were more likely to promote positive attitudes towards treatment recommendations. They also found that if clinicians conveyed that little could be done to improve their health, the patients lost hope and could not perceive the benefit in attending rehabilitation; however, patients who revealed that they felt supported and well informed of their health options experienced greater belief in their health care professionals and the recommendations that they made.

Further analysis of patients' attitudes towards pulmonary rehabilitation found that three common themes emerged when identifying why COPD patients decline pulmonary rehabilitation programs: construction of self; relinquishing control; and engagement with others (Harrison et al., 2015). Harrison and colleagues found that the construction of self in declining pulmonary rehabilitation frequently involved patients fearing the censure of others; this fear involved their peers' negative evaluations of their reasons for requiring pulmonary rehabilitation and included both verbal and non-verbal appraisals. A patient's sense of self-worth could be influenced by the censure of others

as well as how they viewed themselves of being capable or even worthy of the care and costs (personal and financial) involved in attending pulmonary rehabilitation programs. Pulmonary rehabilitation attendance was also influenced by the patients' level of guilt; that is, how personally responsible they saw themselves for their illness and the inconvenience for their family and friends, again leading to the decision of whether they were worthy of the program.

The Harrison et al. (2015) study also identified that patients' pulmonary rehabilitation attendance was influenced by their inability to relinquish control.

Primarily, patients displayed resistance to help-seeking through applying negative views of the hospital environment, or attempted to minimise the impacts of their COPD by attributing the limitations to their other illnesses. In the final theme, engagement with others, patients distanced themselves from their illness by referring to the illness and its challenges via indirect discussions, often referring to their personal complications in third person or discussing their issues as though the problems belonged to a group. In addition to this, patients frequently identified their own efforts at exercise and used these efforts to minimise the usefulness of pulmonary rehabilitation, finding them as equivalent to that of the proposed program, without the inconvenience of attending an external venue. The results of the Bulley et al. (2009) and Harrison et al. (2015) studies identify that the views of both the referring clinician and the patient are important for uptake and completion of pulmonary rehabilitation programs.

2.4. Self-management

Self-management is one of the guidelines for managing COPD. Current self-management interventions range from standardised programs such as 'Better living with COPD' (Queensland Health and Lung Foundation of Australia, 2012) to modified

versions of the 'Better living with long term airways disease (BELLA)' (Sohanpal et al., 2012). Although there are many forms of COPD self-management interventions, the content of these programs is largely similar. The educational component of these programs primarily focuses on identifying, understanding and relieving the symptoms of COPD, in addition to reducing and managing the various risk factors that lead to complications (Bischoff et al., 2012; Kara & AŞTi, 2004; Wadell et al., 2013), initiatives which are derived from the GOLD recommendations (see; GOLD, 2016a).

Although self-management remains a key component of these guidelines, there is currently no standardised self-management program that is recommended via these guidelines. Due to this, the delivery methods of the programs can vary greatly, from trained practice nurses (see; Bischoff et al., 2012), to DVDs (see; Stellefson et al., 2009), or instructor delivered training and educational brochures (see; Kara & AŞTi, 2004). Furthermore, there are diverse methods through which this training is conveyed and various timelines dedicated to this training phase. For instance, Blackstock, Webster, McDonald, and Hill's (2014) patients were exposed to 45 minutes of instructor based training twice a week for eight weeks; whereas McGeoch et al. (2006) implemented a one-hour patient training session and provided an information pack for later reference.

Regardless of the differences in the delivery and training of these self-management interventions, the purpose of these programs remains the same: to provide patients with an aspect of control over their treatment by improving their COPD knowledge and involving them in the planning and management of their illness (Newman, Steed, & Mulligan, 2004). The training included in self-management programs can involve a variety of aspects designed to increase patient awareness and understanding of COPD, in addition to the identification of lifestyle changes that will be

required in order to maintain good physical and mental health. A recent meta-analysis by Zwerink et al. (2014) investigated randomised controlled trials and non-randomised clinical trials that provided self-management interventions to COPD patients. In order to be included in the meta-analysis, only structured interventions between patients and health care providers that were health goal-based and provided feedback with the aim of improving patients' self-management abilities were accepted. To ensure consistency between the studies each intervention must have had two or more contact moments and at least two of the following six components: (1) smoking cessation, (2) exercise, (3) medication education, (4) self-recognition and self-management of exacerbations, (5) coping with breathlessness, and (6) nutritional guidance. Studies were excluded if they were solely education based or included only pulmonary rehabilitation.

Delivery methods of the self-management interventions in the Zwerink et al. (2014) study were varied, with information provided to participants via verbal, written and/or audio visual media. Assessment of the COPD patients' outcomes was measured via the primary outcome measures of number of hospital admissions and HRQoL, and the secondary outcome measures of days in hospital, exacerbation related emergency department visits, other health care facility visits, number of exacerbations requiring prescription of corticosteroids and/or antibiotics, rescue medication use, symptom scores, anxiety and depression, self-efficacy, lost work days, lung functioning, exercise capacity, and mortality.

The results of this study found that self-management interventions significantly improved COPD patients' HRQoL across all domains of the SGRQ, with the impact domain reaching the minimal clinically important difference on randomised control trials. When clinical control trials were added, all domains reached the minimal clinically important difference, although heterogeneity was high. The meta-analysis also

found that the number of respiratory related hospital admissions was significantly reduced by at least one admission when compared with COPD patients undergoing treatment as usual; this finding was also significant for all-cause hospital admissions. COPD patients were also found to experience a significant reduction in their dyspnoea as a result of the self-management interventions (Zwerink et al., 2014).

The meta-analysis results for number of days in hospital, corticosteroid prescription resulting from exacerbation, lung functioning, exercise capacity, and mortality were not significant. All other outcome variables (exacerbation related emergency department visits, other health care facility visits, number of exacerbations requiring prescription of antibiotics, rescue medication use, anxiety and depression, self-efficacy, and lost work days) were unable to be statistically analysed via a meta-analysis. Subgroup analyses were proposed for exercise, duration of follow-up, exacerbation action plan, and behavioural components. Only the subgroup analysis for the inclusion/exclusion of an exercise program was conducted for its effect on COPD patients' HRQoL and respiratory related hospital admissions; no significant differences were found (Zwerink et al., 2014).

The findings of the Zwerink et al. (2014) meta-analysis have identified that self-management interventions can significantly improve COPD patients' health and well-being, symptoms, and number of hospital admissions, whether the latter be respiratory related or caused by other illnesses. However, this study was unable to statistically examine other important COPD patient outcomes, including the subgroup analyses on various self-management program components. These results indicate that self-management interventions provide significant improvements to COPD patients; however, additional meta-analytical examinations are required with the inclusion of new

studies in order to further test COPD patient outcomes, in addition to examining the most effective content for inclusion in future self-management interventions.

2.5. Barriers to COPD patients' behavioural and lifestyle changes

As discussed above various barriers to behavioural and lifestyle changes have been identified for chronic illness patients, including those with COPD. Adherence research into the proposed behavioural and lifestyle changes identified that aspects such as side-effects, incorrect dosing (Bourbeau & Bartlett, 2008), depression (Albrecht et al., 2016; Khdour et al., 2012), physiological (Katsenos & Constantopoulos, 2011), personal (Goldbart et al., 2013), and social consequences (Wagner et al., 2004) are all important in patient adherence. Although some intrapersonal aspects such as depression have been investigated, the influence of other concepts such as resilience, readiness to change, and HRQoL on behavioural and lifestyle changes are yet to be examined in COPD patients.

Recent research investigating prolonged grief in chronic illness patients has found that prolonged grief regarding the patient's loss of functioning or future plans was associated with increases in hospitalisations and the length of hospital stays (Holland et al., 2016). Holland et al. (2016) suggested that one possible reasons for this relationship is that when patients experience grief and are unwilling to accept their illness, they are less likely to be adherent and/or proactive in managing their illness. Other research has identified that the experience of grief resulting from a chronic illness has a detrimental effect on an individual's sense of self, impacting upon their self-esteem (Brion, Menke, & Kimball, 2013). In addition to this, grief proactive adherence in chronic illness patients has also been suggested to be associated with resilience factors such as problem solving (Murawski et al., 2009), shared decision making (Arbuthnott & Sharpe, 2009),

self-efficacy, and social support, where patients high in these factors feel a greater sense of control and have more confidence in their ability to undertake healthy behaviours (Marino, Sirey, Raue, & Alexopoulos, 2008).

The relationship between HRQoL and treatment adherence has been studied in COPD patients. These findings have identified that there may be a dual relationship between HRQoL and treatment adherence, where low HRQoL improves adherence and high HRQoL is associated with lower adherence rates (Ágh et al., 2015). The relationship between COPD patients' HRQoL and resilience is yet to be comprehensively studied. One factor closely related to the resilience factor, professional support, has been found to be related to COPD patients' HRQoL; that is, the effect of supported pulmonary rehabilitation programs on COPD patients' HRQoL (Almagro & Castro, 2013; Haave & Hyland, 2008). However, among other resilience factors, this study will examine the relationship between a patient's HRQoL and their perceived level of professional support, as provided by pulmonary rehabilitation programs.

Grief as a barrier to behavioural and lifestyle changes

Grief resulting from a COPD diagnosis is well recognised by health care professionals (Boer et al., 2014). It has also been recognised that the experience of grief during a chronic illness can seriously impact upon the patient's self-esteem (Brion et al., 2013), especially when the patient is experiencing illness disturbances that are disrupting their personal and professional responsibilities (Lindgren, Storli, & Wiklund-Gustin, 2014). The term 'grief' is commonly defined as a psychological, social, physical and behavioural response resulting from the loss of a loved one through death (Hayes, 2008; Wittmann et al., 2010b). The influence of grief occurring as the result of a chronic or terminal illness diagnosis is in its infancy in research studies. To date only a handful

of studies have investigated the occurrence and impact of grief in chronic illness patients (see; Brion et al., 2013; Hayes, 2008), as opposed to studying the grief of friends and family members following their deaths. Grief in chronic illness, especially that of COPD, ensues from patients experiencing a multitude of changes and losses (Peters, 2013), including their independence, friendships, autonomy, privacy and eventually life (Egan & Arnold, 2003).

Patients' grief can be expressed in different ways: emotional, cognitive, and/or behavioural (Doka, 2012). Over the millennia the notion of grief has morphed from the 8th century poem of 'Beowulf', where the people's open expression of emotion following the loss of their hero king was acceptable, to Vogther's PhD thesis in 1703 regarding the 'Illness of Grief' (Parkes, 2010), to today's most accepted five stages of grief model 'On death and dying' by Elizabeth Kübler-Ross (Brion et al., 2013). Dr Kübler-Ross's grief theory was developed in the late 1960s and envisaged five stages within the grieving process: denial and isolation, anger, bargaining, depression, and acceptance (Kübler-Ross, 1973). This theory was applied to individuals with a terminal illness shortly before their deaths; however, it is now known that the feeling of grief just prior to death is similar to the sense of loss experienced due to functional impairments and increasing symptoms associated with chronic or terminal illnesses. These losses create extensive life changes that impact self-esteem (Brion et al., 2013), increase feelings of reactive emotions (Felgoise, Nezu, Nezu, & Reinecke, 2006) and feelings of hopelessness (Mystakidou et al., 2009). It is important to note that grief is an individual process and is experienced differently by each individual; however, the grief stage model provides a framework for understanding the complexity of grief and how people can progress through to acceptance (Kübler-Ross et al., 2014).

Although grief has been accepted as a common occurrence in COPD, no studies have yet researched the impact of grief on COPD patients. A recent study by Boer et al. (2014) has commenced this research with the development of a COPD grief questionnaire. In their paper Boer and colleagues identified four stages of grief that COPD patients progress through; denial, resistance, sorrow and acceptance. These stages of grief are characteristically similar to that of Dr Kübler-Ross' five stages of grief; denial and isolation, anger, bargaining, depression, and acceptance (Kübler-Ross, 1973). However, Boer et al. note that the stage of bargaining is lost in COPD patients due to the prolonged nature of COPD and the slow decline in symptoms that these patients experience.

Although most patients progress similarly through the stages of grief, some patients can skip, revisit some stages or fail to progress from the first stage of denial (Kübler-Ross et al., 1972). This is especially so in the case of COPD patients, who can experience sudden acute exacerbations leading to admission to an intensive care unit, which can then be followed by months or years without another hospital admission.

Thus, COPD patients can begin to come to terms with their illness and its limitations, then experience one or a series of exacerbations and/or functional limitations that can cause them to revert to a previous grieving stage. This fluctuation between wellness and illness, as well as the progressive decline, can occur over decades, drawing out the grieving process, slowing patients' progression to acceptance (Boer et al., 2014). The direct impacts of these fluctuations on the grieving process and how each stage of grief can impact COPD patients' ability to make to the recommended behavioural and lifestyle changes will be discussed below.

Denial

The first stage of grief most frequently appears upon diagnosis of a chronic illness, but can be utilised by the patient as a defence mechanism at varying times due their illness (Kübler-Ross, 1973), protecting their self-esteem (Lindqvist & Hallberg, 2010). Denial shelters the individual from feeling the full effects of the emotional thoughts and feelings that often erupt following traumatic news (Telford, Kralik, & Koch, 2006). This protection from fully grasping the truth provides the individual with the time that is needed to gather themselves and reduce the occurrence of other, often more destructive, defence mechanisms (Kübler-Ross, 1973), such as displacement where increasing aggression over the diagnosis can be targeted at another person or object. Because denial involves avoiding the idea that one has an illness, this can lead to individuals initially avoiding being tested for a formal COPD diagnosis, downplaying their illness as not that serious, or emotionally disconnecting from the situation (Brion et al., 2013). Thus, denial assists individuals in dealing with the initial shock (Kübler-Ross et al., 2014) that can result from diagnosis of a chronic illness such as COPD. The emotional, behavioural and cognitive process of denial is presumed to be the primary reason that inhibits many COPD patients implementing the behavioural and lifestyle changes that are recommended to them; that is, adhering to the prescribed medication regimen and partaking in positive health behaviours such as exercise (Brion et al., 2013). Although denial can persist for an extended period, most patients eventually become unable to continue denying their illness. Once this occurs they begin to process the gravity of their situation, experiencing feelings of frustration, anger and sorrow (Kübler-Ross et al., 1972).

Resistance

In the resistance (or anger) stage the patient may become so angry, aggressive and difficult that staff, family, and friends may feel uncomfortable attending to their needs (Kübler-Ross, 1973). Anger is an important stage of the grieving process and helps patients to express some of the emotions and cognitions they are feeling (Kübler-Ross et al., 2014). The anger experienced can help patients identify their deepest areas of pain, providing an outlet for these feelings — a way for it to escape (Brion et al., 2013). Kübler-Ross et al. (2014) identified that the emotion anger assists individuals to feel as though they are grounded when it seems that the remainder of their world is out of control. Patients in the anger stage can have lower levels of self-esteem, questioning whether they are willing or able to continue taking their medications, as they often feel that they are controlled by their dosing schedule and that they have lost their freedom (Brion et al., 2013). Anger may also be internalised by some, resulting in feelings of shame and self-blame, which may be reflected in their need to hide their illness and the medications that help to control it (Brion et al., 2013).

Sorrow

When a patient is able to express the real reason for their anger or denial, that is, 'Why me?' then the patient is able to confront their reality and can begin to experience feelings of depression (Kübler-Ross et al., 1972). Sorrow (or depression) develops as a result of a realisation of the losses that have already occurred and the losses that will continue to occur up to and including the patient's death (Kübler-Ross, 1973). The stage of sorrow develops as the patient begins to live in the present (Kübler-Ross et al., 2014) and the idea of acceptance becomes a possibility. As the patient begins to recognise that life has forever changed, their self-esteem can decrease as they become confronted with

their impending death (Brion et al., 2013). Following this the patient becomes preoccupied with the idea of looming death, giving priority to their sadness at this outcome as opposed to focusing on the required lifestyle changes that will assist in managing their illness and promoting a better HRQoL (Brion et al., 2013). Sorrow is a natural progression through the grieving process as it allows unanswered questions to be processed (Kübler-Ross et al., 2014), such as 'why fight when I'm going to die anyway?' These feelings of helplessness and impending doom produce unhealthy coping strategies (Brion et al., 2013), which are often in opposition to the behavioural and lifestyle changes that have been recommended to the patient.

Acceptance

When a patient is helped through these stages either with dialogue and understanding or via natural progression, the patient can often reach the stage of acceptance; that is, feeling somewhat at ease with the changes that have and are going to occur (Kübler-Ross et al., 1972). Patients who reach this stage experience increases in self-esteem as they no longer feel alone in their illness; the isolation of what they have been going through lifts and they begin to see a life worth living (Brion et al., 2013). Essentially, patients begin to accept the recommended lifestyle and behavioural changes, and to integrate them into their lives (Kübler-Ross et al., 2014). An ability to identify with others who share similar pains and experiences is a key component of the acceptance stage, where patients begin to see a new 'normal' life (Brion et al., 2013) that involves living with the chronic illness and the behavioural and lifestyle changes that go with it. Thus, acceptance is about shifting the perspective from impending death to living with the disease and managing it in order to focus on quality of life rather than quantity of life.

Readiness to change in the context of behavioural and lifestyle changes

Whenever an individual is confronted with a diagnosis of chronic illness, they are often also faced with major lifestyle changes. These changes are adopted by some, while others can either reject them or fail to successfully adapt to them (Prochaska et al., 1992). Investigations into individuals' reactions to and progressions towards change resulted in the development of a model of change known as the Transtheoretical Model. The Transtheoretical Model evolved through the study of change in smokers who were undergoing treatment (Prochaska, Redding, et al., 2008). It was then expanded to examine behaviour change in relation to various areas including substance abuse, alcoholism, sun safety, cancer screening, and preventative medicine (Prochaska, Redding, et al., 2008). The Transtheoretical Model recognises five stages of change and also considers the processes and principles of change as well as acknowledging that relapse to previous stages is common when changing one's behaviour (Emdadi et al., 2007). Although readiness to change consists of five specific stages, it should be noted that some individuals can score high on more than one stage, especially as they begin to integrate and implement new strategies for their changing behaviour (Strand et al., 2007). For the purposes of this research, the model used will only incorporate the stages of change in order to determine if a relationship exists between COPD patients' treatment recommendations and their readiness to undertake these recommendations. The five stages of change through which individuals progress to make these lifestyle changes are discussed in detail below.

Pre-contemplation

The first stage, pre-contemplation, recognises that individuals in this stage are either oblivious about their need for change or are not interested in exploring change

(DiClemente et al., 2004). In COPD patients these changes often involve adhering to medication regimes, smoking cessation, and completing pulmonary rehabilitation (Yang et al., 2017). Although COPD patients in pre-contemplation are not considering change, their significant others recognise that there is an issue and can insist that they seek help. If change commences as a result of this external pressure from family and friends it is usually short lived, with patients reverting back to their old habits once things stabilise (Prochaska et al., 1992). The attitudes of pre-contemplators were investigated in a study by Hilberink, Jacobs, Bottema, de Vries, and Grol (2005), which found that COPD patients in the pre-contemplation stage had lower self-efficacy, viewed smoking as a sociable activity, and saw fewer benefits in smoking cessation than patients who had moved into or beyond the contemplation stage. It has also been found that an association exists between lung cancer survivors in pre-contemplation and their quality of life, where pre-contemplators had significantly worse quality of life than did participants in the contemplation, preparation, or maintenance stages (Clark et al., 2008). One of the realisations from the readiness to change model is that individuals in the pre-contemplation stage will require a very different style of intervention to individuals who are in any of the proceeding stages, as they are not contemplating or recognising the need for change (Curtis, Gibbon, & Katsikitis, 2016), have low selfefficacy, and are also heavily focused on the consequences of change rather than the benefits (Emdadi et al., 2007).

Contemplation

The second stage in the readiness to change model involves contemplating the need for change. Individuals in this stage begin to consider their need for change and are contemplating implementing these changes in the near future (Clark et al., 2008). In the contemplation stage individuals begin to consider the benefits of change (Prochaska,

Redding, et al., 2008), yet they often feel indecisive about taking action (Stockford, Turner, & Cooper, 2007). This indecisiveness stems from the previous stage, as the consequences of change are still fresh in their minds and they are thus still highly aware of the disadvantages regarding the changes that they are considering (Sherman & Carothers, 2005). As a result of this indecisiveness the weighing up of the benefits and consequences of change can persist for an extended period of time (Prochaska et al., 1992) and can lead to a relapse to pre-contemplation. Resent research regarding readiness to change in smokers has found that in comparison to pre-contemplators, contemplators were better able to envisage the long-term health benefits associated with smoking cessation. Specifically, contemplators recognised that ceasing smoking would reduce respiratory issues and lung cancer risk, as well as provide improvements in selfsatisfaction, health benefits and physical abilities (Hilberink et al., 2005). It has also been recognised that contemplators are able to recognise and implement practices that can decrease the triggers associated with the undesired behaviours that would reduce the probability of change (Flott, 2015). Although change is becoming a possibility for contemplators, they still perceive fewer benefits associated with proposed change as opposed to individuals in the following stages (Emdadi et al., 2007). Thus, actionorientated interventions are not well accepted by contemplators, and as a result they will require a different intervention to that of individuals in the preparation, action or maintenance stages (Prochaska, Redding, et al., 2008) in order for them to undertake the proposed behavioural and lifestyle changes.

Preparation

The next stage of readiness to change, preparation, involves the planning and implementation of small changes necessary for the individual to undertake action (Stockford et al., 2007). In this stage individuals are prepared to take action within a

shorter time period (usually one month; Prochaska, Redding, et al., 2008), and have often developed a plan of action in which they begin setting up the process for change or have attempted to implement small changes within the previous year (Prochaska et al., 1992). Research regarding readiness to change in COPD patients undertaking smoking cessation has found that patients in the preparation stage are experiencing greater symptomatic complaints than patients in the pre-contemplation stage (Hilberink, Jacobs, Schlösser, Grol, & de Vries, 2006). In another study, Hilberink et al. (2005) also found that COPD patients' self-efficacy and social support regarding their smoking cessation was significantly higher for preparers than it was for those in the preceding readiness stages. They also found that COPD patients who had reached the preparation stage experienced more regret about not undertaking smoking cessation when they first began suffering health complaints. This increase in support and confidence, combined with a newfound insight into the benefits of smoking cessation, provides an increased opportunity for entering the next stage (Hilberink et al., 2005).

Action

Following preparation COPD patients move into the action stage, where they make behavioural, environmental, and/or experiential modifications to effect the desired changes (Kerns & Habib, 2004). The action stage is time and energy intensive; it commences on the first day of change and continues for six months (Prochaska et al., 1992). Studies have found that support during this time is crucial for prevention of relapse (Flott, 2015); however, it has also been identified that high self-efficacy is a predominant factor in transitioning from preparation to action (Hilberink et al., 2005). In addition to this, social support, enjoyment, behavioural control and self-determination were also recognised as having a strong influence in progressing through the stages from preparation and action to maintenance (Spencer, Adams, Malone, Roy,

& Yost, 2006). Another factor found to be associated with the action stage is that of positive affect, where patients score higher with positive emotions such as feelings of joy, interest and confidence – aspects that are believed to be instrumental in active coping (Strand et al., 2007). In the action stage individuals become more focused on the benefits of change, and less on the perceived negative consequences of change (Prochaska, Redding, et al., 2008). Thus, individuals in the action stage are readier to accept and undertake action-orientated interventions (Prochaska, Redding, et al., 2008). Although patients are motivated, relapse remains a concern during the action stage, as this stage is the most challenging of all the five stages (Prochaska, Redding, et al., 2008).

Maintenance

The final stage of readiness to change involves maintenance of the behavioural, environmental, and/or experiential modifications. Patients are considered to be in the maintenance stage after six months of continuous action on the chosen lifestyle change (Prochaska, Redding, et al., 2008). In this stage individuals focus on continuing with their progress and preventing relapse into the previous stages (Stockford et al., 2007). Past research on patient quality of life has found that lung cancer survivors in the maintenance stage had a better quality of life than did patients who had not commenced physical activity; that is, they had a better quality of life than patients who were in precontemplation or contemplation (Clark et al., 2008). It has also been found that individuals' self-efficacy for the behavioural change was found to increase along these stages of change, with the maintenance stage producing the highest self-efficacy scores (Emdadi et al., 2007). In the maintenance stage, the perceived benefits of change continue to remain strong and few negative consequences are recognised. Maintenance

is generally considered to be a continuing process that can be lifelong (Prochaska, Redding, et al., 2008).

Resilience and its effect on behavioural and lifestyle changes

Resilience is a diverse concept which encompasses various risk and protective factors that influence an individual's health and well-being (Panter-Brick & Eggerman, 2012). There are many definitions of resilience; however, it is commonly defined as the capacity of an individual to maintain or quickly regain psychological and physical well-being following an adverse event (Black & Dorstyn, 2013; Bonanno, 2004). Resilience involves not only a form of recovery but also the ability for lifelong growth and change as a result of the adverse experience (Reich et al., 2010). The concept of resilience stemmed from research in the 1950s which investigated the concepts of coping and stress resistance (Sun & Stewart, 2007). Since this time various models of resilience have been proposed, including socio-ecological, psychological, and pathological models.

Socio-ecological resilience considers various aspects in combination. Social resilience refers to the way in which social groups, whether community, organisational or other, cope with stressful events. Ecological resilience, on the other hand, involves how the individual's culture or community influences the development and/or maintenance of resilience tools (Adger, 2000). The strength of ecological resilience relies upon a dose-dependent relationship; that is, the longer the individual belongs to a culture or community the more influential the environment is (Bronfenbrenner, 1994b). Thus, socio-ecological resilience considers coping to be a result of the individual's internal and external protective factors, their social relationships, as well as the influence of cultural and environmental resources (Sun & Stewart, 2007). This concept

has been investigated in various studies, including one that examined resilience in Indigenous individuals' smoking cessation attempts. In this study Bond, Brough, Spurling, and Hayman (2012) found that smoking cessation in the Indigenous study group was impeded by social stereotypes and stigmas that influenced resilient aspects such as the individual's' self-esteem. It has also been found that behavioural changes such as smoking cessation are tied to the individual's social network (Christakis & Fowler, 2008), where smoking can be a community orientated activity: essentially, a part of their cultural identity (Bond et al., 2012).

Psychological resilience encompasses the notion that resilience is primarily a result of the individual's internal traits (Ong, Bergeman, Bisconti, & Wallace, 2006) and that from these traits an individual is able to respond appropriately to adversity (Fletcher & Sarkar, 2013). One of the primary components of psychological resilience utilises that of positive emotions (Tugade & Fredrickson, 2004). The use of positive emotion-based coping in stressful situations usually involves the application of positive meaning and/or humour to troublesome experiences in order to regulate negative emotions (Ong, Bergeman, & Bisconti, 2004). Research by Ong et al. (2006) has demonstrated that highly resilient individuals frequently utilise positive emotion to assist in coping when they experience excessive amounts of stress. Other components of psychological resilience that are also considered to assist in coping with aversive events include self-efficacy, self-esteem, and spiritualty (Fletcher & Sarkar, 2013). These traits involve the individual's belief and confidence in themselves as well as their sense of purpose and feelings of success in life (Haase, 2004; Reich et al., 2010).

Pathological resilience involves the inclusion of neural circuitry in the resilience definition. Here resilience is governed by the development of brain pathways that act as regulatory processes which influence both mood and emotional responses to adverse

events (Reich et al., 2010). These pathways are also thought to be highly interconnected to other regions of the brain which are responsible for learning and memory, emotional responses to environmental stimuli, and even the avoidance of aversive stimuli (Nestler & Carlezon, 2006). Thus, if adverse events occur in early childhood, the brain is likely to experience significant changes in architecture as well as in the physiological and chemical systems that influence coping (Luthar & Brown, 2007). These changes will influence both the learning processes involved in the regulation of emotion and the development of appropriate physiological responses (Reich et al., 2010).

Initial research on resilience focused upon investigating traumatic experiences in childhood (Herrman et al., 2011; Reich et al., 2010). More recently, the scope of resilience research has been slowly increasing to investigate other aspects, including that of adult resilience (Herrman et al., 2011). Examples of adult resilience studies include individual reactions following a terrorist attack, loss of a loved one due to AIDS (Bonanno, 2005), and being diagnosed with chronic illness (Kralik, Van Loon, & Visentin, 2006b). The aspects investigated in resilience research involve various protective influences primarily consisting of individual and contextual factors. Individual factors involve the behavioural and cognitive abilities of the individual (Black & Dorstyn, 2013), such as coping, self-efficacy and self-esteem (Reich et al., 2010). Contextual factors involve social and environmental assets (Black & Dorstyn, 2013), including professional, family and community social support (Reich et al., 2010). It is believed that the combination of these individual and contextual protective influences have an additive effect which enhances an individual's ability to adapt and regain psychological and physical well-being following an adverse experience (Herrman et al., 2011; Pinkerton & Dolan, 2007).

The factors utilised for the resilience model in this study involve self-esteem, self-efficacy, coping, problem solving, decision making, professional support, and relationships. Each of these is discussed in detail below.

Self-esteem

Self-esteem is a characteristic that begins to develop shortly after birth and continues to evolve over the lifespan (Mann, Hosman, Schaalma, & de Vries, 2004). It is often defined in terms of self-respect, whereby an individual has confidence in their emotional and cognitive skills, as well as their character and social attributes (Juth, Smyth, & Santuzzi, 2008; Veselska et al., 2009). Low self-esteem is often presented via cognitive, affective, or behavioural reactions in terms of self-hate, anger, frustration, sadness, or via attempts to please others to obtain love and respect (Baumeister, 2013). Self-esteem is often considered an innate characteristic that forms part of an individual's personality (Fortes, Delignières, & Ninot, 2004). The strength of this characteristic has been found to be high in older adults (Collins & Smyer, 2005), a finding that supports the notion that self-esteem does not experience dramatic fluctuations in healthy adults (Fortes et al., 2004).

When evaluating the relevance of self-esteem to chronic illness, researchers have consistently found that patients diagnosed with COPD have lower levels of self-esteem (Hesselink et al., 2004; Kaptein et al., 2008), which impacts both psychologically and physiologically on these individuals. Self-esteem usually acts as a buffer against traumatic events and stressors (Mann et al., 2004); however, when older adults with high self-esteem are diagnosed with a chronic illness they can find it difficult to maintain their self-esteem (Ninot, Delignières, & Varray, 2010). The issue here is, when low self-esteem is combined with a chronic illness such as COPD, patients can

experience high levels of negative affect, which is when they become more susceptible to the development of a mental illness such as severe depression (Juth et al., 2008).

Although self-esteem is seen as primarily being linked to psychological distress, past research has found that it also has strong links to physiological aspects. The physiological areas that have been linked to self-esteem involve symptom frequency, physical pain (Nagyova, Stewart, Macejova, van Dijk, & van den Heuvel, 2005), functional limitations and perceived symptom severity (Juth et al., 2008). A study by Juth et al. (2008) found that patients with a chronic illness who had low self-esteem were more likely to report a greater severity of symptoms (coughing/wheezing), and more illness related limitations on their daily living. In addition to this, Nagyova et al. (2005) found that there was a strong association between a patient's self-esteem and their reported level of pain. Patients with lower self-esteem had more difficulty adjusting to the disease's progression and reported higher levels of pain than did patients with high self-esteem. These findings demonstrate that patients who have lower levels of self-esteem will have greater difficulties undertaking proposed behavioural and lifestyle changes, as both their physiological and psychological experiences present as further barriers to the adherence of recommendations such as pulmonary rehabilitation or smoking cessation.

Self-esteem can also interplay with other resilience factors, potentially further weakening a patient's ability or willingness to adapt and change in order to maintain good health and well-being. This interplay was demonstrated in a study by Hesselink et al. (2004), where they investigated the coping resources of individuals diagnosed with asthma and COPD. They found that COPD patients reported lower levels of self-esteem, self-efficacy, and health-related quality of life than patients with asthma. This finding indicates that the progressive lung deterioration experienced by COPD patients

leads to greater losses both physically and psychologically. It has also been recognised that patients with low resilience factors experience greater difficulties undertaking behavioural and lifestyle changes, as low levels of self-esteem and self-efficacy have been found to contribute to patients' failed attempts at smoking cessation (Wilson et al., 2011).

Self-efficacy

The development of self-efficacy begins in infancy and continues to evolve across the lifespan (Leary & Tangney, 2003). Self-efficacy involves an individual's belief in their own ability to successfully perform a behaviour in order to manage a task or situation (Bandura, 1982; Davis et al., 2006). It is a key motivating factor for successful self-management (Andenæs, Bentsen, Hvinden, Fagermoen, & Lerdal, 2014), as it directly influences whether an individual decides to undertake or avoid specific activities (Bourbeau et al., 2004). This decisional process is influenced by their self-assessed level of competence as well as their desire to have control over the situation (Benight & Bandura, 2004; Marino et al., 2008). Benight and Bandura (2004) have identified that the influence of self-efficacy includes motivational, cognitive, and affective domains; that is:

Self-efficacy beliefs...affect whether individuals think in self-enhancing or self-debilitating ways; how well they motivate themselves and persevere in the face of difficulties; the quality of their emotional life and vulnerability to stress and depression; resiliency to adversity; and the choices they make at important decisional points which set life courses. (p. 1131)

Self-efficacy is an attribute that is susceptible to either growth or decline depending upon the individual's success on a given task (Leary & Tangney, 2003).

Bandura (1982) has identified four different sources for self-efficacy change, a process he termed self-efficacy theory. The first and most influential source, enactive attainment, is developed through personal experience. Here the individual gains direct feedback regarding their competence by being directly involved in the experience.

Successful achievement of the task supports their assessment of personal competence, while poor performance can lead to a reduction in self-efficacy (Davis et al., 2006). The second source of self-efficacy attainment involves learning via observation and is termed vicarious experience. During observation, individuals learn about the possibility of success or failure in a situation through the experiences of others (Bandura, 1982). A sense of personal self-efficacy towards the task is then obtained if the individual completing the task is considered to have comparable capabilities to the observer (Davis et al., 2006).

Verbal persuasion is the third strongest source of self-efficacy and involves verbal assurances of the individual's competence. In order for verbal persuasion to be effective the individual providing the assurances must be personally respected by the receiver and the proposed task must be attainable and realistic (Bandura, 1982). The final source of self-efficacy involves feedback from an individual's physiological or emotional state. Here an individual's capabilities are confirmed through feedback received via their level of physiological or emotional arousal (Davis et al., 2006). Excessive stress, high visceral arousal, pain or fatigue following a performance degrades the assessment of their ability to achieve, lowering their self-efficacy.

Studies investigating the relationship between COPD patients and their levels of self-efficacy have found associations on a number of different factors. A recent study by Andenæs et al. (2014) found that higher levels of self-efficacy were associated with having a higher quality of life in relation to mental but not physical components. Thus,

patients with higher self-efficacy had better mental health when compared to patients with lower levels of self-efficacy, a result that is equivalent to previous findings where lower levels of anxiety and depression were found in high self-efficacy patients (Bentsen, Wentzel- Larsen, Henriksen, Rokne, & Wahl, 2013). Although linked with mental health, Bentsen et al. (2013) propose that increasing patients' levels of self-efficacy may encourage them to partake in social and physical activities that could improve their physical quality of life as well as leading to reductions in other health issues such as depression.

The maintenance of physical capabilities remains an important component in the management of COPD. The influence of this activity on COPD patients' self-efficacy was investigated by Davis et al. (2006), who administered a series of self-management and exercise programs on three groups of COPD patients. A three-hour education session was coupled with one of three exercise programs: low intensity – home walking; mild intensity – moderate supervised exercise; and high intensity – extensive supervised exercise. The researchers found that all of the programs significantly improved patients' self-efficacy for managing shortness of breath and walking. Of interest in these findings is that there was no dose-dependent relationship between the three intervention groups. That is, patients experienced increases in self-efficacy regardless of whether they were assigned to the low, mild or high intensity intervention groups.

Possible explanations for the results could involve the implementation of the four sources of self-efficacy theory into the intervention program. Firstly, all patients undertook the prescribed exercise program, increasing their competence through enactive attainment. Vicarious experience could also provide an increase in the patients' levels of self-efficacy, where the direct observation of their instructor demonstrating the breathing techniques could have influenced their own belief in their competence. Verbal

persuasion was also used with all participants to increase their confidence and competence. Finally, all patients were trained to assess their own physiological state. This process could increase recognition and boost patient confidence, especially when they feel they are achieving their set goals with minimal arousal. These results could indicate that self-efficacy levels can be increased with minimal supervision, provided that the patient education program incorporates self-efficacy theory components into its training.

Coping and problem solving

Coping and problem solving are inter-related concepts; this thesis will later refer to these concepts simply as coping. Coping is a construct that is viewed by some as an outcome of resilient actions (Connor & Davidson, 2003); however, this paper recognises coping as a distinct component of resilience, which involves the use of a behavioural and cognitive skill set to either emotionally or physically manage the current situation (Stratta et al., 2015). Problem solving adds further to this through the use of cognitive and behavioural operations that are guided by a set of goals, which are further influenced by the individual's knowledge, emotions, cognitive, social, and personal abilities (Frensch & Funke, 2014). Teaching problem solving skills assists individuals to further develop their cognitive and behavioural skills and to use these new skills adaptively (Murawski et al., 2009). The positive use of problem solving skills during a crisis reflects an active coping process (Sinclair & Wallston, 2004). That is, each time an individual resolves an issue, it enhances their future competence for solving problems and thus increases their coping ability (Leipold & Greve, 2009). Improved problem solving has also been found to be a mediator for treatment adherence, as it assists patients to reduce barriers, allowing them to find alternative

ways to undertake and cope with their treatment recommendations (Murawski et al., 2009).

In recent decades, research on coping has been extensive, and various coping strategies have been identified (Deimling et al., 2006). One of the most influential strategies proposes three primary coping styles: problem-focused, emotion-focused, and defensive coping (Lazarus & Folkman, 1984). On initial recognition of a stressful event an individual begins to appraise the situation in order to determine if the event can be modified by taking action (Lazarus, 2006). If action is possible, then the individual is able to react via problem-focused coping (Worthington & Scherer, 2004). Problemfocused coping is in line with that of problem solving: the problem is assessed, possible plans of action are considered, the most appropriate plan that fits the desired outcome is chosen, and action is taken (Lazarus & Folkman, 1984). The primary difference between problem solving and problem-focused coping is that problem-focused coping extends beyond environmental factors to include intrapersonal considerations (Lazarus & Folkman, 1984). Thus, problem-focused coping involves an individual utilising cognitive and behavioural strategies in order to change their personal situation, either externally or internally (Lazarus, 2006). If the stressful situation cannot be amended or acted upon, the individual will then react using emotion-focused coping (Worthington & Scherer, 2004).

Emotion-focused coping is a generally a cognitive regulatory process aimed at reducing stress through the alteration of one's emotions (Lazarus & Folkman, 1984). This regulation is achieved through the use of strategies such as self-soothing, optimism, reappraising, distancing, reassurance, or avoidance of the stressful event (Lazarus, 2006). An important distinction here is that unlike problem-focused coping, emotion-focused coping infrequently changes the outcome of the situation; instead it

alters the individual's emotional experience and how they process the event (Worthington & Scherer, 2004). This emotional regulation of the situation reduces anxiety and increases the individual's assurance that they can cope (Lazarus, 2006). Although emotion-focused coping is often cognitive, there are several behavioural approaches that individuals can use as a distraction, such as using physical exercise, meditation, or alcohol (Lazarus & Folkman, 1984). Essentially, emotion-focused coping can become a form of distorted reality or self-deception which, if used inappropriately, can further exacerbate the situation, especially if the patient decides to downplay their health issue (Deimling et al., 2006; Lazarus & Folkman, 1984).

Finally, if the individual is unable or unwilling to process the stressful situation then they will use a defensive coping strategy. Defensive coping is the process of repressing or denying a stressful event in order to avoid psychological distress (Gleiberman, 2007). This form of coping assists individuals to avoid feeling anguish and/or overtly displaying distress (Coifman, Bonanno, Ray, & Gross, 2007). A recent meta-analysis found that the use of defensive coping was significantly associated with suffering from several serious health issues, with the most prominent being cancer or hypertension (Mund & Mitte, 2012). Further research into defensive coping has found that the use of this coping style is associated with a patient's mental and physical quality of life outcomes. Kaltsouda et al. (2011a) found that patients who used defensive coping had higher rates of depressive symptoms and a lower quality of life on the mental health domain. In contrast to this, they also found that patients who used this defensive coping style had a higher quality of life on the physical well-being domain. These results indicate that defensive coping can act as a buffer for patients' distress caused by physical limitations, yet the reduction of this distress is likely to be short-lived, with the

long-term use of this form of coping being maladaptive and possibly resulting in adverse health outcomes (Reich et al., 2010).

Studies that have examined coping have found that the use of coping strategies declines with age (Deimling et al., 2006). The reasons behind this could involve becoming less reactive to stress (Mroczek & Almeida, 2004) or that continual changes occur throughout the lifespan that increase adaptation and acceptance of the individual's current situation (Deimling et al., 2006). Nevertheless, the importance of coping, including that of problem solving, is an important concept for individuals with a chronic illness such as COPD, as it has been found to mediate treatment adherence, promote action, and can allay adverse emotions while the patient begins to adapt to their changing life.

Decision making

Decision making for patients with a chronic illness is a complex process that is primarily driven by information provided by their clinicians regarding their current and future well-being, and is referred to as shared decision making (SDM). SDM is operationally defined as an interactive process that involves both the patient and the clinician collaboratively discussing a number of treatment options and then making a decision regarding the option that best aligns with the patients' values and beliefs (Barry & Edgman-Levitan, 2012; Joosten et al., 2008). The use of SDM in a clinical context transforms medical care from a disease focus to a more holistic approach that directly involves the patient in the decision making process (Barry & Edgman-Levitan, 2012); thereby empowering the patient to be more involved in their treatment (Joosten et al., 2008), which can have a positive impact on treatment adherence (Robinson, Callister, Berry, & Dearing, 2008). It can also improve health outcomes such as HRQoL, health

care utilisation (Wilson et al., 2010), and patient clinician communication (Robinson et al., 2008).

Research on decision making has found that patient involvement and disease knowledge are influential components for patients when deciding upon and adhering to a course of action. A study by Stack and Martin (2005) found that a patient's involvement in their medical decisions is related to their health outcomes. Specifically, patients who undertook sole or collaborative (patient and clinician) decision making responsibilities for their treatment had lower mortality rates and higher transplantation rates than did exclusively clinician governed decisions over the four-year follow-up. It was also found that when patients were actively involved in their medical decisions that they were more adherent to the prescribed treatment plan. Adherence increased as the discussion of these plans provided the patient with a high understanding of the treatment options, with the final treatment decision being chosen as it corresponded with the patient's values and beliefs (Arbuthnott & Sharpe, 2009).

Relationships

Resilient themes in individuals' lives are shaped from the social relationships that they have experienced across their lifespan (Reich et al., 2010). The concept of a relationship can exist in a variety of forms and can include connections with family, friends, and spiritual entities (Day, 2009). These varying relationships can provide individuals with various forms of support that assist in the maintenance and growth of their physical and psychological well-being (Reich et al., 2010). The different types of support that these relationships can provide can include instrumental, esteem, and informational (Gottlieb & Bergen, 2010); however, this research will investigate another form that has strong basis in chronic illness research: socio-emotional support.

This is defined as support that provides an emotional release and is gained through relationships provided by the community, groups, or interpersonal relations with family, friends, professional or work colleagues (Barkley, 2008; Ozbay, Fitterling, Charney, & Southwick, 2008). The strongest form of socio-emotional support involves support that is provided by family and friends (Greeff & Holtzkamp, 2007b). Past research has found that support derived from these interpersonal relationships can provide motivation and positive benefits for individuals with a chronic illness. One study found that supportive positive peer relationships increased COPD patients' motivation for continuing with exercise classes (Genoe & Zimmer, 2017), while another identified that supportive relationships provided improvements to COPD patients' overall functioning and health, an outcome believed to be due to patients' increased medication adherence resulting from these supportive relationships (Marino et al., 2008). Although the provision of supportive relationships has been found to have positive effects on patients, the reverse has also been found, where negative relationships were associated with increased hospital readmissions in heart failure patients (Tsuchihashi-Makaya, Kato, Chishaki, Takeshita, & Tsutsui, 2009).

Another study that investigated negative relationship support in COPD patients found that patients experienced increased levels of anxiety when they felt 'let down' or believed that others were being insensitive to their needs (DiNicola, Julian, Gregorich, Blanc, & Katz, 2013). These findings indicate that it's the quality, not quantity, of supportive relationships that provides the most positive and influential effect on patients' health outcomes (Barkley, 2008; Franks, Cronan, & Oliver, 2004; Goodenow, Reisine, & Grady, 1990). The benefits of supportive interpersonal relationships can be extensive and have also been reported to reduce morbidity and mortality rates in individuals who have been diagnosed with various medical illnesses, a result which was

not restricted by geographical or patient populations (Ozbay et al., 2008). Although interpersonal relationships have been found to influence patients' adherence and health outcomes, the impact of spiritual relationships is less clear.

Investigations into the influence of spirituality on chronic illness patients' HRQoL and behavioural and lifestyle changes are few. To date the studies have found mixed results, with some studies finding no relationship between spirituality and quality of life (Blinderman et al., 2009; Salsman, Yost, West, & Cella, 2011) and others finding significant associations (Adegbola, 2011b; Hasegawa et al., 2017). In addition to finding a link between spiritualty and quality of life, Adegbola (2011b) also found that spirituality was associated with patients' self-efficacy. This finding suggests that high spirituality enhances patients' confidence, which adds to the motivation for undertaking the behavioural and lifestyle changes that produce positive health outcomes (Adegbola, 2011b). Another study that investigated spirituality in Greek COPD patients found that patients' religious beliefs provided them with comfort and a sense of protection: a form of coping. These patients believed that their god had and would continue to help them overcome the adversities of their illness (the power of god). They also believed that they would continue to exist in some form (e.g. afterlife or reborn) after their death (Tzounis et al., 2016). Although spirituality research is sparse, the findings above indicate that research on spiritual relationships is an important area of investigation and should be considered when exploring the influence of relationships on patients' health outcomes and well-being.

Professional support

The influence of support is important to assist in the maintenance and growth of physical and psychological well-being (Reich et al., 2010). There are many different

types of support, including instrumental, esteem, and informational (Gottlieb & Bergen, 2010); however, this research will investigate another form that has strong basis in chronic illness research: professional support. This is defined as support provided by a qualified health care professional or team, which focuses on providing the patient with emotional support, encouragement, and knowledge regarding their illness so that they can undertake a self-management approach (Medical Board of Australia, 2014). Past research has found that positive support can provide motivation and benefits for individuals with a chronic illness, including increasing adherence to clinicians' treatment recommendations. One such study found that positive professional support provided by a referring clinician increased COPD patients' motivation for completing pulmonary rehabilitation (Harris et al., 2008b), while another identified that professional support provided improvements to COPD patients' perception of pulmonary rehabilitation, whereby patients viewed it as worthwhile to attempt (Bulley et al., 2009). While provision of support has been found to have positive effects on patients, the reverse effect has also been found, where unsupportive comments by the professional team increased the likelihood of dropout from pulmonary rehabilitation (Fischer et al., 2007).

A study that investigated a lack of appropriate support for COPD patients also found that poor professional support, where patients felt 'let down' or believed others were being insensitive to their needs, increased the patients' levels of anxiety (DiNicola et al., 2013). Appropriate professional support has been found to reduce morbidity and mortality rates (Ozbay et al., 2008) and increase patients' adherence to medication, especially when shared decision making is implemented (Wilson et al., 2010). In addition to this, research has identified that patients who are not provided with adequate disease knowledge from their clinician are at a greater risk of hospitalisations or

mortality across a range of conditions including COPD (Omachi, Sarkar, Yelin, Blanc, & Katz, 2013) and asthma (Mancuso & Rincon, 2006). Thus, research identifies that positive and collaborative support provides the most positive and influential effect on patients' health outcomes (Barkley, 2008; Franks et al., 2004; Goodenow et al., 1990).

Relationship between HRQoL and behavioural and lifestyle changes

HRQoL is a multidimensional concept that remains ill-defined; however, HRQoL has varying definitions of well-being in clinical research, depending upon which health issue is the primary focus (Fayers & Machin, 2013). HRQoL involves mental, physical, and social aspects and is generally best defined as the individual's perceptions of their mental, physical, and social capabilities and how these capabilities are impacted by their medical condition over a period of time (Centers for Disease Control and Prevention, 2017). More specifically, when considering the HRQoL of COPD patients, it reflects the gap between the patients' actual and desired capabilities (Almagro & Castro, 2013), and includes aspects such as the patients' symptomatic experiences, as well as their physical and psycho-social functioning (Connor & Davidson, 2003). It is recognised that many COPD patients experience a reduced HRQoL as a result of the disease and its limitations (Cully et al., 2006b). The relationships between HRQoL and various behavioural and lifestyle changes have been studied extensively, with research generally finding that a patient's HRQoL can be enhanced following certain behavioural and lifestyle changes such as self-management, pulmonary rehabilitation, medication adherence, and smoking cessation.

A recent meta-analysis by Zwerink et al. (2014) found that self-management programs significantly improved COPD patients' HRQoL across all SGRQ domains, including the perception of their symptoms, disturbances on activities of daily living,

psycho-social functioning, and their overall well-being, with the findings reaching the minimal clinically important difference. These improvements in patients' HRQoL are believed to be a result of increases in patients' symptom recognition (Turnock et al., 2005), disease knowledge, exercise capacity (Bulley et al., 2009), strength and endurance (Hayton et al., 2013), and self-efficacy for managing their disease – aspects that also reinforce the use of self-management (Cosgrove, Macmahon, Bourbeau, Bradley, & O'Neill, 2013).

As mentioned above, the focus of pulmonary rehabilitation is to increase exercise capacity, independence, support, and self-efficacy, as well as reduce symptomatic experiences of the disease (Almagro & Castro, 2013). Through improving these areas of a patient's life via pulmonary rehabilitation, patients also experience significant improvements in their HRQoL – improvements that were greater than those provided by medication alone (Lacasse, Goldstein, Lasserson, & Martin, 2006). A study by Haave and Hyland (2008) found that all patients experienced increases in their quality of life following the pulmonary rehabilitation program, but that the improvements experienced were not sustained at a six-month follow-up. When analysing these results via habitation status, they found that patients living alone experienced greater increases in their quality of life than those who co-habituated, and that these increases in quality of life remained strong at the six-month follow-up, a result believed to be due to the support provided by the pulmonary rehabilitation program.

Medication adherence and HRQoL in individuals with chronic illness is complex, with quality of life influencing medication adherence (Almagro & Castro, 2013) and medication adherence influencing quality of life (Restrepo et al., 2008). A recent systematic review by Ágh et al. (2015) found that patients who rated their quality of life as high were less adherent with their medication, suggesting that patients who felt better

were more likely to be non-adherent. This non-adherence was believed to be related to a patient's need to reduce the negative effects of the medications, such as side effects and illness related social stigma. Other studies have also found that adherence to medication regimes was associated with improvements in COPD patients' quality of life (Restrepo et al., 2008). As COPD medications are specifically designed to reduce symptoms and exacerbations, and slow disease progression, it is likely that these benefits will increase patient adherence, as patients associate their positive well-being with the medications, which overrides the aforementioned negative aspects (Ágh et al., 2015).

Smoking cessation is one of the primary treatment recommendations for the management of COPD (Almagro & Castro, 2013). Continued smoking in COPD has been found to be associated with poor HRQoL irrespective of patients' disease severity (Joseph, Pascale, Georges, & Mirna, 2012). Furthermore, this relationship was found to be dose dependant, where heavier smokers experienced poorer HRQoL than did light smokers (Joseph et al., 2012). Although smokers were found to have a lower HRQoL than non-smokers, this relationship is reversible: increases in COPD patients' HRQoL were seen within two months of smoking cessation (Papadopoulos et al., 2011). This result is not altogether surprising, as continued smoking is related to a higher incidence of depression (Almagro & Castro, 2013) and a rapid decline in lung functioning in COPD patients (Papadopoulos et al., 2011). The benefits of smoking cessation in COPD patients extends beyond improving lung functioning and HRQoL (Joseph et al., 2012) to reducing other systemic health issues and mortality (Papadopoulos et al., 2011).

2.6. Conceptual framework for barriers to adherence to treatment recommendations

During the course of history the treatment of illness has evolved from the primitive medicine provided by medicine men and women, to a two-fold approach — strong versus weak illnesses that were treated either by stimulants or sedatives (Rogers, 2010), to today's current eclectic models that include various aspects of the individual — the biological, psychological and social determinants — as well as the illness (Bayliss et al., 2014). The diversity of illness models is continually evolving to provide comprehensive paradigms that more appropriately reflect the distinct internal and external influencing factors that relate to the patient group. Thus, as COPD patients experience gradual declines in their physical and lung functioning, with sporadic severe and sudden exacerbations (Boer et al., 2014; Yang et al., 2017), it is proposed that the patients will also experience fluctuations in their emotional and mental capabilities. It is these intrapersonal fluctuations that have included HRQoL within the resilience, readiness to change, and self-management model proposed for this study.

Resilience, readiness to change, and self-management model

The conceptual framework chosen for this study involves the concepts of resilience, readiness to change, self-management, and behavioural and lifestyle changes (Figure 1). In this model resilience, readiness to change, and self-management are identified as influencing a COPD patients' behavioural and lifestyle changes. It is also recognised that the patients' level of resilience, their readiness to change, and their use of self-management will influence whether the patient chooses to undertake the behavioural and lifestyle changes that have been recommended to them by their clinicians.

Resilience in this model (Figure 2) is comprised of disease specific grief factors which include self-esteem and defensive coping, in addition to professional support, relationships, decision making, coping, and self-efficacy. The model's readiness to change component consists refactored stages of the readiness to change scale precontemplation, contemplation, and action.



Figure 1. Resilience, readiness to change, and self-management model.

In resilience the patient's use of defensive coping is expressed through the patient denying that they have an illness or that the illness impacts upon their life. COPD patients' self-esteem, on the other hand, is identified as being conveyed through the emotions that the patient feels as a result of illness and its disturbances; these emotions are anger, sorrow, and acceptance. Professional support in the resilience model considers the patients' beliefs regarding the disease specific professional support that is provided by a multidisciplinary pulmonary rehabilitation team. Specifically, it examines the extent of COPD patients' pulmonary rehabilitation knowledge through their beliefs

regarding the benefits and consequences of the supported program. The model also comprises the COPD patients' competence in managing their illness; that is, whether they are capable, able to cope, problem solve, make decisions, and maintain healthy relationships.

In the resilience, readiness to change, and self-management model it is recognised that comprehensive self-management interventions will provide COPD patients with the knowledge required to adequately manage their disease and its limitations. This improved self-management ability is identified as directly influencing the COPD patients' HRQoL, as they will be able to pre-empt the required treatment or be able to seek professional assistance prior to experiencing significant declines in health, thus improving HRQoL. This model also identifies that patients who have adequate self-management abilities, understand their lung capacity, and have a more comprehensive knowledge of their disease will be more likely to undertake the behavioural and lifestyle changes that their clinician has recommended, thus promoting behaviour change and increasing adherence to their treatment recommendations.

The resilience, readiness to change, and self-management model also recognises that the components of resilience can directly influence a COPD patients' HRQoL. That is, patients who have high levels of self-esteem believe they are worthy of the treatment they are receiving, improving their well-being as a result. Patients with high self-efficacy feel that they are more capable of taking action when challenged by illness intrusions; this positive action would further be enhanced if the COPD patient was efficient in coping, and/or decision making. Further to this, COPD patients who are able to maintain strong relationships, either personally or with their clinicians, would have better access to support when facing illness setbacks such as acute exacerbations, and this support would decrease the likelihood of patients using defensive coping

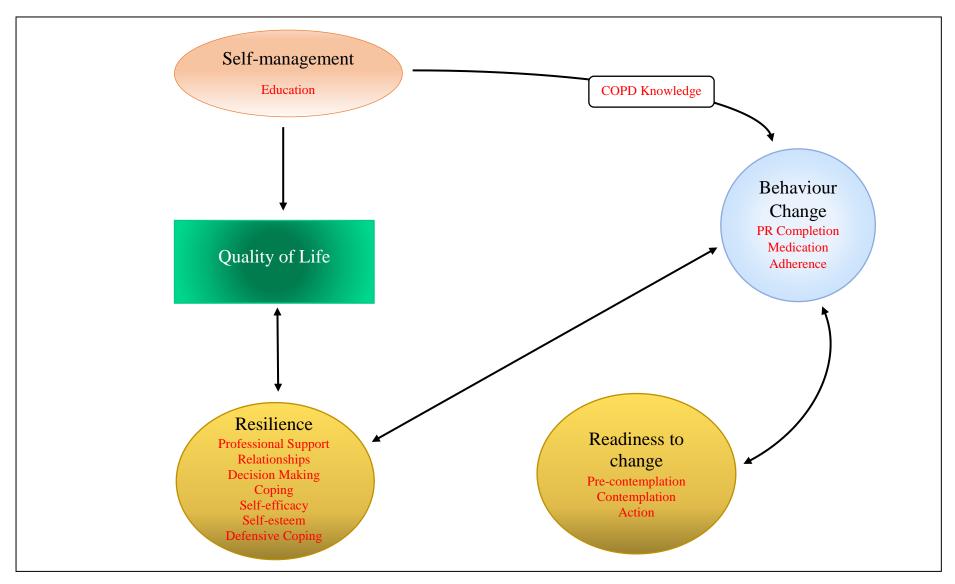


Figure 2. Resilience, readiness to change and self-management model: a comprehensive view. Pulmonary Rehabilitation (PR)

mechanisms such as denial. Thus, COPD patients who have the confidence to self-efficiently manage their disease, have access to supportive relationships, and feel competent in deciding on the best course of action to take during illness disturbances, will experience a better HRQoL.

Having strong resilience is also proposed to be associated with COPD patients' pulmonary rehabilitation completion and medication adherence. Again, self-esteem is seen as an important component, as it considers a COPD patients' worthiness to receive treatment that will promote their health and well-being. Patients must also have good levels of self-efficacy, as without this they will not have the confidence required to undertake and implement the recommended behaviour changes. Confidence is further linked to COPD patients' ability to make decisions and coping during times of stress. Having supportive relationships, whether with family, friends or their health care professionals, will further encourage COPD patients' pulmonary rehabilitation completion and medication adherence and reduce the likelihood that patients will deny they have an illness or are experiencing disturbances.

Finally, the resilience, readiness to change, and self-management model recognises that COPD patients' adherence to medications is associated with their readiness to change and undertake their clinicians' recommendations. This model proposes that patients who are dismissive about their illness or experience low motivation are less likely to undertake the behavioural and lifestyle changes that have been recommended to them by their clinician, whereas COPD patients who are accepting of their illness, are ready to take action and actively participate in maintaining their health and well-being, are more inclined to adhere to the prescribed medication regimes recommended by their clinicians.

Chapter 3: Methodology

3.1. Introduction

This chapter describes the methodological procedure used to test the hypotheses and answer the research questions proposed in this thesis. The study design used for this thesis is identified and the terms relevant to the research hypotheses are further defined. A description of the participants recruited in the study is provided, including the inclusion and exclusion criteria used during the recruitment process. These criteria were set to ensure that the study participants shared similar characteristics. An outline of the procedure used to recruit participants and obtain the quantitative data is also provided. This chapter finishes with a description of questionnaire items, independent and dependent variables, as well as the statistical analyses used to identify the relationships between the variables.

3.2. Research design

The conceptual framework proposed for this study suggests a non-experimental design. Thus, a convenience, cross-sectional research design was identified as the most fitting approach to examine the relationships between COPD patients' resilience, readiness to change, their health outcomes and adherence. The factors under investigation involve patients' self-management abilities, individual and contextual resilience, and readiness to change, with the outcome measures including the patients' HRQoL, completion of pulmonary rehabilitation, and medication adherence.

3.3. Definition of terms

Grief in the context of COPD is defined as a four-stage process in which patients fluctuate between intense feelings of denial, resistance, sorrow, and/or acceptance throughout the course of their illness (Boer et al., 2014). These stages can represent

different factors of resilience that are directly related to the disease. Denial refers to patients refuting and/or ignoring the existence of their impairments and is referred to as defensive coping. The remaining three factors examine COPD patients' disease specific self-esteem. Resistance examines the patients' feelings of frustration and anger resulting from their illness and its impairments, and how these impact upon their daily life. The term sorrow refers to patients' experience of sadness over their impairments and the limitations these impairments cause on a daily basis. The negative emotions COPD patients experience during both the resistance and sorrow stages can lower their sense of self-worth. Acceptance examines whether patients have learned to live with their illness and the limitations that they experience; thus, they acknowledge their limitations and are satisfied with their current health status, making them feel worthier of care.

Readiness to change is a four-stage process where individuals progress along a continuum of behaviour change, beginning with the behaviour change being out of conscious awareness (pre-contemplation), to becoming aware of the need to change (contemplation), commencing change and actively implementing the changes (action), and finally maintaining these behaviour changes (maintenance; DiClemente et al., 2004).

Resilience is commonly defined as the capacity of an individual to maintain or quickly regain psychological and physical well-being following an adverse event (Black & Dorstyn, 2013; Bonanno, 2004). Resilience involves not only a form of recovery but also the ability for lifelong growth and change as a result of the adverse experience (Reich et al., 2010). The resilience factors utilised in this study included self-esteem, self-efficacy, coping, defensive coping, decision making, relationships, and professional support.

Medication adherence is defined as the extent to which the COPD patients followed the medication regimen prescribed by their clinicians (Morisky, Green, & Levine, 1986).

Smoking status is defined via three categories: non-smoker, ex-smoker, and current smoker. However, as current smoker numbers were low in study (13), current and ex-

Pulmonary rehabilitation completion is defined as the completion of 62.5% of the exercise sessions. This figure was derived from Queensland Health's Helensvale and Robina clinics classification of completion, that is, 10 of their 16 sessions. This classification allowed for a moderate amount of patient setbacks, whether functional or situational. The categories included for this variable were did not complete, completed, and never referred.

3.1. Participants and sampling

smokers were combined.

The participants for this study were obtained using a purposive sampling approach. Subjects recruited for this research came from the South-East Queensland region. The participants either attended educational seminars delivered by Lung Foundation Australia and/or Queensland Health community health centres, or were approached within the medical assessment unit, respiratory ward, acute medical ward or general medicine ward at Robina Hospital or Gold Coast University Hospital.

Participants at the education days attended these programs voluntarily following a referral from a clinician or via an invitation from the institution (Lung Foundation Australia only). The educational topics discussed during these seminars were delivered via a multidisciplinary health care team on topics such as understanding COPD (and other lung conditions for Lung Foundation Australia), types of medication available and what these medications are used to control, safety and convenience aids, psychological aspects associated with COPD, and speech and swallowing difficulties.

Inclusion criteria

Participants were asked to participate if they were aged over 40 years, had received a clinician's spirometry confirmed diagnosis of COPD (mild to severe), and were attending the COPD education day at Helensvale or Robina community health, Lung Foundation Australia's education seminars, or were receiving treatment at various hospital areas such as the medical assessment unit, respiratory or medical wards at Robina or Gold Coast University hospitals.

Exclusion criteria

Participants were excluded if they had a serious cognitive impairment (e.g. Alzheimer's or dementia), or any other unstable medical, major psychiatric, or neurological condition (e.g. Parkinson's disease) that would have interfered with their ability to communicate responses or maintain their independence. Participants were also excluded if they were unable to communicate in English effectively or if they were unable to provide informed consent.

Sample size

In 2013 the prevalence of moderate to severe COPD in the Australian population was reported to be 8.4% (Lung Foundation Australia, 2014). Based on this prevalence and using the formula devised by Charan and Biswas (2013) for calculating the sample size for medical research, the number of participants was obtained. The formula (below) identified that a minimum of 118 participants would be required for this research study $(p = 8.4\%, d = 0.05, and (Z_{1-\alpha/2}) = 1.96)$.

Sample size =
$$\frac{Z_{1-\alpha/2}^2 p(1-p)}{d^2}$$

3.2. Data collection

The data for this study was collected between September 2015 and November 2016. Data was collected on Monday through to Wednesday from the Gold Coast University Hospital's medical assessment unit, respiratory, and general medicine wards and from Robina Hospital's acute medical unit, specialist, and general wards on Thursdays and Fridays. Data was also collected from participants on various education days. The first education day was conducted by Lung Foundation Australia in Brisbane in September 2014, and subsequent COPD education day data collections were held every second month at both the Helensvale and Robina community health centres.

At the Gold Coast University and Robina hospitals participants were identified through nurse and clinician briefings, as well as via inpatient medical history sheets. Individuals who were identified as eligible were approached in person on the wards and were introduced to the research topic and asked if they would like to receive more information about the study. Individuals who expressed further interest were requested to provide contact details for follow-up and were provided with a study pack that contained the information sheet, consent form, questionnaire, research team contact details, and reply-paid envelope. Patients in the hospital wards were also provided with the option of the research team member assisting them with completing the questionnaire during their hospital stay. This option was provided as the inpatients were keen to participate, wanted to occupy some of their time in hospital, yet did not feel well enough to complete the questionnaire on their own.

At the education days individuals were initially approached as a group, and the proposed study was outlined by a member of the research team. Once potential participants were given an overview they were approached individually during lunch time to enquire as to their interest in obtaining additional information for participation.

If interested the individual's contact details were obtained and they were then provided with a study pack (detailed above). Participants were also informed that they could contact the research team if they had any further queries regarding the study. Individuals who had not responded via submitting the consent form and questionnaire were followed up with a phone call to enquire if they were still interested in participating and whether they required assistance to complete the questionnaire. If assistance was required they were offered a choice of receiving it in person or over the phone.

Participants were also informed that they could withdraw their consent at any time during the study by contacting a member of the research team listed on the information sheet provided in the study pack.

3.3. Procedure and ethics

Ethics approvals (Appendix A) for this study was obtained from Griffith University Human Research Ethics Committee (Protocol Number: MED/40/15/HREC; Griffith University Reference No: 2015/677). Ethics approval was also obtained from Queensland Health's Gold Coast Hospital and Health Service Human Research Ethics Committee via the completion of the National Ethics Application Form (NEAF) and was approved in October 2015 (HREC/15/QGC/232).

Potential participants were approached and provided with a verbal description of the study, their responsibilities, anonymity, and confidentiality of the information that they would be providing. Consent was considered to be given (as explained in the information sheet and consent form) if the questionnaire was completed and returned to the research team. Data collection was conducted over a period of 14 months. All returned survey data was input into IBM SPSS Statistics v21 software to be analysed. Following data input and data cleaning the questionnaires were deidentified and patient

information was disposed of via shredder in accordance with confidentiality requirements.

3.4. Materials

A comprehensive questionnaire was developed for assessing COPD patients' individual and contextual resilience factors, readiness to change, HRQoL, adherence to recommended behavioural and lifestyle changes, and their demographic characteristics (Appendix B). The questionnaire is comprised of 106 questions, with 65 using a four to seven-point Likert scale, 21 using frequency or graded scales, 13 using dyadic, and 7 using categorical measures. Six specific scales were utilised in this questionnaire in order to examine the direct aspects of the patients' behavioural, emotional, and cognitive states. These scales included questions to assess the patients' adherence to medications (adapted from; Khalesi, Sharma, Irwin, & Sun, 2016), knowledge of supported pulmonary rehabilitation programs (benefits and consequences of pulmonary rehabilitation (PRBCS)), their stage of grief (via the Acceptance of Disease and Impairments Questionnaire (ADIQ); Boer et al., 2014), level of resilience (via a modified version of the Connor-Davidson Resilience Scale (CD-RISC); Connor & Davidson, 2003), readiness to change (modified version; Heather & Rollnick, 1993), in addition to their HRQoL (St George Respiratory Questionnaire; (Jones, Quirk, & Baveystock, 1991a)), and various demographic variables.

The medication adherence questionnaire was adapted from a set questions utilised in hypertension research by Khalesi et al. (2016) and assessed patients' adherence to their medications via four questions, with three response options; never, occasionally, and always. The questions included 'Have you ever forgotten to take your respiratory medication', 'If you feel your respiratory symptoms got worse or remained unimproved, do you stop taking your respiratory medication', 'If you think your respiratory

symptoms are improving, do you stop taking your respiratory medication', and 'Do you take your medicine at the same time every day'. The adherence questionnaire was found to have moderate reliability (Cronbach's $\alpha = 0.50$). A reliability analysis was run with the current COPD sample and was found to be good (Cronbach's $\alpha = 0.80$).

The PRBCS is a newly developed scale that examines COPD patients' beliefs regarding how the professionally supported pulmonary rehabilitation program will impact upon their health outcomes. The scale consists of 14 questions that ask patients to rate their agreement via a seven-point Likert scale: strongly disagree, disagree, somewhat disagree, undecided, somewhat agree, agree, and strongly agree. A factor analysis found three factors for the current COPD sample which examines patients' perception of how pulmonary rehabilitation will influence their health and well-being ('Improve a COPD patients' quality of life'), their reliance on external services ('Reduce COPD patients' ability to perform basic home duties'), and the programs impact on potential risks ('Increase the risk of injury'). The reliability for the current sample was good ($\alpha = 0.72$) and displayed good content validity with the questions accounting for 59.93% of the variance.

The ADIQ assessed COPD patients' current stage of grief via 14 questions. The ADIQ has been found to have a good reliability (Cronbach's α between 0.80 to 0.83) and also proved to be a valid measure (Boer et al., 2014). This questionnaire asks patients to rate their level of agreement on a five-point Likert scale: not at all true, rarely true, sometimes true, often true, and almost always true. It queries patients' four stages of grief: denial ('I try to ignore my impairments'), resistance ('I feel frustrated with my impairments'), sorrow ('I become sad when I experience an impairment'), and acceptance ('I can accept my impairments'). An in-depth review into the contents of the ADIQ found that the scale could also be used to analyse the resilience factors of defensive coping (which incorporates denial) and COPD patients' disease specific self-

esteem. As stated previously, self-esteem involves how an individual perceives their own worth. When considering this self-worth from a disease perspective, COPD patients can experience different emotional reactions such as anger and sorrow towards their impairments when they lack confidence in their emotional, cognitive, and behavioural ability to manage their illness appropriately (Juth et al., 2008; Veselska et al., 2009). These responses can further influence their social competency and connections, which have a direct link to their feelings of worth (Juth et al., 2008). To confirm the reliability of the ADIQ on the current sample, a Cronbach's alpha was conducted and was found to be excellent (Cronbach's $\alpha = 0.87$); a subsequent validity analysis found that the content validity for the current COPD sample was excellent, with 78.1% of the variance being accounted for via the 14 questions.

An abbreviated version of the CD-RISC was used to assess COPD patients' individual and contextual resilience via 25 questions. Previous assessment of the CD-RISC has found it to have excellent reliability (Cronbach's $\alpha = 0.89$) and a good validity (Connor & Davidson, 2003). This questionnaire asks participants to rate their feelings over the last month on a five-point Likert scale: not at all true, rarely true, sometimes true, often true, and almost always true. To ensure that the data fit was appropriate, a factor analysis was conducted on the current COPD sample. The factor analysis found that four factors were more appropriate for this sample. The newly identified four factors comprised: self-efficacy ('Can deal with whatever comes'), coping ('Under pressure, I focus and think clearly'), decision making ('Make unpopular or difficult decisions'), and relationships ('Have close and secure relationships'). To check that the CD-RISC remained reliable and valid further analyses were conducted. The reliability of the CD-RISC increased and was found to be excellent ($\alpha = 0.92$), with the content validity reflecting good validity with 56.58% of the variance being accounted for via the 25 questions.

The readiness to change questionnaire was developed to enquire into alcoholics' readiness to change their drinking habits. For this study, the readiness to change questionnaire was adapted to assess COPD patients' readiness to change their behavioural and lifestyle activities through their readiness to undertake their clinicians' recommendations. This questionnaire component consisted of 12 survey items. The reliability of the original alcohol-based readiness to change questionnaire ranged between 0.73 and 0.86 (Cronbach's α) and was found to be a valid measure of change in behaviour (Heather & Rollnick, 1993). The current version of the questionnaire asks patients to rate their feelings regarding their clinicians' recommendations via a fivepoint Likert scale: strongly disagree, disagree, unsure, agree, and strongly agree. A factor analysis on the current sample found three factors: pre-contemplation ('I don't think I need to undertake my clinician's recommendations'), contemplation ('I am at the stage where I should start thinking about following my clinicians' recommendations'), and action ('I am actually changing my treatment regimen right now'). However, the reliability for the current COPD sample was found to be acceptable (Cronbach's α = 0.55) although, the content validity was good with the questions accounting for 58.88% of the variance.

COPD patients' HRQoL was assessed via the SGRQ (Jones et al., 1991a). The initial reliability of the SGRQ was excellent (Cronbach's α = 0.95) and also had a good validity (Jones et al., 1991a; Meguro, Barley, Spencer, & Jones, 2007). Another study on the internal reliability (α >0.70) was excellent and the test-retest correlations were also found to be excellent (r=0.795 to 0.900; Barr et al., 2000). Factor loading was recalculated via a confirmatory factor analysis for the current COPD sample, with five factors being identified. The SGRQ is a self-report measure that assesses a patient's HRQoL (high scores indicating a poor HRQoL). The five new factors identified in the analysis found that the SGRQ measured HRQoL via patients' limitations on their

activities, breathlessness, symptoms, coughing experiences and medication impacts. The first domain assesses the limitations to patients' activities of daily living that occur as a result of their breathlessness. The second factor measures the patient's level of breathlessness both currently and in comparison with others. The third factor assesses the patient's perception of their symptoms through a self-report of their breathlessness, cough, and sputum production. Domain four examines the coughing experiences of the patients, with the final factor enquiring into the patient's medication experiences. A final overall score is also calculated in order to examine the patient's overall HRQoL. The reliability of the SGRQ for the COPD sample obtained for this study was found to be acceptable (Cronbach's $\alpha = 0.55$).

The demographic variables included in this study enquired into patients' age, gender, marital status, number of individuals living in their household, religion, ethnicity, years since COPD diagnosis, average hours of weekly exercise, employment status, highest level of education, annual household income, wellness program completion, and co-morbidities diagnosed by a clinician (diabetes, heart disease, high blood pressure, asthma, cognitive illness, neurological disorder, anxiety or depression, other mental illness, other chronic lung disease, cancer, and other diseases not yet listed), with a total comorbidities score being calculated from this section of data.

3.5. Data management

During the data collection period 360 patients were asked to participate in the research study. Returned questionnaires that had more than 50% of response data points missing were excluded from the final analysis. In total 159 COPD patients finished and returned completed questionnaires, providing a response rate of 44.2%. Cross-tabulation and descriptive analyses were used to identify demographic categories that did not have representative items; that is, cells that contained either no answers or less than 5%. In

order to reduce these inconsistencies in the data, categories were regrouped. The dataset was also explored for outliers, with any outliers being replaced with the mean or coded as missing values. Dichotomous missing values from the SGRQ were imputed with the assistance of Associate Professor Alan Wee-Chung Liew via a categorical imputation method.

In order to ensure that categorical data points contained adequate numbers, several nominated categories were combined. Knowledge of pulmonary rehabilitation was reduced from five categories (very poor, poor, average, good, and very good) to three (poor, average, and good); smoking status was condensed into two categories (nonsmoker and ex-smoker/smoker) from five (non-smoker, ex-smoker, and smokes less than 7 cigarettes per day, smokes 8 to 20 cigarettes per day, and smokes more than 20 cigarettes per day), due to low numbers of smokers recruited in the study. Some of the demographic variables were also condensed to simplify statistical analysis; age was reduced from five (\leq 45, 46-55, 56-65, 66-75, and 76+ years) to three (\leq 65, 66-75, and 76+ years) age groups; marital status from five (married, divorced/separated, de-facto, single, and widowed) to two (married/de-facto and divorced/separated/single/widowed) groups; employment status from four (unemployed/disability, part-time, full-time, and retired) groups to two (working, and retired/unemployed/disability); and education from five (junior/intermediate certificate [Year 10] or before, senior/leaving certificate [years 11-12], TAFE certificate, undergraduate degree, postgraduate degree) to two (primary/secondary and tertiary education) groups.

3.6. Statistical analyses

Statistical analyses for each of the studies differed according to each hypothesis.

To provide a detailed description each statistical analysis is described with the corresponding hypothesis. The variables, variable type, and level of measurement for

this paper are presented in Table 2. Listed therein are the independent and dependent variables that are based on the gaps identified in the current literature review. The independent and dependent variables will vary according to each research hypothesis and will be outlined in the hypotheses listed below. The COPD patient demographic variables are also presented in Table 2; the demographic variables are considered to be confounding variables and will be controlled for in each independent study.

Table 2. COPD patient survey variables and their levels of measurement

Variable	Type of Variable	Level of Measurement
Trust	Independent	Ordinal
Self-esteem	Independent	Ratio
Self-efficacy	Independent	Ratio
Defensive coping	Independent	Ratio
Coping	Independent	Ratio
Decision making	Independent	Ratio
Relationships	Independent	Ratio
Professional support	-	
Health and well-being	Independent	Ratio
Reliance on external services	Independent	Ratio
Potential risks	Independent	Ratio
Readiness to change	-	
Pre-contemplation	Independent	Ratio
Contemplation	Independent	Ratio
Action	Independent	Ratio
HRQ ₀ L	•	
Activity	Dependent	Ordinal
Symptoms	Dependent	Ordinal
Breathlessness	Dependent	Ordinal
Cough	Dependent	Ordinal
Medication	Dependent	Ordinal
Pulmonary rehabilitation completion	Dependent	Nominal
Demographic characteristics	-	
Age	Confounding	Nominal
Gender	Confounding	Dichotomous
Marital status	Confounding	Dichotomous
Education	Confounding	Dichotomous
Smoking status	Confounding	Dichotomous
Recruitment location	Confounding	Dichotomous
Diagnosis anxiety or depression	Confounding	Dichotomous
Diagnosis hypertension	Confounding	Dichotomous
Other lung disease	Confounding	Dichotomous
Total number of comorbidities	Confounding	Ratio

Hypothesis 1: COPD patients who undertake self-management interventions will experience greater increases in HRQoL when compared with patients who continue treatment as usual.

The statistical analysis for the self-management meta-analysis utilised the Mantel-Haenszel random effects method. This method allowed for the assessment of sources of heterogeneity within the self-management components. Subgroup analyses were conducted to analyse educational and functional components of interest. Publication bias was assessed using Egger Regression Analysis and sensitivity was examined to ensure that a specific publication(s) was not responsible for the results. The dependent variables in the meta-analysis consisted of the COPD patients' health and well-being outcomes; that is, their levels of anxiety and depression (HADS), self-efficacy (COPD self-efficacy scale), exercise capacity (six-minute walk distance), number of hospital admissions, and HRQoL (SGRQ). The independent variable consisted of the self-management educational intervention program or treatment as usual. For the subgroup analysis, the educational components were extracted and involved the exacerbation action plan, COPD disease education, and exercise information; in addition to this the duration of the intervention was also used to examine its influence on the outcome variables.

Following a literature search for articles containing the predefined keywords, 559 articles were identified. Following an analysis of the articles and removal of irrelevant studies based on the inclusion/exclusion criteria and quality analysis, 25 articles remained for inclusion in the self-management meta-analysis. Further descriptions of the statistical analysis and methodology used for hypothesis 1 can be found in chapter 4.1.

Hypothesis 2: High levels of resilience is associated with a better HRQoL in an Australian COPD sample.

For hypothesis 2 a decision tree analysis was conducted to identify the resilience factors important in COPD patients' HRQoL. Bivariate analysis of the demographic variables was assessed via independent t-tests and chi-squared analysis in order to identify which factors could potentially confound the final analysis. Any factors that were found to be significant with an alpha of 0.05 were automatically included in the final analysis. Thus, the confounding factors included for their influence on the dependent variable COPD patients' HRQoL (SGRQ activity, symptoms, breathlessness, cough, and medication) were the patients' marital status, recruitment location, diagnosis of anxiety or depression, and their total number of comorbidities. The resilience factors (independent variables) included in the study were comprised of the refactored CD-RISC (self-efficacy, coping and problem solving, decision making, and relationships); ADIQ denial; self-esteem, which was derived from combined scores of the ADIQ resistance, sorrow, and acceptance scores; and professional support which consisted of the PRBCS factors: health and well-being, reliance on external services, and potential risks scores.

A decision tree analysis with an alpha of 0.05 was run for each of the HRQoL domains with the aforementioned independent variables. The decision tree method in this study is able to analyse both continuous (regression tree) and categorical outcome variables (classification tree; Ming, 2001b) in order to identify which variables are of importance to COPD patients' HRQoL. Of particular interest was to identify which resilience factors have the strongest relationship to patients' activities of daily living, perception of symptoms, levels of breathlessness, coughing experiences, and medication use. The significant variables were also reported in the tree diagram which contains the level of importance and figures that denote the direction of the significant findings. A

further explanation of the statistical analysis and methodology can be found in chapter 4.2.

Hypothesis 3: Low levels of resilience is related to poor completion rates of pulmonary rehabilitation programs in Australian COPD patients.

Hypothesis 3 contains a similar format to that of hypothesis 2. The method used to analyse the data included a decision tree; yet the factor of importance was the categorical variable, pulmonary rehabilitation completion (completed, did not complete, and never referred). Prior to running the decision tree analysis bivariate analyses of the demographic variables were assessed. As above, the tests included independent t-tests and chi-squared analyses with an alpha of 0.05 to identify potential confounding factors. No demographic factors were found to be significant and thus were not included in the decision tree analysis. The independent variables in this study included the resilience factors from the refactored CD-RISC (self-efficacy, coping, decision making, and relationships); ADIQ (defensive coping from denial, and self-esteem consisting of combined scores from the ADIQ resistance, sorrow, and acceptance stages); and professional support which involved the PRBCS factors: health and well-being, reliance on external services, and potential risks scores.

A decision tree analysis with a significance level of 0.05 was run for the pulmonary rehabilitation completion outcome with the independent variables stated above. As the decision tree can analyse both continuous (regression tree) and categorical outcome variables (classification tree; Ming, 2001b) it was able to appropriately identify variables of importance for a categorical dependent variable. The study's primary interest was to identify which resilience factors were important for the completion of and referral to pulmonary rehabilitation programs. The significant variables were also presented diagrammatically, indicating their level of importance and the cut-off scores and direction for each of the independent variables. Further

descriptions of the statistical analysis and methodology used for hypothesis 3 can be found in chapter 4.3.

Hypothesis 4: Australian COPD patients with high levels of resilience and readiness to change will display higher adherence to the medication regimens prescribed by their clinicians.

Hypothesis 4 contains a similar format to that of hypotheses 2 and 3. A decision tree analysis was run to examine the relationship between the factors of resilience and readiness to change and COPD patients' adherence to medication regimens. The outcome variable in this study involved a COPD patient's medication adherence; classified as fully adherent, or not adherent (missing one or more doses over the last month). The dependent variables included both resilience factors and readiness to change. Initial bivariate analyses were conducted of the demographic variables in order to identify potential confounds prior to running the decision tree. As above, the bivariate analyses included independent t-tests and Chi-squared analyses with an alpha of 0.05. Demographic factors that were found to be of significance were included in the decision tree analysis. Thus, the confounding factors included for their influence on the dependent variables COPD patients' resilience and readiness to change were the patients' age, employment status, household income, diagnosis of anxiety or depression, heart disease, and other lung disease. The independent variables included in this study were the patients' level of resilience (self-efficacy, coping, decision making, relationships, trust, defensive coping, self-esteem, and professional support) and their stage of readiness to change (pre-contemplation, contemplation, and action).

The results of the decision tree were considered to be significant with an alpha of 0.05. Decision tree analyses are able to test both continuous (regression tree) and categorical outcome variables (classification tree; Ming, 2001b), thus making it a useful method to identify the most important grieving stages in relation to COPD patients'

readiness to change. Finally, graphical representations clearly display the variables of importance and the direction of this influence on the outcome variable. A further explanation of the statistical analysis and methodology can be found in chapter 4.4.

Hypothesis 5: The St George Respiratory Questionnaire is a reliable and valid measure of HRQoL in COPD patients in Australia.

Hypothesis 5, as stated above, is a validation and reliability analysis of the SGRQ for the current Australian COPD sample. The primary statistical procedures used for this study included an exploratory factor analysis followed by a confirmatory factor analysis. The exploratory factor analysis was utilised in order to identify factors within the HRQoL scale. A reliability assessment (Cronbach α) was also conducted to ensure that the measure contained good internal consistency. Following the initial analyses, structural equation modelling was used to ensure good model fit. A confirmatory factor analysis was run to examine the factors identified through the exploratory factor analysis as well as to inspect the convergent validity of the data provided by the new model. An alpha of 0.05 was used to test the statistical significance outcomes for this study. The factors identified by the confirmatory factor analysis include the limitations that COPD patients experience on their activities of daily living; the levels of breathlessness experienced daily; patients' perception of symptoms; patients coughing experiences both at rest and during activity; and the impact of medications on COPD patients' daily lives. Further descriptions of the statistical analysis and methodology used for hypothesis 5 can be found in chapter 4.5.

3.7. Summary

This chapter outlined the study's use of a convenience, cross-sectional design, which was chosen as a result of the conceptual framework devised for this study. This framework was developed as a result of gaps in the research investigating the

relationships between COPD patients' individual and contextual resilience factors and their health outcomes, including their readiness to change and undertake the behavioural and lifestyle changes that aim to assist in improving their health outcomes. Participation was sought from COPD patients in the South-Eastern region of Queensland between September 2015 and November 2016. Ethics approval was obtained from both Griffith University Human Research Ethics Committee and Queensland Health's Gold Coast Hospital and Health Service Human Research Ethics Committee. The questionnaire developed for this study assessed various individual and contextual factors, readiness to change, HRQoL, adherence to pulmonary rehabilitation and medication, and the patients' demographic factors. Of the 360 participants approached, 159 returned completed questionnaires. The data obtained by these questionnaires was used to statistically analyse four hypotheses developed from the chosen framework. A fifth hypothesis was developed to combine and examine past research for a meta-analysis on self-management.

Chapter 4: Results

4.1. Self-management Interventions and their Effect on Quality of Life and Health
Outcomes in Chronic Obstructive Pulmonary Disease Patients

Introduction

This study aimed to explain the first research question which is further explained in the conceptual framework (section 2.6) and literature review of this thesis that selfmanagement interventions improve COPD patients HRQoL. The framework proposed that standardised self-management interventions which provide disease knowledge, exercise information, nutritional guidance, or other training such as action plans will assist patients in adequately managing their disease and its limitations which would result in improvements their HRQoL through promoting behaviour change. A metaanalysis was undertaken to analyse the effect of self-management interventions via various published randomised control trials on COPD patients' HRQoL, exercise capacity, self-efficacy, and number of hospital admissions. Self-management interventions are proposed to improve these health and well-being factors; however, the results of these outcomes have not been consistent. In addition to this, subgroup analyses on the self-intervention training components have never been conducted. Understanding which training components provide significant improvements to COPD patients' health and well-being is crucial and can assist in determining which components are required for future interventions.

Statement of contribution to co-authored published paper:

This section includes a co-authored manuscript submitted for publication to Respiratory Medicine as an original research paper. The status of the co-authored paper, including all authors, is: **Cannon D,** Buys N, Sriram KB, Sharma S, Morris N, Sun J, The effects of chronic obstructive pulmonary disease self-management interventions on

improvement of quality of life in COPD patients: A meta-analysis, Respiratory

Medicine (2016), doi: 10.1016/j.rmed.2016.11.005.

The research candidate has made the following contributions to this study:

• Devised gaps in research for meta-analysis study.

• Undertook an extensive search of the literature and obtained relevant articles.

• Extracted, and interpreted data for meta-analysis.

• Analysed the data and interpreted the findings.

Prepared the manuscript and submitted to the Respiratory Medicine.

Danielle Cannon (26/03/2018)

Supervisor and corresponding author: Jing Sun (26/03/2018)

Abstract

This article aimed to analyse the outcome of self-management randomised control

trials and their impact upon chronic obstructive pulmonary disease patients' health

outcomes using meta-analysis approach. PubMed, Scopus, CINAHL, Web of Science

databases and Cochrane Library, were searched for articles between 1990 and

December 2015 by two researchers. Self-management programs significantly improved

patients' quality of life across all domains of the St George Respiratory Questionnaire

(SGRQ; activity -2.21 (95% CI: -3.61 to -0.80), p=0.002; impact -3.30 (95% CI: -5.28

to -1.32), p=0.001; symptoms -3.12 (95% CI: -4.94 to -1.03), p=0.001; total -3.32 (95%

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CI: -4.60 to -2.04), p<0.001), the six-minute walk test (-30.50 (95% CI: 3.32 to 57.68), p=0.028), and across three domains of the chronic obstructive pulmonary disease self-efficacy scale (negative effect -1.22 (95% CI: -2.31 to -0.14), p=0.027; physical exertion -1.27 (95% CI: -2.52 to -0.02), p=0.047; behavioural risk factors -0.58 (95% CI: -0.99 to -0.16), p=0.007). Subgroup analyses revealed that chronic obstructive pulmonary disease education (p < 0.01) was the strongest component with improvements on all aspects of the SGRQ and the six-minute walk test. Providing an exacerbation action plan significantly improved SGRQ activity and impact scores whilst exercise information had a positive effect on activity and symptom scores (p<0.05). Interventions with a duration of less than five weeks (p<0.05) significantly improved symptom and activity scores, in addition to the number of patient hospital admissions. Thus, self-management interventions are effective at improving the health outcomes of chronic obstructive pulmonary disease patients, especially when disease education is provided.

Introduction

Chronic obstructive pulmonary disease (COPD) is a preventable and treatable condition which is characterised by frequent dyspnoea and an increased inflammatory response in both the airways and the lungs when patients are exposed to damaging gases and/or particles (GOLD, 2017b). The risk factors for the development of COPD involve a gene-environment interaction (Eisner et al., 2010; GOLD, 2017b). Genetic influences such as alpha-1 antitrypsin and the gene encoding matrix metalloproteinase 12 (MMP12) have been identified as contributing to declines in lung functioning (GOLD, 2017b). Environmental factors include age and gender, lung growth and development, socio-economic status, asthma and bronchial hyperreactivity, chronic bronchitis, infections, and exposure to particles, such as cigarettes, and occupational chemicals and dusts (GOLD, 2017b). The primary symptom of COPD, dyspnoea has been reported in

94% of COPD patients (Blinderman et al., 2009) and is characterized by persistent airflow limitation (Abramson et al., 2015a), hyperinflation, abnormal gas exchange, mucus hypersecretion, pulmonary hypertension, exacerbations, and other systemic issues such as cardiac issues (GOLD, 2017b). These and the other symptoms of COPD decrease patients sense of control, increase their levels of anxiety and depression, in addition to reducing their confidence and ability to perform activities of daily living; all of which greatly impacts the quality of life of the patient (Abramson et al., 2015a).

In order to maintain COPD patients' well-being and quality of life, the Lung Foundation Australia and the Thoracic Society of Australia and New Zealand recommend patients undertake a self-management approach to manage their illness (Abramson et al., 2015a) as an adjunct to medical treatment. Self-management programs for COPD patients have been adapted from successful asthma management strategies (Khdour, Kidney, Smyth, & McElnay, 2009). They are defined as approaches which encourage individuals to make behavioural changes which enhance the social, emotional, and physical aspects of their health; with the primary outcomes of improving both functioning and quality of life (Cameron-Tucker, Wood-Baker, Owen, Joseph, & Walters, 2014). These programs often involve providing patients with knowledge about their illness, exercise information, understanding what medications to take and when, as well as how best to manage exacerbations in order to maintain their health and reduce the probability of being hospitalised (Spruit et al., 2013).

Self-management programs were developed with the aim of improving COPD patients' clinical outcomes (Fan et al., 2012). However, research on the efficacy of self-management programs has returned mixed results; these inconsistencies were found across various outcomes including patients' exercise capacity, anxiety, depression, and quality of life (Bischoff et al., 2012; Bourbeau et al., 2003; Jonsdottir et al., 2015; McGeoch et al., 2006; Mitchell et al., 2014; Monninkhof, van der Valk, Van der Palen,

Van Herwaarden, & Zielhuis, 2003). The equivocal nature of these results is reflected in the range of outcome measures used to evaluate the efficacy of self-management programs. A review of recent randomised control trials (RCT) investigating COPD patients' self-efficacy via the COPD Self-efficacy Scale (CSES) found that only two (Kara & AŞTi, 2004; Wang et al., 2013) of five papers returned statistically significant improvements in patients' self-efficacy for managing their disease. On trials which examined patients physical and emotional quality of life as measured by the Chronic Respiratory Questionnaire (CRQ), only three (Apps et al., 2009; Ghanem, ELaal, Mehany, & Tolba, 2010; Rea et al., 2004) of the seven papers found significant differences between the control and intervention groups.

Similar inconsistencies were also found on trials which examined patients exercise capacity, were only 6 (Blackstock et al., 2014; Ghanem et al., 2010; Nguyen et al., 2013; Ninot et al., 2011; Norweg, Whiteson, Malgady, Mola, & Rey, 2005; Wang et al., 2013) of 10 studies found self-management interventions significantly increased patients distance travelled on the Six Minute Walk Distance (6MWD). Improvements on COPD patients' levels of anxiety however were consistently improved with five (Apps et al., 2009; Bucknall et al., 2012b; Jonsdottir et al., 2015; Mitchell et al., 2014; Walters et al., 2013) of six studies reporting decreases in patients Hospital Anxiety and Depression Scale (HADS) anxiety scores; a result which was not reflected on patients HADS depression scores, which remained unaffected in all studies. Finally, trials which utilised the quality of life measures the Short Form-36 (SF-36) and the Euro Quality of Life-5 Dimension (EQ-5D) provided little support for the efficacy of self-management interventions on COPD patients' quality of life, with only one (Ghanem et al., 2010) of nine papers finding a significant improvement resulting from the intervention.

The heterogeneity of these results may reflect the variation between selfmanagement programs themselves, where programs differ in the content, delivery (e.g. face-to-face, or pamphlet), and duration of the program. This lack of standardisation within self-management interventions creates ambivalence about what educational content to include, what duration is most appropriate, as well as whether exercise is an important component for improving patients' quality of life. A previous meta-analysis and its recent update aimed to identify the impact of self-management interventions on COPD patients' health outcomes (Zwerink et al., 2014). These papers analysed various outcome measures using both clinical control trials and RCTs with their primary analysis only including RCTs. The updated Cochrane review by Zwerink et al. (2014) reported significant improvements on all aspects of COPD patients' quality of life as measured by the St George Respiratory Questionnaire (SGRQ) total, impact, activity, and symptoms; with the impact domain revealing a minimal clinically important difference. The analysis also found that COPD patients' who undertook these selfmanagement programs had significant reductions in their risk of being admitted to hospital for respiratory and/or all other health issues. Significant improvements were also found for the levels of dyspnoea experienced by the self-management groups as measured by the (modified) Medical Research Council Scale. However, no significant differences were found between the intervention and control groups on either patients' lung functioning parameters (FEV₁ and/or FEV₁/FVC), mortality, number of respiratory or all-cause hospital days, use of corticosteroids, and their exercise capacity (6MWD); even though the intervention group (MD 33.7m) exceeded the minimal clinically important difference of 30 metres.

The Zwerink et al. (2014) meta-analysis examined the subgroups for inclusion versus exclusion of a standardised exercise program and behavioural components. The authors found no significant differences in these subgroups for either of the primary outcome measures; hospital admissions or health-related quality of life (SGRQ total only).

Although numerous studies have investigated the effectiveness of selfmanagement programs on COPD patient well-being, the efficacy of these selfmanagement programs is still unclear. That is, it is still not known if self-management programs provide a significant benefit to COPD patients' exercise capacity, selfefficacy for managing their disease, or their levels of anxiety and depression. Furthermore, it is yet to be investigated as to which subgroups; that is, which educational components and/or whether the length of the intervention is an important consideration in improving patients' hospital admissions, quality of life, and exercise capacity. Thus, this study aims to further investigate the efficacy of self-management programs on COPD patients' health outcomes. The prior meta-analysis by Zwerink et al. (2014) included papers which had only two of the chosen educational topics, and excluded trials with less than two contacts via a health care professional, as well as trials which provided only self-management education as the intervention. In addition to this, they also included trials where the control group received the self-management education information. To enhance the strength of this meta-analysis, this study included not only newly published self-management RCTs, but also previous RCTs, regardless of patients' contact with health care professionals or whether the intervention was solely education based. Furthermore, trials were excluded from this meta-analysis if they contained less than four of the chosen educational topics; making the analysed interventions more standardised. In addition to this, studies were excluded if the control groups had been given access to the self-management educational material. This study will review trials which have investigated changes in patients' well-being via a set of preordained outcome measures;

- Number of respiratory related hospital admissions
- Quality of life via the St George Respiratory Questionnaire

- Self-efficacy as measured by the COPD Self-efficacy Scale
- Exercise capacity utilising the Six Minute Walk Distance
- Anxiety and Depression as measured by the Hospital Anxiety and Depression
 Scale

Finally, this study will also use subgroup analyses to examine which educational components significantly contribute to the improvements of COPD patients' well-being; that is, whether the provision of exercise information, COPD education, and an exacerbation action plan contribute to improvements in patients' outcomes on hospital admissions, quality of life (SGRQ Symptoms, Activity, Impact, and Total domains), and exercise capacity. In addition to this, subgroups will also be run to examine whether the duration of the intervention is a significant factor in improving these same outcomes for COPD patients'.

Method

The meta-analysis protocol was registered at the Prospero International Prospective Register of Systematic Reviews (Registration ID: PROSPERO 2014: CRD42015026772; website: http://www.

crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=C CRD42015026772). An extensive literature search of electronic databases was conducted to locate relevant RCTs between January 1990 and October 2015. The searched databases included Cochrane Library, PubMed, Scopus, CINAHL, and Web of Science. Terms and keywords used in the title/abstract searches included "COPD" and "self-management" or "self-efficacy" or "anxiety", or "depression". The reference lists of relevant articles were scanned to locate any additional studies.

Selection Criteria

Inclusion criteria for the study involved patients aged over 18 years with a diagnosis of COPD as measured by FEV₁. Trials must have used a randomised control design where participants were randomised to self-management education (intervention) or a program which offered education/training without self-management information or usual care (control). Outcome variables included quality of life (SGRQ), exercise capacity (6MWD), hospital admissions, anxiety and depression (HADS), and patients' self-efficacy (CSES). Finally, in order to be included in the data analysis the studies must have incorporated at least four of the following educational components in the self-management intervention: Exacerbation action plan, COPD education, medication information, management of exacerbations, management of stress and/or anxiety, nutritional guidance, exercise program/information, or managing a healthy lifestyle.

Quality of Studies

All papers were subjected to a quality assessment via the PEDro scale. The items assessing quality were chosen to evaluate the strength of the methodologies, the quality of reporting, and the level of variability in RCTs. Each paper was assessed independently by two reviewers and any discrepancies were resolved via discussion (Table 3).

Data Extraction

All citations and abstracts were downloaded to EndNote X7 for review.

Duplicates were deleted and the titles and abstracts of the remaining articles were screened for inclusion and checked by a second examiner. Figure 3 outlines the number of papers identified throughout this screening process. Data on the SGRQ, 6MWD, hospital admissions, HADS, CSES and the subgroup variables (COPD education, exacerbation action plan, exercise information, and intervention duration) were then

Table 3. Quality assessment results of included studies

	Random	Allocation	Blinding of	Blinding of	Blinding of	Similar at	Key outcome measurement	Intention	Between group	Measure of	Total
Trial	Allocation	Concealment	Subjects	Assessors	Researchers	baseline	85%	to treat	comparison	variability	score
Bischoff et al. 2012	X	X		X			X	X	X	X	7
Blackstock et al. 2014	X	X		X		X		X	X	X	7
Borbeau et al. 2003	X	X		X		X	X	X	X	X	8
Bucknall et al. 2012	X					X		X	X	X	5
Casas et al. 2006	X		X					X	X	X	5
Coultas et al. 2005	X	X		X				X	X	X	6
Garcia-Aymerich et al. 2007	X	X	X			X		X	X	X	7
Ghanem et al. 2010	X						X	X		X	4
Jonsdottir et al. 2015	X	X					X	X	X	X	6
Kara and Asti, 2004	X					X	X	X		X	5
Khdour et al. 2009	X					X		X	X	X	5
Koff et al. 2009	X					X	X	X	X	X	6
McGeoch et al. 2006	X	X				X	X	X	X	X	7
Mitchell et al. 2014	X	X		X		X	X	X	X	X	8
Monninkhof et al. 2003	X	X				X	X	X	X	X	7
Nguyen et al. 2013	X					X	X	X	X	X	6
Ninot et al. 2011	X						X	X	X	X	5
Rea et al. 2004	X						X	X	X		4
Rice et al. 2010	X			X		X	X	X	X	X	7
Sassi-Dambron et al. 1995	X					X		X	X	X	5
Taylor et al. 2012	X	X						X	X	X	5
van Wetering et al. 2010	X	X	X			X		X	X	X	7
Walters et al. 2013	X	X				X		X		X	5
Wang et al. 2013	X					X	X	X	X	X	6
Watson et al. 1997	X					X	X	X		X	5

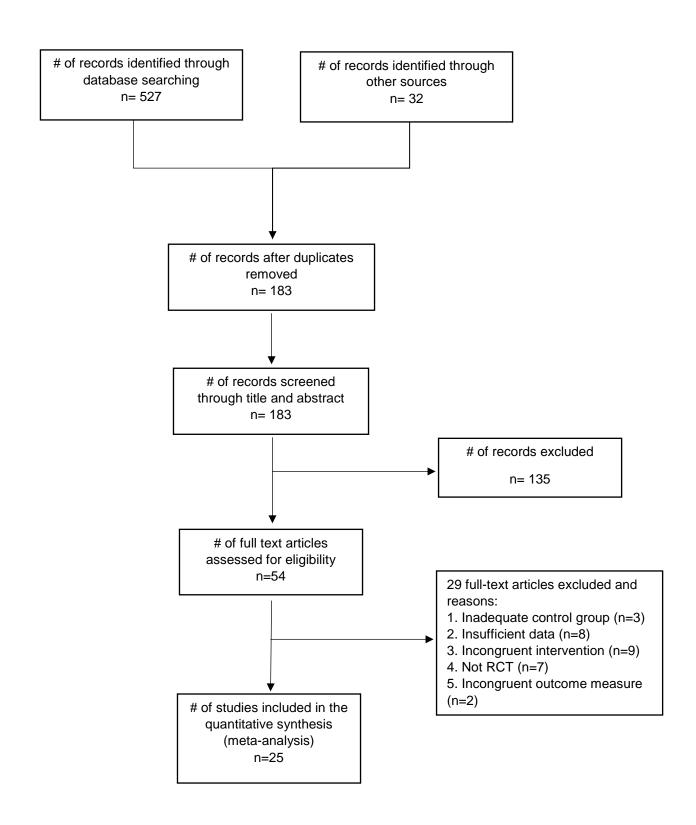


Figure 3. PRISMA flow chart of included studies.

Table 4. Egger's regression analysis on publication bias

Variables	t (95% confidence interval)	P value
SGRQ symptoms	0.55 (-2.17 to 1.29)	0.59
SGRQ activity	0.89 (-0.89 to 2.15)	0.39
SGRQ impact	0.48 (-1.60 to 2.50)	0.64
SGRQ total	0.63 (-1.03 to 1.88)	0.53
Anxiety	3.50 (0.71 to 6.10)	0.03
Depression	0.39 (-5.42 to 7.22)	0.71
6 minute walk	2.50 (-0.11 to 7.80)	0.06
COPD Self-Efficacy Scale negative affect	0.28 (-59.55 to 56.99)	0.83
COPD Self-Efficacy Scale emotional arousal	0.61 (-29.95 to 32.95)	0.65
COPD Self-Efficacy Scale physical exertion	0.37 (-79.77 to 75.26)	0.78
COPD Self-Efficacy Scale weather/environment	1.21 (-26.28 to 31.79)	0.44
COPD Self-Efficacy Scale behavioural risk factor	0.34 (-35.59 to 37.56)	0.79
COPD Self-Efficacy Scale total	0.13 (-49.33 to 48.32)	0.92
Hospital admission	1.38 (-5.54 to 1.66)	0.23

Notes. P value more than 0.05 indicating no publication bias

extracted from the remaining articles and imported into a Comprehensive Meta-Analysis package for statistical examination.

Data Analysis

Mean differences and 95% confidence intervals (CI) were used. The Mantel-Haenszel random effects method was used in order to assess the sources of heterogeneity of the self-management components. Subgroup analyses were run on components of interest; COPD education, exacerbation action plan, exercise information, and intervention duration. Heterogeneity was estimated based on the I^2 index for all studies. Low heterogeneity was considered with an I^2 of less than 30%, and moderate heterogeneity at 30% – 50%. The detailed effect of improvements on patients' quality of life was further explored using subgroup analysis to assess whether there were possible sources of heterogeneity. Publication bias using Egger Regression Analysis (Table 4) was used and sensitivity was analysed to assess whether the significant result was not due to a particular study or studies.

Results

The initial database searches identified 559 articles which were downloaded and imported into EndNote. Three hundred and seventy-six duplicates were removed and

the remaining 183 articles were then screened through title and abstract and assessed for eligibility using the selection criteria detailed above. The remaining 54 articles were then screened via the PEDro and 29 were excluded (three had inadequate control groups, eight had insufficient data, nine incongruent intervention, seven were not RCT's, two had incongruent outcome measures). The 25 remaining articles were included in the analysis and were found to be of high (8 points or more, 2 articles), moderate quality (5-7 points, 21 articles), and low quality (2 articles).

Description of Included Studies

Twenty-five RCTs (Table 5), which examined the effects of self-management interventions on COPD patients' health outcomes, were included in the analysis, with a total of 4,082 participants. Of these studies 16 did not receive any blinding and nine were single blind; three blinding of subjects and six blinding of assessors. All studies had a control group, which received continued care via their GP's and/or specialists, with some studies providing additional benefits such as free health care, drug benefit plans, assessment of inhalation technique, disease information brochure, exacerbation management, smoking cessation and/or pulmonary rehabilitation programs. The intervention group generally received continued care by their GP's and/or specialists and were instructed on a variety of educational components composed of a combination of inhalation techniques, breathing and coughing techniques, energy conservation, relaxation exercises, exacerbation action plan, maintaining a healthy lifestyle, smoking cessation, nutritional guidance, interpersonal relationships, managing stress and emotions, travelling and hobbies, exercise information, oxygen therapy, COPD education, medication education, managing exacerbations, managing stress and depression, and importance of immunisation. The studies were conducted in various countries including Canada, Egypt, Belgium, Turkey, France, China, United States, Spain, Iceland, United Kingdom, New Zealand, Netherlands, and Australia. COPD

Table 5. Summary of included studies

Author (Date)	Study Group COPD/Control	Sample	Mean age (SD)	Gender (Male/ Female)	Design and Location	Length of Intervention	Characteristics of Interventions Self-management Group	Characteristics of Interventions Usual Care Group	Outcome variables
1. Bischoff, et al. 2012 (Bischoff et al., 2012)	Self- management Usual care	55 55	65.5 (11.5) 63.5 (10.3)	37/18 28/27	Single blind, Netherlands	4 weeks	Continued care by GP/specialists and practice nurse; Self-management program - Exacerbation action plan; COPD education; breathing techniques; managing exacerbations; maintaining a healthy lifestyle; managing stress and anxiety (optional); and home exercise (optional)	Continued care by GP/specialists	CSES
2. Blackstock , et al. 2014 (Blackstock et	Exercise training plus self-	141	72.4 (10.0)	89/52	Single blind, Australia	8 weeks	Continued care by GP/specialists and a biweekly exercise training program; Self-management program - Managing	Continued care by GP/specialists and a biweekly exercise	6MWT Hospital admissions
al., 2014)	management Exercise training	126	72.0 (8.4)	72/54			exacerbations; medication education; respiratory function tests; home oxygen therapy; exercise; managing stress and anxiety; nutritional guidance; interpersonal relationships; energy conservation; community resources; swallowing; airway clearance	training program	
3. Bourbeau et al. 2003 (Bourbeau et al., 2003)	Self- management Usual care	96 95	69.4 (6.5) 69.6 (7.4)	50/46 56/39	Single blind, Canada	8 weeks	Continued care by GP/specialists; free health care; drug benefit plan; Self-management program - inhalation techniques; breathing and coughing techniques; energy conservation; relaxation exercises; exacerbation action plan; maintaining a healthy lifestyle; nutritional guidance; interpersonal relationships; managing stress and emotions; travelling and hobbies; exercise; oxygen therapy	Continued care by GP/specialists; free health care; drug benefit plan	Hospital admissions SGRQ 6MWT
4. Bucknall, <i>et al</i> . 2012 (Bucknall et al., 2012a)	Self- management Usual care	232 232	70.0 (9.3) 68.3 (9.2)	88/144 82/150	No blinding, United Kingdom	8 weeks	Optimisation of long term treatment; inhalation technique assessed; offered smoking cessation advice and pulmonary rehabilitation; Selfmanagement program - COPD	Continued care by GP/specialists; optimisation of long term treatment; inhalation technique	Hospital admissions SGRQ HADS CSES

							education; managing exacerbations; medication education; breathing techniques; relaxation exercises; exacerbation action plan	assessed; offered smoking cessation advice and pulmonary rehabilitation	
5. Casas, <i>et al</i> . 2006	Integrated self-	65	70.0 (9.0)	50/15	Single blind, Spain and	1 week	Spain, specialised nurse visit within 72hrs of discharge with specialised	Continued care by GP/specialists;	Hospital admissions
(Casas et al., 2006)	management Usual care	90	72.0 (9.0)	79/11	Belgium		nurse remaining as case manager; Belgium, regular GP visits usually home visits; Self-management program - COPD knowledge; managing exacerbations; medication education; oxygen therapy; exercise	,	
6. Coultas, <i>et al.</i> 2005	Collaborative management	51	68.8 (10.4)	17/34	Single blind, United	1 week	COPD specialist nurses; Self-management program - COPD	Continued care by GP/specialists;	SGRQ
(Coultas, Frederick, Barnett, Singh, & Wludyka, 2005)	Usual care	51	70.1 (7.0)	27/24	States		education; medication education; smoking cessation (maintaining a healthy lifestyle); exacerbation action plan	provided COPD education booklet	
7. Garcia- Aymerich, et al. 2007 (Garcia- Aymerich et al., 2007)	Integrated care Usual care	21 41	72 (10.0) 73 (9.0)	17/4 37/4	Single blind, Spain	1 week	Primary care team and COPD specialist nurses; Self-management program - COPD education; smoking cessation (maintaining a healthy lifestyle); exercise; nutritional guidance; non-pharmacological treatment information; managing exacerbations	Continued care by GP/specialists	SGRQ
8. Ghanem, et al. 2010 (Ghanem et al., 2010)	Pulmonary rehabilitation self- management	25	57.0 (11.6)	No data	No blinding, Egypt	8 weeks	Continued care by GP/specialists pulmonary rehabilitation; Self-management program - COPD knowledge; medication education;	Continued care by GP/specialists	6MWT
	Usual care	14	56.4 (9.0)				oxygen therapy; managing exacerbations; nutritional guidance; exercise		
9. Jonsdottir	Self-	48	59.4 (4.7)	19/29	No blinding,	26	Continued care by GP/specialists; Self-	Continued care by	SGRQ
et al. 2015	management	52	58.7 (4.4)	27/25	Iceland	weeks	management program - COPD	GP/specialists	HADS

(Jonsdottir et al., 2015)	Usual care						education; smoking cessation (maintaining a healthy lifestyle); exercise; nutritional guidance; medication education; breathing techniques; inhalation technique; relaxation techniques; stress and		
10. Kara and Asti, 2004 (Kara & AŞTi, 2004)	Self- management Usual care	60 Total	61.1 (11.3) 61.4 (11.1)	47/13 Total	No blinding, Turkey	4 weeks	depression management Outpatient clinic nurse; Self- management program - Smoking cessation (maintaining a healthy lifestyle); COPD education; medication education; exercise; nutritional guidance; stress management; exacerbation management; breathing	Educational advice at initial interview then continued care by GP/specialists	CSES
11. Khdour, et al. 2009 (Khdour et al., 2009)	Self- management Usual care	86 87	65.6 (10.1) 67.3 (9.2)	38/48 38/49	No blinding, United Kingdom	1 week	techniques; oxygen therapy; Usual hospital and outpatient care; Self-management program delivered by clinical pharmacist - COPD education; medication education; importance of adherence; inhalation technique; exacerbation management; exercise; breathing techniques; smoking cessation (maintaining a healthy lifestyle); exacerbation action plan	Usual hospital and outpatient care	Hospital admissions SGRQ
12. Koff, et al. 2009 (Koff et al., 2009)	Proactive integrated care Usual care	20 20	66.6 (9.1) 65.0 (8.2)	9/11 10/10	No blinding, United States	12 weeks	Continued care by GP/specialists; Self-management program - COPD education; medication education; smoking cessation (maintaining a healthy lifestyle); exacerbation management; nutritional guidance; oxygen therapy; breathing techniques; exacerbation action plan	Continued care by GP/specialists	SGRQ
13. McGeoch <i>et al.</i> 2006 (McGeoch et al., 2006)	Self- management Usual care	86 73	69.8 (11.6) 72.1 (9.9)	45/41 49/24	No blinding, New Zealand	1 week	Continued care by GP/specialists; Self-management program - Exacerbation management; exacerbation action plan; exercise; nutritional guidance; relaxation techniques; breathing	Continued care by GP/specialists	SGRQ Hospital admissions HADS

							techniques; smoking cessation (maintaining a healthy lifestyle); immunisation		
14. Mitchell <i>et al</i> . 2014	SPACE for COPD	89	69 (8.0)	54/35	Single blind, United	6 weeks	Continued care by GP/specialists; Self-management program - COPD	Continued care by GP/specialists	HADS
(Mitchell et al., 2014)	Usual care	95	69 (10.1)	47/48	Kingdom		education; managing stress; breathing techniques; medication education; energy conservation; exacerbation action plan; exercise; nutritional guidance; travelling; interpersonal relationships; smoking cessation (maintaining a healthy lifestyle)		
15. Monninkh	Self-	127	65.0 (7.0)	85/42	No blinding,	16	Continued care by GP/specialists;	Continued care by	SGRQ
of et al. 2003 (Monninkhof et al., 2003)	management Usual care	121	65.0 (7.0)	84/37	Netherlands	weeks	exacerbations managed by COPE study office; standardised pharmacological treatment; Self-management program - Exacerbation management; exacerbation action plan; exercise; COPD education; relaxation techniques; nutritional guidance; interpersonal relationships	GP/specialists; exacerbations managed by COPE study office; standardised pharmacological treatment	6MWT
16. Nguyen <i>et al.</i> 2013 (Nguyen et al.,	Dyspnoea face-to- face self-	41	68.2 (9.9)	19/22	No blinding, United States	26 weeks	Regular practice nurse visits and telephone calls providing feedback and reinforcement of program Self-	Continued care by GP/specialists; general health	6MWT
2013)	management Usual care	41	69.3 (8.0)	24/17			management program - Exacerbation action plan; exercise; exacerbation management; breathing techniques; stress management; coping; medication education	education program with no information on lung disease; bi- weekly phone calls for general health information	
17. Ninot <i>et al</i> . 2011 (Ninot et al., 2011)	Self- management Usual care	20 18	66 (12.0) 61 (7.2)	18/2 14/4	No blinding, France	4 weeks	Continued care by GP/specialists; telephone support; Self-management program - Smoking cessation (maintaining a healthy lifestyle); exacerbation management; inhaler techniques; nutritional guidance; exercise; coughing techniques;	Continued care by GP/specialists; telephone support	6MWT SGRQ

18. Rea <i>et al</i> . 2004 (Rea et al., 2004)	Self- management Usual care	83 52	Total 68 (6.7)	Total 56/79	No blinding, New Zealand	1 week	Regular scheduled/unscheduled contact with GP and practice nurse; Self-management - Exacerbation action plan; smoking cessation (maintaining a healthy lifestyle); medication education; influenza vaccination	Continued care by GP/specialists	Hospital admissions
19. Rice <i>et al</i> . 2010 (Rice et al., 2010)	Self- management Usual care	372 371	69.1 (9.4) 70.7 (9.7)	363/9 365/6	Single blind, United States	1 week	Continued care by GP/specialists; telephone access to case manager; Selfmanagement program - COPD education; inhalation techniques; medication education; smoking cessation (maintaining a healthy lifestyle); influenza and pneumococcal vaccination; exercise; exacerbation action plan;	Handout on the principles of COPD care; continued care by GP/specialists;	Hospital admissions SGRQ
20. Sassi- Dambron et al. 1995 (Sassi- Dambron, Eakin, Ries, & Kaplan, 1995)	Self- management Usual care	46 43	67.5 (8.0) 67.3 (8.3)	26/20 23/20	No blinding, United States	6 weeks	Continued care by GP/specialists; unplanned support group sessions become researcher facilitated; Selfmanagement program - COPD knowledge; relaxation techniques; breathing techniques; stress management; energy conservation; medication education; muscle relaxation; exercise; exacerbation management	Continued care by GP/specialists; general health education program with no information on lung disease; unplanned support group sessions	6MWT
21. Taylor <i>et al</i> . 2012 (Taylor et al., 2012)	BELLA Self- management Usual care	78 38	69.0 (9.8) 70.5 (10.0)	40/38 13/25	No blinding, United Kingdom	7 weeks	Continued care by GP/specialists; Self-management program - Exacerbation action plan; COPD education; breathing techniques; managing exacerbations; relaxation techniques; exercise; nutritional guidance; sleep; medication education; stress and depression management; interpersonal relationships; support groups; coping; goal setting	Continued care by GP/specialists	HADS SGRQ
22. van Wetering <i>et al</i> . 2010	INTERCOM Self- management Usual care	102 97	65.9 (8.8) 67.2 (8.9)	72/30 69/28	Single blind, Netherlands	16 weeks	Respiratory nurse consults; physiotherapist visits; Self- management program - COPD education; exercise; nutritional	Standard care by a respiratory physician	SGRQ 6MWT

(van Wetering, Hoogendoorn, Mol, Rutten- van Mölken, & Schols, 2010)							guidance; smoking cessation (maintaining a healthy lifestyle)		
23. Walters <i>et al.</i> 2013 (Walters et al., 2013)	Health mentoring Usual care	90 92	68.2 (7.9) 67.3 (7.6)	49/41 47/45	No blinding, Australia	52 weeks	Continued care by GP/specialists; health mentor nurse phone contacts; Self-management program - Nutritional guidance; smoking cessation (maintaining a healthy lifestyle); exercise; alcohol consumption; managing stress and emotions; managing exacerbations; coping; communication skills	Continued care by GP/specialists; research nurse phone contacts	SGRQ HADS
24. Wang et al. 2013 (Wang et al., 2013)	Health belief self- management Usual care	42 46	71.2 (7.4) 72.0 (8.2)	23/19 27/19	No blinding, China	1 week	Continued care by GP/specialists and COPD education manual, Selfmanagement program - Medication education; benefits of treatment and healthy behaviours; increasing support; symptom monitoring; COPD education; managing exacerbations; breathing techniques; oxygen therapy; exercise; smoking cessation (maintaining a healthy lifestyle); nutritional guidance	Continued care by GP/specialists and COPD education manual	CSES 6MWT
25. Watson <i>et al</i> . 1997 (Watson et al., 1997)	Self- management Usual care	29 27	68.0 (10.0) 67.0 (8.0)	18/11 18/9	No blinding, New Zealand	1 week	Practice nurse and action plan booklet; continued care by GP/specialists; Self-management program - Exacerbation management; exacerbation action plan; exercise; nutritional guidance; relaxation techniques; breathing techniques; smoking cessation (maintaining a healthy lifestyle); immunisation; sleep; medication education; coughing techniques; oxygen therapy	Continued care by GP/specialists	SGRQ

Chronic Obstructive Pulmonary Disease (COPD), COPD Self-efficacy Scale (CSES), Hospital Anxiety and Depression Scale (HADS), Six-Minute Walk Time (6MWT), St George Respiratory Questionnaire (SGRQ)

(A) SGRQ Activity

SGRQ Activity Study name Statistics for each study Difference in means and 95% CI Lower limit p-Value Koff et al. 2009 -8.30 -21.06 4.46 0.20 van Wetering et al. 2010 0.02 Taylor et al. 2012 -3.90 -12.13 4.33 0.35 0.01 Rice et al. 2010 -3.61 -6.19 -1.03 Watson et al. 1997 -3.00 -15.83 9.83 0.65 -2.70 -7.17 1.77 0.24 Bourbeau et al. 2003 McGeoch et al. 2006 -2.02 -7.66 0.48 -1.93 -17.39 0.81 Walters et al. 2013 -1.10 -8.04 0.76 -0.70 -6.62 5.22 0.82 Khdour et al. 2009 Jonsdottir et al. 2015 -0.18 -10.52 10.16 0.97 Coultas et al. 2005 -0.10 -7.42 7.22 0.98 -3.38 4.36 0.80 Bucknall et al. 2012 0.49 Monninkhof et al. 2003 0.67 Garcia-Aymerich et al. 2007 3.28 13.22 0.52 -3.61 0.00 -0.80 -21.00 -10.50 0.00 10.50 21.00

(B) SGRQ Impact

Study name		Statistics for	each study		Difference in means and 95% CI
	Difference in means	Lower limit	Upper limit	p-Value	
Ninot et al. 2011	-11.11	-23.27	1.05	0.07	 ■
Bucknall et al. 2012	-7.39	-12.86	-1.92	0.01	→■
Bourbeau et al. 2003	-6.20	-10.57	-1.83	0.01	
Khdour et al. 2009	-6.10	-12.04	-0.16	0.04	 ■
Rice et al. 2010	-6.02	-9.02	-3.02	0.00	
Coff et al. 2009	-6.00	-16.74	4.74	0.27	
van Wetering et al. 2010	-4.60	-8.07	-1.13	0.01	
Watson et al. 1997	-4.00	-11.86	3.86	0.32	 ■
Coultas et al. 2005	-3.70	-11.00	3.60	0.32	
Garcia-Aymerich et al. 2007	-2.41	-10.88	6.06	0.58	├─ड ├─
Walters et al. 2013	-1.20	-7.17	4.77	0.69	—
Taylor et al. 2012	-0.10	-8.69	8.49	0.98	
Monninkhof et al. 2003	0.90	-3.69	5.49	0.70	-
Jonsdottir et al. 2015	2.67	-5.06	10.40	0.50	
McGeoch et al. 2006	3.30	-1.29	7.89	0.16	+=-
	-3.30	-5.28	-1.32	0.00	

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(C) SGRQ Symptoms

Study name		Statistics for	each study		Difference in means and 95% CI				
	Difference in means	Lower limit	Upper limit	p-Value					
Ninot et al. 2011	-13.34	-25.57	-1.11	0.03	 ■				
Watson et al. 1997	-10.00	-21.01	1.01	0.07	│ ─ ॏ ड ─┤ │ │				
Koff et al. 2009	-9.50	-25.00	6.00	0.23	 				
Garcia-Aymerich et al. 2007	-7.29	-19.37	4.79	0.24					
Khdour et al. 2009	-6.80	-13.04	-0.56	0.03	│ │ ■─│ │ │				
Rice et al. 2010	-5.95	-9.67	-2.23	0.00	-				
Coultas et al. 2005	-3.40	-9.10	2.30	0.24					
Jonsdottir et al. 2015	-3.40	-12.00	5.20	0.44					
Walters et al. 2013	-2.60	-8.33	3.13	0.37					
Bucknall et al. 2012	-1.85	-7.80	4.10	0.54	-				
van Wetering et al. 2010	-1.60	-6.73	3.53	0.54					
Monninkhof et al. 2003	-0.50	-6.20	5.20	0.86					
Bourbeau et al. 2003	-0.40	-5.66	4.86	88.0					
McGeoch et al. 2006	2.30	-4.46	9.06	0.50	│				
Taylor et al. 2012	5.20	-5.99	16.39	0.36					
	-3.12	-4.94	-1.30	0.00					

(D) SGRQ Total

tudy name		Statistics for	each study		Difference in means and 95% CI				
	Difference in means	Lower limit	Upper limit	p-Value					
inot et al. 2011	-10.16	-22.07	1.75	0.09	 -		\rightarrow	- 1	1
off et al. 2009	-9.70	-18.78	-0.62	0.04	1 —	_			
ice et al. 2010	-5.08	-7.62	-2.54	0.00		T∎	⊩ ∣		
hdour et al. 2009	-4.41	-9.47	0.65	0.09		I—ī			
ucknall et al. 2012	-4.37	-8.68	-0.06	0.05		1-1			
an Wetering et al. 2010	-4.20	-7.11	-1.29	0.00		- I -i	-		
ourbeau et al. 2003	-4.10	-7.56	-0.64	0.02		1 4	■-		
Vatson et al. 1997	-4.01	-12.67	4.65	0.36		+	_		
oultas et al. 2005	-2.60	-8.26	3.06	0.37		-			
arcia-Aymerich et al. 2007	-2.39	-10.22	5.44	0.55		_			
Valters et al. 2013	-1.70	-7.43	4.03	0.56		- 1 -	1		
aylor et al. 2012	-0.40	-8.57	7.77	0.92		1-	-	_	
Ionninkhof et al. 2003	0.60	-3.99	5.19	0.80			-		
onsdottir et al. 2015	1.10	-6.46	8.66	0.78		-		_	
IcGeoch et al. 2006	1.27	-3.20	5.74	0.58			-	-	
	-3.32	-4.60	-2.04	0.00			◆ □		

Figure 4. SGRQ domain plots; (A) SGRQ Activity, (B) SGRQ Impact, (C) SGRQ Symptoms, (D) SGRQ Total

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Table 6. Overall mean difference for self-management intervention health outcomes

Variable	Mean Difference	p	I^2
	(95% CI)		
SGRQ			
Activity	-2.21 (-3.61, -0.80)	**	0%
Impact	-3.30 (-5.28, -1.32)	**	43.1%
Symptoms	-3.12 (-4.94, -1.30)	**	11.7%
Total	-3.32 (-4.60, -2.04)	***	6.9%
Hospital admissions	0.62 (0.35, 1.11)		72.9%
CSES			
Negative effect	-1.22 (-2.31, -0.14)	*	93.4%
Emotional arousal	-0.54 (-1.17, 0.09)		79.4%
Physical exertion	-1.27 (-2.52, -0.02)	*	95.0%
Weather/environment	-0.67 (-1.40, 0.06)		85.4%
Behavioural risk factors	-0.58 (-0.99, -0.16)	**	59.2%
Total	-0.82 (-1.89, 0.26)		91.0%
HADS			
Anxiety	-0.47 (-1.02, 0.07)		0%
Depression	-0.17 (-0.57, 0.22)		0%
6MWT	30.50 (3.32, 57.68)	*	95%

^{*}effect size significant at p <0.05; ** effect size significant at p <0.01; *** effect size significant at p < 0.001

Chronic Obstructive Pulmonary Disease (COPD), Confidence Interval (CI), COPD Self-Efficacy Scale (CSES), Hospital Anxiety and Depression Scale (HADS), Six-Minute Walk Test (6MWT), St George Respiratory Questionnaire (SGRQ)

patients average age was 67.3 years, they had an average FEV₁ % predicted of 49.5, and extensive comorbidities including diabetes, hypertension, CVD, ischaemic heart disease, endocrine, and gastrointestinal diseases.

Effects of Self-Management Interventions on COPD patients' SGRQ Scores

Of the studies in the analysis, 15 papers reported on all of the SGRQ domains (Figure 4). There were 2,152 participants on the activity domain, 2,317 on the impact, 2,218 on the symptoms, and 2,038 participants for the SGRQ total. Ten papers found an improvement on the intervention groups' SGRQ activity scores (Figure 4A; mean difference -4.48, range: -10.44 to -1.10) as opposed the control group with only six papers finding an improvement (mean difference -3.50, range: -8.51 to -0.50). The pooled mean difference (Table 6) on the SGRQ activity was -2.21 (95% CI: -3.61 to -

0.80, p=0.002), with heterogeneity being not significant ($I^2=0\%$, p>0.05). The intervention groups' SGRQ impact scores (Figure 4B) were also improved on 10 papers (mean difference -6.06, range: -13.70 to -2.70) and the control group finding improvements on 8 papers (mean difference -2.68, range: -11.29 to -0.04). The pooled mean difference on the SGRQ impact was -3.30 (95% CI: -5.28 to -1.32, p=0.001). Heterogeneity was significant (I^2 =43.1%, p<0.05). On the SGRQ symptoms domain (Figure 4C) 13 studies found improvements for the self-management intervention groups' perception of their symptoms with a mean difference of -6.60 (range: -24.40 to -0.26) compared improvements on 9 studies for the control group (mean difference -4.63, range: -17.11 to -1.10). The pooled mean difference on the SGRQ symptoms was -3.12 (95% CI: -4.14 to -1.30, p=0.001). Heterogeneity was not significant (I^2 =11.7%, p>0.05). Finally, 10 papers found an improvement on the intervention groups SGRQ total scores (Figure 4D; mean difference -6.16, range: -13.41 to -2.60) as opposed to only 6 control group papers (mean difference -3.05, range: -11.02 to -0.40). The pooled mean difference on the SGRQ total scores was -3.32 (95% CI: -4.60 to -2.04, p<0.001), with no significant heterogeneity ($I^2=6.9\%$, p>0.05).

Effects of Self-Management Interventions on COPD patients' HADS Scores

Six papers reported on COPD patients' HADS anxiety (Figure 5A) scores (869 participants), of these only two papers found improvements for the intervention group (mean difference -0.34, range: -0.37 to -0.31) and no papers found any improvements for the control groups scores. The pooled mean difference for the HADS anxiety was -0.47 (95% CI: -1.02 to 0.07, p=0.09). Heterogeneity was not significant (I²=0%, p>0.05). The HADS depression scores (876 participants) were improved in three of the six papers for the intervention group (mean difference -0.26, range: -0.30 to -0.19) and on only one paper for the control group (-0.30). The pooled mean difference for the

HADS depression (Figure 5B) scores was -0.17 (95% CI: -0.57 to 0.22, p=0.39). Heterogeneity was not significant (I²=0%, p>0.05).

Effects of Self-Management Interventions on COPD patients' 6MWD

Eight papers reported on 957 COPD patients' 6WMT (Figure 5C), of these six papers found improvements on the intervention groups distance walked (mean difference 46.31, range: 5.90 to 96.97) whereas only three papers reported improvements for the control group (mean difference 26.81, range: 7.00 to 56.00). The pooled mean difference on the 6MWD was 30.50 (95% CI: 3.32 to 57.68, p=0.028); a result which meets the minimal clinically important difference of 30 metres. There was however significant heterogeneity (I^2 =95%, p<0.05) within the sample.

Effects of Self-Management Interventions on COPD patients' Hospital Admissions

Seven papers, with a total of 1,578 participants, reported on the number and percentage of respiratory related hospital admissions (Figure 5D) for the 12 months following the intervention. On average 46.0% (range: 2% to 57%) of the intervention group were readmitted to hospital, as opposed to 68.5% (range: 5% to 100%) of the control group. The pooled mean difference for hospital admissions was not significant, (0.62, 95% CI: 0.35 to 1.11, p=0.106). Heterogeneity was significant ($I^2=72.9\%$, p<0.05).

Effects of Self-Management Interventions on COPD patients' CSES Scores

Only three papers with a total of 258 participants reported on patients' CSES scores (Figure 6A-F). On the CSES negative effect domain all three papers found improvements for the intervention group (mean difference -2.27, range: -5.59 to -0.27) and only two papers found improvements for the control group (mean difference -0.18, range: -0.22 to -0.13). The pooled mean difference for CSES negative effect was -1.22

(95% CI: -2.31 to -0.14, p=0.027), with significant heterogeneity ($I^2=93.4\%$, p<0.05). For the CSES emotional arousal domain two papers found improvements for both the intervention (mean difference -0.60, range: -0.95 to -0.24) and control groups scores (mean difference -0.14, range: -0.15 to -0.12), with a pooled mean difference of -0.54 (95% CI: -1.17 to 0.09, p=0.09). Heterogeneity was significant ($I^2=79.4\%$, p<0.05). On the CSES physical exertion improvements were found with the intervention group (mean difference -1.60, range: -3.38 to -0.05) for all three papers, whereas only one paper found an improvement for the control group (mean difference -0.18). The pooled mean difference for the CSES physical exertion was -1.27 (95% CI: -2.52 to -0.02, p=0.047), with significant heterogeneity ($I^2=95\%$, p<0.05). For the CSES weather/environment two papers found improvements for the intervention group (mean difference -0.82, range: -1.46 to -0.18) and only one found an improvement for the control group (-0.31). The pooled mean difference for the CSES weather/environment domain was -0.67 (95% CI: -1.40 to 0.06, p=0.07). Heterogeneity was significant $(I^2=85.4\%, p<0.05)$. On the CSES behavioural risk factors all three papers found improvements for both groups (intervention mean difference -0.75, range: -1.04 to -0.17; control mean difference -0.18, range: -0.35 to -0.09), with a pooled mean difference of -0.58 (95% CI: -0.99 to -0.16, p=0.007). Heterogeneity was not found to be significant ($I^2=59.2\%$, p>0.05). Finally, on the CSES total all three papers found an improvement for the intervention group (mean difference -3.62, range: -9.55 to -0.15) and only two papers found improvements for the control group (mean difference -0.12, range: -0.21 to -0.03). The pooled mean difference for the CSES total domain was -0.82 (95% CI: -1.89 to 0.26, p=0.135). Heterogeneity was significant ($I^2=91\%, p<0.05$).

(A) HADS Anxiety

Anxiety Difference in means and 95% CI Study name Statistics for each study Difference Lower limit p-Value -1.30 -2.33 -0.27 0.01 Bucknall et al. 2012 0.50 Mitchell et al. 2014 -0.40 -1.56 0.76 -1.58 0.98 0.65 -0.08 -1.62 1.46 0.92 McGeoch et al. 2006 -1.46 1.74 0.86 0.14 0.70 Taylor et al. 2012 0.39 -1.62 2.40 -0.47 -1.02 0.07 0.09 2.00 -1.00 0.00 1.00

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Favours Control Favours Self-Manage

(B) HADS Depression

			Depres	sion					
Study name		Statistics for	each study			Difference	in means	and 95% C	1
	Difference in means	Lower limit	Upper limit	p-Value					
Mitchell et al. 2014	-0.66	-1.47	0.15	0.11	1	\rightarrow	+	- 1	- 1
Jonsdottir et al. 2015	-0.44	-1.73	0.85	0.50	-	-		—l	
Bucknall et al. 2012	-0.21	-1.08	0.66	0.64		+		-	
Taylor et al. 2012	0.00	-1.25	1.25	1.00		+		+	
Walters et al. 2013	0.10	-0.95	1.15	0.85				\rightarrow	
McGeoch et al. 2006	0.25	-0.60	1.10	0.56		-			
	-0.17	-0.57	0.22	0.39		-	•	-	
					-2.00	-1.00	0.00	1.00	2.00

Favours Self-Manage Favours Control

Favours Self-Manage Favours Control

(C) 6MWT

Study name		Statistics for	each study		Difference in me	ans and 95% CI
	Difference in means	Lower limit	Upper limit	p-Value		
Wang et al. 2013	126.84	83.29	170.39	0.00		├-■
Ghanem et al. 2010	68.15	50.73	85.57	0.00		
Ninot et al. 2011	34.00	-24.65	92.65	0.26		
Sassi-Dambron et al. 1995	18.50	-26.85	63.85	0.42		■
van Wetering et al. 2010	13.90	3.09	24.71	0.01		
Nguyen et al. 2013	10.62	-43.91	65.15	0.70	—	■—
Blackstock et al. 2014	-3.00	-34.09	28.09	0.85	-	⊩
Monninkhof et al. 2003	-11.00	-12.52	-9.48	0.00		
	30.50	3.32	57.68	0.03		◆

(D) Hospital Admission

		Н	ospital A	dmission					
Study name		Statistics fo	or each study			Odds r	atio and	95% CI	
	Odds ratio	Lower limit	Upper limit	p-Value					
Rea et al. 2004	0.44	0.21	0.95	0.04		14	■		- 1
Casas et al. 2006	0.40	0.21	0.78	0.01		-	-		
Bucknall, et al. 2012	0.91	0.62	1.33	0.63					
Blackstock et al. 2014	0.89	0.52	1.55	0.69					
Walters et al. 2013	2.42	0.81	7.28	0.11			+	⊢∣	
Bourbeau, et al. 2003	0.01	0.00	0.12	0.00	←	 			
Mitchell et al. 2014	0.41	0.08	2.19	0.30		+-	-		
	0.62	0.35	1.11	0.11			◆		
					0.01	0.1	1	10	100

Figure 5. HADS anxiety and depression, 6MWT, and hospital admission plots; (A) HADS Anxiety, (B) HADS Depression, (C) 6MWT, (D) Hospital Admission

(A) CSES negative effect

COPD Self-Efficacy Scale Negative Affect

Study name		Statistics for	each study		Difference	in means	and 95% (CI .
	Difference in means	Lower limit	Upper limit	p-Value				
Vang et al. 2013	-6.12	-8.57	-3.67	0.00	⊬■┼			
(ara and Asti 2004	-0.82	-0.95	-0.69	0.00				
Bischoff et al. 2012	-0.05	-0.47	0.37	0.82				
	-1.22	-2.31	-0.14	0.03		lack		

Favours Self-Manage Favours Control

(B) CSES emotional arousal

COPD Self-Efficacy Scale Emotional Arousal

Study name		Statistics for	each study		Di	fference	in means
	Difference in means	Lower limit	Upper limit	p-Value			
Wang et al. 2013	-0.90	-2.62	0.82	0.30		+	+
Kara and Asti 2004	-0.83	-0.99	-0.67	0.00		.	
Bischoff et al. 2012	-0.09	-0.53	0.35	0.69		\vdash	
	-0.54	-1.17	0.09	0.09	4		

Favours Self-Manage Favours Control

(C) CSES physical exertion

COPD Self-Efficacy Scale Physical Exertion

 iii iileans	Difference i		each study	Statistics for		Study name
		p-Value	Upper limit	Lower limit	Difference in means	
		0.00	-2.82	-5.84	-4.33	Wang et al. 2013
		0.00	-0.95	-1.43	-1.19	Kara and Asti 2004
		0.45	0.27	-0.61	-0.17	Bischoff et al. 2012
▶	◀	0.01	-0.36	-2.78	-1.57	
>	•					Discriuii et al. 2012

Favours Self-Manage Favours Control

(D) CSES weather/environment

COPD Self-Efficacy Scale Weather/Environment

Study name		Statistics for	each study		D	ifference	in means	and 95% C	i i
	Difference in means	Lower limit	Upper limit	p-Value					
Kara and Asti 2004	-1.15	-1.32	-0.98	0.00					
Bischoff et al. 2012	-0.31	-0.74	0.12	0.16		-	■┼		
Wang et al. 2013	-0.23	-1.72	1.26	0.76	-			+	
	-0.67	-1.40	0.06	0.07		4			

Favours Self-Manage Favours Control

Figure 6. COPD Self-efficacy scale (CSES) plots; (A) CSES Negative effect, (B) CSES Emotional arousal, (C) CSES Physical exertion, (D) CSES Weather/environment

(E) CSES behavioural risk factors

COPD Self-Efficacy Scale Behavioural Risk Factors

Study name		Statistics for	each study		- 1	D <u>ifference</u>	in means	and 95%	ÇI
	Difference in means	Lower limit	Upper limit	p-Value					
Wang et al. 2013	-0.93	-1.56	-0.30	0.00		-	-		
Kara and Asti 2004	-0.69	-0.93	-0.45	0.00		1	- I		
Bischoff et al. 2012	-0.08	-0.63	0.47	0.78		-	-	.	
	-0.58	-0.99	-0.16	0.01			►		

Favours Self-Manage Favours Control

(F) CSES total

COPD Self-Efficacy Scale Total Study name Statistics for each study Difference in means and 95% CI Difference in means Lower limit Upper limit p-Value Wang et al. 2013 -12.53 -19.50 -5.56 0.00 -0.82 Bischoff et al. 2012 -0.12 -0.58 0.34 0.61 -0.82 -1.89 0.26 0.14

Favours Self-Manage Favours Control

10.00 20.00

-20.00 -10.00 0.00

Figure 6. COPD Self-efficacy scale (CSES) plots (continued); (E) CSES Behavioural risk factors, (F) CSES Total

Subgroup Analysis

Subgroup analyses (Table 7) revealed significant differences across each of the five outcome variables. On the SGRO activity domain significant group differences were found on all of the components exacerbation action plan, COPD education, exercise information, and duration of the intervention. Thus, trials which provided an exacerbation action plan (p=0.011), COPD education (p=0.007), and an exercise component (p=0.001) had a greater effect on COPD patients' SGRQ activity scores than trials without these components (p>0.05). In addition to this, trials with a duration of less than five weeks (p=0.015) had a larger effect than programs with a duration of more than five weeks (p=0.055). Subgroup analyses on the SGRQ impact domain revealed significant results across two of the self-management components; with significant group differences on exacerbation action plan and COPD education. Thus, trials which provided an exacerbation action plan (p=0.009), or COPD education (p<0.001) within the self-management program had a greater benefit on COPD patients' SGRQ impact scores than did trials which did not include these components (p>0.05). Furthermore, COPD patients' SGRQ impact scores were improved whether trials provided (p<0.001) or excluded exercise (p=0.003) and whether trials were less than 5 weeks (p=0.40) or greater than five weeks (p=0.16) in duration. The results of the SGRQ symptoms subgroup analysis revealed significant improvements on three components; where providing COPD education (p<0.001), exercise information (p=0.007), and/or having an intervention of less than five weeks (p<0.001) improved COPD patients' perception of their symptoms, when compared with trials which excluded these components or were greater than five weeks duration (p=0.23). COPD patients' SGRO symptom scores were significant on both trials with (p=0.019) and without (p=0.039) an exacerbation action plan. On the SGRQ total domain significant

Table 7. The subgroup analyses of the effects of education components and program duration on COPD patient health outcomes

		SGRQ Activity				SGRQ Impact		
Variables	No of studies (Participants)	Effect size (95% CI)	I^2	Q-test	No of studies (Participants)	Effect size (95% CI)	I^2	Q-test
Exacerbation Action Plan								
Action Plan	10 (1623)	-2.05 (-3.63, -0.47) *	0%	5.9	10 (1608)	-3.48 (-6.08, -0.88) **	54.1%	19.6†
No Action Plan	5 (529)	-2.79 (-5.86, 0.28)	0%	2.9	5 (529)	-2.96 (-6.12, 0.20)	18.9%	4.93
Overall	15 (2152)	-2.21 (-3.61, -0.80) **			15 (2137)	-3.27 (-5.28, -1.26) **		
COPD Education								
Education	10 (1578)	-2.21 (-3.80, -0.61) **	0%	8.8	10 (1563)	-3.82 (-5.86, -1.78) ***	25.6%	12.1
No Education	5 (574)	-2.20 (-5.18, 0.78)	0%	0.2	5 (574)	-2.84 (-7.49, 1.80)	64.0%	11.1†
Overall	15 (2152)	-2.21 (-3.61, -0.80) **			15 (2137)	-3.66 (-5.53, -1.79) ***		
Exercise Information								
Exercise	12 (1852)	-2.64 (-4.20, -1.09) **	0%	5.6	12 (1856)	-2.80 (-5.07, -0.52) *	50.8%	22.4†
No Exercise	3 (300)	-0.22 (-3.52, 3.08)	0%	1.7	3 (281)	-6.05 (-10.11, -2.00) **	0%	0.6
Overall	15 (2152)	-2.21 (-3.61, -0.80) **			15(2137)	-3.58 (-5.56, -1.59) ***		
Duration of Intervention								
> 5 Weeks	8 (1125)	-1.93 (-3.90, 0.04)	0%	6.0	8 (1106)	-3.10 (-5.62, -0.58) *	37.1%	11.1
< 5 Weeks	7 (1027)	-2.49 (-4.49, -0.49) *	0%	2.8	7 (1031)	-3.65 (-7.13, -0.17) *	55.1%	13.4†
Overall	15 (2152)	-2.21 (-3.61, -0.80) **			15 (2137)	-3.29 (-5.33, -1.25) **		'

^{*}effect size significant at p <0.05; ** effect size significant at p <0.01; *** effect size significant at p < 0.001

Chronic Obstructive Pulmonary Disease (COPD), Confidence Interval (CI), Six-minute walk Test (6MWT), St George Respiratory Questionnaire (SGRQ)

[†] Q-test significant at p <0.05; †† Q-test significant at p <0.01; ††† Q-test significant at p < 0.001

Table 7. The subgroup analyses of the effects of education components and program duration on COPD patient health outcomes (continued)

		SGRQ Symptoms				SGRQ Total		
Variables	No of studies (Participants)	Effect size (95% CI)	I^2	Q-test	No of studies (Participants)	Effect size (95% CI)	I^2	Q-test
Exacerbation Action Plan								
Action Plan	10 (1689)	-2.86 (-5.26, -0.47) *	27.0%	12.3	10 (1554)	-3.20 (-4.92, -1.48) ***	23.4%	11.6
No Action Plan	5 (529)	-3.40 (-6.64, -0.17) *	0%	3.5	5 (529)	-3.37 (-5.67, -1.08) **	0%	3.3
Overall	15 (2218)	-3.05 (-4.98, -1.13) **			15 (2083)	-3.26 (-4.64, -1.89) ***		
COPD Education								
Education	10 (1644)	-3.61 (-5.58, -1.64) ***	0%	7.9	10 (1509)	-3.73 (-5.14, -2.33) ***	0%	8.9
No Education	5 (574)	-2.89 (-7.37, 1.59)	45.1%	7.3	5 (574)	-2.47 (-5.38, 0.43)	25.0%	5.3
Overall	15 (2218)	-3.49 (-5.29, -1.69) ***			15 (2083)	-3.49 (-4.76, -2.23) ***		
Exercise Information								
Exercise	12 (1872)	-3.08 (-5.34, -0.82) **	26.7%	15.0	12 (1821)	-3.02 (-4.50, -1.54) ***	14.4	12.9
No Exercise	3 (346)	-3.11 (-7.08, 0.87)	0%	0.8	3 (262)	-4.47 (-7.67, -1.26) **	0%	1.7
Overall	15 (2218)	-3.09 (-5.05, -1.12) **			15 (2083)	-3.28 (-4.62, -1.93) ***		
Duration of Intervention	. ,	, ,			. ,	, ,		
> 5 Weeks	8 (1171)	-1.41 (-3.70, 0.89)	0%	3.0	8 (1087)	-3.12 (-4.85, -1.39) ***	7.2%	7.6
< 5 Weeks	7 (1047)	-5.13 (-8.17, -2.09) ***	25.7%	8.1	7 (996)	-3.42 (-5.61, -1.23) **	18.3%	7.3
Overall	15 (2218)	-2.76 (-4.59, -0.93) **			15 (2083)	-3.24 (-4.59, -1.88) ***		

^{*}effect size significant at p <0.05; ** effect size significant at p <0.01; *** effect size significant at p < 0.001

Chronic Obstructive Pulmonary Disease (COPD), Confidence Interval (CI), Six-minute walk Test (6MWT), St George Respiratory Questionnaire (SGRQ)

[†] Q-test significant at p <0.05; †† Q-test significant at p <0.01; ††† Q-test significant at p < 0.001

Table 7. The subgroup analyses of the effects of education components and program duration on COPD patient health outcomes (continued)

		6MWT				Hospital Admissions	3	
Variables	No of studies (Participants)	Effect size (95% CI)	I^2	Q-test	No of studies (Participants)	Effect size (95% CI)	I^2	Q-test
Exacerbation Action Plan								
Action Plan	2 (330)	-10.98 (-12.5, -9.46) ***	0%	0.6	4 (974)	0.36 (0.12, 1.08)	78.4%	13.9
No Action Plan	6 (627)	42.03 (8.18, 75.87) *	90.1%	50.5†††	3 (604)	0.87 (0.37, 2.05)	75.6%	8.2
Overall	8 (957)	-10.88 (-12.39, -9.36) ***			7 (1578)	0.62 (0.32, 1.22)		
COPD Education								
Education	3 (639)	39.67 (4.92, 74.42) *	97.1%	137.1†††	3 (803)	0.61 (0.32, 1.17)	59.2%	4.9
No Education	5 (318)	6.23 (-18.30, 30.76)	0%	1.22	4 (775)	0.54 (0.17, 1.74)	82.6%	17.2††
Overall	8 (957)	17.35 (-2.69, 37.39)			7 (1578)	0.59 (0.33, 1.05)		
Exercise Information								
Exercise					5 (979)	0.52 (0.19, 1.40)	79.0%	19.1††
No Exercise					2 (599)	0.69 (0.35, 1.37)	63.5%	2.74
Overall					7 (1578)	0.63 (0.36, 1.11)		
Duration of Intervention								
> 5 Weeks	6 (831)	16.57 (-10.46, 43.60)	95.0%	100.0†††	5 (1288)	0.73 (0.34, 1.60)	74.1%	15.4††
< 5 Weeks	2 (126)	82.58 (-8.30, 173.47)	83.9%	6.2†	2 (290)	0.42 (0.25, 0.69) **	0%	< 0.1
Overall	8 (957)	21.93 (-3.98, 47.84)		,	7 (1578)	0.49 (0.32, 0.75) **		

^{*}effect size significant at p <0.05; ** effect size significant at p <0.01; *** effect size significant at p < 0.001

Chronic Obstructive Pulmonary Disease (COPD), Confidence Interval (CI), Six-minute walk Test (6MWT), St George Respiratory Questionnaire (SGRQ)

[†] Q-test significant at p <0.05; †† Q-test significant at p <0.01; ††† Q-test significant at p < 0.001

differences were found on trials which included COPD education (p<0.001) in the selfmanagement intervention. However, the inclusion and exclusion of both exacerbation action plans and exercise information, as well as the duration of the intervention (less than and greater than 5 weeks) were all significant (p<0.01). Subgroup analyses on the 6MWD revealed that including COPD education (p=0.025) provided a significant benefit to COPD patients as opposed to trials which excluded COPD education (p=0.619) from the self-management intervention. The improvement in COPD patients' exercise capacity was significant across both trials which provided (p<0.001) and excluded (p=0.015) an exacerbation action plan. The duration of the intervention (p>0.05) failed to reach significance on any level and an analysis on 6MWD exercise information was unable to be run as all papers included exercise information in their trials. Finally, subgroup analyses on COPD patients' hospital admissions revealed a significant improvement on the number of hospital admissions when trials were less than five weeks duration (p<0.001). All other educational components exacerbation action plan, COPD education, and exercise information did not reach statistical significance (p>0.05).

Discussion

This meta-analysis reviewed 25 RCTs investigating the effects of self-management interventions on COPD patients' health-related quality of life, exercise capacity, anxiety, depression, and self-efficacy. Based on the meta-analysis the pooled effects revealed that self-management interventions significantly improved all aspects of COPD patients' health-related quality of life, in addition to some aspects of their self-efficacy; primarily, reductions in their feelings of helplessness, breathlessness following physical exertion, as well as improving their nutrition and breathing techniques. It was also found that COPD patients' who undertook self-management experienced significant improvements in their exercise capacity; a result which is clinically relevant

as it met the minimal clinically important difference of 30 metres. Outcomes of self-management interventions which were not found to have significantly improved in this meta-analysis was COPD patients' number of hospital admissions, their levels of anxiety and depression, and other aspects of their self-efficacy such as feelings of anger and stress, and the impact from changes in the surrounding weather and environment.

The pooled effects of a previous meta-analysis by Zwerink et al. (2014) also found improvements on all domains of COPD patients' health-related quality of life, with their SGRQ impact scores reaching minimal clinically important difference. Whilst the current analysis also reported a significant increase in COPD patients' health-related quality of life, our results failed to meet this clinically important difference. Although clear similarities exist between the current study and the recent Cochrane review, differences remain. For example, unlike this study the meta-analysis by Zwerink et al. (2014) did not find a significant improvement in COPD patients' exercise capacity, even though the 6MWD difference (33.7m) exceeded the minimal clinically important difference of 30 metres. In addition to this, Zwerink et al. (2014) detected a significant improvement in the number of respiratory related hospital admissions for the intervention group; a result which was not replicated in the current study. However, this difference could have eventuated from our rigorous inclusion criteria with papers being required to include a least four of eight educational components. Through increasing the similarity of the self-management training programs this could have influenced the results providing a more accurate reflection of the number of hospital admissions of a more standardised intervention program.

Effects of Self-Management Components and Intervention Duration on COPD patients' Health Outcomes

Subgroup analyses revealed that the primary components underlying the significant improvements found in the pooled effects involved the provision of an exacerbation action plan, COPD education, exercise information, and the duration of the self-management program. These subgroups were run to examine the impact of these components on COPD patients' quality of life, exercise capacity, and their number of respiratory hospital admissions. The subgroup COPD education was found to be the most influential component examined, providing significant improvement on all aspects of COPD patients' health-related quality of life (SGRQ activity, impact, symptoms, and total scores) and their exercise capacity (6MWD). In addition to this, providing COPD education in the self-management program was also found to increase patients confidence and competence in managing their disease; aspects which empower the patient to partake in self-management (Cosgrove et al., 2013).

The second most beneficial subgroup involved the duration of the intervention; where interventions with durations of less than five weeks significantly improved COPD patients' perception of their symptoms, number of disturbances they experienced during activities, in addition to significantly reducing the number of respiratory hospital admissions. This result was unexpected, however it may be due to patients' perception that benefits were maximised during the five weeks (so the participants perceived maximum benefit on follow up) during a period of maximum motivation and interest. This was in contrast to trials of longer duration, whereby participants may have plateaued in terms of improvements and therefore did not perceive sustained improvement in symptoms. Younger age and living with others may also explain the success of patients to manage their symptoms and impact of the symptoms in the short term intervention programs (Bucknall et al., 2012a). The benefits of living with others

to gain family and social support have been found to be extensive, from improving patients' adherence to treatment recommendations (Bourbeau & Bartlett, 2008) to decreasing both the situational and emotional barriers that can occur during intervention programs. These factors will need to be examined in future studies.

Improvements in COPD patients' psychosocial functioning and the number of disturbances they experienced during activities (SGRQ impact and activity, respectively) may also be explained by the provision of an exacerbation action plan within the self-management program. Previous research has found that the implementation of an exacerbation action plan has the propensity to reduce the over reliance on the healthcare system and improve patients symptom recognition and respiratory health (Turnock et al., 2005).

Finally, providing exercise information within the self-management program also contributed to significant improvements on COPD patients' perception of their symptoms and the number of disturbances they experience during activities. Through the inclusion of exercise information in the self-management program, COPD patients' are able to increase their cardiovascular knowledge, exercise capacity (Bulley et al., 2009), strength and endurance (Hayton et al., 2013), as well as decrease their levels of dyspnoea (Paz-Díaz et al., 2007); all of which can have a direct impact on a patients symptoms and ability to perform daily activities. This result of improvements in the quality of life of COPD patients' is in direct contrast to that of the Zwerink et al. (2014) meta-analysis, where the inclusion of an exercise program did not provide a significant benefit to any aspect of a COPD patient's health-related quality of life as measured by the SGRQ total or patients number of hospital admissions. Only one other subgroup analysis was conducted in the Zwerink et al. (2014) study (behavioural components) and was found to be not significant.

Implications

The results of this study have identified that self-management programs can provide a significant benefit to COPD patients' health-related quality of life, exercise capacity, and some aspects of their self-efficacy. Considering this, the utilisation of selfmanagement programs would be highly beneficial for newly diagnosed COPD patients as well as existing patients who have been experiencing difficulties managing their illness following numerous exacerbations. Through the provision of self-management programs which include COPD education, an exacerbation action plan, and exercise information, patients will have the opportunity to increase their strength, endurance, as well as their confidence in managing their disease. Furthermore, as COPD patients' self-efficacy was found to be amendable in areas such as reducing helplessness, breathing difficulties, and poor nutritional habits; future self-management programs which incorporate components on dealing with emotional arousal and environmental influences could provide further increases to patients' self-efficacy. Finally, the results of this study highlighted that self-management interventions provide positive outcomes for improving COPD patients' health outcomes and that patient's age, situational, and emotional barriers are also an important consideration. However, due to the multifaceted nature of self-management programs it is recommended that the process of self-management become integrated into patients' usual care, providing patients with ongoing feedback, bolstering their support, in addition to improving their overall health and well-being.

Limitations and suggested further research

To ensure that the results presented in this meta-analysis retained sufficient power the number of subgroups run was reduced. The self-management training components used in the subgroup analyses were limited to three of the eight components due to the inclusion of the subgroup intervention duration. As five components were excluded from the analysis, this study was unable to determine the direct impact of medication information, management of exacerbations, management of stress and/or anxiety, nutritional guidance, and/or managing a healthy lifestyle on COPD patient health outcomes. Thus, future replications should consider the investigation of these or additional components in order to gain an understanding of the effects of these self-management components on COPD patients' health outcomes; providing a comprehensive understanding of the effects of self-management interventions on COPD well-being. These results, in particular the subgroup analyses demonstrate the need to further investigate which components of self-management programs are the most beneficial at improving COPD patients' health outcomes. Through identifying the most influential components and implementing them in a standardised program, it may be possible that self-management interventions could obtain benefits which provide clinically important improvements to patients' well-being.

Conclusion

Our findings reveal that self-management interventions can significantly improve COPD patients' health outcomes. Subgroup analyses revealed that COPD education consistently provided positive benefits to various aspects of COPD patients' well-being. It was also found that the patients' age and level of support is an important consideration in self-management interventions. Thus, disease knowledge in addition to the incorporation of an exacerbation action plan and the provision of exercise information should become compulsory component of all self-management programs in the future. Although self-management interventions have proven beneficial, further analysis into both the predictors of successful self-managers and additional self-management educational components is required in order to identify which factors

should be considered in interventions to further increase patients' proficiency in disease self-management.

4.2. The Effect of Resilience Factors on Chronic Obstructive Pulmonary Disease Patients HRQoL

Introduction

This study examines the second research question which was introduced in the conceptual framework (section 2.6) and literature review of this thesis. This research question examines COPD patients' individual and contextual resilience factors and their relationship to their HRQoL. In this framework COPD patients who have higher levels of resilience feel worthy of care and more competent that they can make appropriate decisions regarding their illness and the disturbances they experience. COPD patients will also have stronger relationships and have more confidence in the support they receive from their health care teams; all of which provide them with the foundations to improve their HRQoL. To examine this relationship a decision tree analysis was undertaken on patients with high HRQoL versus low HRQoL.

Statement of contribution to co-authored published paper:

This section includes a co-authored manuscript submitted for publication to Respiratory Care as an original research paper. The status of the co-authored paper, including all authors, is: **Cannon D,** Sriram KB, Liew A, Sun J, Resilience factors important in Chronic Obstructive Pulmonary Disease subjects' health-related quality of life, Respiratory Care (2018), Accepted for publication.

The research candidate has made the following contributions to this study:

- Identified research gaps and developed the study design.
- Completed and obtained human research ethics approvals from Griffith
 University Human Research Ethics (Protocol Number: MED/40/15/HREC;

Griffith University Reference No: 2015/677) and the Gold Coast Health Ethics

Committees (HREC/15/QGC/232)

Researched and developed the survey instrument.

Recruited participants and collected data from hospitalised patients.

Input and analysed the data, then interpreted the findings.

Prepared the manuscript and submitted to the Respiratory Care.

Danielle Cannon (26/03/2018)

Supervisor and corresponding author: Jing Sun (26/03/2018)

Abstract

Introduction: Common among chronic obstructive pulmonary disease subjects is a

declining health-related quality of life. Although research has identified some factors

associated with health-related quality of life, resilience factors are yet to be fully

investigated. Method: This study examined resilience and demographic factors

associated with health-related quality of life. Participants over 40 years were recruited

from community health programs and hospitals in South-East Queensland. Self-

administered questionnaires queried subjects' health-related quality of life and levels of

resilience. A decision tree examined the factors important to health-related quality of

life in 159 chronic obstructive pulmonary disease subjects. Results: Factors of

importance in COPD subjects' health-related quality of life were found on three

domains of the St George Respiratory Questionnaire. Of importance on the

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breathlessness domain was marital status, defensive coping, coping, number of comorbidities, relationships, decision making, self-esteem, self-efficacy, and professional support health and well-being. On the symptoms domain self-efficacy, recruitment location, anxiety/depression, decision making, self-esteem, coping, relationships, and professional support health and well-being and risks were important. The cough domain found recruitment location, anxiety/depression, professional support health and well-being, coping, and defensive coping to be important for subjects' health-related quality of life. Conclusion: Resilience and confounding factors were of importance in chronic obstructive pulmonary disease subjects' health-related quality of life. Thus, consultation with a medical professional especially at discharge who identifies, encourages, and approves of the subject's disease management abilities will enhance both their resilience and health-related quality of life.

Introduction

Chronic obstructive pulmonary disease (COPD) is a preventable and treatable illness of the lungs characterised by persistent airflow limitation, hyperinflation, abnormal gas exchange, mucus hypersecretion, pulmonary hypertension, exacerbations, and other systemic problems such as cardiac issues and frailty syndrome (Abramson et al., 2015b; GOLD, 2016b; Uchmanowicz, Jankowska-Polanska, Chabowski, Uchmanowicz, & Fal, 2016). Due to the disease and its limitations many COPD subjects experience a reduced health-related quality of life (HRQoL; Cully et al., 2006a; Uchmanowicz, Jankowska-Polanska, Motowidlo, Uchmanowicz, & Chabowski, 2016). HRQoL involves mental, physical, and social aspects and is best defined as the individual's perceptions of their mental, physical, and social capabilities and how they are impacted by their medical condition over a period of time (https://www.cdc.gov/hrqol/concept.htm, July 1, 2017). More specifically, the concept of HRQoL reflects the gap between COPD subjects' actual and desired capabilities

(Almagro & Castro, 2013) and includes their symptomatic experiences, and physical and psycho-social functioning (Connor & Davidson, 2003).

Past research on the characteristics of COPD subjects' HRQoL has identified various predictors of well-being. Blinderman et al. (2009) found that female gender, high symptom distress, greater functional impairments, and poor psychological well-being were associated with having a lower HRQoL. Other studies have found social isolation (Gardiner et al., 2010), other comorbidity's symptoms, age, marital status (Mewes, Rief, Kenn, Ried, & Stenzel, 2016), anxiety, depression (Keil, Vaske, Kenn, Rief, & Stenzel, 2017; Mewes et al., 2016), and gender were significant predictors of COPD subjects' HRQoL (Mewes et al., 2016; Raherison et al., 2014). Although one study has recently investigated and found a correlation between COPD subjects' total resilience and quality of life (Sanyal et al., 2017), no studies have yet investigated COPD subjects' HRQoL and the individual and contextual resilience factors as a collective concept.

The concept of resilience in COPD subjects' HRQoL is important as it has been found to influence how subjects' manage their health and well-being (Hesselink et al., 2004; Juth et al., 2008). This study conceptualises resilience via a socio-ecological approach (Bronfenbrenner, 1994a; Sun & Stewart, 2007) and identifies that resilience comprises various individual and contextual factors which facilitate well-being when experiencing stress (Ungar, Ghazinour, & Richter, 2013). The socio-ecological approach considers the interactions between three key areas. That is, COPD subjects' individual factors such as self-esteem, self-efficacy, and coping (Ungar et al., 2013; Wang et al., 2014); their contextual factors, for instance their support systems, including support from family, friends, and their health care professionals (Bronfenbrenner, 1994a; Ungar et al., 2013); and the interactions within their environment, including their relationships, cultural identity, and the material resources available to them (Ungar et

al., 2013; Wang et al., 2014). Thus, HRQoL is proposed to be associated with subjects' perception of themselves as confident, self-efficiently managing their disease conditions, in addition to, their ability to access to support and encouragement from professionals and their other relationships.

Individuals resilience has been found to fluctuate over time and can influence decisions to undertake actions that improve their health and well-being (Bourbeau et al., 2004). Past research has identified that COPD subjects' frequently experience low levels of self-esteem which can impact upon their motivation and decrease their health and well-being (Reich et al., 2010). COPD subjects' positive use of coping has been found to improve HRQoL (Andenæs, Kalfoss, & Wahl, 2006), especially when subjects' have been provided with disease specific education from health care professionals (Cannon et al., 2016). However, qualitative studies have revealed that the benefits of support and relationships for COPD subjects are unclear with some studies supporting improvements in HRQoL (Bulley et al., 2009; Haave & Hyland, 2008; Harris et al., 2008b) and others reporting few perceived benefits (Bulley et al., 2009; Harrison et al., 2015). Although the value of professional support for improving subjects' HRQoL is uncertain, it has been identified that support from family and friends is beneficial (Greeff & Holtzkamp, 2007a).

Although some resilience factors have been examined individually for COPD subjects' HRQoL (Adegbola, 2011a; Bentsen, Wentzel-Larsen, Henriksen, Rokne, & Wahl, 2010; Cannon et al., 2016; Ezeamama et al., 2016; Juth et al., 2008), no studies have comprehensively examined resilience factors at both individual and contextual levels using a socio-ecological approach. Further no studies have analysed the importance of these factors via a decision tree analysis. The identification of the importance of these resilience factors for each of the HRQoL domains can identify future research directions and potentially inform new practice guidelines for assisting in

the treatment and management of the disease. This study aims to identify which resilience factors are important in COPD subjects across a variety of HRQoL domains.

Method

Participants

Data for this study was obtained between September 2015 and November 2016. Based on the Australian prevalence of 8.4% (http://lungfoundation.com.au/healthprofessionals/clinical-resources/copd/copd-the-statistics/, April 19, 2014) and using the sample size formula devised by Charan and Biswas (2013) a minimum of 118 participants were required for this research study (p = 8.4%, d = 0.05, and ($Z_{1-\alpha/2}$) = 1.96). Three hundred and sixty subjects were asked to participate with 159 completing and returning the questionnaire (44.2% response rate). Participants in this study were aged over 40 years, had a doctor's diagnosis of COPD conducted via spirometry (mild to severe), were attending COPD education days at Brisbane or Gold Coast Health Community Centres (Helensvale and Robina), or were receiving treatment at various hospital areas such as the wards or the medical assessment unit at the Gold Coast University and Robina hospitals. Subjects' were excluded if they had a serious cognitive impairment, any other unstable medical, major psychiatric, and/or neurological conditions. Subjects' were also excluded if they were unable to speak English or provide informed consent. Ethical approval for this study was sought from both Griffith University Human Research Ethics and the Queensland Health's Gold Coast Hospital and Health Service Human Research Ethics Committee.

Study Measures

The independent variables included in this study involve a combination of individual and contextual factors which make up resilience. The individual level factors include self-efficacy, coping, decision making, defensive coping, and self-esteem,

whereas the contextual factors include relationships and professional support. The outcome variable assesses COPD subjects' HRQoL via five domains; activity, breathlessness, symptoms, cough, and medication. A comprehensive discussion of the variables in this study are described below.

Resilience Scale

The Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003): A self-report measure which assesses COPD subjects' individual and contextual resilience factors via 25 questions. The CD-RISC has an excellent reliability (Cronbach's α = 0.89) and a good validity (Connor & Davidson, 2003). This questionnaire asks participants to rate their feelings over the last month on a five-point Likert scale; not at all true, rarely true, sometimes true, often true, and almost always true. Specifically, it queries four factors based on factor loadings for the current sample; self-efficacy ("can deal with whatever comes"), coping ("under pressure, I focus and think clearly"), decision making ("make unpopular or difficult decisions"), and relationships ("have close and secure relationships"). The reliability of the CD-RISC for the current COPD sample was found to be excellent (α = 0.92) and content validity for the questions was good with 56.58% of the variance being accounted for.

Four items assessed subjects' use of defensive coping (via denial), and 10 questions assessed subjects' disease specific self-esteem were measured by Acceptance of Disease and Impairments Questionnaire (ADIQ; Boer et al., 2014). A validation study found the ADIQ to have good to excellent reliability (Cronbach's α between 0.80 to 0.83) and also proved to be a valid measure (Boer et al., 2014). This questionnaire asks subjects to rate their level of agreement on a four-point Likert scale; disagree, slightly agree, strongly agree, and entirely agree. It queries subjects' level of denial ("I try to ignore my impairments"), as well as their self-esteem ("I feel frustrated with my

impairments", "I become sad when I experience and impairment", and "I can accept my impairments"). A reliability of the ADIQ was run with the current sample and was found to have an excellent reliability (Cronbach's $\alpha = 0.865$) in addition to having an excellent content validity with the questions accounting for 78.1% of the variance.

Subjects' professional support is measured by the Pulmonary Rehabilitation Benefits and Consequences Scale (PRBCS). This scale assesses COPD subjects' perceived outcomes of the professionally supported pulmonary rehabilitation programs. A seven-point Likert scale is used to rate these beliefs: strongly disagree, disagree, somewhat disagree, undecided, somewhat agree, agree, and strongly agree. A factor analysis revealed three factors belief scores; health and well-being ("improve a COPD patients' quality of life"), reliance on external services ("reduce COPD patients' ability to perform basic home duties"), and potential risks ("increase the risk of injury"). The reliability for the PRBCS was found to be acceptable ($\alpha = 0.72$) and the content validity was good with the questions accounting for 59.93% of the variance.

Demographic Characteristics

Seven demographic variables were considered in the analysis following a review of the literature. These characteristics included the subject's marital status, age, gender, smoking status, diagnosis of anxiety or depression, total number of comorbidities, and their recruitment location. The results of the bivariate analysis for the subjects' demographic characteristics are presented in Table 8.

Primary Outcome Measure

Subjects' HRQoL was the primary outcome measure for this study and was measured via the St George Respiratory Questionnaire (SGRQ; Jones et al., 1991a).

Factor loadings were calculated for the current sample with five factors being identified.

This self-report measures a subject's disease specific HRQoL (high scores indicating a

Table 8. Relationship between demographic characteristics and HRQoL domain scores of study sample (n=159)

Variable	Acti	ivity		Breathl	lessness		Symp	otoms		Co	ugh		Medi	cation	
	Low	High	p	Low	High	p	Low	High	p	Low	High	p	Low	High	p
	n(%)	n(%)		n(%)	n(%)		n(%)	n(%)		n(%)	n(%)		n(%)	n(%)	
Age															
<65 years (n=43)	20(46.5)	23(53.5)		15(34.9)	28(65.1)		25(58.1)	18(41.9)		20(46.5)	23(53.5)		21(48.8)	22(51.2)	
66 to 75 years (n=67)	31(46.3)	36(53.7)		21(31.3)	46(68.7)		39(58.2)	28(41.8)		43(64.2)	24(35.8)		45(67.2)	22(32.8)	
76+ years (n=48)	18(37.5)	30(62.5)	.59	11(22.9)	37(77.1)	.43	24(50.0)	24(50.0)	.64	30(62.5)	18(37.5)	.15	29(60.4)	19(39.6)	.16
Gender															
Male (n=77)	32(41.6)	45(58.4)		20(26.0)	57(74.0)		39(50.6)	38(49.4)		49(63.6)	28(36.4)		49(63.6)	28(36.4)	
Female (n=81)	35(45.7)	44(54.3)	.60	27(33.3)	54(66.7)	.31	49(60.5)	32(39.5)	.21	44(54.3)	37(45.7)	.23	46(56.8)	35(43.2)	.38
Smoking status															
Non-smoker (n=53)	22(41.5)	31(58.5)		19(35.8)	34(64.2)		35(66.0)	18(34.0)		29(54.7)	24(45.3)		28(52.8)	25(47.2)	
Ex-smoker and smoker	47(44.8)	58(55.2)	.70	28(26.7)	77(73.3)	.23	53(50.5)	52(49.5)	.063	64(61.0)	41(39.6)	.45	67(63.8)	38(36.2)	.18
(n=105)															
Marital status															
Married/de-facto (n=73)	35(47.9)	38(52.1)		28(38.4)	45(61.6)		40(54.8)	33(45.2)		40(54.8)	33(45.2)		46(63.0)	27(37.0)	
Single/divorced/widowed (n=85)	34(40.0)	51(60.0)	.32	19(22.4)	66(77.6)	.03	48(56.5)	37(43.5)	.83	53(62.4)	32(37.6)	.34	49(57.6)	36(42.4)	.49
Recruitment location															
Community (n=87)	42(48.3)	45(51.7)		30(34.5)	57(65.5)		59(67.8)	28(32.2)		63(72.4)	24(27.6)		56(64.4)	31(35.6)	
Hospital (n=72)	27(37.5)	45(62.5)	.17	17(23.6)	55(76.4)	.14	29(40.3)	43(59.7)	<.01	30(41.7)	42(58.3)	<.01	39(54.2)	33(45.8)	.19
Diagnosis anxiety/depression (n=54)	21(39.9)	33(61.1)		13(24.1)	41(75.9)		21(38.9)	33(61.1)		24(44.4)	30(55.6)		25(46.3)	29(53.7)	
No anxiety/depression (n=104)	46(48.2)	56(53.8)	.38	34(32.7)	70(67.3)	.26	66(63.5)	38(36.5)	<.01	69(66.3)	35(33.7)	<.01	69(66.3)	35(33.7)	.02
Number comorbidities (n=159) <i>Mean</i> (SD)*	2.5(1.6)	2.9(1.7)	.14	2.1(1.4)	2.9(1.7)	<.01	2.3(1.3)	3.2(1.8)	<.01	2.3(1.4)	3.3(1.8)	<.01	2.5(1.7)	3.1(1.5)	.02

Note: data presented as number (n) and percent (%); $\chi 2$ = chi-squared analysis; * number of comorbidities via independent *t*-test (*t*); SD = standard deviation; low score equals better HRQoL, high score equals poorer HRQoL

poor HRQoL, and low scores a high HRQoL) via subjects' limitations in activity, breathlessness, symptoms, coughing experiences, and medication impacts. The first domain assesses the subject's limitations to their daily activities which occur as a result of their breathlessness. The second factor assesses the subject's level of breathlessness currently and in comparison to others. The third factor assesses the subject's perception of their symptoms via ratings of their level of breathlessness, cough, and sputum production. The fourth domain examines subjects' coughing experiences and final factor queries the subject's medication experiences. Following factor identification domains were dichotomised into high and low HRQoL owing to the ordinal nature of the data. Cut-off points were determined via analysis of the median; see Table 9. The American version of the SGRQ was found to have good discriminant and construct validity. The internal reliability ($\alpha > 0.70$) was excellent and the test-retest correlations were also found to be excellent (r=0.795 to 0.900; Barr et al., 2000). The reliability of the SGRQ for the COPD sample obtained for this study was found to be excellent (r=0.89).

Table 9. Median and interquartile range (IQR) for determining dichotomisation of domains

	Activity	Breathlessness	Symptoms	Cough	Medication
Median	5	9	1	3	0
	(2-7)	(8-9)	(0-3)	(2-4)	(0-1)
(IQR)	<5	<9	<2	<4	<1
High HRQoL					

Statistical Methods

Decision tree analysis was conducted in order to identify the most important resilience factors for HRQoL in COPD subjects and included possible confounding factors. Decision trees are a useful method for predicting the importance of numerous independent variables and can analyse both continuous (regression tree) and categorical outcome variables (classification tree; Ming, 2001a). In addition to this, the prediction models can be represented via a decision tree diagram (Loh, 2011b). The tree analysis is

a robust method and can be used with data that has missing values, is non-homogenous, or not normally distributed (Ming, 2001a). This tree analysis was conducted with an alpha of 0.05.

Results

The study sample consisted of 159 COPD subjects, of which 87 (54.7%) were recruited from the community and 72 were recruited from the Robina and Gold Coast University Hospitals. Of the sample 51.3% were female and almost half (42.4%) of the participants were aged between 66 to 75 years with a further 30.4% being over 76 years. A large proportion of the sample (n=145, 91.2%) did not smoke, with 92 (57.9%) of the participants being ex-smokers; thus only 13 (8.2%) of the recruited participants continued to smoke. The marital status of the sample was roughly even with 45.9% of participants being married or in a de-facto relationship. Comorbid illnesses within the COPD sample was 2.71 (SD1.64) with one participant reporting 8 other comorbidities. Anxiety and depression was common within the sample with 34.2% reporting that they had received a diagnosis from their doctor. Those who had completed a pulmonary rehabilitation program made up 39.1% of the sample whilst 26.9% of participants have never been referred to a program.

The psychological aspects of the current sample found that most of the participants have reached the stage of acceptance ($\bar{\chi}$ 4.02, SD 0.96) within the grief model. However, they still continued to experience strong feelings of anger (resistance $\bar{\chi}$ 3.13, SD 1.05) regarding their illness and the limitations it places on their lives. The resilience scores of the sample were strong (CD-RISC total 69.47 (SD 15.71)) with the individual factor scores being relatively consistent across each of the factor loadings. Finally, the HRQoL of the current COPD sample revealed moderate to low HRQoL across three domains and for their overall well-being (activity $\bar{\chi}$ 4.25 (SD 2.47),

breathlessness $\bar{\chi}$ 8.12 (SD 1.84), cough $\bar{\chi}$ 3.10 (SD 1.98), and total $\bar{\chi}$ 56.25 (SD 17.16)), yet high HRQoL for the remaining two domains; symptoms $\bar{\chi}$ 1.89 (SD 2.04) and medication $\bar{\chi}$ 0.74 (SD 1.42).

Bivariate analyses (Table 1) found numerous potential confounding relationships with the HRQoL domains; marital status, recruitment location, diagnosis of anxiety or depression, and total number of comorbidities. These potential confounds were thus included in decision tree analysis. The results of the decision tree identified the factors which are of importance for COPD subjects' HRQoL. On the HRQoL breathlessness domain seven resilience factors and two confounding factors were found to be important for COPD subjects' levels of breathlessness (Figure 7). The most important factor on the breathlessness domain was the subjects' marital status. On the first branch of decision tree COPD subjects who were married or de-facto and used defensive coping; had high self-esteem, believed that supported pulmonary rehabilitation would improve their health and well-being, and had one or no other comorbidities were found to have high HRQoL. High HRQoL was also found for single, divorced, or widowed COPD subjects who had high levels of coping, good decision making abilities, high self-efficacy, and less than two comorbidities. The overall prediction accuracy for the HRQoL symptoms decision tree analysis was reasonable, 62.26% (Table 10).

Table 10. Decision tree analysis accuracy by class for the breathlessness, symptoms, and cough domains

Class	True positive rate	Precision	ROC area
Breathlessness			
High HRQoL	0.298	0.341	0.507
Low HRQoL	0.759	0.720	0.507
Total	0.623	0.608	0.507
Symptoms			
High HRQoL	0.591	0.591	0.532
Low HRQoL	0.493	0.493	0.532
Total	0.547	0.547	0.532
Cough			
High HRQoL	0.817	0.655	0.594
Low HRQoL	0.394	0.605	0.594
Total	0.642	0.634	0.594

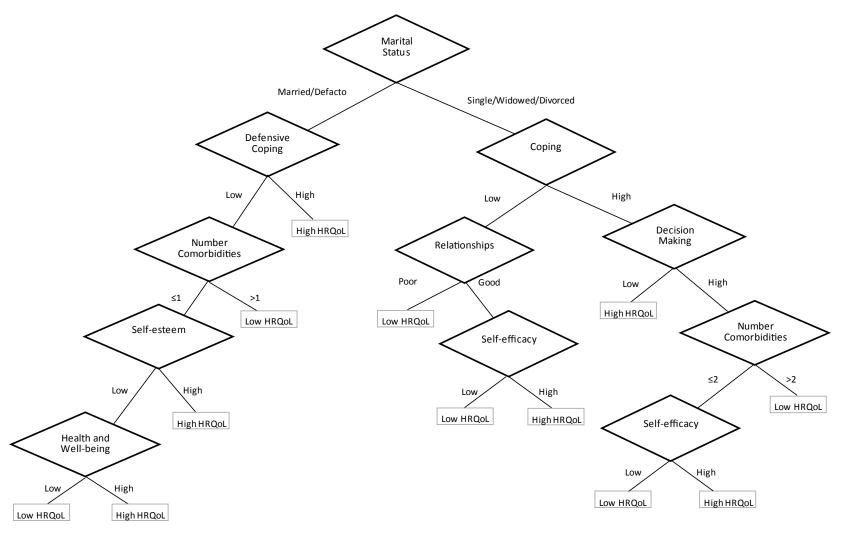


Figure 7. Decision tree diagram indicating resilience pathways important to COPD patients HRQoL on the breathlessness domain. COPD subject HRQoL breathlessness scores are presented as either high or low for each outcome for the corresponding resilience or confounding factor. Resilience factor scores are presented as whether COPD subjects scored high or low on that factor.

The decision tree results for the HRQoL symptoms domain found that seven resilience factors and two confounding factors were important in COPD subjects' perception of their symptoms (Figure 8). The most important factor on the symptoms domain was the COPD subjects' level of self-efficacy; where poor self-efficacy directly determined poor HRQoL. However, on the symptoms domain high HRQoL was found in subjects with high level of self-efficacy, and high self-esteem when subjects had no anxiety and depression, and were recruited from the community; when subjects had low self-efficacy, and low coping, but good relationships, and high beliefs that supported pulmonary rehabilitation would improve their health and well-being they also found to have a high HRQoL on the symptoms domain. Hospitalised subjects with high self-efficacy, good decision making abilities, high levels of coping even though they were diagnosed with anxiety and depression also displayed high HRQoL. The overall prediction accuracy for the HRQoL symptoms decision tree analysis was found to be reasonable, 54.72%.

The third HRQoL domain to have important factors was the cough domain (Figure 9). The decision tree analysis found that three resilience factors and two confounding factors were important for COPD subjects' coughing experiences. The most important factor was the recruitment location of the subject, with subjects recruited from the community having a better HRQoL. COPD subjects' who were recruited from the hospital had a better HRQoL if they did not have anxiety or depression and had high beliefs in supported pulmonary rehabilitation improving their well-being; in addition to this, COPD subjects with good coping abilities who utilised defensive coping were also able to maintain a good HRQoL. This was also true for subjects' who had a diagnosis of anxiety or depression yet had good coping skills. The HRQoL symptoms decision tree analysis overall prediction accuracy was reasonable, 64.15%.

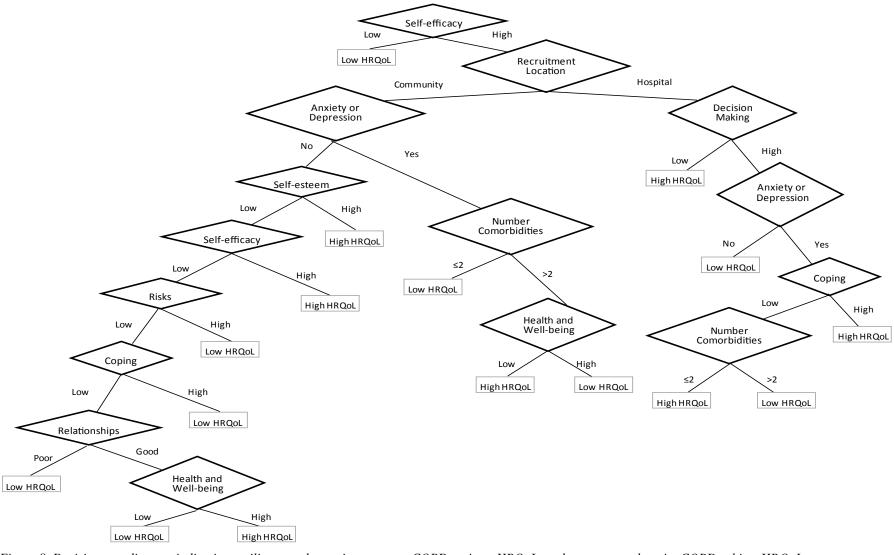


Figure 8. Decision tree diagram indicating resilience pathways important to COPD patients HRQoL on the symptoms domain. COPD subject HRQoL symptoms scores are presented as either high or low for each outcome for the corresponding resilience or confounding factor. Resilience factor scores are presented as whether COPD subjects scored high or low on that factor.

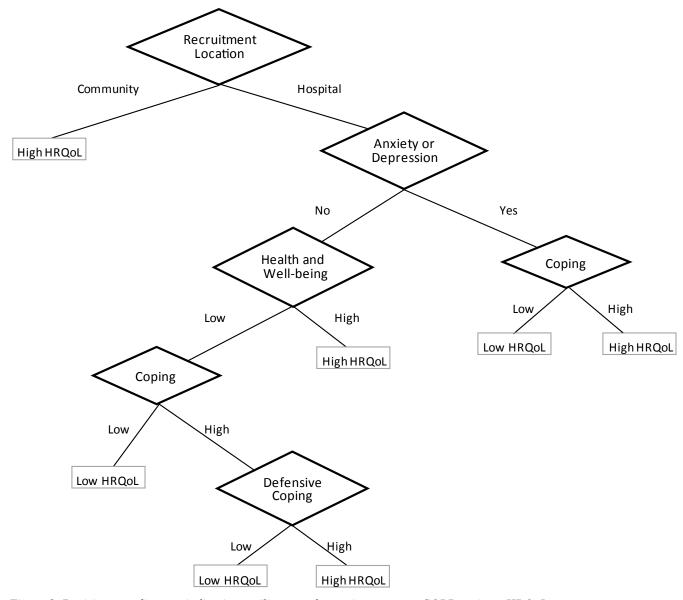


Figure 9. Decision tree diagram indicating resilience pathways important to COPD patients HRQoL on the cough domain. COPD subject HRQoL cough scores are presented as either high or low for each outcome for the corresponding resilience or confounding factor. Resilience factor scores are presented as whether COPD subjects scored high or low on that factor.

The outcome variables activity and medication did not find any resilience factors or confounds to be important in COPD subjects HRQoL.

Discussion

The decision tree analysis identified associations with both individual and contextual level resilience factors and COPD subjects' HRQoL. With the exception of the professional support sub-variable reliance on external services, all individual and contextual resilience factors were found to be associated with COPD subjects' HRQoL

throughout the breathlessness, symptoms, and/or cough domains. When considering the confounding factors, the subjects' recruitment location, number of comorbidities, marital status, and diagnosis of anxiety or depression were found to be important on some of the HRQoL domains.

HROoL Related Breathlessness

A COPD subject's current breathlessness experiences were found to be associated with their levels of resilience when marital status and comorbidities were controlled for in the model. Similar results have been found in other studies, where COPD subjects' who were educated in breathing techniques were found to become empowered, increasing their self-efficacy, leaving them feeling better equipped to cope, including making decisions regarding potential episodes of dyspnoea (Milne, Moyle, & Cooke, 2009). Interventions which provided breathing techniques have also been found to increase COPD subjects' beliefs in professionally supported programs being able to improve their health and well-being (Vercoulen, 2012). These programs further promoted the idea that subjects' would require assistance from family and friends with some tasks, especially when their dyspnoea was high (Milne et al., 2009); a finding which is consistent with our current results that good relationships are important for HRQoL (breathlessness and symptoms).

The association between COPD subjects' HRQoL and their use of defensive coping has been little studied in COPD, yet has had inconsistent results in other HRQoL chronic illness research. These studies found that the use of defensive coping was significantly related to poorer HRQoL (Carvalho et al., 2013) and significantly higher rates of emergency room visits over a period of 12 months (González-Freire, Vázquez-Rodríguez, Marcos-Velázquez, & de la Cuesta, 2010). In contrast to this, another study found that defensive coping was associated with marginally better physical HRQoL

(Kaltsouda et al., 2011b). Thus, defensive coping may act as a buffer against the harsh reality of the illness and its consequences, providing short-term relief from the distress caused by having a chronic illness such as COPD (Kaltsouda et al., 2011b).

HRQoL Related Symptoms

Subjects' perception of their symptomatic experiences was found have various complex associations with both resilience and confounding factors. Although many of these associations have not yet been directly studied, these findings are consistent with similar previous chronic illness research (Bentsen et al., 2010; Esteban et al., 2009). Subjects' who had higher baseline self-efficacy were found to exhibit significant improvements in HRQoL following a pulmonary rehabilitation program (Bentsen et al., 2010). Other research has found that subjects' who had been admitted to the hospital with multiple exacerbations had a worse perception of their symptoms than subjects' who had exacerbations for which they were not hospitalised (Esteban et al., 2009).

The subsequent associations with subjects' symptomatic HRQoL found in this study have been similarly identified in other research. Firstly, high self-esteem was found to be associated with subjects' who experienced less symptoms such as sputum production (Nicolson & Anderson, 2003). Secondly, high self-esteem in COPD subjects has also being found to be associated with better relationships and coping abilities; aspects which are associated with fewer COPD symptoms (Juth et al., 2008). Positive professional support, where subjects' believe that the support will improve their health and well-being is recognised as increasing adherence to programs which improve subjects' HRQoL (Thorpe, Johnston, & Kumar, 2012). However, if subjects' believed that the program would worsen their symptoms they refused to participate in these programs; reducing the probability of improving their symptom management and HRQoL (Guo & Bruce, 2014). Finally, the number of comorbidities that a subject has

was also found to influence a COPD subjects' HRQoL symptoms; where subjects' with fewer comorbidities were found to have a better HRQoL (Almagro & Castro, 2013).

Unexpected findings included hospitalised COPD subjects with poor decision making having high HRQoL and subjects without anxiety or depression ranking with poor HRQoL. When considering subjects with poor decision making it was expected that poor choices would lead to poorer HRQoL. However, research has suggested that seemingly poor decisions could actually provide the subject with some relief, for instance, being less adherent with medications to avoid side effects (Ágh et al., 2015). The finding that COPD subjects' without depression having a low symptomatic HRQoL could be explained via past research which has found that subjects' admitted to hospital tend to experience higher rates of depressed feelings during their admission; feelings which usually dissipate 12 weeks after discharge (Hill et al., 2008).

HRQoL Related Cough

The finding that COPD subjects' recruitment location was associated with their coughing experiences is consistent with previous research (Burgel et al., 2009; Juth et al., 2008; Nicolson & Anderson, 2003). Firstly, high levels of coughing and sputum production are associated with the exacerbations which frequently lead to hospitalisations (Burgel et al., 2009). In addition to this, the primary cause of exacerbations and acute coughing experiences usually results from a bacterial or viral respiratory infection (Boixeda et al., 2012); disturbances which are strongly associated with hospitalisations, poor well-being, and increased mortality rates (Burgel, 2012).

The second association that anxiety and depression are important in subjects' HRQoL cough has been established in previous studies where depression or anxiety have been found to be significantly related to low HRQoL in COPD subjects (Burgel et al., 2013). It is also recognised that anxiety is the factor which is most strongly related

to subjects' breathlessness. One study found that a severe bout of coughing can create dyspnoea which increases subjects' anxiety (Willgoss, Yohannes, Goldbart, & Fatoye, 2012) and anxiety can also cause breathlessness (Bailey, 2004) which can promote the action of coughing to gain better lung clearance (Yang et al., 2017). It was also found that COPD subjects' who believe that professional support will improve their health and well-being have a higher HRQoL on the cough domain. This finding is supported by research that investigates COPD subjects following pulmonary rehabilitation interventions; these subjects' are better able to cope with their disease by managing their breathlessness and coughing experiences, providing them with more independence and a better HRQoL (Thorpe et al., 2012).

Resilience factors for the HRQoL domains medication and activity were found to be unimportant in this COPD sample. The influence of resilience on medication based HRQoL is under researched in COPD subjects, with the closest research considering the relationships of resilience factors and medication adherence in other health publications. These papers identified that self-efficacy and support could be factors which influence chronic illness subjects' adherence to medications (Lareau & Yawn, 2010). Another paper which investigated adherence in a psychiatric population found that when medication interfered with resilience and resilience supporting factors that subjects' adherence decreased in order to preserve their current state (Deegan, 2005).

When considering the insignificant association between HRQoL activity and COPD subjects' individual and contextual resilience factors one similar publication found that COPD subjects' quality of life on physical health was correlated with their overall resilience (Sanyal et al., 2017). However, the physical health score used in this study contained a diverse array of items which were not directly related to our activity score, including pain, fatigue, and sleep. As our paper opposes these past findings, more

research on the importance of resilience factors for COPD subjects' HRQoL is required in order to clarify these outcomes.

Implications

The results of this study demonstrate that COPD subjects' individual and contextual resilience factors are associated with their HRQoL. It was also found that various demographic factors influenced the results.

Subjects' belief in their own self-esteem and self-efficacy have been recognised as important factors in coping with the adverse experiences and lifestyle changes that are required following the diagnosis of a chronic illness (Kralik, Van Loon, & Visentin, 2006a; Uchmanowicz, Jankowska-Polanska, Motowidlo, et al., 2016). Individuals who have low levels of self-esteem and self-efficacy tend to have more negative appraisals of their situation and as a result are less adept at managing stressful situations (Reich et al., 2010). Aspects which have been identified as impairing COPD subjects' self-esteem and self-efficacy is their ability to control their situation, having feelings of guilt over causing their illness, and their need for consistent complex medication regimens (Lindqvist & Hallberg, 2010). In addition to this, it has also been identified that subjects' with a mental illness experience continual declines in self-esteem following onset and diagnosis of their illness (Wittmann et al., 2010a). This finding is important for COPD subjects, as anxiety and depression are common comorbidities in COPD, and can thus lead to further deterioration of subjects' self-esteem, self-efficacy, and COPD symptoms (Uchmanowicz, Jankowska-Polanska, Motowidlo, et al., 2016).

In order to improve COPD subjects' HRQoL, subjects' need to be able to hold positive views of their own self-worth and have competence for managing their disease. The subjects' feelings regarding their illness need to be shifted from a perspective of culpability, shame, and guilt, to providing feelings of empowerment and empathetical

support, both from professionals and their external relationships. Subjects' frequently feel disempowered and unworthy of care following hospitalisation (Harrison et al., 2015) and as subjects' recruited from the hospital who had poor coping abilities and other comorbidities, primarily anxiety or depression, were found to experience a poorer HROoL in this study, it is important to consider both the medical and psychological aspects of the subject at discharge. Promoting self-esteem, self-efficacy, and coping can be achieved through the identification of subjects' health goals and encouraging the use of positive health behaviours to achieve these goals (Vonk & Smit, 2012b). Research has found that the approval of these positive health behaviours from a health care provider promotes stronger and more enduring changes in the subjects' self-esteem ((Vonk et al., 2004 as cited in; Vonk, 2006)). In a COPD context, the enhancement of subjects' resilience would be best achieved through the identification and encouragement of positive health behaviours such as exercise, medication adherence, and early exacerbation identification. Identification of these behaviours can be achieved during consults with medical professionals (e.g. GP or specialists) or during hospital discharge via a respiratory nurse, with referral to intervention programs being made to further these skills if necessary.

Limitations and Recommendations

Although this study highlights some positive findings, it does have a number of limitations that need to be considered when interpreting the results. Firstly, this study relies upon data that is obtained via self-report questionnaire, which is a subjective measure and is based on the individual's perspective. As a result, the answers provided in the questionnaire may not objectively reflect the real experiences or severity of subjects' who are undergoing extreme difficulties. In addition to this, all participants in this study were recruited from two regions (Brisbane and Gold Coast) in South-East Queensland. Recruiting participants in this way may not generalise the results to other

areas of Australia and other international cultural locations. A third limitation involves the recruitment of community participants; that is, that all community participants were recruited from COPD education seminars. Recruiting participants from such locations indirectly excludes non-hospitalised participants who are not actively undertaking education. Participants not undertaking education could be in denial about their illness or may not be motivated enough to undertake such courses; an aspect which could impact the outcome of the results. Finally, as the study is cross-sectional it only allows for the interpretation of relationships between the variables and does not provide the opportunity to assess any causal conclusions. Thus, future replications should look at obtaining data from large randomised controlled trials to examine the cause and effect relationship between resilience and HRQoL. In addition to being expanded to other areas in order to contain a more representative sample to assist in generalisability of the results across the COPD population.

Conclusion

COPD subjects' individual and contextual resilience and confounding factors were found to be important in their HRQoL. Specifically, high HRQoL was found in subjects' who had high levels of self-esteem, self-efficacy, good coping, relationships, and positive views of supported pulmonary rehabilitation programs. COPD subjects' recruitment location, marital status, levels of anxiety/depression, and number of comorbidities were also found to be associated with the HRQoL and these factors were controlled for in the models. These findings indicate that resilience is important in COPD subjects' who have other comorbidities, especially after being admitted to hospital. Thus, COPD subjects require identification, encouragement, and approval of their current disease management abilities from a health practitioner, especially at the time of hospital discharge in order to improve their resilience and ultimately HRQoL. Furthermore, new treatment recommendations and referrals to intervention programs

need to be conveyed in a way that aligns with the individual's goals and beliefs in order to maintain the subject's resilience.

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4.3. COPD patients Levels of Resilience and its Effect on Completion of Pulmonary Rehabilitation Programs

Introduction

This paper addresses the third research question which was introduced in the conceptual framework (section 2.6) and literature review of this thesis. This question examines the relationship between pulmonary rehabilitation completion and COPD patients' individual and contextual resilience factors. This framework identifies that pulmonary rehabilitation programs are more likely to be completed by COPD patients who have higher levels of resilience. Patients with higher resilience will feel that they are competent enough to complete the program, that they are worthy of their invitation to complete, and that they will have appropriate support from their health care team. Having positive relationships with their health care team will decrease their need to use defensive coping regarding their illness and the limitations they are experiencing. This relationship was examined via a machine learning decision tree analysis which categorised patients as either having completed or not having completed pulmonary rehabilitation.

Statement of contribution to co-authored published paper:

This section includes a co-authored manuscript submitted for publication to Clinical Rehabilitation as an original research paper. The status of the co-authored paper, including all authors, is: **Cannon D,** Sharma S, Sun J, A quantitative study of resilience factors affecting completion of pulmonary rehabilitation programs, Clinical Rehabilitation (2018), Submitted for publication.

The research candidate has made the following contributions to this study:

• Identified research gaps and developed the study design.

Completed and obtained human research ethics approvals from Griffith
 University Human Research Ethics (Protocol Number: MED/40/15/HREC;
 Griffith University Reference No: 2015/677) and the Gold Coast Health Ethics
 Committees (HREC/15/QGC/232)

• Researched and developed the survey instrument.

• Recruited participants and collected data from hospitalised patients.

• Input and analysed the data, then interpreted the findings.

• Prepared the manuscript and submitted to Clinical Rehabilitation.

Danielle Cannon (26/03/2018)

Supervisor and corresponding author: Jing Sun (26/03/2018)

Abstract

Objective: Chronic obstructive pulmonary disease patients' adherence to pulmonary rehabilitation programs has been found to be consistently low. Resilience is influential in the maintenance of health and well-being especially in times of stress. This study aims to investigate the effect of chronic obstructive pulmonary disease patients' resilience on pulmonary rehabilitation completion. Design: Participants over 40 years were asked to complete a survey which examined both resilience and pulmonary rehabilitation completion. Setting: Participants were recruited from community health centres and hospitals in South East Queensland. Main measures:

Decision tree analysis examined the resilience factors important in pulmonary rehabilitation completion. Results: Of the 155 patients 39.4% had completed and 60.6% had not completed pulmonary rehabilitation. Patients low in trust, who perceived the programs risk to be high did not complete the program. Non-completion was found in patients who had good interpersonal relationships, however non-completion was also found in patients with poor interpersonal relationships if they also had low self-efficacy. High self-efficacy predicted non-completion when patients had poor decision making and good coping abilities. Conclusion: Resilience was found to affect chronic obstructive pulmonary disease patients' completion of pulmonary rehabilitation. Of particular importance to non-completion was the resilience factors of trust, perceived risk, interpersonal relationships, self-efficacy, decision making, and coping.

Introduction

Pulmonary rehabilitation programs are a core component of chronic obstructive pulmonary disease (COPD) patients illness management (Bourbeau, 2010), yet these programs are heavily underutilised (Hayton et al., 2013). The aim of pulmonary rehabilitation is to improve patients physical functioning, independence, nutrition, support, exercise capacity, and quality of life (Bulley et al., 2009; Queensland Health and Lung Foundation of Australia, 2012). Recent studies have shown that pulmonary rehabilitation has reduced hospitalisations, exacerbations (Selzler et al., 2012), social isolation (Sohanpal et al., 2012), dyspnoea, and patients' levels of depression and anxiety (Paz-Díaz et al., 2007).

Various factors influencing COPD patients' completion of pulmonary rehabilitation have been identified, primarily via qualitative studies (Arnold et al., 2006; Fischer et al., 2007; Guo & Bruce, 2014; Keating et al., 2011a). These factors include poor knowledge or awareness of the program (Arnold et al., 2006), patient readiness,

anxiety, disease severity (Guo & Bruce, 2014), physical capacity, social support, access to supervision via a multidisciplinary team (Fischer et al., 2007), and lack of perceived benefit (Keating et al., 2011a). Underlying some of these influential factors are components of resilience such as trust which develops through aspects such as knowledge and relationships (Marshall et al., 2008) and support whether it be from family and friends or health care professionals (Bulley et al., 2009).

Resilience is an important concept to consider in pulmonary rehabilitation completion as it influences an individual's health and well-being (Panter-Brick & Eggerman, 2012). Resilience is defined as the capacity of an individual to maintain or quickly regain psychological and physical well-being following an adverse event (Black & Dorstyn, 2013; Bonanno, 2004). Resilience is comprised of both individual (self-esteem and self-efficacy) and contextual factors (support and relationships) which interact to protect an individual's health and well-being (Ungar et al., 2013). The socioecological model identifies resilience as an interaction between the individual's characteristics or traits (self-efficacy), their social support systems, and the interplay of these factors with their environment (Bronfenbrenner, 1994b; Sun & Stewart, 2007; Ungar et al., 2013). This framework considers how interactions between factors such as self-efficacy, professional support, their cultural identity, and their material resources are utilised to overcome adversity (Ungar et al., 2013; Wang et al., 2014).

The importance of each resilience factor can vary throughout the lifespan, yet for older individuals aspects such as self-efficacy and spiritual relationships have been found to be the most important for maintaining health and well-being (Ezeamama et al., 2016). COPD patients have also expressed that other determinants such as support, coping, motivation (Thorpe et al., 2014), and self-esteem are important for their completion of pulmonary rehabilitation (Harrison et al., 2015). Although some resilience factors have been identified as important, the socio-ecological interplay

between these factors on pulmonary rehabilitation is yet to be investigated. Thus, this research will examine this interplay via a decision tree analysis, identifying the hierarchy of resilience factors and their importance for COPD patients' completion of pulmonary rehabilitation programs.

Method

Study Design and Subjects

Ethics (Protocol Number: MED/40/15/HREC; Griffith University Reference No: 2015/677) and the Gold Coast Health Ethics Committees (HREC/15/QGC/232). This cross-sectional study utilised convenience sampling to recruit participants from Gold Coast hospitals and community health centres between September 2015 and November 2016.

Study participants were over 40 years of age, had a mild to severe spirometry confirmed clinician's diagnosis of COPD, were attending Helensvale or Robina community clinics, or were patients at the Gold Coast University or Robina hospitals. Exclusion criteria included being unable to speak English, provide written informed consent, having a serious cognitive impairment, an unstable medical, major psychiatric, and/or neurological condition. One hundred and fifty-five subjects (Figure 10) consented to participate and returned completed questionnaires. Participants were provided with packs containing the information sheet, consent form, and questionnaire to either complete at home or with a researcher if required. Participants were informed that they could withdraw their consent at any time during the study and that returned data would be kept confidential.

A G*Power analysis determined that 96 participants would be required to attain a power of 0.80 with an alpha of 0.05. The effect size (d=0.58) for this sample size was

figure was calculated from a study conducted by Cassidy and colleagues (Cassidy et al., 2014). The response rate for the study was 43.1% with 360 patients being asked to participate in the study and 155 completing and returning a completed questionnaire.

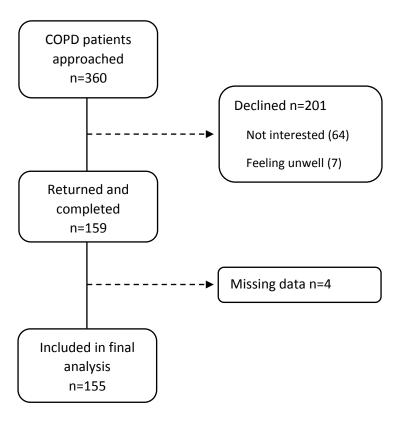


Figure 10. Recruitment flow chart.

Study Measures

Resilience Scale

Patients resilience was obtained via a combination of scales. A refactored version of the Connor-Davidson Resilience Scale (Connor & Davidson, 2003) was used to assess COPD patients' self-efficacy, coping, decision making, and relationships via 25 items on a five-point Likert scale, with low scores indicating a poorer resilience. The scale was found to have excellent reliability (Cronbach's $\alpha = 0.89$) and good validity in past samples (Connor & Davidson, 2003). The reliability and content validity for the current COPD sample was excellent to good ($\alpha = 0.92$ and 61.0% respectively).

Defensive coping was assessed via 4 questions (via denial), and patients disease specific self-esteem was measured by 10 questions on Acceptance of Disease and Impairments Questionnaire (Boer et al., 2014) via a four-point Likert scale. Low scores on defensive coping signified less denial and low scores on self-esteem indicated a poorer resilience. Original validation found the instrument had good to excellent reliability (Cronbach's α between 0.80 to 0.83) and a good validity (Boer et al., 2014). Reliability and validity analysis for the current sample found both to be excellent (α = 0.865 and 78.1% respectively).

Trust was assessed by a single question which queried COPD patients' knowledge of pulmonary rehabilitation programs; good, average, and poor knowledge of pulmonary rehabilitation; with good knowledge reflecting high trust in the program.

Professional support was assessed by the Pulmonary Rehabilitation Benefits and Consequences Scale. This scale queries COPD patients' perception of the outcomes of a professionally supported pulmonary rehabilitation program via a seven-point Likert scale. Factor analysis found three factors for this measure; health and well-being, reliance on external services, and perceived risks. Low scores on well-being indicated a poorer resilience and low scores on reliance on external services and perceived risks signified greater resilience. Reliability of the current sample was acceptable ($\alpha = 0.72$) with the content validity being good (59.93%).

Demographic Characteristics

Thirteen demographic variables were considered in the analysis following a review of the literature; marital status, age, gender, education, smoking status, and comorbid diagnoses (e.g. anxiety or depression). The results of the patients' demographic characteristics are presented in Table 11.

Primary Outcome Measure

Pulmonary rehabilitation completion was the primary outcome measure for this study and queried whether COPD patients completed at least 10 sessions of the program. This figure, that is 10 of the 16 sessions, was deemed as adequate for completion via the staff at the Helensvale and Robina community clinics who ran the pulmonary rehabilitation programs.

Statistical Methods

Statistical analyses were conducted via SPSS v20. Chi-square and independent sample t-test were used to examine potential confounds. Data were presented as mean and standard deviation, and number and percent. Factor analysis was conducted with a varimax rotation to examine the factors and content validity for the current sample. Reliability analysis were also conducted using Cronbach's α to ensure that the measures remained reliable. A decision tree analysis was used to identify the resilience factors which were important for the completion of pulmonary rehabilitation in COPD patients. An alpha of 0.05 was used to detect significance in all analyses.

Results

The study sample consisted of 155 COPD patients, of which 61 (39.4%) had completed pulmonary rehabilitation, 53 (34.2%) were referred but did not complete at least 10 sessions of pulmonary rehabilitation, and 41 (26.4%) had never been referred to a pulmonary rehabilitation program. Of the completers 34.9% were less than 65 years, 38.5% were between 66 and 75 years, and 44.6% were aged over 76 years with average time since completion being 2.4 (SD 2.32) years. The sample was 51.3% female with completion of pulmonary rehabilitation being common in both males and females (40.5% and 38.3% respectively) as opposed to not completing (59.4% and 52.5%). Of the 13 smokers (8.2%) recruited in the study only one completed pulmonary

rehabilitation with the majority (n=9) never being referred to the program. Hypertension (52.3%) and asthma (48.7%) were the most frequent comorbidities, however, individuals diagnosed with hypertension tended to have higher rates of completion than did individuals with asthma (45.0% and 33.8% respectively). The bivariate analyses (Table 11) revealed that a COPD patients age, gender, level of education, smoking status, marital status, and other comorbidities were not associated with their completion of pulmonary rehabilitation. As these demographic variables were not found to confound the results only the resilience factors were entered into the final decision tree analysis.

The decision tree revealed that both individual and contextual resilience factors were important for COPD patients' completion of pulmonary rehabilitation programs (Figure 11); trust, self-efficacy, decision making, coping, interpersonal relationships, and professional support risks. When examining the reasons for not completing pulmonary rehabilitation it was found that COPD patients who had poor trust and believed that the professionally supported pulmonary rehabilitation programs would increase health risks (>1) were less likely to complete the program. It was also found that COPD patients who had average trust in the program did not complete pulmonary rehabilitation program. The third reason for COPD patients not completing pulmonary rehabilitation involved patients having good trust in the program and good interpersonal relationships (>12). A fourth pathway for patients' non-completion involved having high trust in the program, poor interpersonal relationships (≤ 12), and poor self-efficacy (≤ 26) . The final pathway for non-completion involved COPD patients having high trust, poor interpersonal relationship (≤ 12), good self-efficacy (> 26), poor decision making skills (\leq 13), and good coping abilities (>40). The overall prediction accuracy for the decision tree analysis was 71.15% (Table 12).

Table 11. Demographic characteristics across for pulmonary rehabilitation non-completion and completion (n=155)

Variable		Completed (A) Number (%)	Did not Complete (B) Number (%)	t or χ^2	p value
Age	<65 years	15(34.9)	28(65.1)	$\chi^2 = 0.94$	0.63
Age	66 to 75 years	25(38.5)	40(61.5)	λ 0.54	0.03
	76+ years	21(44.7)	26(55.3)		
Gender	Male	30(40.5)	44(59.5)	$\chi^2 = 0.08$	0.77
	Female	31(38.3)	50(61.7)	70	
Education	Primary/secondary education	37(37.0)	63(63.0)	$\chi^2 = 0.30$	0.59
	Tertiary education	22(41.5)	31(58.5)	~	
Smoking status	Never smoked	21(40.4)	31(59.6)	$\chi^2 = 0.04$	0.85
_	Smoker and ex-smoker	40(38.8)	63(61.2)		
Marital status	Married/de-facto	27(38.0)	44(62.0)	$\chi^2 = 0.10$	0.76
	Single/divorced/widowed	34(40.5)	50(59.5)		
Comorbidities	Number of comorbidities (mean \pm SD)	$2.61(\pm 1.34)$	$2.76(\pm 1.73)$	t=0.56	0.58
Diagnosed with	Diabetes	7(38.9)	11(61.1)	$\chi^2 = 0.01$	0.96
	Heart disease	17(32.7)	35(67.3)	$\chi^2 = 1.69$	0.19
	Hypertension	36(45.0)	44(55.0)	$\chi^2 = 2.35$	0.13
	Asthma	25(33.8)	49(66.2)	$\chi^2 = 1.95$	0.16
	Other lung disease	23(41.8)	32(58.2)	$\chi^2 = 0.22$	0.64
	Anxiety or depression	22(41.5)	31(58.5)	$\chi^2 = 0.16$	0.69
	Cancer	10(33.3)	20(66.7)	$\chi^2 = 0.57$	0.45
	Other disease	18(35.3)	33(64.7)	$\chi^2 = 0.43$	0.51

Table 12. Decision tree analysis accuracy by class

Class	True positive rate	Precision	ROC area
Did not complete pulmonary rehabilitation	0.758	0.766	0.662
Completed pulmonary rehabilitation	0.639	0.629	0.666
Total	0.712	0.712	0.663

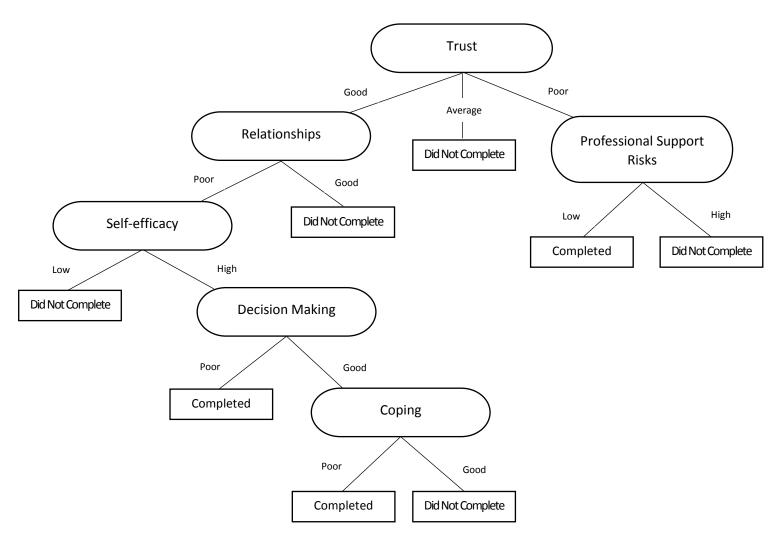


Figure 11. Decision tree for COPD patients resilience factors and pulmonary rehabilitation completion.

The first reason identified for COPD patients' completion of pulmonary rehabilitation involved having poor trust in the program and believing that the risks (\leq 1) associated with the program were low. A second pathway for COPD patients' completion of pulmonary rehabilitation included patients having good trust in the program, poor interpersonal relationships (\leq 12), good self-efficacy (>26), and good decision making skills (>13). The final reason for completion of pulmonary rehabilitation programs for COPD patients involved patients trusting in the program, yet having poor interpersonal relationships (\leq 12), good self-efficacy (>26), poor decision making skills (\leq 13), and poor coping abilities (\leq 40).

Discussion

The most important resilience factor for COPD patients was the individual factor trust, with the second most important factors being contextual; relationships and professional support risks. The remaining important factors consisted of individual level factors; self-efficacy, decision making, and coping.

A COPD patient's trust in the pulmonary rehabilitation program was found to have the greatest influence over their completion. Even though trust was found to be highly influential for pulmonary rehabilitation completion, other resilience factors also contributed to COPD patients program completion. Past research investigating COPD patients' pulmonary rehabilitation completion has found that trusting pulmonary rehabilitation is safe was frequently expressed as important for completion in qualitative interviews (Halding et al., 2010; Hogg, Grant, et al., 2012; Marshall et al., 2008; Wilson et al., 2007). The components which COPD patients expressed as being important for trust in pulmonary rehabilitation included access to accredited professionals and other COPD patients in order to increase opportunities to openly discuss disease concerns (Halding et al., 2010; Hogg, Grant, et al., 2012). Other components involved access to

knowledge regarding the content and benefits of pulmonary rehabilitation and having positive patient clinician relationships (Wilson et al., 2007).

Although some research has found high trust to improve confidence and completion, our results found that non-completion occurred in COPD patients who had high trust combined with strong interpersonal relationships. This association of supportive interpersonal relationships being found to reduce completion is in contrast to many qualitative studies (Arnold et al., 2006; Bulley et al., 2009; Guo & Bruce, 2014; Halding et al., 2010), yet is consistent with one study which qualitatively examined the relationship between self-care and professional care in COPD patients (Kielmann et al., 2010). This study found that having an overly high sense of trust and a strong relationship with their health care provider decreased COPD patients help seeking behaviours, as they felt confident handling their illness limitations (Kielmann et al., 2010). This finding indicates that COPD patients may feel that they already have the best knowledge to improve their health outcomes or believe that others may perceive them as incapable if they ask for help; only seeking professional assistance when they have lost control (Harrison et al., 2015). This study also found that the influence of interpersonal relationships, whether they be with family, peers, spiritual, or professionally orientated improved COPD patients completion of pulmonary rehabilitation when combined with other resilience factors, including having high selfefficacy and good decision making skills.

Feeling capable or having high self-efficacy provides COPD patients with motivation to undertake and complete activities which can both challenge and improve health outcomes (Marino et al., 2008). However, having low self-efficacy coupled with poor interpersonal relationships was found to reduce patients' likelihood of completing pulmonary rehabilitation in this study. This result is supported by previous research which has identified that self-efficacy is a determining factor for which activities a

COPD patient will undertake or avoid (Bourbeau et al., 2004), and has been found to be a predictor for exercise adherence (Davis et al., 2006). Individuals who have performed poorly in past or believe that they will fail on their current attempt will avoid undertaking the activity, especially if they lack interpersonal relationships which can provide encouragement and support (Davis et al., 2006). In addition to finding that low self-efficacy reduced pulmonary rehabilitation completion rates, this study also found that having high self-efficacy and feeling confident in their ability to make decisions regarding their illness increased COPD patients' completion of pulmonary rehabilitation.

Decision making is a complex concept and can look at both patients efficacy regarding their decision making abilities as well as the reasons for why COPD patients have made their decisions (Albrecht et al., 2008). To the best of our knowledge this is the first paper which examines COPD patients' efficacy regarding their decision making abilities and its relationship to pulmonary rehabilitation completion. Past research has identified that patient efficacy regarding their treatment decisions is influenced by collaboration, support, and the clinician communicating disease knowledge; improving patients understanding of the illness as well as available treatment options (Albrecht et al., 2008). Although research in this area is limited, the impact of patient efficacy for decisions can also be inferred from qualitative studies which have investigated COPD patients motives regarding adherence to pulmonary rehabilitation (Guo & Bruce, 2014; Keating et al., 2011a). These studies have identified that patients decisions regarding completing pulmonary rehabilitation are influenced by the programs impact on their other comorbidities (Keating et al., 2011a), fear of the consequences of the program, in addition to the programs perceived benefits (Guo & Bruce, 2014; Keating et al., 2011a). Thus, patients efficacy regarding their decisions is heavily influenced by their

perceptions including their ability to manage their illness if they were to complete pulmonary rehabilitation (Fischer et al., 2009).

A COPD patient's coping ability was also found to be an important factor for completion of pulmonary rehabilitation; where patients with good coping abilities did not complete the program and those with poor coping were more likely to complete. This result is in contrast to some qualitative studies which found that patients did not complete pulmonary rehabilitation if they had poor coping abilities (Arnold et al., 2006; Johnston et al., 2012). However, other studies confirmed our findings, where patients frequently completed pulmonary rehabilitation if they were having difficulties coping with their illness, as they believed that completing the program would assist them in controlling their illness and managing their daily activities (Fischer et al., 2007). This drive to complete pulmonary rehabilitation has been found to persist in patients even when their illness intrusions became overwhelming, causing them to forego one or two of the scheduled sessions (Arnold et al., 2006).

The perceived risks to the patients' health resulting from the pulmonary rehabilitation program were also found to be of importance in individuals who had low trust in the program. That is, patients who had low trust and perceived that the professionally supported pulmonary rehabilitation program would increase the risks to their health were less likely to complete pulmonary rehabilitation than patients who did not believe that there would be any adverse health risks. This finding is supported by previous qualitative studies which examined patients' beliefs regarding the consequences of pulmonary rehabilitation (Keating et al., 2011a; Thorpe et al., 2014). These studies found that patients believed that pulmonary rehabilitation would increase their levels of dyspnoea, potential injury, health risks for other comorbid disorders, as well as the risk of experiencing an exacerbation (Keating et al., 2011a). Other factors identified as being perceived as a risk for completion was the patients age, recovery

time, and the potential for hospitalisations following the strenuous activity that accompanies pulmonary rehabilitation (Thorpe et al., 2014).

As a COPD patients level of trust is the primary determining factor for pulmonary rehabilitation completion it is suggested that the promotion of pulmonary rehabilitation information including the benefits of the program need to be communicated before or at referral. Upon diagnosis COPD patients undergo drastic changes to their lifestyle and are required to adapt and implement strategies in order to maintain their health (Halding et al., 2010). Dyspnoea remains a primary health concern for COPD patients and can create resistance to accepting some lifestyle changes (Guo & Bruce, 2014). Open dialogue regarding the monitoring and safety of patients throughout the program will increase patients' self-efficacy, reduce the perceived risks, whilst promoting the benefits of undertaking the program (Guo & Bruce, 2014; Hogg, Grant, et al., 2012; Marshall et al., 2008).

Furthermore, having accredited professionals providing program information will assist in improving COPD patients trust of the program and present them with appropriate knowledge so that they can make an informed decision about undertaking pulmonary rehabilitation (Halding et al., 2010). In addition to this, the provision of a peer support group both prior to and during the program can assist in alleviating COPD patients fears regarding the risks of pulmonary rehabilitation and increase self-efficacy and patients' completion rates (Keating et al., 2011a; Thorpe et al., 2014). Providing peer support will reduce feelings of isolation and normalise the coping difficulties that COPD patients experience, encouraging patients to consider alternative coping strategies including those provided in pulmonary rehabilitation (Fischer et al., 2007).

A number of limitations have been identified within this study. The main limitation involves the cross-sectional study design, as the data was collected at a single

unable to examine whether the patients who declined to participate differed in any way to the patients who completed the survey instrument. In order to strengthen these findings, future research should implement an experimental design capturing both baseline and follow-up data of patients who competed and did not complete pulmonary rehabilitation, including both self-report and clinical data in order to reduce any potential bias. Another limitation is that the answers for the study were gained via self-report and as a result are open to response bias; however, the reliability and validity of the measures was good to excellent providing suitable and consistent results. It should also be noted that the participants for the study were recruited from Queensland's South East which limits the generalisability of the findings. Thus, future research should expand the recruitment locations to include participants from other geographical locations and cultures to gain a more representative sample.

Clinical Messages

- COPD patients trust in pulmonary rehabilitation was the most important resilience factor for completion, followed by their interpersonal relationships and beliefs regarding the risks of the program.
- COPD patients' self-efficacy, decision making, and coping abilities were also important for pulmonary rehabilitation completion.

Acknowledgements

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4.4. The Effect of Resilience and Readiness to change on COPD patients Medication Adherence

Introduction

Study four examines the fourth research question which was introduced in the conceptual framework (section 2.6) and literature review of this thesis. This research question examines whether the individual and contextual resilience factors of COPD patients are associated with their adherence to medication regimens. This framework proposes that COPD patients with higher levels of resilience are more adherent to their medications as they have a high sense of self-worth, feel as though they can make appropriate decisions regarding their medications, and feel competent to manage complex medication regimens. Their trust in their clinicians and their relationship with significant others further assists them in being more adherent. In addition to this COPD patients who are not contemplating change will be less adherent to their medication regimens than will patients who are in the action stage of readiness to change regarding their clinicians' treatment recommendations. This relationship was examined via a decision tree analysis which categorised COPD patients as highly adherent or having poor adherence.

Statement of contribution to co-authored published paper:

This section includes a co-authored manuscript submitted for publication to Annals of Medicine as an original research paper. The status of the co-authored paper, including all authors, is: **Cannon D,** Buys N, Sun J, A machine learning method based analysis on readiness to change and resilience factors affecting Chronic obstructive pulmonary disease patients' medication adherence, Annals of Medicine (2018), Under review.

The research candidate has made the following contributions to this study:

Identified research gaps and developed the study design.

Completed and obtained human research ethics approvals from Griffith

University Human Research Ethics (Protocol Number: MED/40/15/HREC;

Griffith University Reference No: 2015/677) and the Gold Coast Health Ethics

Committees (HREC/15/QGC/232)

• Researched and developed the survey instrument.

• Recruited participants and collected data from hospitalised patients.

Input and analysed the data, then interpreted the findings.

• Prepared the manuscript and submitted to the Annals of Medicine.

Danielle Cannon (26/03/2018)

Supervisor and corresponding author: Jing Sun (26/03/2018)

Abstract

Objective: Substandard medication adherence is common in chronic obstructive

pulmonary disease patients. Readiness to change determines whether patients will be

accepting of the recommendations made to them. Furthermore, resilience is identified as

important in the maintenance of health and well-being. This study investigates the

importance of readiness to change and resilience to medication adherence in chronic

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obstructive pulmonary disease patients. Method: Participants over 40 years completed a survey examining their readiness to change and resilience and the importance of these factors on their medication adherence via machine learning analysis method.

Participants were obtained from South-East Queensland community health centres and hospitals. Results: Full medication adherence was found in 93 (58.5%) of the 159 patients. The machine learning decision tree identified high adherence in patients with good trust, self-esteem, coping, decision making, low pre-contemplation and high action. Confounding factors influencing medication adherence included employment status, income, comorbidities, and household income were controlled for in the analysis. Conclusion: Readiness to change and resilience was important for chronic obstructive pulmonary disease patients' adherence to medications. Specifically, patient clinician relationships promoting trust and involving the patient in treatment decisions were found to be of particular importance as this enhances other aspects of resilience and encourages patients into action increasing adherence.

Key Words: Decision making, defensive coping, medication adherence, professional support, readiness to change, relationships, resilience, self-esteem, trust

Key Messages

- This study investigated the association between readiness to change and resilience to COPD patients' adherence to medications via machine learning analysis.
- Medication adherence was found to be higher in COPD patients who had high levels of trust, self-esteem, coping, good decision making abilities, were low in pre-contemplation and high in action.
- A patient's resilience and readiness to change are important factors to consider in COPD patients adherence to medications.

Introduction

Chronic obstructive pulmonary disease (COPD) is a preventable and treatable illness of the lungs which is characterised by persistent airflow limitation, hyperinflation, abnormal gas exchange, mucus hypersecretion, pulmonary hypertension, exacerbations, and other systemic problems such as cardiac issues (GOLD, 2017a; Yang et al., 2017). Current recommendations for the treatment and management of COPD involve both pharmacological and non-pharmacological approaches (Bryant et al., 2013). Poor medication adherence has found to be a common issue with COPD patients (Ismaila et al., 2014; Krigsman, Nilsson, & Ring, 2007; Sriram & Percival, 2016) and is defined as the divergence from prescribed treatments through the overuse, underuse, or the improper use of medications (Restrepo et al., 2008). Studies investigating the benefits of adherence to respiratory medications have found that high adherence is associated with fewer all-cause hospital admissions (Simoni-Wastila et al., 2012) and exacerbations in COPD patients (Ismaila et al., 2014).

A review of recent studies investigating the factors which influence patients' adherence to medications have identified that the number of respiratory medications, number of doses (Agh et al., 2011), smoking status (Agh et al., 2011; Hayes, 2016; Khdour et al., 2012), past adherence (Huetsch, Uman, Udris, & Au, 2012), readiness to change (DiClemente et al., 2008), medication beliefs, depressed mood, and COPD severity (Khdour et al., 2012) are associated with patients adherence to respiratory medications. It was also found that that the resilience factors self-efficacy (Khdour et al., 2012) and social support (Lareau & Yawn, 2010) are associated with a COPD patients adherence to medications.

The relationship between COPD patients' readiness to change, resilience and their medication adherence is important to consider, as these factors have been found to

be associated with maintaining patients' health and well-being (DiClemente et al., 2008; Panter-Brick & Eggerman, 2012). Readiness to change considers an individual's motivation to successfully implement changes that are required (Prochaska et al., 1992). This process consists of five stages, from the individual not considering change (precontemplation) through to action and maintenance of these changes (Emdadi et al., 2007).

Resilience is commonly defined as the ability to regain and or maintain psychological and physical well-being following an adverse experience (Black & Dorstyn, 2013; Bonanno, 2004). Resilience is comprised of individual (coping) and contextual factors (professional support) which assist in conserving patients' health and well-being (Ungar et al., 2013). The socio-ecological model of resilience involves an interaction between the patients' individual and contextual factors, and the interchange between these factors and the environment (Bronfenbrenner, 1994b; Sun & Stewart, 2007; Ungar et al., 2013). That is, how individuals use factors such as social support, their cultural identity, and their material resources to assist them in coping with stress (Ungar et al., 2013; Wang et al., 2014).

Self-efficacy has been identified as an important factor for the maintenance of older individuals health and well-being (Ezeamama et al., 2016) as self-efficacy involves patients beliefs regarding their readiness to change (DiClemente et al., 2008) and their capacity to manage their disease and its limitations (Risser, Jacobson, & Kripalani, 2007). Other factors which are considered important for patients adherence to medications include their self-esteem (Maeda et al., 2013), trust regarding their treatment, the level of support they receive, and their ability to make appropriate decisions regarding managing illness disturbances such as exacerbations (Lareau & Yawn, 2010). Few studies have investigated readiness to change and resilience in relation to the medication adherence. Thus, this research will investigate the relationship

between readiness to change, individual and contextual resilience factors and medication adherence in COPD patients via a decision tree analysis.

Material and Methods

Patients

Recruited participants were over 40 years, had a spirometry confirmed diagnosis of COPD (mild to severe) from their doctor, were attending pulmonary rehabilitation clinics at Helensvale or Robina community health centres, or were admitted to the Gold Coast University or Robina hospitals. If patients had a serious cognitive impairment, any other unstable medical, major psychiatric, and/or neurological conditions they were excluded from the study. They were also excluded if they were unable to provide informed consent or speak English. Of the 360 COPD patients approached, 159 participants returned completed written consent forms and questionnaires which assessed patients stage of readiness to change, resilience, and medication adherence. The questionnaires were either returned via post or were returned in person to a member of the research team at the hospital.

Ethical clearance was gained from both Griffith University Human Research Ethics and the Gold Coast Health Ethics Committee (Protocol Number: MED/40/15/HREC; Griffith University Reference No: 2015/677).

Study Measures

Included in this study are the independent variables which comprise COPD patients' readiness to change and resilience. The primary outcome variable is the level of medication adherence for the COPD patients; with adherent COPD patients being adherent with their medication all of the time and non-adherent patients missing one

dose or more per week. A comprehensive discussion of the variables in this study are described below.

Readiness to change Scale

The readiness to change questionnaire is a 12 item scale developed to enquire into readiness to change behaviours. In this study, the questionnaire was modified to assess COPD patients' readiness to undertake their clinicians' recommendations. Initial reliability of the original measure ranged between 0.73 and 0.86 (Cronbach's α) and it also displayed good validity (Heather & Rollnick, 1993). Patients were asked to rate their agreement with the statements on a five-point Likert scale: strongly disagree to strongly agree. Factor analysis on the current sample found three factors; precontemplation ("I don't think I need to undertake my clinician's recommendations"), contemplation ("I am at the stage where I should start thinking about following my clinicians' recommendations"), and action ("I am actually changing my treatment regimen right now"). Analysis of the current COPD sample found an acceptable reliability (Cronbach's α = 0.55) and good content validity with 58.9% of the variance accounted for.

Resilience Scale

Resilience in this study consists of three scales. The first The Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) is a 25 item measure which assesses individual and contextual factors. The CD-RISC was found to have excellent reliability (Cronbach's $\alpha = 0.89$) and a good validity (Connor & Davidson, 2003). Participants were asked to rate their feelings regarding the 25 statements over the last month on a five-point Likert scale; not at all true to almost always true. The CD-RISC queries four factors which were created based on a factor analysis of the current sample; self-efficacy ("can deal with whatever comes"), coping ("under pressure, I focus and

think clearly"), decision making ("make unpopular or difficult decisions"), and relationships ("have close and secure relationships"). An analysis of the current COPD sample found the reliability to be excellent ($\alpha = 0.92$), and the content validity to be good with the questions accounting for 56.6% of the variance.

Defensive coping (via denial) was assessed via four and COPD patients disease specific self-esteem via 10 questions of the Acceptance of Disease and Impairments Questionnaire (ADIQ; Boer et al., 2014). The ADIQ was found to have good to excellent reliability (Cronbach's α between 0.80 to 0.83) and proved to be a valid measure (Boer et al., 2014). Subjects are asked to rate their agreement on a four-point Likert scale; disagree to entirely agree. It enquires into patients' level of denial ("I try to ignore my impairments"), as well as their self-esteem ("I feel frustrated with my impairments", "I become sad when I experience and impairment", and "I can accept my impairments"). The reliability of the current sample was found to be excellent (Cronbach's $\alpha = 0.87$) with the content validity also being excellent with 78.1% of the variance being accounted for by the questions.

Professional support was measured by the Pulmonary Rehabilitation Benefits and Consequences Scale (PRBCS). The PRBCS assesses COPD patients' beliefs regarding the perceived outcomes of the professionally supported pulmonary rehabilitation programs via a seven-point Likert scale; strongly disagree to strongly agree. Factor analysis found three factors; health and well-being ("improve a COPD patients' quality of life"), reliance on external services ("reduce COPD patients' ability to perform basic home duties"), and potential risks ("increase the risk of injury"). An analysis of the PRBCS found the reliability to be acceptable ($\alpha = 0.72$) with a good content validity (59.9% of the variance accounted for).

Demographic Characteristics

Twelve demographic variables were considered in the analysis following a review of the literature. These characteristics included the patient's age, gender, marital status, employment status, household income, smoking status, recruitment location, diagnosis of anxiety or depression, asthma, heart disease, other lung disease, and their total number of comorbidities. Chi-squared and independent t-tests revealed that the potential confounds included age, employment status, household income, diagnosis of anxiety or depression, heart disease, and other lung disease. The results of the bivariate analysis for the patients' demographic characteristics are presented in Table 13.

Primary Outcome Measure

The primary outcome measure for this study was patients' adherence to medications. Patients medication adherence was measured by a medication adherence scale developed by Khalesi et al. (2016) this four item self-report measure assesses an individual's medication adherence via three response options; never, occasionally, and always. The medication adherence scale was recoded for this study to categorise patients as either highly adherent (always adhering to their dosing regimens) or not adherent (not adhering to their dosing regimen one or more times a week). The reliability of the medication adherence scale on its first validation was found to be moderate (Cronbach's $\alpha = 0.50$) with the reliability increasing for this COPD sample ($\alpha = 0.80$).

Statistical Methods

A decision tree analysis was run to examine which resilience factors were pertinent to medication adherence regimens in COPD patients, whilst controlling for potential confounds. The decision trees is useful machine learning analysis method for predicting independent variables level of importance on either a continuous (regression

tree) or categorical outcome variable (classification tree; Ming, 2001b). The decision tree analysis also allows for graphical representations of these levels of importance via a tree diagram (Loh, 2011a). A major strength of the decision tree is that it can be used on data that has missing values, is not homogenous, or is not normally distributed (Ming, 2001b). This tree analysis for this study was conducted with an alpha of 0.05.

Results

Of the 159 COPD patients included in the study, 93 (58.5%) were found to be adherent to their medication regimens all of the time. Females made up 51.3% of the sample with approximately half (45.9%) of the sample being married or in a de-facto relationship. Of the participants nearly a third (30.4%) were over 76 years, with 75.2% being retired.

Bivariate analyses (Table 13) revealed numerous potential confounding relationships, including the patients age, employment status, household income, diagnosis of anxiety or depression, heart disease, and other lung disease. These confounds were included in final decision tree analysis to control for potential bias. The decision tree found that readiness to change and both individual and contextual resilience factors were important in COPD patients' adherence to medication regimens (Figure 12). The COPD patients' employment status, household income, and age were found to influence their adherence to medications, but were controlled for. This was followed by their use of defensive coping, their stage of readiness to change, and their decision making abilities. The first branch of the decision tree identified that COPD patients who had good medication adherence did not use defensive coping, and had good trust in professionally supported programs. It was also found that those with moderate to high incomes who were in the action stage were also highly adherent; those who chose not to disclose their income and were low in pre-contemplation or high in

pre-contemplation, had high in defensive coping were also adherent. Patients who were not adherent to medications were found to have average to poor trust, used defensive coping, were not taking action, or if high in pre-contemplation were did not use defensive coping strategies.

The second branch of the decision tree found that retired patients who were adherent had good decision making skills, were low in pre-contemplation, or high in

Table 13. Relationship between demographic characteristics and medication adherence of study participants (n=159)

Variable	Medicati		
	Adherent	Not Adherent	p
	n(%)	n(%)	_
Age			
\leq 75 years (n=110)	56(50.9)	54(49.1)	
76+ years (n=48)	37(77.1)	11(22.9)	.002
Gender			
Male (n=77)	43(55.8)	34(44.2)	
Female (n=81)	50(61.7)	31(38.3)	.452
Marital status			
Married/de-facto (n=73)	41(56.2)	32(43.8)	
Single/divorced/widowed (n=85)	52(61.2)	33(38.8)	.523
Employment status			
Working/looking for work (n=39)	13(33.3)	26(66.7)	
Retired (n=118)	80(67.8)	38(32.2)	<.001
Household Income			
<\$40,000 (n=84)	45(53.6)	39(46.4)	
\$40,000+ (n=29)	14(48.3)	15(51.7)	
Prefer not to say (n=44)	34(77.3)	10(22.7)	.014
Smoking status			
Non-smoker (n=53)	30(56.6)	23(43.4)	
Ex-smoker and smoker (n=105)	63(60.0)	42(40.0)	.682
Recruitment location			
Community (n=87)	54(62.1)	33(37.9)	
Hospital (n=71)	39(54.9)	32(45.1)	.364
Comorbid diagnosis			
Anxiety/depression (n=53)	25(47.2)	28(52.8)	
No anxiety/depression (n=104)	68(65.4)	36(34.6)	.028
Asthma (n=75)	41(54.7)	34(45.3)	
No asthma (n=79)	49(62.0)	30(38.0)	.354
Heart Disease (n=53)	37(69.8)	16(30.2)	
No heart disease (n=102)	55(53.9)	47(46.1)	.056
Other lung disease (n=57)	28(49.1)	29(50.9)	
No other lung disease (n=100)	65(65.0)	35(35.0)	.052
Total number comorbidities (n=159) Mean (SD)	2.5(1.6) *	3.0(1.6) *	.076

Note: data presented as number (n) and percent (%); $\chi 2 = \text{chi-squared analysis}$; * number of comorbidities via independent *t*-test (*t*); SD = standard deviation

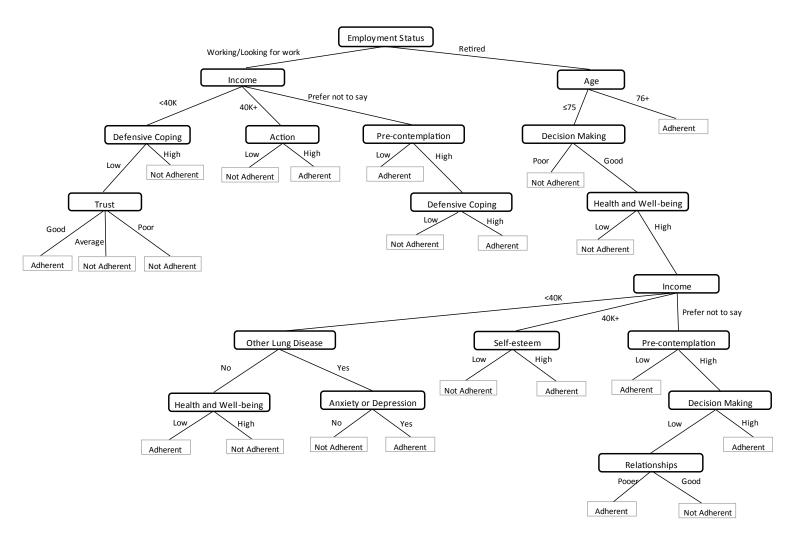


Figure 12. Decision tree diagram indicating readiness to change and resilience pathways important to chronic obstructive pulmonary disease patients medication adherence. Chronic obstructive pulmonary disease patients medication adherence are presented as either fully adherent or not adherent (missing one or more doses a week) for each outcome for the corresponding readiness to change, resilience, or confounding factor; scores are presented as whether patients scored high or low on that factor.

pre-contemplation but had good decision making skills, or poor decision making combined with poor interpersonal relationships, all of them in the older age group of 76 years or more. It was also found that patients who had high self-esteem were adherent and they were in the group of moderate to high incomes. Patients were adherent when they had low incomes, another lung disease other than COPD, and depression. In the other token, patients showed medication adherence when they did not have another lung disease and did not believe that professionally supported interventions would improve their health and well-being. Poor adherence was found in retired patients had poor decision making skills, and good relationships, were low in self-esteem, did not have anxiety or depression, and believed that professionally supported interventions would improve their health and well-being. These patients were 75 years or younger. The prediction accuracy for the overall decision tree analysis was reasonable, 59.49% (Table 14).

Table 14. Decision tree analysis accuracy by class for medication adherence

Class	True positive rate	Precision	ROC area
Adherent	0.677	0.649	0.591
Not adherent	0.477	0.508	0.585
Total	0.595	0.591	0.588

Discussion

Associations were found between COPD patients adherence to medications and their readiness to change and individual and contextual level resilience factors.

Readiness to change stages associated with medication adherence involved the precontemplation and action stages, whilst the resilience factors included defensive coping, decision making, trust, self-esteem, interpersonal relationships, and professional support health and well-being beliefs. The confounding factors included patients' employment status, household income, age, and diagnosis of anxiety or depression, or another lung disease.

The machine learning analysis found that COPD patients medication adherence was associated with their level of trust; patients with good trust were adherent when compared with patients with average or poor trust. This result is equivalent with past research which has found that patients trust in an intervention is important for their adherence (Halding et al., 2010; Hogg, Grant, et al., 2012; Marshall et al., 2008; Wilson et al., 2007) and in promoting better health outcomes (Lee & Lin, 2009). This trust is often acquired through the relationships that the patient has with their family, friends, and clinicians (Marshall et al., 2008).

Our finding of poor relationships being associated with good medication adherence was in direct opposition with other studies which have found that supportive relationships were associated with adherence (Lehane & McCarthy, 2009; Rosland, Heisler, & Piette, 2012). Further to this, other studies reported that this positive association was mediated by patients' self-efficacy (Luszczynska et al., 2007; Maeda et al., 2013). These findings indicate that this association is influenced by other factors. For instance, the duration of chronic illnesses infers that patients often develop stable and enduring patient clinician relationships (Lee & Lin, 2009), where older patients have better relationships with their clinicians than younger patients due the ongoing visits (Nguyen et al., 2009). Other factors which may influence the association between relationships and medication adherence and were identified in this study include the patients' readiness to change and their decision making abilities. Past chronic illness research has identified that patients' readiness to change is an important component of adherence behaviours (DiClemente et al., 2008; Piatt & Chiasson, 2016). These studies confirm our findings that high pre-contemplation and low action leads to poor adherence in medications for COPD patients (DiClemente et al., 2008; Piatt & Chiasson, 2016). It has been identified that many factors can lead to the readiness to change stages, such as, stigma, modesty, multiple disease related disturbances, and

patients level of self-efficacy (Prochaska, Redding, et al., 2008). In addition to this, it has also been recognised that poor decision making is linked to some patients readiness to change, where they can fail to recognise their need to take action and undertake treatments which will improve their health and well-being (DiClemente et al., 2008).

This study found that patients who were adept at making decisions were more likely to be adherent to their medication regimes. This finding is consistent with past research which identified that patients who were involved in their treatment decisions were more adherent (Brown & Bussell, 2011; Wilson et al., 2010). This outcome identifies that patients who make treatment decisions with their clinicians are not only being educated on the decision making process for their disease, but are also receiving direct feedback regarding the appropriateness of their decisions whilst being provided with possible alternative treatment options (Brown & Bussell, 2011). This feedback promotes self-esteem, self-efficacy, and builds a trusting patient clinician relationship (Hayes, 2016; Lareau & Yawn, 2010).

High self-esteem in adherent behaviour has been found in another paper which identified that chronically ill patients could perceive their future as healthy regardless of their current disease disturbances (Stewart & Yuen, 2011). This enhanced view of their self-esteem can further promote their ability to cope through increasing their other sources of strength such as enhancing their self-efficacy, access to external support, and their initiative to take action (Maeda et al., 2013).

Implications

The results of this study found that medication adherence in COPD patients is complex and involves various resilience factors and the patients' readiness to change.

COPD patients level of trust was found to influence their adherence as patients who can trust in their clinician and their ability to cope were found to be more adherent. Factors

found to increase patients trust involve having access to knowledgeable clinicians and peer groups in order to provide discussions regarding their disease concerns (Halding et al., 2010; Hogg, Grant, et al., 2012). This increases trust as COPD patients are provided with an environment which creates supportive relationships and the exchange of knowledge (Marshall et al., 2008). In addition to this, COPD patients developing a trusting relationship with the clinician assists in promoting positive encounters and encouraging dialogue to discuss medication adherence issues (Lareau & Yawn, 2010; Lee & Lin, 2009).

The role of supportive relationships including that of family and friends on medication adherence has not been fully determined as it has been found to be influenced by other mediating factors. In this study COPD patients in precontemplation, with poor decision making abilities, and good relationships were found to be less adherent to their medications. This could indicate that patients who are not considering change and are less adept at making appropriate decisions are more likely to rely upon their significant others to provide care, over taking their medications (Brown & Bussell, 2011). These patients were more often younger and believed that professionally supported programs would enhance their health and well-being; indicating that they are more reliant on others for maintaining their health outcomes (Luszczynska et al., 2007; Maeda et al., 2013).

As clinicians prescribe a number of behavioural and lifestyle changes in order for COPD patients to maintain their health, it is likely that these patients may feel overwhelmed when undertaking new medication regimens. This feeling is likely to impact upon their adherence and require a different approach to proposing behavioural and lifestyle changes; specifically recommendations which are focused upon the patients goals and are directed at their current stage of readiness to change (Prochaska, Spring, & Nigg, 2008). Furthermore, support is important as this stage as patients are

more likely to undertake changes if they find that they have appropriate support that builds self-esteem (Stewart & Yuen, 2011), encourages trust and increases the patients belief that the changes are achievable (DiClemente et al., 2008).

Further actions which can promote medication adherence in COPD patients include involving the patient in the treatment decision making process. This action improves patients' knowledge of the disease, self-efficacy, self-esteem, as well as fostering a strong trusting patient clinician relationship (Brown & Bussell, 2011; Hayes, 2016; Lareau & Yawn, 2010). Improving the trust between the patient and clinician during treatment decisions can also improve the likelihood that patients will take action as they are able to dispel the myths or their concerns regarding the prescribed medications (Lareau & Yawn, 2010). Thus, improving COPD patients' medication adherence can be achieved through improving their resilience and prescribing recommendations that are delivered according to their stage of readiness to change. Primary focuses for clinicians should include involving the patient in their treatment decisions, providing feedback regarding their choices, promoting disease knowledge, and developing a positive patient clinician relationship that is stimulates trust and improves self-esteem.

Strengths, Limitations, and Recommendations

This study was the first of its kind to investigate the association between readiness to change, resilience and medication adherence in COPD patients. The readiness to change and resilience factors were comprehensively assessed in relation to the medication adherence. Machine learning method was introduced to the topic for the first time to identify predictors of medication adherence in COPD patients, an important issue in COPD patients rehabilitation (Bryant et al., 2013). This study has a number of limitations which need to be addressed. Firstly, the data obtained in this study was

gained via self-report measures. Thus, the patients' answers may be moderated and may not accurately reflect their actual difficulties or the severity of their experiences.

Secondly, the participants in this study were recruited from South-East Queensland (Gold Coast and Brisbane), which reduces the generalisability of the findings as the results need to be interpreted with caution when being compared to other geographical locations. Another recruitment limitation involves the community participants who were obtained from COPD education seminars. Recruiting participants from these seminars implies that the majority of education day participants were more ready to change and were less likely to be in denial of their illness when compared to individuals who refused to undertake the COPD education seminars. Finally, the cross-sectional design of the study does not allow for causal interpretations. Considering that this research has identified that relationships exist, future research regarding COPD patients' resilience, readiness to change, and medication adherence should be examined via experimental studies to better determine if individual and contextual resilience factors and readiness to change directly affect COPD patients' adherence to medication regimens.

Conclusion

Both resilience factors and readiness to change were found to be important in COPD patients adherence to medication regimens. In particular, high medication adherence was consistently found in COPD patients who had good trust, self-esteem, coping, decision making abilities, were older, were low in pre-contemplation, and were taking action. Other factors which were found to influence medication adherence included their employment status, other comorbidities, and their household income. These findings indicate that in order to improve COPD patients' adherence to medications, clinicians will need to focus on delivering care which is directed at the COPD patients current stage of change, in addition to, forming a trusting relationship with their patient which concentrates on communicating disease information and open

dialogue of treatment options. The patient should be encouraged to become involved in the treatment decisions and be provided with alternative treatment options if the they feel that the prescribed medications are not in line with their goals.

Acknowledgements

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4.5. Validation of the St George Respiratory Questionnaire in Australian COPD patients.

Introduction

This study examines the validity of the SGRQ in the current COPD sample.

Utilising questionnaires in different cultural or geographical locations often requires a revalidation of the instrument. This is especially so if the researcher wants to ensure that the survey instrument is classifying the responses appropriately for the specific sample of participants. Thus, the SGRQ underwent refactoring and a validity assessment to ensure that it appropriately assessed COPD patients HRQoL.

Statement of contribution to co-authored published paper:

This section includes a co-authored manuscript submitted for publication to Thorax as an original research paper. The status of the co-authored paper, including all authors, is: **Cannon D,** Buys N, Sun J, Validation and normalisation of the St George Respiratory Questionnaire in chronic obstructive pulmonary disease patients in Australia, Thorax (2018), Submitted for publication.

The research candidate has made the following contributions to this study:

- Completed and obtained human research ethics approvals from Griffith
 University Human Research Ethics (Protocol Number: MED/40/15/HREC;
 Griffith University Reference No: 2015/677) and the Gold Coast Health Ethics
 Committees (HREC/15/QGC/232)
- Researched the survey instrument.
- Recruited participants and collected data from hospitalised patients.
- Input and analysed the data, then interpreted the findings.

Prepared the manuscript and submitted to the Thorax.

Danielle Cannon (26/03/2018)

Supervisor and corresponding author: Jing Sun (26/03/2018)

Abstract

The St George's Respiratory Questionnaire assesses the health-related quality of life of individuals with respiratory diseases. This measure is widely used throughout the world and has been translated into different languages. Currently, the St George's Respiratory Questionnaire has been examined for its validity and reliability across multiple translations and cultural variations. However, these validations have primarily utilised correlational analyses, with few using confirmatory or exploratory factor analysis methods. This study examined the St George's Respiratory Questionnaire's factor structure using both exploratory and confirmatory factor analyses. The exploratory factor analysis identified that the St George's Respiratory Questionnaire was best represented by a five-factor model with the new domains assessing patients' disturbances for their activities, breathlessness, symptoms, cough, and medication experiences; with the all the factors accounting for 50.91% of the variance (individual factor variances were 14.72%, 12.24%, 8.63%, 7.84%, and 7.48% respectively). The reliability of the overall model was found to be high (Cronbach α of 0.89); with the domains ranging between (Cronbach α) 0.69 and 0.86. The confirmatory factor analysis verified that the five-factor structure is suitable and contains a parsimonious fit for the

data (CFI, 0.79). Thus, the refactored St George's Respiratory Questionnaire was found to be both reliable and valid in a sample of chronic obstructive pulmonary disease patients in Australia. A follow-up study is needed with a large sample to further confirm the validity of the St George's Respiratory Questionnaire to assess quality of life in Australian chronic obstructive disease patients.

Introduction

The St George's Respiratory Questionnaire (SGRQ) was designed to measure respiratory-related health disturbances in patients with lung disease (Jones et al., 1991a). Since its initial development it has become one of the most widely used health-related quality of life (HRQoL) measures (Ringbaek, Martinez, & Lange, 2012), with modified versions for specific languages and diseases (Ferrer et al., 1996; Xu et al., 2009). Although the SGRQ has been validated for different languages, diseases, and delivery modes (in-person and telephone), it is yet to the best of our knowledge, to be validated in Australia and via postal administration (Jones & Forde, 2009).

The SGRQ is a 50-item measure enquiring into patients breathing difficulties and the impact of these difficulties on daily life. It queries disturbances via categorical responses comprising three domains (symptoms, activity, impacts) and a total score (Jones & Forde, 2009). Although the original SGRQ factorial validation discussed the domains found in the analysis, no data was presented for the identification of these domains (Jones, Quirk, Baveystock, & Littlejohns, 1992). A review of three studies examining the SGRQ via factor analysis have found that the data is not fully confirmed by the original factors (Martínez García, Perpiñá Tordera, Román Sánchez, & Cataluña, 2005; Mölken, Roos, & Van Noord, 1999; Paap et al., 2015).

Mölken et al. (1999) found 18 factors (73% of the variance) via an exploratory factor analysis (EFA), however, these factors were difficult to label. When reduced to three factors, the variance accounted for was only 28%, yet the factors became more

aligned with the original SGRQ domains. The Martínez García et al. (2005) study found some similarities on all the domains following a factor reduction (13 to 4 factors; 98% to 36.8% of the variance respectively) with the third and fourth factors comprising questions from the impact domain. Finally, a study by Paap et al. (2015) examined the SGRQ via two and three-factor models via bifactor analysis. They identified the original domains were poorly represented with the three-factor model accounting for 32% of the variance. These results indicate that only a few studies have investigated the factor analytic structure of the SGRQ and that the factors may need to be revised, especially when used with different populations.

The aim of this study was to examine the validity and reliability of the SGRQ on a sample of Australian chronic obstructive pulmonary disease (COPD) patients responding via postal administration. Firstly, the study will examine the factor structure of the SGRQ on the current COPD patient sample. Following refactoring of the SGRQ, the reliability of the remaining items would be assessed for their ability to accurately measure HRQoL.

Method

Cross-sectional study investigating the reliability and validity of the SGRQ via self-report questionnaire on Australian COPD patients via postal administration.

Included participants had a spirometry confirmed clinician diagnosis of mild to severe COPD, aged over 40 years, admitted to Gold Coast University or Robina hospitals or attending COPD education clinics at Brisbane, Helensvale, or Robina community health centres. Patients with serious cognitive impairment, any other unstable medical, major psychiatric, and/or neurological conditions, or were unable to speak English or provide informed consent were excluded from the study. Ethical clearance was gained from Griffith University Human Research Ethics (2015/677) and Gold Coast Health Ethics Committee (MED/40/15/HREC).

Measures

The original four-week version of the SGRQ measured COPD patients HRQoL. The questionnaire contains 50 items, 10 scored via categorical frequencies or ratings and the remaining 40 being dichotomised, indicating the presence or absence of the disturbance. The first eight questions query the patients' symptomatic experiences and frequencies over the previous four weeks. The final questions enquire into how the patient's chest condition interrupts their ability to undertake activities and how their condition impacts upon their daily life. Scoring of the SGRQ domains and total score is obtained by entering responses into an excel based scoring calculator provided by the St George's University of London. High scores indicate poorer HRQoL.

Data Collection

Questionnaires were distributed to COPD patients at the Gold Coast University and Robina hospital, or education days (Lung Foundation Brisbane, Helensvale, or Robina community health centres). Participants were provided with a verbal introduction to the study. Individuals who expressed further interest provided contact details for follow-up and were offered a pack which contained the information sheet, consent form, questionnaire, research team contact details, and reply-paid envelope. Participants were directed to contact a member of the research team for any questions. Due to the severity of COPD symptoms, some hospitalised patients (12.6%) requested assistance with completing the questionnaire during their hospital stay. A research team member read the questions and record the patients' answers. After three weeks patients with unreturned questionnaires were contacted to query if they had any questions regarding the survey. Of the 360 asked to participate, 159 returned completed questionnaires (44.2% response rate). Questionnaires were incomplete if more than 24% of the questions were missed.

Statistical Analysis

Data was analysed using SPSS (IBM Corp., 2011) version 20.0 for EFA and MPlus (Muthén & Muthén, 2017) version 8 for confirmatory factor analysis (CFA). An examination of the SGRQ domains was performed via a principle component analysis with a varimax rotation. EFA was performed to identify the appropriate number of factors for the data. Factor loadings were extracted to examine which items loaded on the factors and ascertain the constructs for each domain. Items not loading on factors were removed from future analyses. Reliability was examined via Cronbach α and convergent validity via full information maximum likelihood structural equation modelling.

The five-factor model identified by the EFA was verified via CFA. The CFA model was examined through various fit indices to provide a more robust method of determining the model fit (Jaccard & Wan, 1996); including Chi-squared (χ^2) analysis, Comparative Fit Index (CFI), Tucker Fit Index (TFI), Root Mean Squared Estimate (RMSEA). χ^2 analysis examines the model fit by comparing the correlations of the current model with an estimated model (Birch et al., 2001); however, χ^2 analysis is sensitive to sample size and is best used in conjunction with other measures (Byrne, 1998). The following methods were used to determine the best fitting model: a small χ^2 result (Birch et al., 2001); larger CFI and TFI (Brown, 2003); and low RMSEA values (Dorman, 2003). The closer the CFI and TFI are to 1 the better the model fit (Brown, 2003), RMSEA values are preferred to be close to or below 0.05, comparing it with a perfect fit of zero (Brown, 2003; Dorman, 2003).

Pearson's correlations were conducted to examine the associations between the domains. CFA provided results regarding the convergent validity of the data within each

of the factors as per their loadings. Finally, independent *t*-tests and one-way ANOVAs were conducted on anthropometric variables to examine the sensitivity of the factors.

Exploratory factor analysis

The EFA of SGRQ data is presented in Table 15 and displays the three possible models. The scree plot (Figure 13) for the data confirms that six or five factors could be meaningfully extracted and would adequately represent the data.

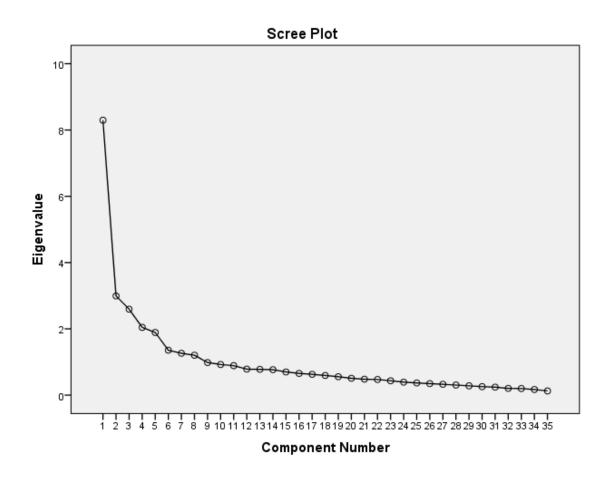


Figure 13. Scree plot based on factor analysis of the SGRQ data

Results

Of the 159 COPD patients recruited for this study almost half were male (48.7%) with 72.8% being over 66 years, including 30.4% who were over 76. The recruitment location of the participants was roughly even with just over half (54.7%) from the community. Approximately half of the sample (45.9%) were married or in a de-facto

Table 15 Exploratory factor analysis loadings with varimax rotation for the different factor models

Item		5 Factor Model				4 Factor Model				3 Factor Model		
	1	2	3	4	5	1	2	3	4	1	2	3
A 15.1 Take a long time to get washed or dressed	0.79					0.79				0.65		
A 11.4 Walking outside on the level	0.77					0.77				0.53		
A 11.2 Getting washed or dressed	0.75					0.76				0.58		
A 11.3 Walking around at home	0.70					0.70				0.55		
A 15.2 Cannot take a bath/shower or take a long time	0.67					0.68				0.61		
I 12.4 Breathless when bending over	0.57					0.57				0.43		
I 12.3 Breathless when talking	0.49					0.50						
I 13.8 Everything seems too much of an effort	0.47		0.45					0.48		0.67		
I 13.3 Afraid or panic when I cannot get my breath	0.38			0.32		0.39				0.40		
A 15.9 Heavy manual work, running, cycling, swim fast		0.84					0.85				0.79	
A 15.8 Carry heavy loads, jog, walk fast, digging in garden		0.78					0.78				0.73	
A 15.7 Climbing hills, weeding, light gardening,		0.73					0.74				0.72	
A 15.3 Walk slower than others or stop for rests		0.67					0.65				0.70	
A 15.6 Hurry or walk fast, have to stop or slow down		0.65					0.62				0.59	
A 15.5 Stop or walk slowly up one flight of stairs		0.64					0.63				0.70	
A 15.4 Housework takes a long time or stop for rests		0.62					0.61					
I 12.6 Get exhausted easily		0.50					0.50				0.60	
A 11.5 Climbing a flight of stairs		0.45					0.45				0.56	
I 16.5 Cannot move far from bed or chair			0.76					0.71		0.54		
I 16.3 Cannot go out to do the groceries			0.74					0.63		0.58		
I 16.2 Cannot go out for entertainment or recreation			0.66					0.62		0.35		
I 13.6 Become frail or an invalid because of my chest			0.54					0.60		0.62		
I 16.4 Cannot do housework			0.52			0.49				0.63		
I 13.7 Exercise is not safe for me			0.46					0.52		0.60		
I 13.1 Cough or breathing is embarrassing in public				0.65								0.27
I 13.2 Chest problem nuisance to family and friends				0.64				0.26				0.22
I 12.2 Cough makes me tired				0.60				0.30		0.29		
I 12.1 Cough hurts				0.59				0.49		0.40		
I 12.5 Cough or breathing disturbs my sleep				0.47				0.33			0.25	
I 13.4 Not in control of my chest problem				0.46				0.41				
A 11.1 Sitting or lying still			0.35	0.38				0.49		0.37		
I 14.3 Unpleasant side effects from my medication					0.81				0.78			0.78
I 14.4 Medication interferes with my life a lot					0.81				0.80			0.79
I 14.2 Get embarrassed using my medication in public					0.77				0.78			0.77
I 14.1 Medication does not help me very much					0.73				0.70			0.69

Note: Original St George's factor items are indicated via domain letter, A – Activity domain, I – Impact domain. Boldface items depict items which loaded on the corresponding factor. Only data for items with loadings greater than 0.3 (for non-significant data) are presented.

relationship. Of the participants only 13 (18.2%) were current smokers. Comorbid illnesses were common (2.71, SD1.64), with anxiety and depression most prominent (34.2%).

An unrestricted EFA identified 14 factors accounting for 66.51% of the variance, however, no meaningful constructs were detected. Although eight factors returned an Eigenvalue over one, the scree plot identified that six or five factors would be more appropriate. An EFA of six factors accounted for 54.78% of the variance, however, meaningful constructs were difficult to detect. Factor analyses were conducted for five, four, and three-factor models to more closely resemble the original SGRQ domains (Table 15). These models accounted for 50.91%, 45.51%, and 39.67% of the variance respectively.

The EFA confirmed that the SGRQ consisted of five clear factors from the 35 items; with 3 items with similar loadings across factors being transferred to retain meaningful constructs (11.1, 13.3, and 13.8). Both the three and four-factor models shared similarities with the five-factor model, yet loadings below 0.3 were subsequently deleted. Furthermore, the positioning of the items within the three and four-factor models reduced the constructs clarity and the variance accounted for when compared to the five-factor model.

The first factor of the five-factor model comprised seven questions on activities which increase breathing difficulties (11.2, 11.3, 11.4, 12.3, 12.4, 15.1, 15.2, for example, a question item 'Cannot take a bath or shower or take a long time') and loaded on the activity domain. The second factor, breathlessness, included items which the participant has to stop or slow down due to breathlessness (11.5, 12.6, 15.3, 15.4, 15.5, 15.6, 15.7, 15.8, and 15.9, e.g. 'Difficult to do heavy manual work, running, cycling, swim fast'). The third domain, symptoms, consisted of questions 11.1, 13.6, 13.7, 13.8,

16.2, 16.3, 16.4, 16.5 (e.g., 'Cannot move far from my bed or chair') and involved how their symptoms impact upon their daily life. Cough was identified as the fourth factor (items 12.1, 12.2, 12.5, 13.1, 13.2, 13.3, 13.4, e.g., 'Cough or breathing is embarrassing in public') which enquired into their coughing and breathing experiences. The final factor, medication, includes four items (14.1, 14.2, 14.3, 14.4, e.g., 'My medication interferes with my life a lot') and queries the impacts that medications have upon the patient's life. Overall the variance accounted for was at good level of 50.91%, with the individual factors accounting for 14.72%, 12.24%, 8.63%, 7.84%, and 7.48% of the variance respectively.

The reliability analysis of the overall model was high (Cronbach α of 0.89). Analysis of each of the factors found that domains were reliable, with Cronbach α levels being 0.86 for activity, breathlessness α =0.87, symptoms α =0.78, cough α =0.69, and medication α =0.80.

A CFA (Figure 14) was conducted to examine the goodness-of-fit for the five-factor model (Table 16). Table 17 shows the goodness-of-fit estimations, χ^2 , CFI, TFI, and RMSEA. The three models displayed a good fit for the data, with the five-factor model displaying a superior fit over three and four-factor models. The analysis displayed that the items significantly correlated with the proposed factors for this model. The results of the CFA demonstrate that a five-factor model is most suitable and contains a parsimonious fit for the data.

The Pearson's correlations identified moderate to low significant correlations between most of the domains (activity, breathlessness, symptoms, cough; see Table 4). The associations between the medication domain and the other four domains were found to be very weak and not significant, however, these data represent issues which can impact upon COPD patients' HRQoL. Finally, an examination of the sensitivity of

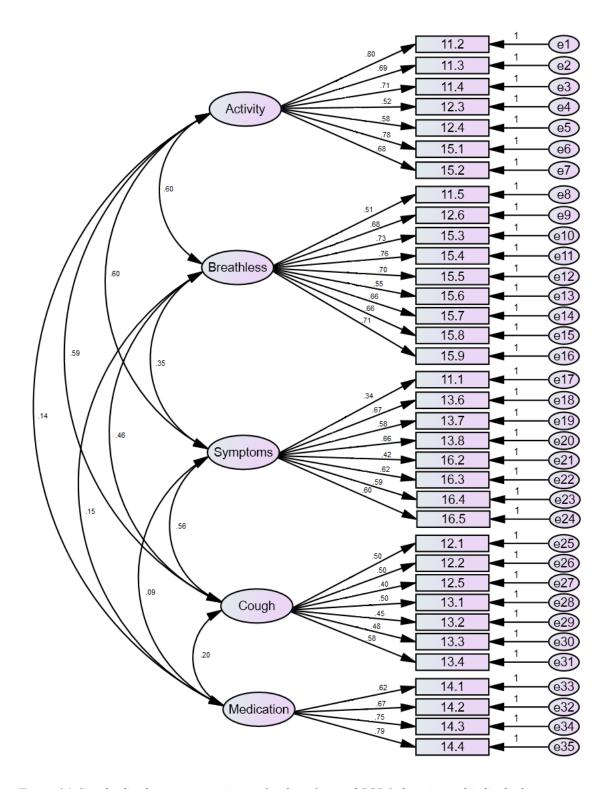


Figure 14. Standardised parameter estimates for the refactored SGRQ domains and individual items. Breathless - breathlessness

the five domains revealed relationships between COPD patients' HRQoL and their anthropometric variables (Table 5). The cough domain was most sensitive with COPD patients with worse coughing experiences being younger (less than 65 years versus over

76), female, recently hospitalised, having anxiety/depression, more comorbidities, and lower resilience than patients who had fewer coughing related disturbances. On the activity domain patients who scored higher had more comorbidities, were recently hospitalised, and had low levels of resilience. High scores on the breathless domain were associated with a diagnosis of anxiety/depression, more comorbidities, and low resilience. High symptom domain scores were associated with recent hospitalisations, anxiety/depression, more comorbidities, and low resilience. The medication domain did not detect any differences for the COPD patients' anthropometric variables.

Table 16 Confirmatory factor analysis based on the five-factor structure

	Parameter estimate	Standard Error	t ratio	p value
Activity 1	0.80	0.04	22.07	< 0.001
Activity 2	0.69	0.05	14.27	< 0.001
Activity 3	0.71	0.05	15.30	< 0.001
Activity 4	0.52	0.06	8.33	< 0.001
Activity 5	0.58	0.06	10.15	< 0.001
Activity 6	0.78	0.04	19.80	< 0.001
Activity 7	0.68	0.05	13.78	< 0.001
Breathlessness 1	0.51	0.06	7.85	< 0.001
Breathlessness 2	0.68	0.05	13.21	< 0.001
Breathlessness 3	0.73	0.04	17.24	< 0.001
Breathlessness 4	0.76	0.04	18.09	< 0.001
Breathlessness 5	0.70	0.05	14.83	< 0.001
Breathlessness 6	0.55	0.06	8.96	< 0.001
Breathlessness 7	0.66	0.05	12.50	< 0.001
Breathlessness 8	0.66	0.05	12.28	< 0.001
Breathlessness 9	0.71	0.05	14.67	< 0.001
Symptoms 1	0.34	0.08	4.25	< 0.001
Symptoms 2	0.67	0.06	12.00	< 0.001
Symptoms 3	0.58	0.06	9.08	< 0.001
Symptoms 4	0.66	0.06	11.53	< 0.001
Symptoms 5	0.42	0.08	5.59	< 0.001
Symptoms 6	0.62	0.06	9.82	< 0.001
Symptoms 7	0.59	0.06	9.21	< 0.001
Symptoms 8	0.60	0.06	9.49	< 0.001
Cough 1	0.50	0.08	6.70	< 0.001
Cough 2	0.50	0.08	6.44	< 0.001
Cough 3	0.40	0.08	4.89	< 0.001
Cough 4	0.50	0.08	6.45	< 0.001
Cough 5	0.45	0.08	5.68	< 0.001
Cough 6	0.48	0.08	6.08	< 0.001
Cough 7	0.58	0.07	8.08	< 0.001
Medication 1	0.62	0.06	10.05	< 0.001
Medication 2	0.67	0.06	12.02	< 0.001
Medication 3	0.75	0.05	15.25	< 0.001
Medication 4	0.79	0.05	16.86	< 0.001

^a Not computed because the item's loading had been fixed to unity to scale the factor

Table 17 Model fit indices from confirmatory factor analysis of 35 item models

	χ^2/df	CFI	TFI	RMSEA
Three-factor model	2.09	0.73	0.71	0.08
Four-factor model	2.00	0.69	0.67	0.08
Five-factor model	1.77	0.79	0.77	0.07

Table 18 Correlations between the refactored SGRQ domains

	Activity	Breathlessness	Symptoms	Cough
Activity				
Breathlessness	0.54***			
Symptoms	0.51***	0.32***		
Cough	0.46***	0.37***	0.41***	
Medication	0.10	0.12	0.06	0.14

^{*}*p*<0.05, ***p*<0.01, ****p*<0.001

Discussion

The EFA demonstrated that the SGRQ was best represented by a five-factor model in this study's population. The five domains included activity, breathlessness, symptoms, cough, and medication, with all the domains accounting just over half of the variance; 14.1% to 22.9% more than similar studies (Martínez García et al., 2005; Mölken et al., 1999; Paap et al., 2015), suggesting that five factors adequately explain the domains of the SGRQ in an Australian COPD sample. The reliability of the overall model and the individual domains were found to be good to excellent.

The first factor of the five-factor model involved the activity domain. This differs from the original validations by Jones et al. (1991a) and Meguro et al. (2007) which identified symptoms as the first factor. The second factor identified involved the patients' breathlessness experiences, which was not represented in any of the above validation studies. These variances could be a result of differences in the patient groups climate. For instance, the heat and humidity experienced in Australia increases blood flow as capillaries open to cool the body; increasing the load on lungs causing breathlessness and limiting the patients' ability to perform activities when compared to

Table 19 HRQoL differences between anthropometric variables and resilience levels for the COPD sample (n=159)

Variable	Activity		Breathlessness		Symptoms		Cough		Medication	
	Mean (± SD)	t	Mean (± SD)	t	Mean (± SD)	t	Mean (± SD)	t	Mean (± SD)	t
Age										
<65 years (n=43)	4.05(2.45)	F=0.62	8.44(0.98)	F=1.51	2.09(2.43)	F=0.61	3.74(1.90)	F=3.50*	0.88(1.38)	F=0.41
66 to 75 years (n=67)	4.12(2.69)		7.84(2.26)		1.67(1.84)		2.93(2.10)		0.69(1.53)	
76+ years (n=48)	4.56(2.14)		8.21(1.77)		1.96(1.96)		2.73(1.75)		0.63(1.28)	
Gender										
Male (n=77)	4.34(2.53)	-0.51	8.14(1.83)	-0.19	2.13(2.26)	-1.54	2.77(1.83)	2.02*	0.61(1.16)	0.96
Female (n=81)	4.14(2.41)		8.09(1.88)		1.63(1.79)		3.40(2.07)		0.83(1.62)	
Smoking Status										
Non-smoker (n=53)	4.23(2.52)	-0.03	8.19(1.54)	0.36	1.36(1.57)	-2.54*	3.21(1.93)	0.54	1.00(1.90)	1.77
Ex-smoker and smoker (n=105)	4.24(2.45)		8.08(2.00)		2.13(2.21)		3.03(2.01)		0.58(1.07)	
Marital Status										
Married/de-facto (n=73)	3.97(2.57)	-1.24	7.82(2.11)	-1.81	1.81(1.97)	-0.37	2.99(1.90)	-0.60	0.68(1.44)	-0.30
Single/divorced/widowed (n=85)	4.46(2.37)		8.36(1.55)		1.93(2.11)		3.18(2.05)		0.75(1.40)	
Recruitment Location										
Community (n=87)	3.83(2.47)	-2.42*	8.01(1.98)	-0.81	1.26(1.54)	-4.30***	2.41(1.79)	-5.20***	0.74(1.60)	-0.01
Hospital (n=72)	4.76(2.38)		8.25(1.67)		2.64(2.32)		3.93(1.88)		0.74(1.19)	
Comorbidities										
Anxiety/depression (n=54)	4.65(2.28)	-1.50	8.61(0.76)	-3.19**	2.46(2.06)	-2.57*	3.98(1.94)	-4.37***	1.02(1.62)	-1.78
No anxiety/depression (n=104)	4.03(2.55)		7.86(2.17)		1.60(1.99)		2.62(1.82)		0.60(1.30)	
Total (n=159; Pearson's <i>r</i>)	0.279*		0.191*		0.252**		0.410**		0.125	
Resilience level										
Low level (n=73)	4.92(2.13)	3.20**	8.64(0.81)	3.16**	2.38(2.23)	2.90**	3.82(1.93)	4.40***	0.82(1.48)	1.01
High level (n=78)	3.71(2.52)		7.78(2.26)		1.44(1.74)		2.50(1.76)		0.59(1.35)	

^{*}p<0.05, **p<0.01, ***p<0.001; SD – standard deviation

patients in colder climates (e.g. United Kingdom). An exploratory bifactor analysis using a two and three-factor solution by Paap et al. (2015) found similar domains to our study. They identified that their domains related to the impact of moderate to heavy activities (factor 1) and light activities (factor 2) on the patients breathing, with factor 3 on the three-factor solution consisting of a previously unidentified domain; pain or symptoms due to treatment.

The third factor in this study the symptoms domain, remained following the removal of the original SGRQ symptoms items. This removal makes it difficult to compare our findings to previous validation studies. One other study utilised CFA on the original SGRQ symptoms data but excluded the activity and impact from this analysis (Lo et al., 2015). Lo et al. (2015) found the symptoms domain to be unidimensional after removing the first two questions. Although confirming the original symptoms domain, an EFA was not conducted to verify the factors loadings, nor did they report unidimensionality on the remaining domains. Another study by Martínez García et al. (2005) conducted an EFA and similar to this study they found that the SGRQ structure was similar to original yet was better explained with a fourth factor. Unfortunately, a CFA was not conducted to determine the comparative fit of their four-factor model.

Correlations between the domains in our study found that all but the medication domain were moderate to weakly correlated. These results identify that four of the five factors represent a unidimensional concept of HRQoL. Although the medication domain association was negligible, it does examine issues which may impact HRQoL. Examinations into other validation studies which retained the original three factors has found that the symptoms domain correlated with other HRQoL measures, including the Short Form-36 (SF-36), Chronic Respiratory Questionnaire (CRQ), Nijmegen Integral

Assessment Framework (NIAF; Barr et al., 2000; Chan et al., 2002; Daudey et al., 2010; Xu et al., 2009). The correlations between these other HRQoL domains (psychological, social, physical activity, and/or emotional) and the SGRQ symptoms domain were moderate to weak; confirming the SGRQ items were examining patients HRQoL. However, when these studies examined the relationship with other symptomatic measures (e.g. FEV₁, and MRC dyspnoea scale), very few displayed the strength of association meeting the minimum criterion for conceptual similarity (*r*=0.70, 49% of common variance accounted for by both variables). As such, meaningful correlations were only found on one of four symptom domain comparison for Daudey et al. (2010), and no comparisons in Barr et al. (2000), Chan et al. (2002), Xu et al. (2009) or Yorke, Jones, and Swigris (2010); results which are not fully supportive of the validity of the domain.

An examination into the activities domain found that our scale included 7 of the original 16 items relating to disturbances when undertaking mild to moderate activities. Of these seven items all but two were consistent with the original version. Previous studies confirm that the activity items correlated (moderate to weak) with the majority of other HRQoL (e.g. SF-36) domains, including symptomatic, social, emotional, and psychological (Barr et al., 2000; Chan et al., 2002; Daudey et al., 2010; Xu et al., 2009). Again, these correlations identify that the SGRQ items measure the concept of HRQoL. Daudey et al. (2010) found a conceptually similar correlation between the SGRQ activity and subjective impairment on the NAIF. However, this association was not found on two other activity based domains on the NAIF; failing to reach conceptually similar level ($r \ge 0.70$). Yorke et al. (2010) found correlations reaching conceptual similarity for the activities domain for physical functioning and physical components summary. However, this strength was not identified in the role physical domain (SF-36). Barr et al. (2000), Chan et al. (2002), and Xu et al. (2009) each identified one

conceptually similar correlation (SF-36 physical functioning) but again no other activity based domains reached this conceptually similar level.

The impact domain (not identified in our study) displayed correlations with other HRQoL measures in previous studies. However, the impact domain did not share any conceptual similarities with other psycho-social domains in these studies, indicating a lack of strength for the original SGRQ impact domains' validity (Barr et al., 2000; Chan et al., 2002; Daudey et al., 2010; Xu et al., 2009; Yorke et al., 2010).

The remaining three factors found in this study breathlessness, cough, and medication comprise a combination of the original activity and impact domains (see; Jones et al., 1991a; Meguro et al., 2007). Our EFA identified these items as specific symptomatic and medication experiences which directly impact upon these patients. Although we deleted the original symptom items, the existence of a symptoms domain was identified within these remaining 35 items, in addition to a domain which examines medication experiences. The identification of these new domains provides a specific analysis of symptomatic experiences and the impact that coughing or breathlessness has on COPD patients' ability to undertake activities; perspectives which have not been identified previously.

The five-factor model established by the EFA was found to have a high reliability and good content validity, advocating that retaining only 35 items did not detract from the measures strength and is thus suitable for measuring Australian COPD patients' HRQoL via postal administration. Furthermore, the results support the diversity of the first-order factors obtained by the EFA as explaining the multi-dimensional concept of HRQoL.

The results presented in table 1 clarify that the five domains identified by the EFA are confirmed by CFA and are representative of South Eastern Queensland Australian

COPD patients. When identifying which of the three, four, and five-factor models was the most appropriate, table 3 demonstrates that the five-factor model displayed the best fit. The χ^2 analysis was lower for the five-factor model than it was for the three and four-factor models. An examination of the CFI and TFI again identified that the five-factor model was superior to the three and four-factor models. The RSMEA figures were within close proximity, however, the five-factor model again displayed a lower figure, demonstrating a better fit.

This study illustrates the significance of using both EFA and CFA in determining the factor structure for COPD patients in different geographical locations. A review of SGRQ validation literature highlights that few studies have used EFA or CFA for validation (see; Lo et al., 2015; Paap et al., 2015). To date most SGRQ validation studies have utilised correlational analysis to confirm modified questionnaires are consistent with the original version. Specifically, studies have used convergent and discriminant methods using Spearman rank and Pearson's r correlations to test validity (Barr et al., 2000; Chan et al., 2002; Xu et al., 2009).

Issues with correlational methods occur when shared measures (e.g. self-report only) are used to interpret the association. Whereby, it is unclear as to whether the relationship is due to the data collection method or the responses; the same can also be true for discriminant correlations when using different measures (Harrington, 2009). The strength of CFA is that it examines how constructs are interrelated through their structural composition, identifies factor patterns, and the existence of a latent variable from an a priori observation (Brown, 2015). Furthermore, it confirms whether the structure remains consistent within the questionnaire when modified (Harrington, 2009).

Sensitivity analysis of the five-factor model for detecting differences in COPD patients' anthropometric variables was confirmed across the domains, excluding the

medication domain. These results provide further evidence for the five-factor models' ability to distinguish between COPD patients' HRQoL and variables which were found to be influential in past studies (Almagro & Castro, 2013; Esteban et al., 2009; Hill et al., 2008). For instance, poor symptomatic HRQoL has been found in patients who had been admitted to hospital as a result of exacerbations (Esteban et al., 2009), an aspect which includes patients reporting higher levels of coughing experiences (Burgel et al., 2009). Poor HRQoL has also been found in patients who have more comorbidities (Almagro & Castro, 2013), including diagnoses of anxiety or depression (Hill et al., 2008).

Limitations

This study has several limitations which need to be considered. Firstly, a small sample of patients were recruited from two regions in South Eastern Queensland. The small sample size can increase distortions in the refactored data, escalating model error and issues with loadings (de Winter, Dodou, & Wieringa, 2009); thus, results need to be interpreted with caution. Furthermore, restricting the recruitment of patients reduces the generalisability of the findings as participants may not represent the diversity of patients outside those areas. Secondly, participants were recruited from COPD education days or hospitals. Potential participants not attending these locations could have different symptomatic experiences and perceive their HRQoL differently. Thus, patients who were potentially experiencing more stability in their condition or refused to seek alternative treatments were excluded. Thirdly, the questionnaire was completed via self-report and returned via postal administration. The issue is that a family member or friend may have assist them; which could have influenced their responses. However, the aim of this validation study was also to determine the strength and reliability of the measure via postal administration. The final limitation involves the absence of follow-

up data, which removes the ability to reassess the strength of the model following improvements resulting from an intervention.

Conclusion

Although various validation studies have been undertaken on the SGRQ, few have included EFA or CFA. As the SGRQ is widely used in individuals with respiratory illnesses, it is important that the measure is explored and confirmed for its factor fit and reliability. This study identified that the SGRQ is reliable and valid for use with Australian COPD patients via postal administration. It was also found that the refactored 35 item SGRQ contained additional and more specific HRQoL domains than the original. The new five-factor structure allows for the examination of COPD patients activity, breathlessness, symptomatic, coughing, and medication experiences on their daily life.

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Chapter 5: Discussion

5.1. Introduction

This chapter reviews each of the research hypotheses and discusses the findings regarding these hypotheses. The clinical implications, strengths, and limitations of these research findings are also discussed, along with recommendations for future research.

The final section of chapter 5 provides an overall conclusion for the thesis.

5.2. Overview of findings in relation to the research hypotheses

It has frequently been identified that COPD patients experience ongoing declines to their HRQoL as a result of their deteriorating health and increasing limitations. Investigations into how to improve patients' HRQoL and promote behavioural and lifestyle changes have examined various areas, yet no studies have investigated whether there is a relationship between these outcomes and COPD patients' individual and contextual resilience and their readiness to change. This study aimed to investigate COPD patients' barriers to behavioural and lifestyle changes using a resilience, readiness to change, and self-management model. Essentially this thesis examined COPD patients' levels of resilience, their stage of readiness to change, and selfmanagement abilities, and how these factors were related to their HRQoL, completion of pulmonary rehabilitation, and their adherence to prescribed medication regimens. The conceptual framework (see chapter 2, section 2.6) proposed for this research identified that individual and contextual resilience factors, along with a COPD patient's readiness to change, will be associated with their adherence to the behavioural and lifestyle changes recommended by their clinician. It is also recognised that COPD patients who undertake self-management programs will benefit from improvements in HRQoL as a result of actively undertaking the behavioural and lifestyle changes that are implemented in self-management interventions. In order to test this framework a crosssectional study was undertaken. This study recruited 159 mild to severe spirometry confirmed COPD patients who were patients either at South Eastern Queensland hospitals or community health centres. The patients provided responses to the aforementioned variables via a self-administered questionnaire. The self-management meta-analysis reviewed databases of published randomised control trials and combined the data from these articles in robust statistical analysis. The individual hypotheses and the results of this research are overviewed below.

Hypothesis 1: COPD patients who undertake self-management interventions will experience greater increases in HRQoL when compared with patients who continue treatment as usual.

The results of the meta-analysis supported the hypothesis that self-management interventions improve all domains (symptoms, activity, and impact) of COPD patients' HRQoL when compared with patients undertaking treatment as usual. Multiple previous randomised control trials have investigated the effect of self-management programs on various aspects of COPD patients' health and well-being outcomes, including their exercise capacity, levels of depression and anxiety, self-efficacy, and HRQoL, with inconsistent results. A previous meta-analysis found that self-management interventions improved the HRQoL of COPD patients but was unable to specify which components of self-management provided these significant benefits. The current study expanded on this past research, finding that all domains of COPD patients' HRQoL were improved as a result of the self-management intervention. This meta-analysis also investigated the influence of other factors that may contribute to COPD patients' HRQoL. It was found that self-management interventions were also able to improve patients' levels of self-efficacy, breathlessness, and exercise capacity.

These findings suggest that providing COPD patients with training regarding how to manage their illness in collaboration with their clinician provides not only increases

in their levels of confidence and competence for managing their disease, but also the skills to improve their ability to exercise and appropriately manage their dyspnoea and/or exacerbations. Essentially this self-management training improves all aspects of COPD patients' HRQoL though providing them with the ability to better manage their symptoms, which allows them to participate in activities of daily living. These activities extend beyond basic self-care to include those that are important to our psycho-social needs, including social engagements. All of these aspects provide the foundations for life enjoyment or what is considered quality of life.

To explore which components of self-management interventions were significantly associated with improvements to COPD patients' HRQoL, this study conducted a number of subgroup analyses. It was found that the provision of COPD education, an exacerbation action plan, and exercise information improved COPD patients' HRQoL. It was also found that the duration of the self-management program was important to consider when developing future intervention programs.

The analysis of these subgroups identified that providing disease specific education to COPD patients was highly important for improving their HRQoL across every domain. This form of knowledge is thought to improve COPD patients' confidence and competence for managing their disease, as they better understand their illness, including their triggers for exacerbations, the limitations they can expect, and techniques that they can use to reduce their feelings of breathlessness. Through recognition of their increasing limitations resulting from the disease, patients are better informed on how best to approach activities (both activities of daily living and social events), so they can maintain a level of independence and sociability, which is important for maintaining a better quality of life.

It was also found that the self-management interventions with a shorter duration (less than five weeks) provided improvements to COPD patients' HRQoL, specifically for the perception of their symptoms, and the number of disturbances they experienced during activities. It is believed that COPD patients who participate in programs of longer duration may experience plateaus in their improvements, motivation and interest, and as a result perceive fewer enhancements in their HRQoL due to this extended program. In addition to this, it is believed that other factors may influence improvements in the patients' HRQoL during short duration interventions; these include the age of the patient and their level of support, with both younger patients and those with good support being better able to manage their symptoms and the situational barriers (e.g. transportation) that can disrupt attendance. Nevertheless, these other potential influencing factors will need to be controlled in future studies.

Another important educational component for improving COPD patients' HRQoL identified in the subgroup analysis included providing an exacerbation action plan. The exacerbation action plan was found to decrease the number of disturbances patients experienced during activities, and improve their psychosocial functioning. Provision of this plan allows patients to have the confidence that they can act quickly should they experience an exacerbation. Through increasing COPD patients' confidence, they are then more likely to partake in activities of daily living and social events, thereby providing patients with a return to at least some of the activities that they were able to undertake prior to their illness.

The final self-management educational component that was found to improve COPD patients' HRQoL included the provision of exercise information. This information provides COPD patients with confidence regarding safe exercise for their current abilities and an understanding of their limitations when partaking in exercise. This then allows patients the freedom to undertake strength and endurance training that

is appropriate for their level of impairment – exercise that will improve their symptomatic experiences and the number of disturbances they experience during their daily routines.

According to the conceptual framework (see chapter 2, section 2.6) proposed in this study, self-management interventions improve COPD patients' HRQoL and promote behaviour change through the provision of disease specific education. This meta-analysis confirmed the first hypothesis, identifying that COPD patients who undertake self-management interventions, especially those that provide COPD education, an exacerbation action plan, and exercise information over a short duration, will experience improvements in their HRQoL. More specifically, they will see improvements in their perception of symptoms, the number of disturbances they experience when performing activities of daily living, and the limitations to their psycho-social functioning.

Hypothesis 2: High levels of resilience is associated with a better HRQoL in an Australian COPD sample.

The results of this study partly supported the second hypothesis that there is a relationship between COPD patients' levels of resilience and their HRQoL (breathlessness, symptoms, and cough) while controlling for potential confounding factors. It was found that COPD patients who had higher HRQoL on the breathlessness domain had higher levels of individual and contextual resilience factors after controlling for the patients' marital status and other comorbidities. Specifically, COPD patients who had high self-efficacy, coping, and decision making abilities were found to experience fewer dyspnoea related disturbances. It is believed that these patients with higher level of self-efficacy had more confidence in their use of breathing techniques that assisted them in reducing the number of breathlessness disturbances they experienced. Understanding when to utilise breathing techniques displays good decision

making abilities and enhances COPD patients' ability to cope with breathing difficulties.

It was also found that having good support from both professional and social connections was important for COPD patients' experience of breathlessness related disturbances. COPD patients were less likely to experience declines in their HRQoL breathlessness if they believed they had good support from their health care clinicians. This effect was synonymous for COPD patients who received strong support from their friends or family members. Clinicians, family, and friends can provide COPD patients with reinforcement of the correct breathing techniques and/or promote the use the medications or assist them with activities whenever they are experiencing dyspnoea, allowing the patients' breathlessness to subside.

The use of defensive coping is usually seen as a negative concept. Defensive coping in this study, however, was found to improve COPD patients' HRQoL for breathlessness. Patients who scored high in defensive coping were more determined to dispel their illness, implying that they may take different approaches to reducing their dyspnoea and may suffer less anxiety regarding their breathlessness due to downplaying their breathlessness experiences.

Further support for hypothesis 2 was found on the HRQoL symptoms domain where COPD patients who had high resilience had a better perception of their symptomatic experiences. The individual resilience factors of importance to patients' perception of their symptoms included their self-beliefs, specifically their self-efficacy and self-esteem. COPD patients with high levels of self-efficacy will feel more confident in their ability to manage their symptoms, while high self-esteem patients will feel worthy of care, making patients more likely to undertake strategies to manage their symptomatic experiences.

The implementation of strategies to manage symptoms suggests that patients are utilising problem- and emotion-focused coping to improve their experiences. The results of this study found that having good coping abilities was important in maintaining HRQoL, especially in hospitalised patients. However, for community based COPD patients, coping was also closely linked to professional and social support connections — support which is provided consistently for hospitalised patients, reducing its importance for this group. Support in this study was found to be associated with higher HRQoL on the symptoms domain. In particular, COPD patients with good relationships were more likely to receive support from family and friends when they experienced illness disturbances. This support reduces patients' need to perform activities and allows them to focus on recovering from their illness disturbances.

On the cough domain the individual level factors of coping and defensive coping and the contextual level factor professional support were found to be important for hospitalised COPD patients' HRQoL while controlling for anxiety and depression. This finding is unsurprising as coughing and sputum production are both common in hospitalised patients who are experiencing exacerbations. It was found that in order for hospitalised patients to have a high HRQoL on the cough domain, they needed to also have good coping abilities, where they could use the skills they had acquired to reduce the impact of their coughing experiences. However, COPD patients who had lower belief in the benefits of professionally supported programs were found to experience more coughing related disturbances. This could indicate that these patients are not undertaking programs or learning techniques that assist in managing coughing experiences.

The HRQoL factors that were not supported in this hypothesis included the HRQoL domains activity and medication. On these domains a COPD patients' level of resilience was not found to be important for improvements or declines in their HRQoL.

When considering a COPD patient's ability to undertake activities of daily living (such as cleaning and cooking), it is proposed that these activities are not important to patients' resilience, as COPD patients do not require feelings of confidence or worthiness to complete these activities as they have been performing them for decades. In addition to this, the finding that medication experiences had no relationship with resilience is not surprising, as medication is regulated by clinicians; any associated difficulties would be discussed with the clinicians, who would then assist in rectifying the issue, making it an externally based concern.

The conceptual framework (see chapter 2, section 2.6) proposed for this study identified that a COPD patient's levels of resilience would be associated with their HRQoL. This theory was supported by this research, although not all aspects of patients' HRQoL share this association (activity and medication). Both individual and contextual level resilience factors were found to be important for HRQoL (breathlessness, symptoms, and cough). Of particular importance was the patient's sense of self, including their levels of self-esteem, self-efficacy and ability to cope. However, having other individuals to rely upon for support and assistance was also a key component related to HRQoL.

Hypothesis 3: Low levels of resilience is related to poor completion rates of pulmonary rehabilitation programs in Australian COPD patients.

This research supported the hypothesis that COPD patients' referral and completion of pulmonary rehabilitation programs was associated with their level of resilience. As depicted in the resilience, readiness to change, and self-management model, the individual factors of self-esteem, self-efficacy, decision making, and coping, along with the contextual factors relationships and professional support, were important for completion.

Having low or even average belief in professionally supported pulmonary rehabilitation was found to be associated with low completion rates. Belief in the benefits of these supported programs was established as an important component for pulmonary rehabilitation completion, as COPD patients who have poor beliefs in the program might feel as though it is not safe, that the support provided by the health professionals guiding the program would be insufficient, or that these professionals would be unable to adequately care for their health and well-being during the program. This implies that poor beliefs can result from COPD patients holding inadequate knowledge of the program's content and benefits.

The results also demonstrated that COPD patients who are low in self-esteem and self-efficacy are less likely to complete rehabilitation programs. It is proposed that this lack of confidence in their ability to perform the exercises offered in the program reduces the likelihood that they will undertake or complete the program. This low self-efficacy can also influence the patient's confidence to make appropriate decisions and cope during the program. However, this study identified that COPD patients with high self-esteem and self-efficacy were less likely to be referred to or complete the program. This finding could indicate that COPD patients who have high levels of self-worth and confidence in their own abilities are more likely to be overlooked for a referral or feel that they are already managing well and will not gain any further benefits from completing the program.

These results further demonstrated that the interpersonal relationships COPD patients have with family and friends are important for determining whether they will complete or be referred to the program. This study found that having strong supportive relationships reduced the likelihood of referrals and completion. Having good social support can improve COPD patients' confidence regarding their current health status, making them feel (and be perceived) as though they can manage their disturbances as

they already have appropriate support. Thus, patients with high support have more confidence, which reduces their help seeking behaviour through increasing their reliance on their support networks.

As per the conceptual framework (see chapter 2, section 2.6), COPD patients with high levels of resilience are more likely to undertake the behavioural and lifestyle changes that are recommended to them by their clinician. In this study, this behavioural and lifestyle change is pulmonary rehabilitation exercise training. The framework was mostly supported by this research, in that COPD patients who have high confidence in their abilities and their health care professionals are more likely to undertake and complete pulmonary rehabilitation. However, it was found that having high levels of support can actually reduce referral and completion rates in COPD patients. COPD patients' beliefs that the professionally supported pulmonary rehabilitation programs would be of low risk, reduce their reliance on health care services, and improve their health and well-being was also found to be influential for completion; the more risks and fewer benefits patients perceived, the less likely they were to complete.

Hypothesis 4: Australian COPD patients with high levels of resilience and readiness to change will display higher adherence to the medication regimens prescribed by their clinicians.

The hypothesis that a COPD patient's resilience and readiness to change is associated with their medication was supported by this research. In the resilience, readiness to change, and self-management model it was proposed that COPD patients' medication adherence would be related to their levels of resilience and their readiness to change. This research confirmed that all individual and contextual factors, except coping and self-efficacy, and all readiness to changes stages, except contemplation, were important in COPD patients' adherence to medications, while controlling for the patients' age, income, employment status and other comorbidities.

Again, it was found that a COPD patient's sense of self was important for their adherence to the behavioural and lifestyle changes recommended by their clinician. Patients who are high in self-esteem tend to feel worthier of clinicians' time and of the care they are receiving. In addition to this high self-esteem patients have the ability to hold positive views of the future and can be more orientated towards achieving goals that are directed at leading a healthy life.

Being adept at making decisions was also found to be highly important for COPD patients' adherence to medications. This resilience factor is often strengthened by the clinician—patient relationship, especially when the clinician provides the patient with information regarding the disease and available treatment options, and the patient is involved in the decision making process. Patient involvement in treatment decisions provides confidence for future illness decisions and promotes trust between the patient and health care professional.

The results of this study identified trust as an important factor for COPD patients' adherence to medication regimens. It was found that high trust was associated with high medication adherence and that COPD patients who had poor or even average trust were less adherent to their medications. This result identifies that COPD patients need to feel confident that the recommended behavioural and lifestyle change is safe, appropriate and in their best interest in order to be fully adherent. Although some degree of trust can be acquired through status (e.g. a medical degree), mainly it is developed though building positive relationships. Older COPD patients are often found to have better relationships with their health care professionals as they have had many years consulting with the same clinician/s. This can lead them to have more trust in recommendations for improving health and well-being.

Defensive coping in the resilience and readiness to change study was found to

interfere with COPD patients' adherence to medications. This study found that patients who utilised defensive coping, especially denial, were less adherent to their medications than were patients who accepted their illness and its limitations. In denying their illness, COPD patients are less inclined to adhere to the medications prescribed to treat their illness. The results of this study confirmed this interpretation, as COPD patients in the pre-contemplation stage were less adherent to their medications. COPD patients on the other end of the spectrum, in the action stage, were found to be highly adherent, taking their medications strictly as prescribed.

Based on the conceptual framework (see chapter 2, section 2.6), adherence to medication regimes is associated with COPD patients' levels of resilience and their stage of readiness to change. It was identified that COPD patients with high levels of resilience were more adherent to this behavioural and lifestyle change. It was also confirmed that the patients' stage of readiness to change is an important consideration, as COPD patients who are not considering change are less likely to be adherent than those who are currently taking action. These results provide strong support for the resilience, readiness to change, and self-management model.

Hypothesis 5: The St George Respiratory Questionnaire is a reliable and valid measure of HRQoL in COPD patients in Australia.

In order to accurately examine the HRQoL in COPD patients for this thesis, the SGRQ measure utilised in this study needed to be valid and reliable for the study population. An exploratory factor analysis and confirmatory factor analysis identified that the SGRQ is a valid and reliable measure following refactoring; supporting the hypothesis.

For the Australian sample, the exploratory and confirmatory factor analyses identified that the SGRQ was best represented by a model that contained five factors over the original three. The domains for the refactored model comprised activity,

breathlessness, symptoms, cough, and medication. To the best of our knowledge, in an extensive list of validation papers only one other study has utilised confirmatory factor analysis on the SGRQ since its initial validation. This paper identified that the three domains (symptoms, activity, and impact) were unidimensional for their Taiwanese patients; although they never conducted an exploratory factor analysis to examine the factor loadings (Lo et al., 2015). As COPD is such a debilitating illness, it is important to be able to accurately assess the patients' HRQoL and identify which aspects of their HRQoL have the greatest deficiencies. Through the identification of these deficiencies health care professionals can target behavioural and lifestyle changes to improve the problem areas. However, the use of measures that have not been calibrated to the sample being investigated will not accurately measure or identify these deficiencies.

In our study the SGRQ was found to have a symptoms and activity domain similar to the original and modified versions (Jones et al., 1991a; Meguro et al., 2007).

However, the first eight questions were removed from our analysis due to scoring issues, leaving our symptoms items different to that of the original version. The activity domain of our study contained five of the original 16 items and was found to directly examine the disturbances patients experience as a result of mild to moderate activities.

The remaining three factors identified in our study were found to contain items that assessed COPD patients' breathlessness, cough, and medication experiences, none of which were identified as domains in the original and modified versions. The breathlessness domain specifically assessed patients' breathlessness experiences while performing activities, whereas the cough domain included items related to COPD patients' coughing experiences. Finally, medication examined the impact of medications on COPD patients' daily life.

Overall, the reliability of the five-factor model was found to be high, with each of the domain reliabilities ranging from good to high. It was also determined that the validity of the model was good, indicating that the five factors devised by the exploratory and confirmatory factor analyses are suitable for measuring the HRQoL of COPD patients in Australia.

5.3. Implications

The research conducted for this thesis has a number of clinical implications.

Firstly, this research identified that self-management programs can provide numerous benefits to COPD patients' HRQoL in addition to promoting behaviour change. As found in this research, COPD patients can experience continual fluctuations in their health status as a result of disease related disturbances. The prompt management of fluctuations in their symptoms is of high importance, as COPD patients' health can deteriorate rapidly. Providing COPD patients with self-management skills is thus important for them to be able to maintain not only stable health outcomes, but also their HRQoL, exercise capacity, and disease specific self-efficacy (Zwerink et al., 2014).

Providing COPD patients, whether they be newly diagnosed or long-term sufferers, with disease specific education, exercise information and an exacerbation action plan greatly enhances their life satisfaction through increasing their independence and their ability to undertake social, employment, or other daily living activities (Bulley et al., 2009; Hayton et al., 2013; Paz-Díaz et al., 2007). Self-management programs specifically focus on the promotion of behavioural and lifestyle changes in order to promote better health outcomes, reduce helplessness, and improve health habits.

The second study enhanced our understanding on the relationship between COPD patients' individual and contextual resilience and their HRQoL. The results of this study identified the importance of nurturing COPD patients' resilience in order for them to

cope with the continual declines that they experience in their health and well-being. Of particular importance for COPD patients is their self-belief, including their self-esteem and self-efficacy. COPD patients require high levels of self-esteem and self-efficacy in order to perceive their health disturbances as short-term occurrences that they will be able to manage effectively. In order to achieve this, COPD patients must feel worthy of the care that they are receiving from their family, friends, and clinicians (Harrison et al., 2015). They must also feel as though they are capable of managing their illness, having the necessary skills and knowledge to cope with their illness disturbances when they occur.

Another important consideration is the other comorbidities that the patient may have, in particular, mental illnesses. The presence of anxiety or depression in COPD patients has been identified as being associated with lower levels of self-esteem, self-efficacy, and leading to increases in COPD patients' respiratory symptoms (Uchmanowicz, Jankowska-Polanska, Motowidlo, et al., 2016; Wittmann et al., 2010b). These results identified that COPD patients who have a high sense of self-worth and feel competent in managing their illness have a higher HRQoL. Thus, health professionals, family, and friends who provide COPD patients with empathetical support and empowerment regarding their illness and its disturbances are likely to help COPD patients improve their HRQoL. This support was found to be especially important in COPD patients who were hospitalised or had recently been discharged, as these patients had recently undergone disturbances with which they could not cope without assistance.

In order to improve COPD patients' HRQoL, disease management needs to progress from predominantly symptom management to improving patients' self-esteem, self-efficacy, and coping abilities. This can be achieved through educating COPD patients on their treatment options beyond pharmacological treatment to include non-

pharmacological options such as pulmonary rehabilitation. Further to this, the identification of the patients' health goals can be used to tailor the behavioural and lifestyle changes recommended by clinicians. Tailoring these recommendations can promote feelings of self-efficacy and self-esteem as patients feel confident that they can achieve the changes (Harrison et al., 2015; Vonk & Smit, 2012a). Furthermore, they will be driven to implement the changes as they are in line with the patients' goals. Finally, encouraging the patients' use of positive health behaviours (e.g. medication adherence, exercise, and early exacerbation identification) can emphasise to the patient that they are capable in their coping abilities, as well as to build their self-esteem and self-efficacy.

The third set of implications has developed from the findings that COPD patients' individual and contextual resilience is related to their completion of pulmonary rehabilitation programs. Positive relationships, both personal and professional, were found to be the main determinants for COPD patients' completion of pulmonary rehabilitation, followed by the patients' level of self-esteem, self-efficacy, decision making, and coping abilities. Positive clinician-patient relationships, where the details and benefits of the pulmonary rehabilitation program are communicated, are crucial for completion of the program, as this helps to build patients' confidence for improving their well-being (Halding et al., 2010; Hogg, Grant, et al., 2012). It was also revealed that COPD patients who have high levels of support from their family and friends are less likely to complete or be referred to pulmonary rehabilitation programs. Thus, there are gaps in our understanding for why patients who have good support are not being referred or fail to complete pulmonary rehabilitation. Further research is required in order to determine if the support they receive provides the patients and their clinicians with confidence that they are coping well and that the program would be of little benefit.

If COPD patients perceive fewer benefits or that the program will increase the risks to their health and well-being, they will be less likely to complete it. However, the results of this research suggest that completion will be increased through providing full program information before starting the program, including that the program is individually tailored to the patient's abilities and focuses on their progressive improvements in strength and endurance. Through provision of this information patients can be confident that they will be successful in completing the program and that undertaking pulmonary rehabilitation will not decrease their ability to cope with daily activities throughout the course of the program (Wilson et al., 2007). Essentially, providing program information will decrease patients' perceived risks, improve their self-efficacy, and their understanding, allowing them to make an informed decision regarding the program.

Fourthly, this study identified that COPD patients' levels of resilience and their readiness to change is relevant for their adherence to prescribed medications. These complex associations revealed that COPD patients' level of trust in their clinician is important for their adherence to medications. The promotion of trust between a patient and their health care provider is often improved from clinicians being knowledgeable and informative regarding the illness and available treatment options (Halding et al., 2010; Hogg, Grant, et al., 2012). COPD patients need to feel as though they are able to discuss their disease concerns, either with their clinicians or their peers; these discussions can normalise their condition, increase their self-esteem, and promote open dialogue regarding the adverse effects of the medications and possible solutions (Lareau & Yawn, 2010; Lee & Lin, 2009).

To further promote adherence to medications it was found that the decision making process was important. The provision of disease and treatment information builds trust between the patient and clinician, and involves the patient in the decision

making process (Marshall et al., 2008). Patients' confidence in their decision making abilities was found to improve adherence. Including COPD patients in their treatment decisions will not only increase the patients' trust and knowledge, it will also increase their self-esteem, and self-efficacy for managing their illness. This shared decision making process allows for patients to query their clinicians on medication concerns or myths, potentially resolving any reservations the patient may have through immediate feedback and allowing them to make an informed decision.

In addition to resilience, it was also identified that the COPD patients' stage of readiness to change was important for their adherence to medications. It was found that COPD patients who were in the pre-contemplation stage were less adherent with their medications. Patients in pre-contemplation frequently deny their illness or its severity, refuting their need for treatment (Prochaska, Spring, et al., 2008). This was also identified in patients who were high in the resilience factor of defensive coping, where they were less adherent to their medications. These patients' decisions are based on their altered perception of their current health status. Improving adherence in these patients requires open dialogue between the patient and the clinician or other health care providers, in order to reduce the negative association they have about their illness. Not until patients accept that they have an illness will they be ready to make decisions that aim to improve their health and well-being. Similarly, COPD patients in the action stage are focused on decisions that involve undertaking the behavioural and lifestyle changes their clinicians are proposing; it is a time when various behavioural changes should be discussed with the patient.

Finally, this study identified that the reduced 35-item SGRQ is a valid and reliable measure of HRQoL in Australian COPD patients. However, the factors that comprised this model differed from that of the original version. This abridged version can be used to accurately examine more factors than the original, including how the disease impacts

upon Australian COPD patients' ability to perform activities; when breathlessness causes them to stop or slow down; how their symptoms impact upon their daily life; their coughing experiences; and the impact that respiratory medications have upon their daily life. The 35-item SGRQ will reduce the time taken to administer and gives a more specific identification of COPD patients' symptomatic difficulties.

Combined, these results suggest that resilience, readiness to change, and self-management are important components to consider for the implementation of behavioural and lifestyle changes for COPD patients and improvements in their HRQoL. Behavioural and lifestyle changes begin with the individual accepting the need to make changes. Undertaking training in self-management skills is an important beginning for disease management behaviour changes. Self-management training improves COPD patients' disease specific self-efficacy and assists in improving their life satisfaction. Although there is yet no standardised criteria for inclusion in self-management interventions, this research identified that the provision of disease specific education, exacerbation identification and management strategies, and safe exercise information were critical components to include for improving COPD patients' HRQoL.

The conceptual framework for this study extended the link between self-management and HRQoL to propose a relationship between COPD patients' levels of resilience and readiness to change with their HRQoL and adherence to behavioural and lifestyle changes. Identified in the meta-analysis, self-management interventions improved an aspect of COPD patients' resilience: their self-efficacy. Patients high in self-efficacy were found to have greater HRQoL. Patients who are educated on disease management strategies have confidence in their own abilities and are better equipped to cope with the functional limitations and frequent disturbances they experience as a result of their illness, improving both their HRQoL and self-esteem. Although patients who are provided with self-management education are better equipped to manage their

illness disturbances, patients with low self-esteem will not feel worthy of receiving the training and will be less likely to undertake a self-management approach or the other behavioural and lifestyle changes that are recommended by their clinicians.

COPD is frequently identified as a disease that is caused by lifestyle choices such as smoking (Stellefson et al., 2009; Yang et al., 2017). This identification as a self-inflicted disease carries with it judgement and stigma, which can greatly impact on a patient's self-esteem. Self-esteem has been found to be highly important in behavioural and lifestyle changes as well as the patient's HRQoL. To assist in raising COPD patients' self-esteem the stigma associated with the disease needs to be reduced. Patients need to experience empathetical support and be informed that the disease can also develop from other causes: one-third of the patients in this study had never smoked cigarettes. Providing disease knowledge to the patient not only reduces the stigma, it assists with empowering the patient to partake in decisions regarding the management of their disease.

COPD patients' decision making abilities were found to be important for their HRQoL, completion of pulmonary rehabilitation, and adherence to medication regimens. Patients' disease specific decision making abilities can be enhanced through open dialogue between the clinician and patient (Brown & Bussell, 2011). Prior to making decisions, COPD patients need to be educated on their disease and their treatment options, including both pharmacological and non-pharmacological. These options then need to be combined with the patients' health goals, with treatment options being discussed for their benefits and limitations. Providing the patient with the opportunity to be involved with their treatment decisions can strengthen the patient—clinician relationship, improve trust, increase patient self-efficacy, self-esteem, HRQoL, and adherence to recommended behavioural and lifestyle changes.

Supportive relationships, whether they be from clinicians, other health care providers, family or friends, are crucial for COPD patients' HRQoL and adherence to behavioural and lifestyle changes. COPD patients who have adequate support from these relationships are better able to cope when they experience illness disturbances. Having assistance with performing activities of daily living can reduce patients' anxiety, and anxiety has been found to increase patients' levels of dyspnoea (Bailey, 2004). Furthermore, supportive relationships can increase COPD patients' self-esteem, encouraging them to persist with their behavioural and lifestyle changes following an illness disturbance, as they trust that the changes are achievable and beneficial.

Trusting in a clinician, health care professional, or in the proposed recommendations was highly important for COPD patients' adherence to medications. As mentioned previously, trust is developed through supportive professional relationships. The dialogue of these relationships needs to convey experience, knowledge, and a willingness to consider patients' health goals. When COPD patients have trust, they have a sense of safety and belief that the benefits will outweigh the risks of undertaking the recommended behavioural and lifestyle changes. Trust reduces patients' defensiveness and can assist the decision making process. Patients who have a positive trusting relationship with their clinician feel that they have been provided with all possible treatment options and that they can discuss any concerns that they may have in order to make an informed decision.

Although the use of defensive coping in this study was found to be related to improvements in COPD patients' HRQoL, it is believed that such improvements would be short lived, acting only as a buffer against anxiety caused by the illness disturbances. When examining defensive coping in relation to adherence to behavioural and lifestyle changes, a negative association was found: patients who denied their illness or its severity were less adherent to their medications and less likely to complete pulmonary

rehabilitation. Low adherence was also found in COPD patients who were in the precontemplation stage; essentially denying their need to make behavioural and lifestyle changes in order to improve their health status.

Pre-contemplation is a difficult stage to dispel, as patients may heavily deny their health issues, downplaying their complications to other causes. It is only when COPD patients begin to accept that they need to take action that they begin to consider and implement the changes that can improve their well-being (Prochaska, Redding, et al., 2008). Motivating patients to transition into action from pre-contemplation will involve the COPD patient and clinician developing a supportive, trusting relationship in which the disease, treatment options and patient's health goals can be openly discussed in order to develop a gradual health plan involving behavioural and lifestyle changes. Patients' focus will need to be on symptom management that fosters improvements in self-management skills, self-efficacy, and self-esteem.

5.4. Limitations of the research

Although this thesis has identified some positive findings, there are several limitations that need to be considered when interpreting the results. Firstly, the meta-analysis only ran subgroup analyses on four components to ensure that adequate power was maintained. This excluded five educational components from being analysed for their effect on COPD patients' HRQoL, and those effects remain unknown.

Secondly, the main limitation for the following four studies for which patient data was collected involves the study design. A cross-sectional observational study design was employed, with the data being collected at a single time point. Collecting data in this way limits the interpretation of the results to an examination of the relationships between the variables and does not provide the opportunity to assess any causal conclusions. A self-report questionnaire was utilised in this research and the data

obtained may be subjective and may not accurately reflect the actual experiences or severity of impacts that are occurring in the patient's life. Nevertheless, the reliability and validity of each of the measures was found to be good to excellent, providing suitable and consistent results.

A third limitation involves the recruitment of the participants, who were obtained via convenience sampling. All participants for the final four studies were recruited from South-Eastern Queensland. Limiting the recruitment location to this region reduces the generalisability of the findings, indicating that the results need to be interpreted with caution when being compared with COPD patients in other geographical locations. The participants were recruited from the Gold Coast University or Robina hospitals, or from COPD education seminars held at Brisbane, Helensvale or Robina community health centres. The primary limitation regarding the hospitalised patients is that many reported feeling too unwell to partake in the study; thus, we were unable to examine whether the patients who declined to participate differed in any way to the patients who completed the survey instrument. In addition to this, participants recruited from the community were all attending COPD education seminars, which excluded non-hospitalised patients who were not actively undertaking education. Non-hospitalised patients not attending COPD education may have been in different stages of readiness to change (e.g. precontemplation) or had different levels of resilience, which could have changed the outcome of the results.

Fourthly, further limitations regarding the participants need to be considered when interpreting the results. Almost all of the COPD patients recruited in this study were Caucasian. In the past smoking was heavily influenced by socio-economic status and culture. Considering this, the sample obtained was not representative of other ethnic cultures, which made it difficult to draw conclusions about the impact of COPD on other cultural groups in Australia. Another limitation involves the unknown disease

severity of the COPD patients. As this study undertook self-report measures, we were unable to obtain accurate records of the patients' current FEV₁ status. The failure to obtain this information means that comparisons between the patients' disease severity could not be conducted, nor could they be controlled for.

Finally, it was identified that the refactored SGRQ model fit was good, but it is required to be more robust in order to maintain strong validity when measuring COPD patients' HRQoL. This lower model fit means that the HRQoL results need to be interpreted with caution.

5.5. Recommendations for future research

The results of this study have demonstrated that relationships exist between COPD patients' individual and contextual resilience, and their HRQoL and pulmonary rehabilitation program completion. Associations have also been identified between COPD patients' individual and contextual resilience, readiness to change and adherence to medication regimens. The identification of these relationships paves the way for future research regarding COPD patients' levels of resilience, readiness to change, and adherence to behavioural and lifestyle changes. Thus, future research on these topics should undertake experimental research designs. When considering COPD patients' completion of pulmonary rehabilitation programs, future intervention studies should examine COPD patients' change in resilience (with the inclusion of a factor on trust in the program), from baseline to post intervention and 12-month follow-up. Current findings suggest that COPD patients either have high levels of resilience before starting pulmonary rehabilitation or experience increases in resilience as a result of completing the program.

Second to this is COPD patients' readiness to change. The associations in this thesis inferred that COPD patients' readiness to change may influence their adherence

to clinicians' recommendations to behavioural and lifestyle changes. Future studies could firstly examine whether the COPD education seminars provided by Lung Foundation Australia or Helensvale and Robina Community health centres progresses COPD patients from a stage of pre-contemplation through to contemplation or action of disease self-management, pulmonary rehabilitation completion, and/or improves their medication adherence. This would be best achieved by conducting assessments of COPD patients' readiness to change before and after their participation in COPD education seminars. Further follow-ups could investigate whether COPD patients in the action stage became more adherent to their medications, undertook a self-management approach, or completed pulmonary rehabilitation.

To address the issue of obtaining a representative sample of COPD patients, it is recommended that future studies should expand the recruitment of COPD patients to include participants from various cultural and socio-economic groups, plus participants from the community who are not actively participating in disease specific programs, thereby increasing the generalisability of the findings. Further to this, future association studies should also incorporate clinical patient data such as FEV₁, weight and current exercise capacity, in order to reduce bias and control for physical differences between the patients.

Regarding future meta-analysis studies on COPD patient self-management interventions, replications should investigate the influence of other educational components in order to gain a better understanding of which components to include in self-management programs. The identification of important educational components can assist the development of a standardised self-management intervention for COPD patients. It is also recommended that future meta-analyses conduct subgroup analyses to investigate the stability of improvements in COPD patients' health outcomes at intervals following completion of a self-management intervention. This measure could determine

if such interventions provide long-term benefits and whether these benefits remain clinically relevant.

5.6. Conclusion

The research conducted in this thesis furthered our understanding on COPD patients' barriers to behavioural and lifestyle changes. The results identified that COPD patients who participate in self-management programs experience significant improvements to their HRQoL, especially when the self-management program includes disease specific education. Further to this, it was also determined that COPD patients' individual and contextual level resilience factors are related to their HRQoL. Further examination of COPD patients' resilience found that both individual and contextual resilience factors were associated with their completion of pulmonary rehabilitation programs. It was also identified that COPD patients' adherence to medication regimens was related to both their readiness to change and their levels of resilience. The final study examined the factor structure of the SGRQ, finding that Australian COPD patients require a different factor set in order to examine the relationship of different variables to COPD patients' HRQoL. These results suggest that COPD patients' adherence to behavioural and lifestyle changes is related to their individual and contextual resilience, and their stage of readiness to change. Although further research is needed to identify the causal nature of these relationships, it can be determined that having high levels of resilience and being ready to take action are important for COPD patients' HRQoL and their adherence to pulmonary rehabilitation and medication regimens.

Appendices

Appendix A: Ethics Approvals

GRIFFITH UNIVERSITY HUMAN RESEARCH ETHICS REVIEW

Dear Dr Jing Sun

I write further to the additional information provided in relation to the provisional approval granted to your application for ethical clearance for your project "Understanding COPD Patients Barriers to Behavioural and Lifestyle Changes using a Grief, Readiness-to-change, and Resilience Model." (GU Ref No: 2015/677).

This is to confirm that this response has addressed the comments and concerns of the HREC.

The ethics reviewers resolved to grant your application a clearance status of "Fully Approved".

Consequently, you are authorised to immediately commence this research on this basis.

Regards

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Human Research Ethics and Integrity
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Queensland Health



District Research Governance

Enquiries to:

Research Governance Leader

Phone: Fax: Our Ref: (07) 5687 3880 (07) 5687 3797 SSA/15/QGC/270

Dr Jing Sun Principal Investigator Griffith University – Gold Coast Campus Parklands Drive SOUTHPORT QLD 4222

Dear Dr Sun,

HREC reference number: SSA reference number:

HREC/15/QGC/232

Project title:

SSA/15/QGC/270

Understanding COPD Patients' Barriers to Behavioural and Lifestyle Changes using a Grief, Readiness-to-change, and Resilience Model.

Thank you for submitting an application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

Gold Coast Hospital and Health Service

Ethics approval for this project was granted on 9 October 2015 by the Gold Coast Hospital and Health Service Human Research Ethics Committee and the approval letter contains a list of all the approved documents.

The documents reviewed and authorised that are relevant to this site are listed below.

Document	Version No	Version date
SSA application (AU/3/6BF124)		
Research Collaboration Deed – Project Schedule		

The following conditions apply to this research proposal. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval.

- Proposed amendments to the research protocol or conduct of the research which may affect the
 ethical acceptability of the project are to be submitted to the HREC for review. A copy of the HREC
 approval/rejection letter must be submitted to the RGO;
- Proposed amendments to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted to the research governance officer;
- 3) Proposed amendments to the research protocol or conduct of the research which may affect both the going ethical acceptability of the project and the site acceptability of the project are to be submitted firstly to the HREC for review and then to the research governance officer after a HREC decision is made.

Office
Research Directorate
Level 2, Pathology and Education Building
1 Hospital Boulevard
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61 7 5687 7838

Gold Coast Health Building a healthier community



Office of the Human Research Ethics Committee

Enquiries to: HREC coordinator 10 June 2016 Phone: 07 5687

3879

HREC Ref HREC/15/QGC/232

E-mail:: GCHEthics@health.qld.gov.au

Dr Jing Sun Griffith University Parklands Drive Southport, QLD 4222

Dear Dr Sun

HREC Reference: HREC/15/QGC/232

Project title: Understanding COPD Patients' Barriers to Behavioural and Lifestyle Changes using a

Grief, Readiness-to-change, and Resilience Model

Amendment number: AM01

The following documentation was reviewed and approved at the meeting of the Chair of the Gold Coast Hospital and Health Service Human Research Ethics Committee (HREC) held on 8 June 2016

The amendment will be ratified at the HREC meeting to be held on 22 June 2016.

Document	Version	Date
Protocol amendment - Obtain additional data from hospital records (previous hospital admissions, length of admissions and spirometry results)		06 June 2016

The HREC is constituted and operates in accordance with the National Health and Medical Research Council's "National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the "CPMP/ICH Note for Guidance on Good Clinical Practice".

A copy of this letter must be forwarded to the GCHHS Research Governance Office/r.

It should be noted that all requirements of the original approval still apply.

If you have any queries please do not hesitate to contact the HREC Coordinator on 07 5687 3879 or via GCHEthics@health.qld.gov.au

Yours sincerely

Vanessa Druett HREC Coordinator On behalf of E/Prof Drew Nesdale

Chair HREC

Gold Coast Hospital and Health Service Human Research Ethics Committee (EC00160)

Office Phone 61 7 5687 3879

Research Directorate Building 1 Hospital Boulevard Southport QLD 4215 Level 2, Pathology and Education

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Understanding COPD Patients' Barriers to Behavioural and Lifestyle Changes using a Grief, Readiness-to-change, and Resilience Model HARD COPY QUESTIONNAIRE COVERSHEET

Who is conducting the research

Senior investigator

Dr Jing Sun Griffith University, School of Medicine (07) 567 80924 i.sun@griffith.edu.au

Research Team

Danielle Cannon (*Primary contact*)
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Griffith University Human Research Ethics reference number: MED/40/15/HREC; 2015_677 Gold Coast Health Ethics reference number: HREC/15/QGC/232

Why is the research being conducted?

Undertaking clinicians recommended behavioural and lifestyle changes following a COPD diagnosis is a challenging yet important aspect of treatment. Recent research has demonstrated that many patients experience difficulties in undertaking some of these changes such as smoking cessation, pulmonary rehabilitation, and following a specific medication regimen. This study aims to investigate some of the psychological aspects which may pose as a barrier to adapting to these proposed behavioural and lifestyle changes.

This research is being undertaken as a part of the requirements for the candidature of Danielle Cannon's Doctor of Philosophy.

What you will be asked to do

If you consent to participate in this research you will be required to complete a paper based survey. The survey will take approximately 30 minutes to complete and will ask you questions about your COPD diagnosis, your knowledge and attendance of pulmonary rehabilitation, as well as information about your smoking status, medication use, your psychological well-being and general information about yourself. This survey can be completed either with the researcher at initial contact or at home and returned via a stamped self-addressed envelope. In addition to this, information regarding your last spirometry result, and hospital admissions, including your length of stay will be obtained from hospital records.

The basis by which participants will be selected or screened

To participate in this research participants must be aged over 18 years, and must **not** have a serious cognitive impairment, any other unstable medical or major psychiatric and neurological conditions.

The expected benefits of the research

It is expected that the results of this research will provide a greater understanding of the psychological difficulties that COPD patients' experience. This information can then be used to assist in the development of future services for COPD patients; taking into account these psychological difficulties.

Risks to you

Although there are no perceived risks associated with taking part in this research, it is possible that some of the questions could raise your awareness and increase the distress you feel about your current situation. If your levels of distress increase as a result of your participation in this study it is advised that you discuss these feelings with your general practitioner, contact Lifeline on 13 11 14, or Beyond Blue on 1300 22 4636.

Your confidentiality

Initially the surveys will contain identifying information (participant name) in order to allow participants to withdraw consent and to avoid duplicates within the survey data. Following the data being extracted from all the surveys, all identifying information will be destroyed. As a result participants will not be able to be identified in any publication or reporting of the results. The data obtained from the surveys will be retained by Griffith University and will be stored in accordance with Griffith University's storage guidelines; that is, paper based material (survey responses) will be stored in a locked cabinet, electronic data (coded responses) will be stored on Griffith University's password protected research storage platform. All stored data will be retained in an unidentifiable form for a period of five years and will only be able to be accessed by the research team.

Your participation is voluntary

Participation in this research is voluntary and only be accepted if informed consent is provided by the participant (form attached to the survey). You may also withdraw your consent at any time by contacting the primary contact person on at the top of this form. Although it is preferable for you to answer all questions, you do not have to answer every question unless you wish to do so. It must also be noted that your decision to participate (or not to participate) will in no way impact upon any relationship you may have with any of the research team.

Mechanism for distribution and return

The survey will be either handed to participants in person or mailed out to potential participants. Return questionnaires can either be handed back to the research team in person or can be returned via a self-addressed envelope to the contact person on the research team.

Questions / further information

Should you have any further queries regarding this research you should contact the primary contact person Danielle Cannon on 0410 639 80924 (danielle.cannon@griffithuni.edu.au). Sun 567 Dr Jing on (07)(j.sun@griffith.edu.au), or one of the other researchers listed at the top of this form.

The ethical conduct of this research

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research* (2007). If potential participants have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Research Ethics on (07) 3735 4375 or researchethics@griffith.edu.au.

Feedback to you

The data obtained in this research project will be analysed as group data, results will not be presented in an individually identifiable manner. The group data is intended to be reported via publications, conferences, and/or seminars to the community. At intervals a summary of the results will be sent out to participants via email or post. This document will contain a summary of the key findings regarding the research questions.

Privacy Statement - anonymous or de-identified information

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 4375.

Expressing consent – anonymous or de-identified information

Please retain this sheet for your later reference. By completing this survey, it will be deemed that you have consented to participating in this research project.

Understanding COPD Patients' Barriers to Behavioural and Lifestyle Changes using a Grief, Readiness-to-change, and Resilience Model CONSENT FORM

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By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this research will include completing a survey that enquires into my thoughts and feelings regarding my illness, and that this form will take approximately 30 minutes to complete;
- Information regarding my last spirometry result, and hospital admissions, including my length of stay will be obtained from hospital records;
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
- I understand that there will be no direct benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary;

- I understand that if I have any additional questions I can contact the research team;
 I understand that I am free to withdraw at any time, without explanation or penalty;
- I understand that I can contact the Manager, Research Ethics, at Griffith University
 Human Research Ethics Committee on 3735 4375 (or <u>research-ethics@griffith.edu.au</u>) if I have any concerns about the ethical conduct of the project; and

project; a	and
☐ I agree to	participate in the project.
-	to inclusion of my personal information in publication or reporting of the this research in the project.
Name	
Signature	
Date	



Patients' Perception to Undertake Behavioural and Lifestyle Changes Questionnaire

Date:			
ID:	-		
Your name			
Instruction:			

The following questions are asking about your diagnosis, personal strengths, pulmonary rehabilitation knowledge, level of exercise, smoking, medication use, and your end of life care planning. There are no right or wrong answers. Please be honest, answer all questions and choose only one answer for each question. Your contribution to the project is greatly appreciated.

Thank you very much

1.	Has a medical doctor ever diagnosed you with Chronic Obstructive Pulmonary Disease (COPD)? ☐ Yes ☐ No
2.	Have you ever been referred to a pulmonary rehabilitation program? ☐ Yes ☐ No - if no go to question 5
	☐ Referred by Specialist/GP (Please circle)
3.	Did you complete at least 10 sessions of the pulmonary rehabilitation program? ☐ Yes (Years since completion)
	□ No
	At what stage of illness severity were you referred to the pulmonary rehabilitation program? sease severity
	☐ Mild: FEV1≥ 80% normal
	☐ Moderate: FEV1 50-79% normal
	☐ Severe: FEV ₁ 30-49% normal
	☐ Very Severe: FEV1 <30% normal
	☐ Don't know/cannot remember
Ex	cacerbation frequency (number of exacerbations in last 12 months)
	☐ After 1 exacerbation
	☐ After 2-3 exacerbations
	☐ After 4-5 exacerbations
	☐ After 6 or more exacerbations
	☐ Don't know/cannot remember
5.	How would you rate your overall knowledge of pulmonary rehabilitation programs? ☐ Very poor
	□ Poor
	□ Average
	□ Good
	□ Very good

6.	What is your current smoking status? ☐ Non-smoker
	☐ Ex-smoker
	☐ Smoke less than 7 cigarettes per day
	☐ Smoke 8 to 20 cigarettes per day
	☐ Smoke more than 20 cigarettes per day
	The next four questions refer to your medication use over the last month:
7.	Have you ever forgotten to take your respiratory medication? (select only one)
	□ Never
	□ Occasionally
	□ Always
8.	If you feel your respiratory symptoms got worse or remained unimproved, do you stop taking your respiratory medication? (select only one)
	□ Never
	□ Occasionally
	□ Always
9.	If you think your respiratory symptoms are improving, do you stop taking your respiratory medication? (tick only one)
	□ Never
	□ Occasionally
	□ Always
10.	Do you take your medicine at the same time every day? (select only one)
	□ Never
	□ Occasionally
	□ Always

11. The next set of questions ask you to indicate your level of agreement with the following statements about the potential benefits and consequences of pulmonary rehabilitation programs. Do Pulmonary rehabilitation programs:

1. Improve a COPD patient's	1	2	3	4	5	6	7
general well-being	Strongly Disagree	Disagree	Somewhat Disagree	Undecided	Somewhat Agree	Agree	Strongly Agree
2. Increase the risk of escalating the symptoms or adverse effects of other	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
illnesses, such as a heart attack							
3. Increase the risk of injury	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
4. Improve a COPD patient's quality of life	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
5. Increase COPD patients' exercise capacity	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
6. Increase COPD patients' levels of anxiety	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
7. Reduce exacerbations	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
8. Help COPD patients to reach their health goals	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
9. Improve COPD patients' levels of depression	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
10. Reduce COPD patients' ability to perform basic home duties	1 Strongly Disagree	2 Disagree	Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
11. Increase hospitalisations	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
12. Increase the use of health care services, e.g. GP visits	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
13. Provide a last hope for improving COPD patients' health	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree
14. Help COPD patients to set health goals	1 Strongly Disagree	2 Disagree	3 Somewhat Disagree	4 Undecided	5 Somewhat Agree	6 Agree	7 Strongly Agree

12. COPD Acceptance of Disease and Impairments Questionnaire (Boer et al., 2014): The next set of questions refer to your illness; to what level do you agree or disagree with the following statements?

1. I sometimes pretend that I do not have	1	2	3	4	5
any impairments	Not at all True	Rarely True	Sometimes	Often True	Almost
any impanincitis			True		Always True
2. I do not want to be confronted with my	1	2	3	4	5
impoirmente	Not at all True	Rarely True	Sometimes	Often True	Almost
impairments			True		Always True

3. I try to ignore my impairments	1	2	3	4	5
January Paragraphy	Not at all True	Rarely True	Sometimes	Often True	Almost
			True		Always True
4. I try to forget my impairments as much	1	2	3	4	5
as possible	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
5. I become angry when I notice that I	1	2	3	4	5
cannot do something anymore	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
6. I feel frustrated by my impairments	1	2	3	4	5
5 5 1	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
7. I become angry when I experience an	1	2	3	4	5
impairment	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
8. I become sad when I notice that I cannot	1	2	3	4	5
do something anymore	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
9. I become sad when I think about my	1	2	3	4	5
impairments	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
10. I become sad when I experience an	1	2	3	4	5
impairment	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
11. I have learned to live with my illness	1	2	3	4	5
, and the second	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
12. I can accept my illness	1	2	3	4	5
1 3	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
13. I can accept my impairments	1	2	3	4	5
	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
14. I have learned to live with my	1	2	3	4	5
impairments	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True

13. Connor-Davidson Resilience Scale (Connor & Davidson, 2003):

The next set of items ask you to rate your feelings about the following statements over the past month:

1. Able to adapt to change	1	2	3	4	5
g.	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
2. Have close and secure relationships	1	2	3	4	5
F.	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
3. Sometimes fate or God can help	1	2	3	4	5
1	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
4. Can deal with whatever comes	1	2	3	4	5
	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
5. Past success gives confidence for	1	2	3	4	5
new challenge	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
6. See the humorous side of things	1	2	3	4	5
8	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
7. Coping with stress strengthens	1	2	3	4	5
r S	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
8. Tend to bounce back after illness	1	2	3	4	5
or hardship	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True

9. Things happen for a reason	1	2	3	4	5
7. Things happen for a reason	Not at all True	Rarely True	Sometimes True	Often True	Almost
		,			Always True
10. Best effort no matter what	1	2	3	4	5
To Best effort no matter what	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
11. You can achieve your goals	1	2	3	4	5
11. Tou can deme ve your goans	Not at all True	Rarely True	Sometimes True	Often True	Almost
		-			Always True
12. When things look hopeless, I	1	2	3	4	5
	Not at all True	Rarely True	Sometimes True	Often True	Almost
don't give up					Always True
13. Know where to turn for help	1	2	3	4	5
_	Not at all True	Rarely True	Sometimes True	Often True	Almost
					Always True
14. Under pressure, I focus and think	1	2	3	4	5
clearly	Not at all True	Rarely True	Sometimes True	Often True	Almost
*	1	2	2	4	Always True
15. Prefer to take the lead in problem	1	2	3	4	5
solving	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
16. Not easily discouraged by failure	1	2	3	4	5
, E	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
17. Think of self as strong person	1	2	3	4	5
Try Times of Soil as Suiong Person	Not at all True	Rarely True	Sometimes True	Often True	Almost
					Always True
18. Make unpopular or difficult	1	2	3	4	5
decisions	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
19. Can handle unpleasant feelings	1	2	3	4	5
17. Can nancie ampieasant reenings	Not at all True	Rarely True	Sometimes True	Often True	Almost
		-			Always True
20. Can act on a hunch	1	2	3	4	5
	Not at all True	Rarely True	Sometimes True	Often True	Almost
					Always True
21. Strong sense of purpose	1	2	3	4	5
	Not at all True	Rarely True	Sometimes True	Often True	Almost
					Always True
22. In control of your life	1	2	3	4	5
	Not at all True	Rarely True	Sometimes True	Often True	Almost
22 1171111	1	2	3	4	Always True 5
23. I like challenges	l Not at all True	_		•	_
	Not at all True	Rarely True	Sometimes True	Often True	Almost Always True
24 Vou work to attain your goals	1	2.	3	4	5
24. You work to attain your goals	Not at all True	Rarely True	Sometimes True	Often True	Almost
	110t at all 11uc	Raiciy True	Sometimes True	Onen Hue	Always True
25. Pride in your achievements	1	2	3	4	5
23. I fide in your acine venicitis	Not at all True	Rarely True	Sometimes True	Often True	Almost
					Always True

14. Readiness-to-Change Questionnaire (Heather & Rollnick, 1993):

The next set of questions refer to how you personally feel about your clinicians' treatment recommendations; to what level do you agree or disagree with the following statements?

1. I don't think I need to undertake	1	2	3	4	5
my clinicians' recommendations	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
2. I am trying to incorporate my	1	2	3	4	5
clinicians' treatment	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
recommendations better than I have					
done in the past					

3. I enjoy undertaking new treatment	1	2	3	4	5
regimes, but sometimes I don't	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
continue these changes					9
4. Sometimes I think I should follow	1	2	3	4	5
my clinicians' recommendations	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
better					
5. It's a waste of time thinking about	1	2	3	4	5
my clinicians' recommendations	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
6. I have just recently undertaken my	1	2	3	4	5
clinicians' recommendations	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
7. Anyone can talk about wanting to	1	2	3	4	5
follow their treatment	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
recommendations, but I am actually					_
doing something about it					
8. I am at the stage where I should	1	2	3	4	5
think about following my clinicians'	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
recommendations					
9. The amount I follow my treatment	1	2	3	4	5
recommendations is a problem	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
sometimes					
10. There is no need for me to think	1	2	3	4	5
about changing my previous	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
treatment regimen					
11. I am actually changing my	1	2	3	4	5
treatment regimen right now	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
12. Undertaking these treatment	1	2	3	4	5
recommendations would be pointless	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
for me					
	<u> </u>	D 1			

St George Respiratory Questionnaire (Jones, Quirk, & Baveystock, 1991b):

The next set of questions ask how your breathing is troubling you and how it affects your life:

15.	Ov	er the past 4 weeks, I have coughed:
		Most days
		Several days
		With chest infections
		Not at all
6.	Ov	er the past 4 weeks, I have brought up phlegm (sputum):
		Most days a week
		Several days a week
		A few days a month
		With chest infections
		Not at all

17.	Over the past 4 weeks, I have had shortness of breath:
	☐ Most days a week
	☐ Several days a week
	☐ A few days a month
	☐ With chest infections
	□ Not at all
18.	Over the past 4 weeks, I have had attacks of wheezing:
	☐ Most days a week
	☐ Several days a week
	☐ A few days a month
	☐ With chest infections
	□ Not at all
19.	During the past 4 weeks, how many severe or very unpleasant attacks of chest problem have you had?
	☐ More than 3 attacks
	☐ 3 attacks
	☐ 2 attacks
	☐ 1 attack
	□ No attacks
20.	How long did the worst attack of chest problem last: (Go to question 21 if you had no severe attacks)
	☐ A week or more
	☐ 3 days or more
	□ 1 or 2 days
	☐ Less than a day
21.	Over the past 4 weeks, in an average week, how many good days (with little chest problem) have you had?
	☐ No good days
	□ 1 or 2 good days
	□ 3 or 4 good days
	☐ Nearly every day was good
	☐ Every day was good

22.	If y	you have a wheeze, is it worse in the morning?		
		Yes		
		No		
23.	Но	w would you describe your chest condition?		
		The most important problem I have		
		Causes me quite a lot of problems		
		Causes me a few problems		
		Causes me no problems		
24.	If y	ou have ever had paid employment?		
		My chest problem made me stop work altog	gether	
		My chest problem interferes with my work	or made	e me change my work
		My chest problem does not affect my work		
		Sitting or lying still Getting washed or dressed Walking around at home Walking outside on the level Climbing up a flight of stairs Climbing hills Playing sports or games	each ite it app True	m, please tick (✓) the box as lies to you these days: False □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □
26.	Soı	me more questions about your cough and breath		
		For		m , please tick (\checkmark) the box as lies to you <i>these days</i> :
		My cough hurts My cough makes me tired I am breathless when I talk I am breathless when I bend over My cough or breathing disturbs my sleep I get exhausted easily	True	False

		blease tick (\checkmark) the blease to you <i>these days</i> :	ox as
	True	False	
My cough or breathing is embarrassing in public			
My chest problem is a nuisance to my family, friends or neighbours		_	
I get afraid or panic when I cannot get my breath		_	
I feel that I am not in control of my chest problem			
I do not expect my chest to get any better		_	
I have become frail or an invalid because of my chest			
Exercise is not safe for me			
Everything seems too much of an effort			
28. Questions about your medication. If you are taking no medication go st	raight to q	uestion 29.	
For <i>each item</i> , please to it applies to you			
True False	mese aay	.	
My medication does not help me very much			
I get embarrassed using my medication in public			
I have unpleasant side effects from my medication			
My medication interferes with my life a lot			
29. These are questions about how your activities might be affected by you	r breathing	<u>5</u> .	
		ease tick (🗸) the box	
applies t		cause of your breat	hing:
	True	_	
I take a long time to get washed or dresse			
I cannot take a bath or shower, or I take a long tim			
I walk slower than other people, or I stop for rest			
Jobs such as housework take a long time, or I have to stop for rest			
If I walk up one flight of stairs, I have to go slowly or sto	•		
If I hurry or walk fast, I have to stop or slow dow	n 🗖		
My breathing makes it difficult to do things such as climbing up hills, carryin things up stairs, light gardening such as weeding, dancing, playing bowls or gold	-		
My breathing makes it difficult to do things such as carrying heavy loads			
digging the garden or shovelling snow, jogging or walkin	-	П	
at 8 kilometres per hour, playing tennis or swimmin	-		
My breathing makes it difficult to do things such as very heavy manual work running, cycling, swimming fast or playing competitive sport			

27. Questions about other effects that your chest problem may have on you these days.

30. We would like to know how your chest problem <u>usually</u> affects your daily life.

For *each item*, please tick (\checkmark) the box as it applies to you *because of your chest problem*:

I cannot play sports or games I cannot go out for entertainment or recreation I cannot go out of the house to do the groceries I cannot do housework I cannot move far from my bed or chair	True	False	
31. Here is a list of other activities that your chest prob they are just to remind you of ways in which your b	-		
Going for walks or walking the dog Doing things at home or in the garden Sexual intercourse Going out to church or place of entertainment Going out in bad weather or into smoky rooms Visiting family or friends or playing with child			
Please write in any other important activities th	at your	chest proble	em may stop you doing:
	•••••		
Now, would you tick the box (one only) which	you thi	nk best desc	ribes now your chest affects you:
It does not stop me doing anything I wo It stops me doing one or two things I wo It stops me doing most of the things I w It stops me doing everything I would like	ould like ould lik	e to do	
The final set of questions pertain to information	n about	you: Please	circle your response
32. What is your age ☐ 18-45			
□ 46-55			
□ 56-65			
□ 66-75			
□ 76+			

33. Gender ☐ Male
☐ Female
34. Marital Status ☐ Married
☐ Divorced/Separated
☐ De-facto
□ Single
☐ Widowed
35. Number of individuals in your household (including yourself): ☐ 1 ☐ 2-3
□ 4->6
36. Religion ☐ Catholic
☐ Muslim
☐ Protestant
☐ Other
☐ No religion
☐ Prefer not to say
37. Ethnicity ☐ Caucasian
☐ Aboriginal/Torres Strait Islander
☐ Asian
☐ Middle Eastern
□ Other
38. Length of time since COPD diagnosis (years): □ ≤1
□ 2-3
□ 4-6
1 7-9
□ ≥10

39.	What is your average amount of weekly exercise (hours): $\square \le 1$
	□ 2-3
	□ 4-5
	□ 6-7
	□ ≥8
40.	What is your current employment status? ☐ Unemployed/disability
	□ Part-time
	☐ Full-time
	□ Retired
41.	What is the highest level of education you have completed? ☐ Junior/Intermediate certificate (year 10) or before
	☐ Senior/Leaving certificate (years 11 - 12)
	☐ TAFE certificate or equivalent
	☐ Undergraduate degree
	☐ Postgraduate degree
42.	What is your annual household income? □ ≤\$19,999
	□ \$20,000-\$39,999
	□ \$40,000-\$59,999
	□ \$60,000-\$79,999
	□ ≥\$80,000
	☐ Prefer not to say
43.	Do you think that completing the pulmonary rehabilitation program will affect your disability pension (in the future or currently)? Yes
	□ No
	☐ Unsure

44. Ha	ve or are you completing the wellness program?
	Yes
	No
	Unsure

45. Have you been diagnosed with any of the following diseases?

No	Yes (diagnosed by doctor)
No	Yes (diagnosed by doctor)
No	Yes (diagnosed by doctor/psychologist)
No	Yes (diagnosed by doctor/psychologist)
No	Yes (diagnosed by doctor)
No	Yes (diagnosed by doctor)
No	Yes (diagnosed by doctor)
	No

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