

**Understanding motivation to self-manage and
quality of life in people with Chronic Obstructive
Pulmonary Disease – A Self-Determination Theory
Perspective**

Liam Knox

Department of Psychology
Aberystwyth University

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Supervisors: Dr Rachel Rahman

Dr Gareth Norris

Summary

Chronic Obstructive Pulmonary Disease (COPD) is a condition characterised by breathlessness, coughing, and sputum production, which has a detrimental effect on daily activities and health-related quality of life (HRQoL). Although support for HRQoL and self-management has been identified as crucial for people with COPD, attendance and adherence to medication and pulmonary rehabilitation (PR) is historically low; where, a lack of motivation has been suggested as key factor. Research has recommended that psychological theory should be used to fully understand target behaviours; however, there is a sparsity of literature which implements behaviour change theory in this population. Thus, the aim of this thesis was to understand motivation to self-manage and HRQoL in people with COPD utilising a Self-Determination Theory (SDT) perspective. Three independent studies were implemented to meet the overarching aim.

The first study used a questionnaire-based cross-sectional design in a PR waiting-list to investigate the ability of SDT concepts to predict self-management regulation and HRQoL. Findings showed that these measures could be predicted by both the satisfaction and thwarting of the basic psychological needs.

The second study investigated the mechanisms by which two healthcare interventions worked; PR and a SDT-based, technology-delivered, self-management intervention called PocketMedic. Results found that both interventions, prescribed independently and in combination, could significantly and positively affect multiple SDT constructs, self-management knowledge, and HRQoL.

The third study implemented qualitative interviews for people who had participated in the second study. Results showed that participants discussed their condition in terms of need thwarting and the two healthcare interventions facilitated the satisfaction of their needs.

This thesis provides a novel understanding of motivation to self-manage and HRQoL in people with COPD using a SDT framework and concludes that the neglect of need thwarting limits the current knowledge of this topic. Future research, strengths and limitations are discussed.

Declaration

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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STATEMENT ONE

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references.

A bibliography is appended.

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STATEMENT TWO

I hereby give consent for my thesis, if accepted, to be available for photocopying and for interlibrary loan, and for the title and summary to be made available to outside organisations.

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Chapter One: Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a progressive, irreversible condition which causes dyspnoea, sputum production, and coughing (World Health Organisation; WHO). These symptoms can cause a range of daily living limitations (Russell, et al., 2018) and, as a result, depression and anxiety are common in people with the condition (Schane, Walter, Dinno, Covinsky, & Woodruff, 2008). Therefore, COPD can have a significant detrimental effect on health-related quality of life (HRQoL; Russell, et al., 2018). Despite people with the condition being extensive users of the National Health Service (NHS; Department of Health, 2012; Dhamane, et al., 2015), approximately only 1% of their time is spent with healthcare professionals (NHS England, 2014). The rest of the time, people with COPD are encouraged to self-manage their condition; where, such behaviours include regular exercise, taking medication, and attending healthcare appointments (National Institute for Health and Care Excellence; NICE, 2018). Supporting HRQoL and self-management behaviours have been highlighted as crucial for the care of people with COPD (Kielmann, et al., 2010). Despite the positive relationship between self-management and outcomes such as HRQoL (Benzo, Abascal-Bolado, & Dulohery, 2015), these behaviours are seldom conducted (Russell, et al., 2018) and adherence to medication is historically low (Bogart, et al., 2018; Bourbeau & Bartlett, 2008; Restrepo, et al., 2008). Within the NHS, pulmonary rehabilitation (PR) is considered usual care for people with COPD (NICE, 2011); however, although the programme has been found to be effective (McCarthy, et al., 2015), attendance and adherence to PR is also low (Steiner, et al., 2015; 2016), limiting its wider benefits to a small proportion of the total number of individuals living with COPD. Although adherence to self-management processes in this condition is multifaceted (Restrepo, et al., 2008), one factor

which has been suggested as important is motivation (Russell, et al., 2018; Sheldon, Williams, & Joiner, 2003).

Authors have suggested that behaviour change theory should be used to fully understand behaviour and processes of change before large scale interventions are developed and deployed (Craig, et al., 2008). However, despite these suggestions and studies reporting that employing psychological theory leads to more beneficial outcomes (Albarracin, et al., 2005; Glanz & Bishop, 2010), there is a dearth of literature implementing behaviour change theory (Davies, Walker, & Grimshaw, 2010; Prestwich, et al., 2014). Additionally, the limited use of psychological theory is even less in interventions designed for people with COPD (McCullough, et al., 2016; Richardson, et al., 2014; Riley, et al., 2014). After the review of four psychological theories of health behaviour change, self-determination theory (SDT; Deci & Ryan, 1985) was found to provide a convincing framework which could increase the current understanding of motivation to self-manage and HRQoL in people with COPD. SDT posits that there are three basic psychological needs; autonomy, competence, and relatedness (Deci & Ryan, 1985). The more an environment or activity satisfies these needs, the greater self-determined motivation an individual will experience towards this behaviour (Deci & Ryan, 2002). SDT features different types of motivation on a scale ranging from intrinsic motivation – where a behaviour is conducted for the sheer joy of the activity – to amotivation – where a behaviour is engaged with passively or not at all (Deci & Ryan, 2002; Markland & Tobin, 2004). Wortz, et al. (2012) found that people with COPD are extrinsically motivated to perform self-management behaviours, which falls between the two extremes of this scale (Ryan & Deci, 2000).

There is a sparsity of research which utilises this theory in populations with COPD (McCullough, et al., 2016; Riley, et al., 2014) and studies which do implement SDT generally aim to predict behaviours in people who have completed a PR programme (Cho, Tung, Lin,

Hsu, & Lee, 2017; Stewart, et al., 2014). Additionally, there are current gaps within the literature regarding SDT, such as the role of basic psychological need thwarting in extrinsically motivated behaviours (Bartholomew, Ntoumanis, Ryan, & Thøgersen-Ntoumani, 2011; Olafsen, Niemiec, Halvari, Deci, & Williams, 2016).

This thesis was developed in order to advance the current literature by using a SDT framework to better understand the potential reasons that people with COPD do not engage with self-management activities, and how interventions designed to improve self-management work to improve motivation and HRQoL. The thesis is structured into three studies which contributed different perspectives to the overarching aim.

The first study considered a PR waiting-list group in order to understand the cross-sectional baseline relationships between SDT variables, self-management regulation, HRQoL, and self-management knowledge. Due to previous studies focusing on post-PR populations, individuals who have been diagnosed with COPD but have not had any formal intervention have gone under-researched. This enabled a greater insight into the effects of being diagnosed with COPD and the corresponding influence this had on motivation to self-manage, HRQoL and self-management knowledge.

The second study used a clinical trial design to consider how two healthcare interventions worked both independently and in compliment to effect SDT variables and, in turn, increase self-management regulation, HRQoL, and self-management knowledge. The two interventions prescribed were PR, which represents usual care, and short digital health films, which were deployed with the intention to improve self-management behaviours. This study enabled a greater understanding to be obtained regarding the mechanisms by which both well-researched and novel interventions work.

Finally, a qualitative study with individuals who participated in the second study was conducted to enable a more in-depth consideration of the experiences of participants who engaged with PR and the digital health films. This allowed a better understanding relating to the experiences of psychological need satisfaction and thwarting, and how the two healthcare interventions influenced these factors; thus, helping to better interpret the quantitative findings from the perspective of those with COPD.

This thesis aimed to provide novel insights into the effects of COPD and factors which influence motivation to self-manage and HRQoL. The thesis makes a unique contribution to existing knowledge by considering the role of basic psychological need thwarting and investigating the mechanisms by which two healthcare interventions work, utilising SDT as a theoretical framework.

The following literature review is split into two chapters. First, COPD is defined and the importance of self-management behaviours explained. Then the efficacy of medication, self-management interventions, and PR reviewed and adherence problems are explored. The third chapter explores the use of psychological theory in a health domain and reviews four models before providing an in-depth review of SDT, which represents the most appropriate theory to explain self-management motivation and HRQoL in people with COPD.

Chapter Two: Chronic Obstructive Pulmonary Disease and treatment

2.1 Chronic Obstructive Pulmonary Disease

2.1.1 Definition and symptoms

The WHO defines COPD as a “lung disease characterized by chronic obstruction of lung airflow that interferes with normal breathing and is not fully reversible” (WHO). Conditions such as chronic bronchitis and emphysema, which have been used extensively in the past (WHO), have been reclassified and fall under the definition of COPD (Mannino, Doherty, & Buist, 2006). Although COPD can be present without significant symptoms (Nazir & Erbland, 2009), typical symptoms include dyspnoea (breathlessness), sputum production, and coughing (WHO). Although daily changes in symptoms can occur, significant variation is uncommon in comparison to other respiratory conditions such as asthma (NICE, 2018).

COPD symptoms can become worse during an acute exacerbation, which is defined as the sudden and prolonged increase in symptoms outside of normal daily fluctuations (NICE, 2018). These usually require medication to resolve (Rabe, et al., 2007). Acute exacerbations occur on average 1.5 to 2 times per year among people with moderate to severe COPD (Murphy & Sethi, 2002). Older age, an increased number of previous exacerbations, and lower forced expiratory volume in 1 second (FEV₁; which negatively correlates to disease severity) are all risk factors (Anzueto, Sethi, & Martinez, 2007; Miravittles, et al., 2000). Additionally, the aetiology of an exacerbation cannot be identified in a third of people with COPD (White, Gompertz, & Stockley, 2003).

Depression and anxiety are common co-morbidities in people with COPD and prevalence rates can be up to 40% (Schane, et al., 2008). This is a higher rate when compared with other chronic conditions including stroke, cancer, diabetes mellitus, and coronary artery disease (Schane, et al., 2008). This demonstrates the significant influence that COPD can have on an individual's HRQoL. Multiple studies have linked depression in people with COPD to a loss of functional mobility and ability to tend to daily tasks, and increased symptom burden and mortality (Ng, et al., 2007; McCathie, Spence, & Tate, 2002; Stein, Cox, Afifi, Belik, & Sareen, 2006). Therefore, symptoms of COPD can cause anxiety and depression (Schane, et al., 2008), which can then lead to the increase in perceived symptoms (Reardon, Lareau, & ZuWallack, 2006). This illustrates the negative cyclical effect of COPD and is not surprising that studies have reported a decrease in HRQoL for people with this condition (Esteban, et al., 2009; Seemungal, et al., 1998). The decrease is also perceived as worse by younger people in comparison to those who are older (Martinez, et al., 2016). This could be as a result of the detrimental impact that COPD has being more noticeable by people who are younger, or the symptoms being perceived as outside the normal effects of aging. Russell, et al. (2018) summarise well the effect of COPD on HRQoL:

Emotional needs are considerable; frustration, depression, and anxiety are common. In addition, patients can face an assortment of losses and limitations on their lifestyle and social interaction. Over time, COPD can consume their existence, reducing motivation. Support from family can prove vital, yet tinged with ambivalence and burden. (para. 1)

2.1.2 Causes and diagnosis

In the developed world, cigarette smoking is the most common cause of COPD (Celli & MacNee, 2004). However, other factors may also be important, including exposure to dust, gases, vapours or fumes (Trupin, et al., 2003); malnutrition (Romieu & Trenga, 2001); early-childhood infections (Shaheen, Barker, & Holgate, 1995); genetic predisposition (Silverman, & Speizer, 1996); increased airways responsiveness (O'Byrne, & Postma, 1999); and asthma (Ulrik, & Backer, 1999). Two reviews of epidemiological studies conclude that the proportion of people with COPD attributable to workplace exposures is 15% (American Thoracic Society, 2003; Blanc & Toren, 2007).

The diagnosis of COPD is primarily conducted using spirometry, which measures how fast air moves in and out of the lungs and how deeply a person can breathe (WHO). One of the advantages of this method is that spirometry is easily used, even by older people. The Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines propose that a diagnosis of COPD should be considered when FEV₁ is less than 80% of the predicted value, in combination with a FEV₁/forced vital capacity (FVC; amount of air exhaled during the spirometry test) ratio of 0.7 (Romain, et al., 2001).

Recent GOLD guidelines also classify COPD severity into four stages, where higher stages are indicative of more advanced and severe disease (Rabe, et al., 2007). All stages are determined using spirometry to measure FEV₁. Stage one (mild COPD) is diagnosed when FEV₁ is less than 80% predicted, stage two (moderate COPD) when FEV₁ is between 50% and 80% predicted, stage three (severe COPD) when FEV₁ is between 30% and 50% predicted, and stage four (very severe COPD) when FEV₁ is either less than 30% predicted, or less than 50% predicted in combination with hypoxaemia, with or without hypercarbia

(Rabe, et al., 2007). Hypoxemia is the decrease of oxygen pressure in the blood (Sarkar, Niranjana, & Banyal, 2017); whereas, Hypercarbia is the increase of carbon dioxide in the blood (Feller-Kopman & Schwartzstein, 2018).

Although these specific spirometry values make diagnosing easier for clinicians, it is important to be cognisant of their disadvantages. Loss of lung elasticity and increased airway collapsibility has been shown as a standard course of normal aging (Gelb, & Zamel, 1975); therefore, the FEV₁/FVC ratio decreases with age (Medbo & Melbye, 2007). This can mean that using a specific ratio of 0.7 may over-diagnose COPD in older adults; where, Hansen, Sun, and Wasserman (2007) estimated that this method could miss-diagnose 20% of current smokers over 60 years old and 80% of all people over 70 years old. The 0.7 ratio may also underestimate COPD in younger populations and misclassify other people (Kohler, Fischer, Raschke, & Schonhofer, 2003).

To overcome the disadvantages of relying solely on spirometry, NICE state there is no single diagnostic test for COPD, and diagnoses should be made using clinician experience, physical examination, and medical history, in combination with spirometry (NICE, 2018). Therefore, research in people with COPD, who have only been diagnosed through spirometry, needs to consider the potential influence misdiagnosis has on their interpretations.

2.1.3 Prevalence, outlook, and costs

Reliable prevalence rates are difficult and expensive to collect (Romain, et al., 2001), however, multiple studies have explored the incidence rates of the condition. The Burden of Obstructive Lung Disease (Buist, et al., 2007) was a worldwide study designed to explore COPD prevalence, whilst overcoming problems in disease definition and sampling methods;

limitations that existed in previous studies (Nazier & Erbland, 2012). The study examined twelve countries and found an overall prevalence of moderate COPD or worse of 11.8% for men and 8.5% for women (Buist, et al., 2007). The study also confirmed previous findings regarding the positive relationship between incidence rates and age; with COPD apparent in less than 5% of people aged 40-49 years old, increasing to 19-47% of men and 6-33% of women across the countries, aged 70 or over. Specifically, in the United Kingdom (UK), there are 900,000 people diagnosed with COPD but allowing for under-diagnosis, the true prevalence could be approximately 1.5 million (Health and Safety Executive Report, 2015). Despite an increased understanding of the disease mechanisms, standardisation of diagnosis, and new treatments, COPD remains a major public health problem (Vestbo, et al., 2013).

Before the year 2000, COPD represented a leading cause of global morbidity and mortality (Mannino, Homa, Akinbami, Ford, & Redd, 2002; Chen & Mannino, 1999). Since then, COPD is one of the only chronic diseases increasing in prevalence; where, specifically in the United States of America (USA), mortality because of COPD has increased in the last twenty years (Murphy & Sethi, 2002). Between the periods of 2000-2005 previous trends reversed, whereby more women died from COPD than men (Parameswaran & Murphy, 2012) and it was estimated in 2005, one in twenty deaths in the US were as a result of COPD (Celli & MacNee, 2004). The Global Burden of Disease in 2010 labelled COPD as the third most common cause of death in the world (Lozano, et al., 2010) increasing from fourth in 1990 (Murray & Lopez, 1997). This is seemingly paradoxical considering the total number of deaths due to COPD between 1990 and 2010 fell from 3 to 2.8 million (5.5%); however, can be explained by examining the rate of deaths due to any cause over the same period falling by 17% (Burney, Patel, Newson, Minelli, & Naghavi, 2015).

Understanding the aetiology of co-morbidity in COPD is extremely important, as the presence of other diseases can have a large effect on COPD mortality (Mannino, et al., 2006).

This is evident in the finding that most people with COPD will usually die as a direct result of the condition or a related co-morbidity (Mannino, et al., 2006; Anthonisen, et al., 2005).

Death occurs in 11% of people hospitalised after their first exacerbation; additionally, 49% of people with COPD die within two years of this first admission (Connors, et al., 1996).

Furthermore, patients with co-morbidities hospitalised for a COPD acute exacerbation are five-times more likely to die compared to patients without co-morbidity (Patil, Krishnan, Lechtzin, & Diette, 2003). In the Lung Health Study among people with mild to moderate COPD, lung cancer, cardiovascular events, and other cancers accounted for 22%, 21% and 33% of deaths, respectively; whereas respiratory failure only accounted for 7.8%

(Anthonisen, et al., 2005). However, Jensen, Godtfredsen, Lange, and Vestbo (2006) found that death certificates under report COPD as the cause of death as a whole. Additionally, death certificates were found to have listed COPD as cause of death in people unlikely to have such a thoroughly progressed disease (Jensen, et al., 2006). To avoid these inaccuracies, the Towards a Revolution in COPD Health trial created a Clinical Endpoint Committee to analyse both systematically and independently the cause of death in 911 people with moderate to severe COPD. They found that the top three causes of death were respiratory failure, cardiovascular disease, and cancer, with 35%, 27% and 21% of all deaths, respectively. Additionally, 40% of deaths were definitely or probably related to COPD (McGarvey, et al., 2007).

Due to the progressive nature of the disease, people with COPD are extensive health care users to the extent that COPD is the second most common cause of emergency hospital admission in the UK. Direct NHS costs amount to over £800 million per year and indirect costs to society are estimated at £3.8 billion per year after calculating areas such as workdays lost (Department of Health, 2012). Additionally, exacerbations increase the overall cost of healthcare for people with COPD. Average all-cause total costs for people with three or more

exacerbations and no exacerbations during a 24-month period in the USA were \$56,033 and \$27,133, respectively; whereas average COPD-related total costs were \$12,257 and \$1,605, respectively (Dhamane, et al., 2015).

2.1.4 Self-management knowledge

Even those who use the NHS to a high degree spend approximately only 1% of their time with healthcare professionals (NHS England, 2014); where, the rest of the time people with chronic conditions need to manage themselves. Guidelines do recommend that to enable effective self-care, a self-management plan should be created, and education given to people when they are first diagnosed with COPD (NICE, 2018). Additionally, practitioners may need support or training; especially to care for psychosocial needs (Russell, et al., 2018).

Relevant COPD self-management behaviours include regular exercise, taking medication, and attending healthcare appointments (NICE, 2018). However, the mechanisms behind these behaviours can be more complex and learning them is often an elongated process (Russell, et al., 2018).

Schulman-Green, et al. (2012) conducted a qualitative meta-synthesis of 101 studies which described self-management behaviours in chronic conditions. They found three categories describing self-management processes. Within these groups were tasks and skills. Schulman-Green, et al. (2012) accept that the terms ‘tasks’ and ‘skills’ are used interchangeably within published literature but use definitions established by Samson and Siam (2008), which state that tasks are the essential work of self-management, whereas skills describe the ways an individual accomplishes these tasks.

The first category of processes identified was ‘focusing on illness needs’. This category refers to the self-management tasks and skills required for people to look after their bodies and specific concerns of chronic illness (e.g. annual influenza vaccinations in COPD). Included in these processes are the abilities to learn about their chronic condition, identify their health needs, and perform health behaviours. The tasks and skills identified in this category include acquiring disease information, learning about medication, gaining relevant skills and strategies to manage daily-illness needs, completing health tasks (e.g. attending healthcare appointments), and maintaining health behaviours. These processes can be performed solely by the individual or in conjunction with family members and healthcare practitioners, depending on the needs and available resources. These processes can be dependent on the individuals’ life context, as well as disease severity.

The second category of processes is ‘activating resources’, which refers to support structures at the individual (e.g. friends, family, and healthcare providers) or community level (e.g. social and transportation services). These resources assist individuals to manage their condition, psychosocial, spiritual, and financial domains. Tasks and skills related to these processes are communicating and understanding information from healthcare practitioners, knowledge of and benefit from psychological resources, and social support services. Again, these processes can be dependent on the disease progression, as well as how able an individual is to self-manage their disease. Some may also be hesitant to let others have an active role in their care; for example, older people living with a chronic disease often do not want to burden their children (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). The precise resources used are completely centred upon the individual with the chronic illness and depend on several factors including personal choice, disease progression, and specific needs.

The last category is ‘living with a chronic illness’, which includes the self-management processes related to coping, progressing, and transition from a disease focus, to an integration

of the disease into the individual's life. Within these processes the coping strategies of emotions is a central aspect, where exploring emotions, as well as grieving over the loss of health or physical functioning, are all considered useful for optimal well-being. Other tasks include adjusting to the chronic disease regulatory activities, modifying lifestyle behaviours so the illness fits in, and finding meaning of the chronic condition in the individual's life.

This last category highlights the importance of supporting wellbeing in people with chronic conditions and several studies have also found the positive relationship between self-management processes and HRQoL in populations with COPD (Benzo, et al., 2015). It is therefore not surprising that supporting self-management behaviours and HRQoL have been identified as major aspects which should be incorporated into the care of people with COPD (Kielmann, et al., 2010).

However, despite the positive relationships between self-management processes and health outcomes such as HRQoL, these behaviours are seldom conducted (Russell, et al., 2018).

This can be illustrated by the lack of uptake of influenza vaccinations. Due to the high risk of people with COPD developing complications as a result of influenza, this population group is recommended to receive annual vaccinations (Public Health England, 2014). Unfortunately, studies have repeatedly found that under 30% of people with COPD take advantage of this immunisation (Ciblak & Platformu, 2012; Santos-Sancho, et al., 2012). Adherence to self-management processes in this condition is multifaceted (Restrepo, et al., 2008). People with COPD need disease-specific and comorbidity education, in addition to the use of medications and different devices (Chryssidis Frewin, Frith, & Dawes, 1981; Dolce, et al., 1991).

Although there are undoubtedly multiple reasons why people with COPD do not adhere to treatment programmes and self-management processes, a particularly important factor is motivation (Sheldon, et al., 2003). Aspects such as adherence, behavioural change, and

motivation are also considered essential to effective self-management (Russell, et al., 2018; Schulman-Green, et al., 2012).

In summary, people with this chronic, incurable condition experience a variety of symptoms which can suddenly become worse as a result of an acute exacerbation. In such an event, further medication is typically needed (Rabe, et al., 2007). Depression and anxiety are common co-morbidities (Schane, et al., 2008) and can lead to a perceived worsening of symptoms (Reardon, et al., 2006). As a result, HRQoL is detrimentally affected (Esteban, et al., 2009) and the emotional needs of people with COPD are extensive (Russell, et al., 2018). Self-management behaviours are recommended to those with COPD; however, these are often complex and take a prolonged time to learn (Russell, et al., 2018). Several studies have identified the link between increased self-management and HRQoL (Benzo, et al., 2015) and both of these have been identified as crucial to support people with COPD (Kielmann, et al., 2010).

2.2 Treatment for COPD

COPD treatment uses a mix of medication and disease-management courses (NICE, 2010). Treatment objectives involve controlling for risk factors and increasing exercise tolerance and HRQoL (Nazir & Erbland, 2009). Current recommended treatment for people with COPD typically falls into two categories; pharmacotherapy and PR (Vogelmeier, et al., 2018). However, research has also increasingly examined the efficacy of self-management interventions (Zwerink, et al., 2014).

There are many different types of pharmacotherapy which can be prescribed independently or in combination (NICE, 2016). The section below gives a brief overview of the different types

of medication that can be used to treat COPD, before discussing the issues of adherence within this domain. PR is a multi-disciplinary disease-management programme which incorporates support for self-management processes, in addition to supervised exercise (Wagg, 2012). Due to the inclusion of support for these processes, self-management interventions are discussed and reviewed following the section on pharmacotherapy; before PR, its efficacy, and issues of adherence.

2.2.1 Pharmacotherapy and adherence

COPD pharmacotherapy mainly includes bronchodilators, corticosteroids, and antibacterials, prescribed singularly or in combination with one another; largely to reduce symptoms and increase exercise tolerance (Nazir & Erbland, 2009). Inhalers are considered a useful delivery system due to the easy acquisition and maintenance of inhaler technique given proper instruction in most people, regardless of age (NICE, 2010). However, tablets for some medications are also available and in more severe cases of COPD, long-term oxygen therapy (NICE, 2016; Vogelmeier, et al., 2018). There is strong evidence for the efficacy of drug therapy for people with COPD (Aaron, et al., 2007; Appleton, et al., 2006; Calverley, et al., 2007; Nannini, Cates, Lasserson, & Poole, 2007b), however, for a full discussion on the current guidelines for pharmacotherapy treatment see the GOLD *global strategy for the diagnosis, management, and prevention of COPD – 2019 report* (Vogelmeier, et al., 2018).

Despite the potential benefits of medication for controlling symptomology, adherence to regimens in people with chronic conditions is historically low, with approximately only 50% of pharmacotherapy that is prescribed being taken (Rudd, et al., 1988; Sackett & Snow, 1979). Additionally, only half of people prescribed medication for two or more weeks take a

dose which is high enough to be effective (Dwyer, Levy, & Menander, 1986; Epstein & Cluss, 1982). Adherence in this circumstance is referring to secondary-adherence (e.g. overuse, underuse, or forgetfulness) described by Bourbeau and Bartlett (2008). This problem is particularly evident in people with COPD, where the chronic nature of the condition, polypharmacy (i.e. requirement to take multiple medications), and occasional fluctuations in symptoms all thwart medication adherence (Restrepo, et al., 2008). Additionally, depression has also been linked to low adherence (DiMatteo, Lepper, & Croghan, 2000), which, as described above, is highly prevalent in people with COPD and thus this could explain low adherence in this condition. It has been estimated that between 40% and 60% of people with COPD adhere to the prescription regimen, and only 10% of people perform all the essential metered dose inhaler steps correctly (Restrepo, et al., 2008). The low adherence in COPD is worse than that displayed in other conditions which require inhaler medication, such as asthma (Haupt, Krigsman, & Nilsson, 2008). This issue has also been found more recently, with only 49% of people correctly following therapy regimens (Abdulsalim, et al., 2018), where this rate drops to only 14% of people prescribed multiple inhaler triple therapy (Bogart, et al., 2018).

2.2.2 Self-management interventions

As described previously, the processes involved to effectively self-manage COPD can be complex and take a long time to learn (Russell, et al., 2018); therefore, one treatment option which literature is increasingly beginning to examine is how interventions can support these processes (Kaptein, Fischer, & Scharloo, 2014).

Historically, there has been some disagreement within published literature relating to the precise definition of a self-management intervention, with similar but different definitions being proposed by Alderson, Gow, and Moreland (1999), Barlow, Wright, Sheasby, Turner, and Hainsworth (2002), Clark et al. (1991), and Nakagawa-Kogan, Garber, Jarrett, Egan, and Hendershot (1988). Recently a COPD-specific self-management intervention definition has been proposed stating “A COPD self-management intervention is structured but personalized and often multi-component, with goals of motivating, engaging, and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease” (Effing, et al., 2016 pg. 50). Effing, et al. (2016) also state that the process involves repetitive interactions between patients and healthcare professionals who are trained to deliver such interventions and they should specifically use behaviour change techniques to increase intrinsic motivation, confidence, and competence. The adoption of this definition by the GOLD COPD 2019 report (Vogelmeier, et al., 2018) gives strong support for its validity.

Especially in medical literature, multiple authors consider the term ‘self-management intervention’ synonymous with ‘education’ and ‘giving information’ (Kaptein, et al., 2014). However, these are separate concepts and Figure 2.1 displays the differences between the different disease-management programmes available for people with COPD. It is important to note that these interventions are usually prescribed alongside standard pharmacotherapy and are not considered a replacement for medication (Nazir & Erbland, 2009).

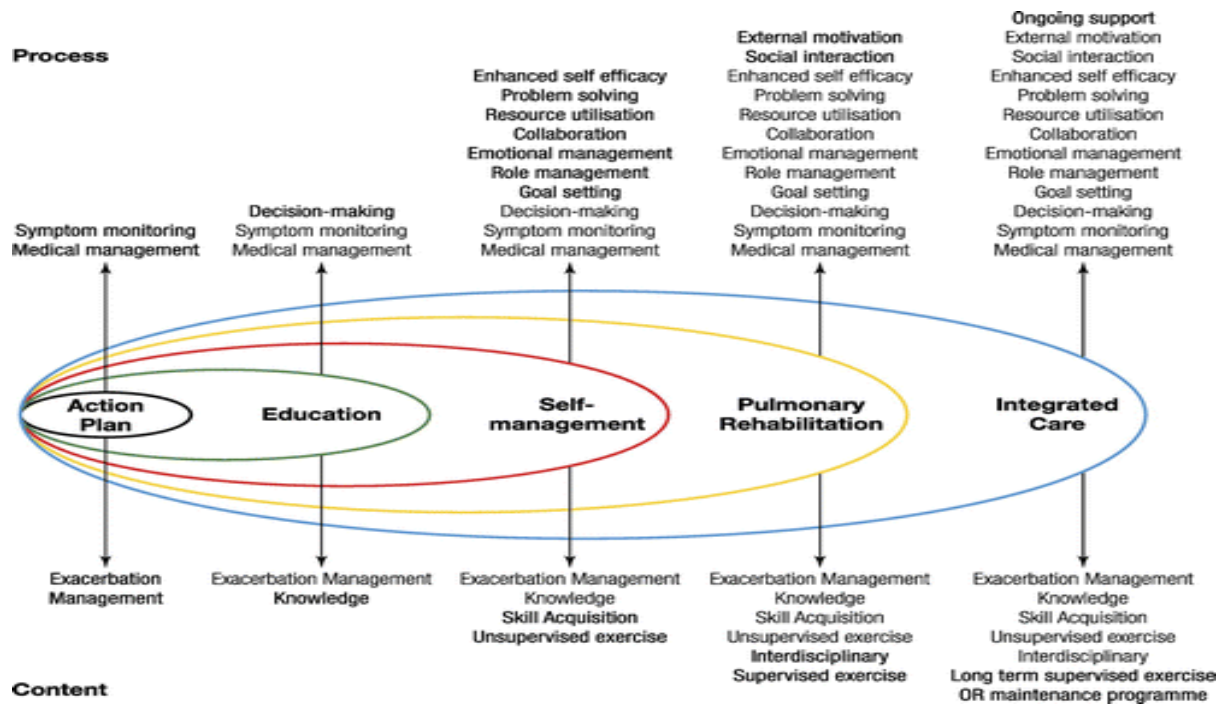


Figure 2.1. Continuum of disease-management programmes for COPD. Wagg (2012).

Reviews have found that education alone does not improve health outcomes (Harris, Williams, Dennis, Zwar, & Powell-Davies, 2008), and disease knowledge is not correlated to an individual's behaviour and is insufficient to achieve behaviour change (Bourbeau & van der Palen, 2009; Petrie & Weinman, 2006; Zwerink, et al., 2014). Therefore, although an important part within self-management interventions, education alone is not recommended for people with COPD (Vogelmeier, et al., 2018). A similar stance is taken on action plans, which usually take the form of a set of instructions that an individual follows so that they can adequately recognise an exacerbation and take steps accordingly (Morgan, 2011). However, there is mixed evidence on their efficacy as a standalone disease-management treatment (Turnock, et al., 2005; Walters, Turnock, Walters, & Wood-Baker, 2010) and adherence to them is also low (Bischoff, et al., 2011).

Published literature assessing the efficacy of self-management interventions within COPD is substantially less compared to the literature available for other conditions; a review searching PubMed for "COPD AND self-management" retrieved 1,130 hits, compared to similar

searches in asthma, cancer, and diabetes mellitus retrieving 3,233, 10,990 and 13,142 hits, respectively (Kaptein, et al., 2014). Self-management interventions should include behaviour change techniques (Effing, et al., 2016). However, within a health domain, studies are seldom conducted with a psychological underpinning (Davies, et al., 2010; Painter, Borba, Hynes, Mays, & Glanz, 2008), where this absence of theory is even more prevalent in COPD self-management interventions (See Chapter Three for a full discussion; McCullough, et al., 2016; Richardson, et al., 2014). Therefore, there could be substantially less published literature evaluating *actual* self-management interventions than the brief search by Kaptein, et al. (2014) implies.

Pinnock, Steed, and Jordan (2016) provide an overview of this relatively small literature base on self-management interventions. Early studies showed original success (Bourbeau, et al., 2003; Gadoury, et al., 2005; Rice, et al., 2010), followed by studies showing no significant differences between groups (Bischoff, et al., 2012; Bucknall, et al., 2012), and one study ending prematurely due to a potential detrimental effect, caused by the self-management intervention (Fan, et al., 2012). However, Fan, et al. (2012) reported very low adherence to the self-management programme and thus this could explain the negative effects that were found (Nici, Bontly, ZuQallack, & Gross, 2014). Additionally, the study by Bucknall, et al. (2012), only classified 42% of the intervention group as successful self-managers and did report a significant reduction in COPD hospitalizations and mortality in this sub-group (Bucknall, et al., 2012).

More current studies and reviews have reported self-management programmes showing significant benefits in respiratory-related hospitalizations, HRQoL, and dyspnoea (Jonsdottir, 2013; Oancea, Fira-Mladinescu, Timar, & Tudorache, 2015; Zwerink, et al., 2014).

Disagreement on the effect of self-management interventions for all-cause hospitalizations is evident; where some studies report no significant differences between groups (Jordan, et al.,

2015; Majothi, et al., 2015; Zwerink, et al., 2014) and others report a significant reduction in this area (Jonkman, et al., 2016), as well as the use of healthcare resources (Jonsdottir, 2013).

Due to small sample sizes and the heterogeneity of interventions designed to increase self-management (Jonsdottir, 2013; Vogelmeier, et al., 2018), identifying individual components responsible for positive benefits is problematic (Pinnock et al., 2016; Wagg, 2012). Several reviews have found that the main factor is the length of the intervention, where duration showed a positive correlation to beneficial health outcomes (Jonkman, et al., 2016; Jordan, et al., 2015; Vogelmeier, et al., 2018). Disagreement again is evident in the benefits of other intervention elements; where exercise has been found to be a key factor leading to significant and clinical improvements in HRQoL in some reviews (Jordan, et al., 2015), as well as no significant improvements in others (Zwerink, et al., 2014). Another review found no characteristics, other than intervention duration, being consistently linked with between-group differences in any clinically relevant outcome (Jonkman, et al., 2016).

A possible explanation for the heterogeneous results may be due to authors neglecting the complex nature of self-management programmes (Bourbeau & van der Palen, 2009).

Although hospitalizations and utilization of healthcare are important outcomes within healthcare, focusing solely on these outcomes to evaluate self-management interventions represents an overly exclusive approach and authors have suggested the measurement of individuals' behaviour as a pivotal outcome (Bourbeau & van der Palen, 2009). At a workshop of COPD self-management experts, recommendations for future research included greater clarity in intervention descriptions, properly designed and powered studies, and self-management process variables being assessed (Effing, et al., 2012). However, despite these suggestions being well-received, the GOLD COPD 2019 Report (Vogelmeier, et al., 2018) still describes the heterogeneity across self-management interventions for follow-up times, outcome measures, and a lack of specifics of the programme. The recent COPD self-

management intervention definition (Effing, et al., 2016) is hoped to result in greater consistency within published literature (Vogelmeier, et al., 2018).

Studies which have followed these recommendations have reported the effectiveness of self-management interventions for increasing self-management knowledge and technique acquisition, COPD knowledge, and participant engagement (Bringsvor, et al., 2018; Turner, Anderson, Wallace, & Kennedy-Williams, 2014). Research has also suggested increased self-management knowledge significantly improves overall health and wellbeing (Majothi, et al., 2015). Another study, however, found that although telephone coaching to promote behaviour change did increase self-management activities, this did not correspond to improved HRQoL (Jolly, et al., 2018). In a qualitative synthesis of nurse-led self-management interventions, Baker and Fatoye (2018) found four key themes; empowerment through new knowledge; psychological wellbeing; expanding social worlds; and increased physical activity. Increased disease-knowledge and support corresponded with an increase in individuals' self-confidence and coping behaviour, and the social and psychological support provided within the self-management intervention improved participants' wellbeing. Additionally, group exercise components were positively viewed because of the increased social interaction this provided the participants and the perceived gain in wellbeing (Baker & Fatoye, 2018).

Turner, et al. (2014) delivered an intervention that was layperson- and practitioner-led with positive results; leading the authors to conclude that both these methods are efficacious in the provision of a self-management intervention. This has also been found in a solely layperson-led intervention for people with COPD (Taylor, et al., 2012) as well as in other chronic conditions (Barlow, et al., 2002). A qualitative analysis by Stevens (2016) has also emphasised the importance of people with chronic conditions learning about others'

experiences, which further gives support for the use of layperson delivered self-management interventions.

The provision of support for self-management knowledge has become a main strategy implemented by the NHS for people with long-term conditions (Goodwin, Curry, Naylor, Ross, & Dulig, 2010). To accomplish this, healthcare practitioners are being urged to move away from the traditional method of acting as the primary decision-maker, to more of a partnership model, where individuals are actively involved in their own health care support (Coulter, Roberts, & Dixon, 2013). Within this partnership model, people with chronic conditions need help to build their confidence in self-management; whether this is with the management of tests and medicines, making lifestyle changes, or coping with emotional and social stressors (Corbin & Strauss, 1988). Specifically, within COPD, improving self-management knowledge, HRQoL, and addressing co-morbidity have all been identified as crucial to support people with the condition (Kaptein et al., 2014; Kielmann, et al., 2010).

Although the literature described above gives evidence for the use of self-management knowledge and interventions to help people with COPD, authors have suggested that the best provision will have to be achieved within already existing routines, healthcare services, and resources available (Pinnock, et al., 2016). One well-structured programme which incorporates a self-management intervention holistically, alongside interdisciplinary, supervised exercise, is PR (Pinnock, et al., 2016; Wagg, 2012); where programmes which incorporate these aspects have been shown to be effective (Jordan, et al., 2015).

2.2.3 Pulmonary rehabilitation

Within the UK, PR programmes follow the definition set out by NICE, which states the following:

“Pulmonary rehabilitation is a multidisciplinary programme of care for people with chronic respiratory impairment, individually tailored and designed to optimise each participant’s physical and social performance and autonomy. People with COPD make up the largest proportion of those referred to pulmonary rehabilitation” (NICE, 2011, Pulmonary rehabilitation programme section, para 1).

The NICE guidelines (2011) state that PR should incorporate physical training, disease education, and nutritional, psychological, and behavioural interventions; such as smoking cessation. However, NICE guidelines (2011) also reflect the inconclusive literature regarding other aspects of PR, such as the optimum length of such programmes. The only recommendation for this is that programmes should last long enough to enable improvements in exercise tolerance to occur (NICE, 2011). The consensus from the National Clinical Guideline Centre (2010) was that PR should last between six and twelve weeks. This finding is supported by systematic reviews which state that longer lasting PR programmes are more effective at increasing HRQoL compared to shorter courses (Beauchamp, Janaudis-Ferreira, Goldstein, & Brooks, 2011; Ries, et al., 2007); however, the effect of duration on exercise is still unclear (Beauchamp, et al., 2011).

Beauchamp, et al. (2011) focused solely on the duration of PR but did not conduct a moderator analysis to investigate the different effects that intensity may have on participant health outcomes. A study investigating the optimum frequency found no differences in

outcomes between a twice-weekly programme lasting nine weeks and a thrice-weekly programme lasting six weeks (Lewis, et al., 2014).

Evaluating the effects of PR can be difficult because the heterogeneous components which are incorporated by different programmes (McCarthy, et al., 2015). For example, as well as the course length and intensity which can be modified, different teams may include different health professional specialities (Steiner, et al., 2015). In other words, some programmes may include dieticians where others may not have access to this speciality. Additionally, PR has been available for a relatively long time across a range of countries; therefore, studies which evaluate the programme to 'usual care' may not be utilising the same comparator condition to one another.

Despite these evaluative issues, research has shown that PR can lead to both statistically and clinically significant improvements in HRQoL, functional and maximum exercise capacity, disease knowledge (Corhay, Dang, Cauwenberge, & Louis, 2014; McCarthy, et al., 2015; Puhan, et al., 2011; Ries, et al., 2007; White, Walker, Roberts, Kalisky, & White, 2006), and reductions in dyspnoea (Corhay, et al., 2014; McCarthy, et al., 2015; Puhan, et al., 2011; Ries, et al., 2007). However, Ratneswaran, Weinman, and Hart (2015) found that changes in exercise capacity and HRQoL showed small correlation to lung function but instead correlated more strongly with state anxiety and self-efficacy. This suggests that psychological factors may be able to explain the positive effects of PR more easily than physiological factors, at least in the short-term. However, few studies have examined this possibility in detail.

Early studies found that PR had no effect on depression (Toshima, Blumberg, Ries, & Kaplan, 1992). More recent studies, however, have shown the effectiveness of PR to improve both anxiety and depression (Cafarella, Effing, Usmani, & Frith, 2012; Coventry, 2009).

Although PR's beneficial effect on mild mental health problems is homogenous across multiple more recent studies, there is still ambiguity regarding which elements of the programme are responsible for these findings (Coventry, 2009). Additionally, there is little evidence to support the ability of PR to support people with more severe anxiety and depression (Coventry, 2009).

Original evaluations of PR demonstrated that the programme had little effect on the number of hospitalisations (Ries, Kaplan, Limberg, & Prewitt, 1995); however, the length of hospital stay was significantly reduced (Griffiths, et al., 2000). More recently, reviews have supported the ability of PR to reduce the number and length of hospitalisations (Corhay, et al., 2014; Puhan, et al., 2011; Ries, et al., 2007), in addition to reducing mortality (Puhan, et al., 2011). The reduction in these outcomes has led economic analyses to conclude that PR is a cost-effective intervention (Griffiths, Phillips, Davies, Burr, & Campbell, 2001; Naylor, et al., 2012).

Rapport, et al. (2015) interviewed participants, their significant others (e.g. spouses and partners), and PR practitioners reporting that the programme had overwhelming support from all three groups. Participants displayed enthusiasm shown by increased activity, control, confidence, willingness to self-manage, and an enhanced sense of group belonging.

Significant others were often described as overprotective prior to PR and described themselves as "feeling helpless". However, post-PR significant others felt less anxious. PR practitioners felt motivated by the appreciation of their work and were often praised for their full understanding of participants' conditions and care, which was described as "a revolution of everyday life".

Most of the evidence described above shows the progressive improvement of PR programmes to help people with COPD. A recent Cochrane review concluded that additional randomised

controlled trials comparing PR and usual care for the treatment of COPD are not warranted (McCarthy, et al., 2015). This large body of supporting literature is likely why PR is recommended to everyone, who remains breathless despite optimal bronchodilators, irrespective of severity and age (NHS England, 2014). This recommendation is echoed by the GOLD COPD 2019 Report (Vogelmeier, et al., 2018). However, PR programmes struggle to offer the service to all who are eligible (Baxter, et al., 2016), and many people are not enrolled within 90 days of referral, another key recommendation (Steiner, et al., 2015).

Ambiguity about what elements of PR are responsible for the positive benefits remains and a sub-group analysis investigating this has found no difference in outcomes between exercise only programmes and courses which are more complex (McCarthy, et al., 2015). McCarthy, et al. (2015) state that this subgroup analysis should be interpreted with caution due to the heterogeneity in the included articles. However, international guidelines have reported that exercise training is the best method currently available for improving muscle function and exercise tolerance, and is widely regarded as the essential part of PR (Ries, et al., 2007; Spruit, et al., 2013).

Although there is large consensus regarding the benefits of PR, research suggests that these benefits are not maintained longitudinally. Bestall, et al. (2003) found that at six months, significant beneficial outcomes were still evident; however, at twelve months improvements in health status had depreciated into non-statistical significance. Similar results have also been found in other studies, where benefits of PR appear to diminish over six to twelve months; however, QoL depreciated less compared to exercise capacity (Foglio, et al., 2007; Griffiths, et al., 2000; Spruit, Troosters, Trappenburg, Decramer, & Gosselink, 2004). This contradicts the findings by Bestall, et al. (2003) who found exercise was still significant between intervention and control groups at 12 months. Investigating how long treatment effects persist is an important objective future research needs to explore (McCarthy, et al.,

2015). Studies investigating causes of this decline in health outcomes have found multiple factors responsible, including the decrease in self-management and regular exercise, and the progression of COPD, comorbidities, and exacerbations (Carr, Goldstein, & Brooks, 2007; Spruit, et al., 2013).

Another problem prevalent in PR programmes is poor adherence (Bourbeau & Bartlett, 2008); however, attendance and adherence rates within research are heterogeneous (Fischer, et al., 2009). Studies have reported non-completion rates between 20% and 40% for programmes with greater than 100 people lasting longer than 7 weeks (Cockram, Cecins, & Jenkins, 2006; Cote & Celli, 2005; Garrod, Marshall, Barley, & Jones, 2006). Other studies have reported 90% adherence for programmes held thrice-weekly lasting up to 12 weeks (Berry, et al., 2003; Donesky-Cuenca, Janson, Neauhaus, Neilands, & Carrieri-Kohlman, 2007). Combined with high non-completion rates, some patients choose not to attend at all when invited (Sabit, et al., 2008); where, it has been estimated that less than 1.5% of eligible people access PR each year in the UK (Yohannes & Connolly, 2004). The PR audit programme reported that for every 100 people referred to PR, 31 do not attend the initial assessment, and of those who do attend, 10 do not enrol onto the programme. Of the remaining 59 who enrol onto PR, 17 do not complete the course. In other words, only 42% of people referred to the programme complete PR (Steiner, et al., 2015; 2016).

Conducting in-depth interviews, Harris, Hayter, and Allender (2008) found fears of exercise and increased dyspnoea, and PR causing problems with comorbidities as common concerns prior to PR. Beliefs that the programme would decrease dyspnoea and allow individuals to regain the ability to do activities, were motivators to attending the course (Harris, et al., 2008). Hayton, et al. (2013) found that participants who were female, currently smoking, and living alone were all less likely to attend PR initially; whereas, another study found barriers

to uptake were a disruption to usual routine, influence of the referring doctor, and the programme timing (Keating, et al., 2011).

Early studies found that non-completion rates could not be predicted by sociodemographic, clinical, or psychological variables prior to PR, and that approximately 20% of all missed appointments are beyond the individuals' control (e.g. absent therapists, hospitalizations; Fischer, et al., 2009). Other research, however, has found that early drop-out was predicted by low educational status and psychoticism (as measured on the Symptom Checklist-90-Revised scale); concluding that psychological assessment prior to inclusion could reduce PR dropout (Tselebis, et al., 2013). Halting, Wahl, and Heggdal (2010) conducted interviews with participants who were adherent to PR, finding social relations, integration, and support influenced perceptions of PR and promoted adherence.

More recently, studies have found that participant characteristics that successfully predict non-adherence include poor shuttle walking distance, hospitalisations (Hayton, et al., 2013), depression (Keating, et al., 2011), and current smoking (Hayton, et al., 2013; Keating, et al., 2011). Travel and transport, alongside a lack of perceived benefit, were consistent predictors of both non-attendance and non-adherence (Keating, et al., 2011).

2.3 Technology-delivered programmes

Although research has investigated barriers to performing behaviours relevant to self-management processes (Bourbeau & Bartlett, 2008; Restrepo, et al., 2008), barriers to self-management intervention attendance and adherence have largely remained unexplored.

Within PR, however, these factors have been thoroughly examined. Several of the reasons for poor attendance and adherence of PR programmes described above included a disruption to

usual routine, programme timing, and travel and transport (Keating, et al., 2011). Therefore, programmes which could overcome these barriers and deliver an intervention at a time which suited the individual and closer to where they lived, may result in increased engagement. This is supported by policies which state that delivering healthcare closer to those in need is a key objective to support people with chronic conditions (Drakeford, 2015). Research has suggested the use of technology as one method to achieve this and overcome commonly seen barriers (Wooton, 2012) and this has also been recommended by the Respiratory Health Implementation Group (2018).

Research which has compared the use of technology to standard care in people with chronic conditions has found the intervention significantly reduced hospitalisations, mortality, and healthcare costs, in addition to increasing HRQoL (De San Miguel, Smith, & Lewin, 2013; Dinesen, et al., 2012; Knox, Rahman, & Beedie, 2017; Steventon, et al., 2012; Vontetsianos, et al., 2005).

Although there are relatively few studies evaluating the use of technology to support people with COPD compared to other chronic conditions (McKinstry, Pinnock, & Sheikh, 2009; Wooton, 2012), preliminary results have been encouraging. Vitacca, et al. (2009) implemented an intensive intervention for people with respiratory failure which included nurse-led telephone calls and daily spirometry and blood pressure readings being transferred to practitioners electronically. Results showed a reduction in hospitalisations, urgent GP calls, and acute exacerbations. Vontetsianos, et al. (2005) implemented a similar intervention but with videoconferencing equipment instead of telephone calls for people with COPD, finding similar reductions in healthcare utilisation, in addition to increased disease and self-management knowledge. Studies which have delivered less-intensive interventions have also shown positive results; where, videoconferencing only has been found to reduce readmissions after a COPD exacerbation (Sorknaes, Madsen, Hallas, Jest, & Hansen-Nord, 2011). Two

reviews comparing COPD technology-delivered care and usual care found no significant benefits on mortality or HRQoL; however, hospitalisations were reduced (McLean, Liu, Pagliari, Car, & Sheikh, 2012; Polisena, et al., 2010). Studies which have compared home-based technology-enabled PR and standard programmes have shown equivalent results between the two conditions in exercise tolerance, dyspnoea, and HRQoL (Holland, et al., 2017). Additionally, research has found similar results for community-based technology-enabled programmes (Stickland, et al., 2011) and authors have concluded that such methods are safe, feasible, and can significantly reduce travel time and distance (Knox, et al., 2019). Although these latter studies have shown the use of technology can support the HRQoL in people with COPD, the two reviews by McLean, et al. (2012) and Polisena, et al. (2010) do highlight the uncertainty of whether these methods are as beneficial to the participants' wellbeing, as they are at reducing healthcare utilisation.

Research which has implemented technology to deliver self-management interventions has also shown promising results. Short films, which were available on the internet, designed to increase self-management motivation and knowledge in a population with diabetes found significant increases in glycaemic control for people who adhered to the intervention (Rice, et al., 2017). Additionally, a recent review including 31 studies conducted in a variety of chronic conditions, which incorporated a wide range of different technologies, concluded that such methods were beneficial at increasing self-management and self-monitoring behaviours (Guo & Albright, 2017). However, there is a scarcity of research which implements technology to deliver self-management interventions for people with COPD (Cruz, Brooks, & Margues, 2014).

A review which investigated the attendance and adherence to technology-enabled interventions found that an average of 33% of people offered such interventions refused outright, but approximately 80% of people who agreed to participate adhered (Gorst,

Armitage, Brownsell, & Hawley, 2014). Broendum, et al. (2016) conducted a study exploring individuals' reasons for refusing to take part in a study investigating the effects of a technology-enabled intervention. The most common reasons for non-participation were personal reasons (e.g. lacking time, not ill enough, or too ill) and technical concerns (e.g. not wanting a computer in the home). Compared to people who consented to participate in the study, individuals who did not participate were older, more often female, had less severe COPD, lower body mass index, more hospitalizations within the last year, and were often diagnosed with osteoporosis (Broendum, et al., 2016). Despite the finding that individuals refused due to a lack of time, authors have suggested that technology-enabled services can minimise the disruption to routines and overcome problems with travel and transport (Wooton, 2012); common barriers to PR (Keating, et al., 2011). Additionally, although people who currently smoke are less likely to attend PR (Hayton, et al., 2013), this was not found to be a factor affecting technology-enabled intervention attendance (Broendum, et al., 2016). Although the above literature provides preliminary evidence for the use of technology to deliver interventions in chronic conditions, research has recommended that more studies are needed to fully investigate their effectiveness (McLean, et al., 2012), especially for people with COPD (Cruz, et al., 2014).

2.4 Chapter summary

COPD is a highly prevalent, debilitating condition that causes dyspnoea, sputum production, and coughing (WHO). Depression and anxiety are common co-morbidities (Schane, et al., 2008) and these can also lead to an increase in perceived symptom burden (Reardon, et al., 2006) and lower medication adherence (DiMatteo, et al., 2000). COPD has a negative impact

on HRQoL (Esteban, et al., 2009) and although self-management behaviours are positively correlated with this factor (Benzo, et al., 2015), there is a lack of such behaviours being conducted (Russell, et al., 2018).

Treatment for COPD generally falls into two categories; pharmacotherapy and PR (Vogelmeier, et al., 2018); however, there is an increase in research examining self-management interventions in people with COPD outside of PR programmes (Kaptein, et al., 2014). Pharmacotherapy can be effective at reducing symptoms and increasing exercise tolerance (Vogelmeier, et al., 2018), however, adherence to medication is often low (Bourbeau & Bartlett, 2008). The definition of self-management interventions is provided by Effing, et al. (2016). Part of this definition explicitly states the need for the inclusion of behaviour change techniques – an element not being met by the relatively small COPD self-management intervention literature currently available (Kaptein, et al., 2014; McCullough, et al., 2016; Richardson, et al., 2014). However, despite this, self-management interventions have been associated with significant benefits for a variety of outcomes, including HRQoL, self-management knowledge, and dyspnoea (Bringsvor, et al., 2018; Turner, et al., 2014; Zwerink, et al., 2014). PR has repeatedly shown positive effects across various outcomes including HRQoL, exercise capacity, disease knowledge, and respiratory-related hospitalizations (Corhay, et al., 2014; McCarthy, et al., 2015; Puhan, et al., 2011; White, et al., 2006) and has been recommended to be prescribed to everyone who is eligible (NHS England, 2014; Vogelmeier, et al., 2018). However, like pharmacotherapy, PR experiences poor attendance and adherence (Bourbeau & Bartlett, 2008; Steiner, et al., 2015; 2016); where, almost one third of those invited to PR do not attend the first assessment, and only 42 out of every 100 complete the programme (Steiner, et al., 2015; 2016).

Technology has been suggested as one method to overcome common barriers to PR (Wooton, 2012). Research into technology-delivered care and self-management interventions has

shown positive results (Guo & Albright, 2017; Stickland, et al., 2011; Vontetsianos, et al., 2005), in addition to high adherence (Gorst, et al., 2014). Furthermore, factors which predict low attendance in other programmes, such as current smoking in PR (Hayton, et al., 2013), are not evident in technology delivered interventions (Broendum, et al., 2016). However, the ability of such interventions to support HRQoL is uncertain (McLean, et al., 2012) and there are relatively few studies investigating their use to deliver self-management interventions in people with COPD (McKinstry, et al., 2009). As a result, authors have suggested more research is necessary upon their use (Cruz, et al., 2014; McLean, et al., 2012).

The above literature demonstrates the poor attendance and adherence displayed across treatments, irrespective of their efficacy, in people with COPD, (Bourbeau & Bartlett, 2008), which is one indicator of poor self-management knowledge (Schulman-Green, et al., 2012). Additionally, the support of HRQoL has been identified as a key factor within this population (Kielmann, et al., 2010). Therefore, it is important to identify concepts which can both explain and predict these factors. Craig, et al. (2008) states that psychological theory should be implemented to explain target behaviours. This is supported by multiple authors highlighting the importance of behaviour change for people with COPD (Effing, et al., 2016; Restrepo, et al., 2008; Vogelmeier, et al., 2018); a key domain explored by various psychological theories and models. Therefore, the following chapter provides an overview of the theories which have been implemented previously, before conducting an in-depth review on the behaviour change model best suited to explain and predict self-management knowledge and HRQoL in people with COPD.

Chapter Three: Psychological behaviour change theory

The aim of this chapter is to provide an overview of the psychological theories that may be applicable to explain and predict self-management motivation and HRQoL in people with COPD. After this, an in-depth critical evaluation of the most appropriate theory or model will be presented. However, first this chapter will consider the importance of utilising psychological theory to understand health behaviours in chronic disease and review previous application of theory to the context of COPD.

Governing bodies (e.g. the UK's Medical Research Council) promote the use of 'Modelling', which is the use of behaviour change theory to understand the target behaviour and processes of change before the piloting and development of larger scale research projects (Craig, et al., 2008). Research has supported this position and stated that the use of psychological theory has the potential to be a positive factor in the development of interventions designed to influence individuals' health behaviour (Griffin, Kinmonth, Skinner, & Kelly, 1999; Marteau, Dieppe, For, Kinmonth, & Schneiderman, 2006; Michie, Sheeran, Rothman, 2007; Painter, et al., 2008; Rothman, 2004). Multiple studies have reported that interventions developed using psychological behaviour change theory produce more beneficial outcomes (Albada, Ausems, Bensing, & van Dulmen, 2009; Albarracin, et al., 2005; Glanz, & Bishop, 2010; Noar, Benac, & Harris, 2007; Swann, Bowe, McCormic, & Kosmin, 2003; Taylor, Connor, & Lawton, 2012, Webb, Joseph, Yardley, & Michie, 2010); including a recent systematic review investigating interventions to enhance adherence in respiratory conditions (McCullough, et al., 2016). Additionally, interventions with more extensive use of theory are commonly associated with larger effect sizes (Lycett, et al., 2018; Webb, et al., 2010). Although some studies have found a null or a negative correlation between theory and intervention

effectiveness (Gardner, Wardle, Poston, & Croker, 2011; Roe, Hunt, Bradshaw, & Rayner, 2007; Stephenson, Imrie, & Sutton, 2000), other authors have challenged these studies for inappropriate theory selection, few theoretical constructs being targeted, or the inappropriate application of the theoretical framework during intervention design (Davies, et al., 2010; Painter, et al., 2008; Prestwich, et al., 2014).

Despite this supporting literature, within the health domain, relatively few studies have implemented psychological theory. A review investigating the use of theory in health behaviour change interventions found that of 193 studies reviewed, only one third reported using a theoretical foundation (Painter, et al., 2008). Of this third, the amount of studies reporting the application of, testing, and building upon theory, were 18%, 3.6%, and 9.4%, respectively. Davies, et al. (2010) similarly investigated this topic in 235 studies, finding only 6% reported explicitly using theory and 22.5% being ‘theory-inspired’. In another review, 56% of 190 interventions designed to increase physical activity and healthy eating reported using theory; however, only 10% reported using theory to select appropriate behavioural change techniques (Prestwich, et al., 2014).

The lack of theory to underpin interventions is even more evident within those designed for people with COPD. Richardson, et al. (2014) performed a review of self-management interventions in chronic disease, finding that only 25% of included COPD studies used a psychological theory. Similarly, a review investigating the use of behaviour change theory for interventions to enhance adherence in chronic respiratory diseases found only 33% of all included studies, and none of the included COPD studies had a theoretical underpinning (McCullough, et al., 2016). The definition of self-management interventions given by Effing, et al. (2016) explicitly states that such interventions need to have behaviour change techniques included. Psychological theory should be used to select appropriate techniques for any intervention (Prestwich, et al., 2014); therefore, according to Effing, et al. (2016), most

of the articles included in the above two reviews (Richardson, et al., 2014; McCullough, et al., 2016) do not evaluate *self-management* interventions. Kaptein et al. (2014) reports the relatively low number of articles within this field of research. If the studies which do not utilise psychological theory are excluded, there could be a significant reduction to the numbers reported by Kaptein, et al. (2014), and a gap in the literature within a population with COPD.

As explained above, the aim of this chapter is to provide an overview of psychological theories and models which may be able to explain and predict self-management motivation and HRQoL in people with COPD. This would typically involve searching literature to investigate what theories have been used previously. However, given that few studies have implemented such theories in a population with COPD (Kaptein, et al., 2014; McCullough, et al., 2016; Richardson, et al., 2014), this chapter will instead investigate the ability of psychological models to explain and predict behaviours pertinent to self-management and HRQoL. See Chapter Two for a full discussion on the processes relevant to self-management knowledge.

Four psychological theories were highlighted as possible models which could be used to explain and predict self-management motivation and HRQoL in people with COPD. These theories were the transtheoretical model (Prochaska & DiClemente, 1983), the theory of planned behaviour (Ajzen, 1991), social cognitive theory (Bandura, 1986), and self-determination theory (Deci & Ryan, 1985), and were selected due to being previously applied to either directly predict the two variables of interest or behaviours relevant to self-management knowledge.

An overview of each of these psychological theories is given below alongside a short evaluation of their internal validity and applicability to explain and predict self-management

motivation and HRQoL. Model applicability will be assessed by investigating how the theory has been previously used to explain or predict the two factors of interest and evaluating the effectiveness of interventions which have used the theory as a psychological underpinning to increase said factors.

3.1 Overview of psychological theories

3.1.1 The transtheoretical model

The transtheoretical model (TTM; Prochaska & DiClemente, 1983) incorporates several different constructs including; stages of change, self-efficacy, decisional balance, and processes of change. These constructs originated from other theories, where TTM integrated these alongside systems of psychotherapy into a single theory, hence the name ‘transtheoretical’ (Sutton, 2015).

In the most widely used version of the model, the stages of change describe five stages: pre-contemplation, contemplation, preparation, action, and maintenance. The first three stages are considered pre-action stages; although the preparation stage is described in similar terms to behaviour change (Sutton, 2015). The latter two stages are post-action stages. Individuals trying to enact healthy behaviour change progress through the stages of change in sequential order; however, they can also drop back to earlier stages and continue this process multiple times before achieving long-term change (DiClemente & Prochaska, 1982; Sutton, 2015).

Self-efficacy incorporates the confidence and temptation to engage in health and unhealthy behaviours in challenging situations, respectively. Decisional balance comprises of the pros

and cons of progressing between stages of change. Lastly, the processes of change include ten different overt and covert behaviours which individuals use to progress between stages (Prochaska, Spring, & Nigg, 2008).

Research evaluating the applicability of TTM have largely employed longitudinal or experimental designs to physical activity, dietary behaviours, and smoking cessation (Sutton, 2015); investigating whether theory constructs can predict progression. Studies investigating stage progression in physical activity have found that self-efficacy, pros, and behavioural processes are the most important predictors (Callaghan, Khalil, & Morres, 2010; Plotnikoff, Hotz, Birkett, & Courneya, 2001). Although these studies used a healthy population, the results have also been replicated in people with diabetes (Plotnikoff, Lippke, Johnson, & Courneya, 2010).

Additional support for the importance of self-efficacy in stage transitions can be found when TTM is applied to dietary behaviours. Self-efficacy and pros were found to predict forward transition from pre-contemplation (de Vet, de Nooijer, de Vries, & Brug, 2005; de Vet, et al., 2006) and solely self-efficacy predicted progression from contemplation (de Vet, Terwee, Knol, & Bouter, 2005). In another study, only the behavioural process ‘self-liberation’ was found to predict onward transition from pre-contemplation (Howath, Schembre, Motl, Dishman, & Nigg, 2013).

Although the above studies do support the ability of theory constructs to predict stage progression in physical activity and dietary behaviours, self-efficacy and pros are not unique to TTM and similar constructs are present in multiple health behaviour change theories (Sutton, 2015). Additionally, experimental designs using randomisation (the ‘gold standard’; Weinstein, et al., 1998) have found no support for the use of TTM to modify physical activity

(Blissmer & McAuley, 2002) or dietary behaviours (de Vet, de Nooijer, de Vries, & Brug, 2008).

Furthermore, despite being one of the first empirical applications of the model, Herzog (2007) conducted a review of smoking cessation in longitudinal studies, finding that results did not support TTM. Although Herzog (2007) originally only found two studies which conformed to the inclusion criteria, when the review was subsequently expanded to include eleven studies, similar results of a lack of support for the model were found. Other studies within a smoking cessation domain have also found no relationship between TTM constructs and stage progression (Guo, Aveyard, Fielding, & Sutton, 2009; Kleinjan, et al., 2008). Experimental studies have also found no evidence to support TTM in pregnant women smokers (Aveyard, et al., 2006), smokers in primary care (Aveyard, Massey, Parsons, Manaseki, & Griffin, 2009), and generic smokers (Dijkstra, De Vries, Roijackers, & van Breukelen, 1998a). Additionally, Quinlan and McCaul (2000) found results which contradict the hypotheses posited by TTM (DiClemente & Prochaska, 1982).

Despite the lack of evidence for the validity of TTM in studies which apply the theory to topics integral to COPD self-management processes (Schulman-Green, et al., 2012; Vogelmeier, et al., 2018), studies directly testing self-management interventions have shown more positive results; including in physical activity post-cardiac rehabilitation (Izawa, Watanabe, Oka, Osada, & Omiya, 2006), osteoarthritis (Heuts, et al., 2005), and rheumatoid arthritis populations (Hammond, Bryan, & Hardy, 2008). However, the intervention delivered by Hammond, et al. (2008) included behaviour change constructs from social cognitive theory (Bandura, 1986) and the health belief model (Rosenstock, 1974) making it difficult to draw conclusive conclusions about the relative contributions of each theory.

Dietary behaviours, physical exercise, and smoking cessation are three factors pertinent to self-management processes (Schulman-Green, et al., 2012), where the importance of the latter two elements is even higher for people with COPD (Higgins, et al., 1982; Vogelmeier, et al., 2018). Given the poor evidence for the use of TTM constructs to predict stage progression and inform effective interventions for these three factors, this theory does not seem appropriate to explain and predict self-management motivation and HRQoL in people with COPD.

3.1.2 The theory of planned behaviour

The theory of planned behaviour (TPB; Ajzen, 1988, 1991) incorporates several concepts pertinent to predicting behaviour. By building upon an earlier model (theory of reasoned action; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975) and adding perceptions of behavioural control, complicated goals and behaviours relevant to health outcomes could be explained (e.g. smoking cessation and physical activity; Ajzen, 1988; 1991; Connor & Sparks, 2015). TPB is visually presented in Figure 3.1.

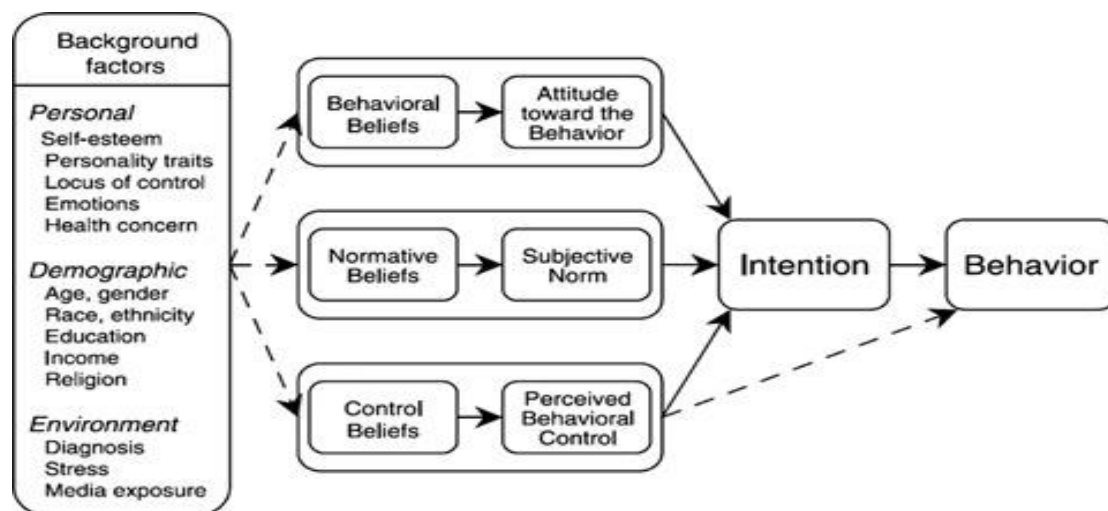


Figure 3.1. The theory of planned behaviour (Ajzen, 1991).

As social cognitive models (SCMs) are theories that specify a single prediction equation for behaviour (i.e. they specify the relationships between constructs which culminates in behaviour; Sutton, 2015), research upon such theories generally assesses how valid each component is at predicting the next in the model and how valid the model is as a whole at predicting a specific behaviour. For example, the level at which behavioural beliefs predicts attitude, and the entire model predicting smoking cessation.

Connor and Sparks (2015) conducted a meta-analysis of meta-analyses to investigate the relationships between the various theory concepts within a health domain, finding moderate correlations between the constructs following the predicted model pathways (e.g. normative beliefs predicting subjective norm). Moderate strength correlations were also found between attitudes, subjective norms, and perceived behavioural control, suggesting that these three constructs measure similar concepts (Connor & Sparks, 2015). However, this analysis did not attempt to control for duplication, where studies present in two or more original reviews would have been analysed more than once. This decreases the validity of the meta-meta-analysis due to the possibility of a study with highly positive results being analysed multiple times and artificially skewing the findings.

Other reviews have found strong relationships for the variables which predict behaviour intention (Ajzen, 1991; Armitage & Connor, 2001; van den Putte, 1991), where this has been replicated when the model has been applied to health-related behaviours (Godin & Kok, 1996; McEachan, Conner, Taylor, & Lawton, 2011). Additionally, correlations have been reported for the antecedents of the variable 'behaviour' (Ajzen, 1991; Armitage & Connor, 2001; Godin & Kok, 1996; McEachan, et al., 2011; Trafimow, Sheeran, Conner, & Finlay, 2002), where aggregating the findings from these studies accounts for between 19% and 36% of the variance explained across multiple behaviours. This latter finding was replicated in a

meta-analysis which applied TPB to internet-based health behaviour change interventions (Webb, et al., 2010); however, large heterogeneity between included studies was reported.

There does appear to be major disparity between the predictive strength of the variables on behavioural intention and the ability of this construct to predict the actual behaviour. Where Yan and Or (2017) found that 74% of behavioural intention variance could be explained by variables present in the TPB; however, only 17% of the variance for the target behaviour was explained by behavioural intention and perceived behavioural control. This phenomenon has been termed the ‘intention-behaviour gap’ and is used to describe an individual who has the volition to conduct, or abstain, from a behaviour, but ultimately doesn’t (Sheeran, 2002). Research has found large intention-behaviour gaps across a variety of health behaviours, including 57% in condom use (Gallois, et al., 1992), 57% in cancer screening attendance (Orbell & Sheeran, 1998), and 54% in exercise adherence (Sheeran & Orbell, 2000). A more recent review also investigated this gap in physical exercise adherence calculating this to be 46% in a total sample size of 3,899 (Rhodes & de Bruijn, 2013). Furthermore, Sheeran (2002) reviewed studies across multiple health domains, calculating 47% of participants failed to carry out their intentions. Therefore, given this theory’s diminished ability to predict *actual* behaviour, it may not be the most applicable to meet the needs of this thesis.

Research investigating variables which influence the intention-behaviour gap have found that self-efficacy, planning, and action control are all possible mediators (Abraham, Sheeran, & Johnston, 1998; Coumeya & McAuley, 1994; Eastabrooks & Carron, 1999; Sniehotta, Scholz, & Schwarzer, 2005). The importance of self-efficacy to predict behaviour has also been found by other authors (Sheeran, et al., 2016), including in medication adherence (Bane, Hughe, & McElnay, 2010). Although TPB does incorporate self-efficacy – where perceived behavioural control is considered a synonymous construct (Luszczynska & Schwarzer, 2015)

– other theories place higher importance on, and provide detailed descriptions of, how to positively influence this variable (Bandura, 1986).

In summary, although TPB constructs have shown good inter-relationships when applied to people within a health domain (Godin & Kok, 1996; McEachan, et al., 2011), the model does not possess the ability to accurately predict target behaviours relevant to self-management processes (Rhodes & de Bruijn, 2013). This includes a large intention-behaviour gap when predicting physical exercise adherence (Sheeran & Orbell, 2000a). Furthermore, self-efficacy has been highlighted as one of the most important variables to predict multiple behaviours, including medication adherence (Bane, et al., 2010; Sheeran, et al., 2016). Although TPB does include the concept of self-efficacy, the theory provides limited guidance on how to influence this variable (Hobbis & Sutton, 2005); where other theories, such as social cognitive theory (Bandura, 1986), more effectively accomplish this. Therefore, the TPB may not be the most applicable to explain and predict self-management motivation and HRQoL in people with COPD.

3.1.3 Social cognitive theory

Social cognitive theory (SCT; Bandura, 1986) originally only included the concept of self-efficacy (Bandura, 1977); however, was later expanded upon with the addition of outcome expectancies, goals, and social structural factors (Luszczynska & Schwarzer, 2015). SCT is illustrated in Figure 3.2. Multiple authors have declared that self-efficacy is equivalent to SCT (Luszczynska & Schwarzer, 2015); however, this has been denied by Bandura (1997). Despite this, many studies implementing the theory only assess self-efficacy (Luszczynska & Schwarzer, 2015). Although these studies are neglecting most of the theory, this is partially

understandable as self-efficacy does have a direct effect on every other construct in the model; therefore, authors designing interventions would likely focus on such an integral component.

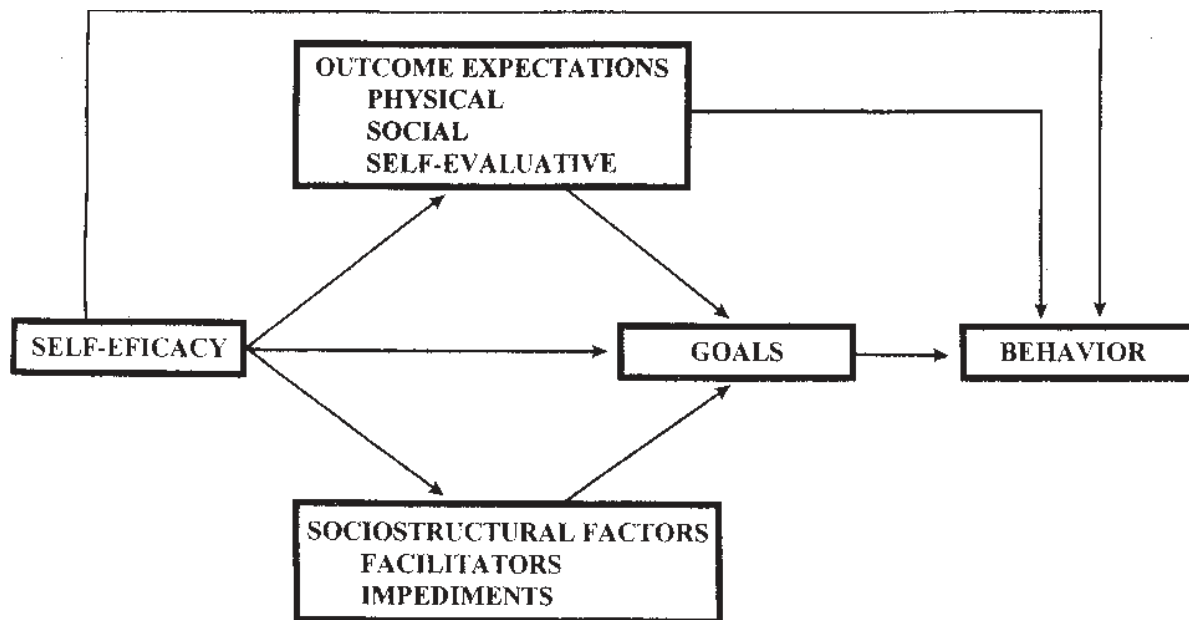


Figure 3.2. Social cognitive theory (Bandura, 2004).

In contrast to the TPB (Ajzen, 1991), investigations into the correlations between various theory concepts have largely gone unpublished (Luszczynska & Schwarzer, 2015).

Therefore, it is difficult to fully conclude the validity of the relationships between SCT constructs. However, one recent study evaluating a SCT-based questionnaire to predict physical activity in people with spinal cord injury, did provide support for the five-factor model (i.e. Figure 3.2; Wilroy, et al., 2017).

SCT has been applied to a wide range of behaviours relevant to self-management and shown to explain medication adherence, adequate exercise, managing stress, and maintaining a balanced diet (Berg, Dunbar-Jacob, & Sereika, 1997; Clark & Dodge, 1999; McCullough, et al., 2016). A lot of these studies were conducted in a population with diabetes, finding self-efficacy and outcome expectancies correlated with blood testing, medication adherence, and

glycaemic control (O’hea, et al., 2009; Williams & Bond, 2002). Although research indicates that self-efficacy is consistently the best predictor of behaviour, relative to the other theory constructs (Fleig, Pomp, Schwarzer, & Lippke, 2013; Magklara, Burton, & Morrison, 2014; O’hea, et al., 2009), it has been found to be a poor predictor of performance when individuals do not process the skills to conduct the target behaviour (i.e. there is no correlation between self-efficacy and performance in these populations; Carmichael & Taylor, 2005; Schunk, 1999). However, after individuals have obtained these skills, self-efficacy can better predict task performance (Zimmerman & Kitsantas, 2005). A review by Jones and Riazi (2011) found that self-efficacy was an important variable to explain various outcomes, including HRQoL, perceived health status, depression, and physical functioning. However, the authors concluded that more studies were necessary to determine if this construct explains any additional variance beyond that of objective disease severity measures (Jones & Riazi, 2011). Within people with COPD attending PR, self-efficacy has been found to positively correlate to exercise tolerance and HRQoL (Lox & Freehill, 1999) and predict attendance and functional exercise improvement (Selzler, Rodger, Berry, & Stickland, 2016). Although Selzler, et al. (2016) found that scheduling self-efficacy significantly increased during PR, task and coping self-efficacy remained unchanged.

Interventions utilising SCT as a theoretical underpinning have reported heterogenous results; where some studies have found positive effects on health outcomes (Richards, Bartlett, Wong, Malouff, & Grunstein, 2007; Sparrow, Aloia, DeMolles, & Gottlieb, 2010) and others have reported no benefits (Aloia, Arnedt, Strand, Millman, & Borrelli, 2013; Bartlett, et al., 2013). Such interventions have been found to have high acceptability, with one study reporting that 82% of participants believed a text-messaging support intervention – called Sweet Talk – had increased their diabetes self-management knowledge and 90% wanted to continue (Franklin, Waller, Pagliari, & Greene, 2006). However, Franklin, et al. (2006) only

found improved glycaemic control for participants randomized to receive Sweet Talk plus intensive therapy, not Sweet Talk plus usual care. One conclusion could therefore be that positive findings are attributable to the intensive therapy. This conclusion is supported by findings from a meta-analysis, which reported that interventions utilising SCT as a theoretical underpinning were associated with an effect size of 0.15 (Webb, et al., 2010); where this is below the threshold to be considered a small effect (Cohen, 1988). This effect size is lower than those found for TTM (0.20; small effect) and TPB (0.36; moderate effect; Webb, et al., 2010).

In summary, SCT has shown a good ability to predict a range of behaviours relevant to self-management knowledge (Clark & Dodge, 1999; McCullough, et al., 2016); both in chronic conditions more generally and specific to COPD (Selzer, et al., 2016). However, studies focusing solely on self-efficacy make it hard to determine the applicability of the theory as a whole (Luszczynska & Schwarzer, 2015). Although self-efficacy on its own can explain self-management behaviours (O’hea, et al., 2009), the concept’s predictive power lessens for people who do not possess the skills needed to conduct the target behaviour (Carmichael & Taylor, 2005). While there is no evidence to suggest that people with COPD have absolutely none of the skills required to effectively self-manage their condition, this is still a negative of SCT, because a model should be able to predict behaviour at all levels of aptitude.

Furthermore, interventions utilising SCT as a theoretical underpinning have been associated with very small effect sizes (Webb, et al., 2010). Therefore, this theory may not be the most appropriate to explain self-management motivation and HRQoL in people with COPD.

3.1.4 Self-determination theory

Self-determination theory (SDT; Deci & Ryan, 1985) focuses on the quality of an individual's motivation to predict a target behaviour, where this is opposed to the other SCMs presented above which emphasise the quantity of motivation (Sheldon, et al., 2003). SDT is rooted upon organismic and dialectical assumptions and has brought together four mini-theories over three decades to help explain social phenomena (Sheldon, et al., 2003). The aggregation of these theories has allowed SDT to be applied to multiple areas where self-motivation and regulation are important factors (Ryan, Patrick, Deci, & Williams, 2008); including health-related behaviours (Deci & Ryan, 2012).

SDT, as presented in Figure 3.3, is less intuitive compared to TPB (Figure 3.1) or SCT (Figure 3.2), where these models have specific pathways ultimately culminating in 'behaviour'. SDT posits that there are three basic psychological needs; autonomy, competence, and relatedness (Deci & Ryan, 1985). The more that these are satisfied, the greater an individual's self-determined motivation will be toward a given behaviour (i.e. intrinsic motivation or extrinsic motivation with regulation types found further to the left of Figure 3.3; Deci & Ryan, 2002) and thus the greater probability that the behaviour will be conducted.

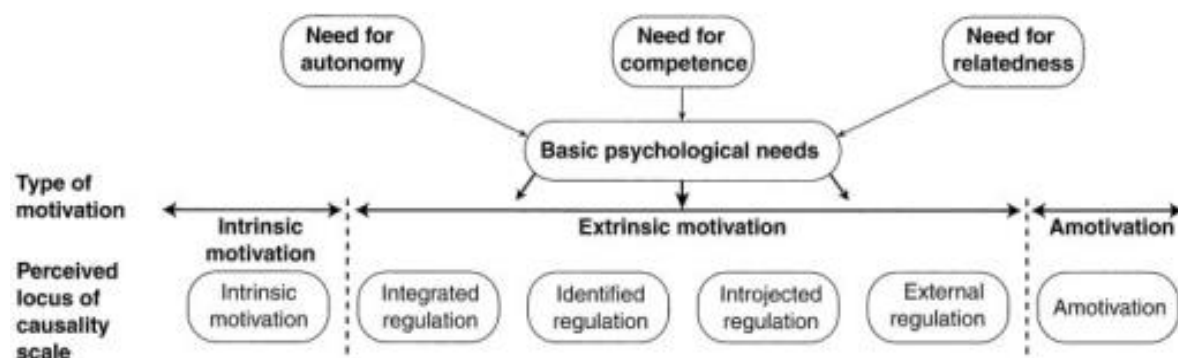


Figure 3.3. The basic psychological needs, self-determined motivation, and locus of causality. Adapted from Hagger and Chatzisarantis, 2007.

Research investigating the relationships between the various theory constructs has found that the basic psychological needs are strongly correlated with one another (Ntoumanis, 2005; Standage, Duda, & Ntoumanis, 2005); with the ability to be aggregated to an overall factor (Hagger, Chatzisarantis, & Harris, 2006). Additionally, interventions which increased participants' self-determined motivation also increased their basic psychological needs (Edmunds, Ntoumanis, & Duda, 2007), which provides support for the relationships between need satisfaction and self-determined motivation. Other findings have also provided evidence for the order of constructs suggested by SDT (Edmunds, et al., 2007; Hagger, et al., 2006a; Standage, Gillison, & Treasure, 2007).

Multiple studies have investigated the relationship between need satisfaction and well-being (Deci & Ryan, 2002), finding higher levels of the basic psychological needs were associated with positive affect, vitality, well-being, perceived health, self-esteem, and general health (Baard, Deci, & Ryan, 2004; Bartholomew, et al., 2011; Ilardi, Leone, Kasser, & Ryan, 1993; Kasser & Ryan; 1999; Reis, Sheldon, Gable, Roscoe, & Ryan, 2000; Sheldon, Ryan, & Reis, 1996); in addition to lower levels of negative affect and symptomatology (Reis, et al., 2000; Sheldon, et al., 1996). Higher self-determined motivation has also been found to be correlated to well-being, vitality, and positive emotions (Bartholomew, et al., 2011; Waaler, Halvari, Skjesol, & Bagoien, 2013).

Research applying SDT to various behaviours relevant to self-management processes has found that more self-determined behaviour positively correlates to engagement and adherence in healthy eating (Hagger, Chatzisarantis, & Harris, 2006; Mata, et al., 2009; Jacobs, et al., 2011), physical activity (Brooks, et al., 2018; Chatzisarantis and colleagues, 2002; 2003), and smoking cessation (Williams, Gagne, Ryan, & Deci, 2002; Williams, et al., 2006). The latter two behaviours are considered key self-management processes for people with COPD (Vogelmeier, et al., 2018). These findings are supported by a comprehensive meta-analysis

including 166 studies, which investigated the use of SDT concepts to predict multiple health behaviours including; physical activity, smoking cessation, glycaemic control, medication adherence, and eating a healthy diet (Ng, et al., 2012). Results showed that higher levels of the basic psychological needs and self-determined motivation significantly and positively correlated to adaptive health outcomes; such as mental health (e.g. lower depression and anxiety) and physical health (e.g. increased physical activity, weight loss, and smoking cessation). Ng, et al. (2012) conclude that SDT is an applicable theoretical framework to explain antecedents and outputs of motivation in a variety of health-related behaviours relevant to effective self-management processes.

Although there are relatively few studies directly applying SDT to people with COPD (Richardson, et al., 2014; McCullough, et al., 2016), results have shown that the basic psychological needs were related to continued self-management processes post-PR (Stewart, et al., 2014). Additionally, one study concluded that healthcare providers need to be cognisant of exercise self-determined motivation for this group (Cho, et al., 2017). Furthermore, the results by Rapport, et al. (2015), described in the previous chapter, indicate the importance of PR to satisfy the needs of competence and relatedness. The importance of these factors is also supported by literature evaluating both PR and self-management interventions (Barlow, et al., 2002; Halding, et al., 2010; Stevens, 2016; Taylor, et al., 2012; Turner, et al., 2014). George, Kong, Thoman, and Stewart (2005) investigated reasons for medication non-adherence in people with COPD, where several of the most common reasons found can be directly related to the unsatisfaction of the basic psychological needs. For example, doctors providing limited options or not sharing information (autonomy); being unsure about medications or lacking understanding (competence); and doctors lacking compassion (relatedness; George, et al., 2005).

Lastly, as described in chapter two, increasing self-management knowledge in chronic conditions is a key strategy for the NHS (Goodwin, et al., 2010); where, to facilitate people being involved in their own care, a partnership model has repeatedly been suggested (Coulter, et al., 2013). Giving people more choice in their own care can be described as supporting the need for autonomy, where the importance of this need within healthcare services is again highlighted by the NICE (2011) definition of PR; where supporting autonomy is explicitly stated.

In summary, SDT concepts correlate well to one another and findings have supported the model schema proposed by Deci and Ryan (2000; Ntoumanis, 2005; Standage, et al., 2007). Higher basic psychological need satisfaction is related to more positive wellbeing and lower symptomatology (Bartholomew, et al., 2011; Reis, et al., 2000; Sheldon, et al., 1996; Waaler et al., 2012) and these needs can be used to explain medication non-adherence (George, et al., 2005). Additionally, the importance of these needs, particularly autonomy, is highlighted in policy documents (Coulter, et al., 2013; Goodwin, et al., 2010; NICE, 2011). Furthermore, there is also strong support for the use of the theory to predict behaviours relevant to COPD self-management processes (Brooks, et al., 2018; Ng, et al., 2012), and the importance of relatedness within such interventions (Halding, et al., 2010; Stevens, 2016). Due to the ability of SDT concepts to predict behaviours relevant to self-management and being one of the only models described in this chapter which directly predicts HRQoL, this theory was applied to explain these two factors in people with COPD. For this reason, it is important to fully describe this model in more depth than the overview above, and the next section provides a comprehensive literature review of this theory.

3.2 Self-Determination Theory: Literature review

3.2.1 Assumptions, basic needs, and the motivation continuum

As stated earlier, SDT aggregates four separate theories, these are: cognitive evaluation theory (Deci, 1975; Deci & Ryan, 1980), organismic integration theory (Deci & Ryan, 1985b; Ryan & Connell, 1989), causality orientations theory (Deci & Ryan, 1985a), and basic needs theory (Ryan & Deci, 2000). Despite representing the last theory to be published, the basic psychological needs are present throughout the earlier theories; where, Ryan and Deci (2000b) explained specific nuances which earlier descriptions had not covered (Deci & Ryan, 2002). Rather than describe and evaluate each of these theories chronologically, this section will provide an in-depth review of the entirety of SDT in its current form.

The underlying assumptions of SDT are that people have a natural propensity to continually develop an intricate and personal sense of self (Deci & Ryan, 2002). This is accomplished through creating interconnections involving both integration within oneself and integration of oneself with others (Angyal, 1963; Deci & Ryan, 2002); where healthy development incorporates relative parity between these two elements. Despite this process naturally occurring, there are specific situations and environments which either support or impede this tendency (Deci & Ryan, 2002; Sheldon, et al., 2003). The level to which this development is facilitated or fragmented is determined by how much the environment satisfies or frustrates three basic psychological needs; autonomy, competence, and relatedness (Ryan & Deci, 2000b).

SDT's concept of autonomy builds upon that described by deCharms (1968), whereby this need concerns engaging in actions due to interest and integrated values (Deci & Ryan, 1985b;

Ryan & Connell, 1989). An autonomous individual conducts behaviour from a sense of self-expression, through which, even when being instructed by external forces, this person experiences causality and worth whilst aligning with those instructions (Deci & Ryan, 2002). Autonomy is not a synonym of independence, where this concept is defined as a complete lack of reliance on external forces (Deci & Ryan, 2002). Instead, Ryan and Deci (2000b) explain that the scales of autonomy and independence are perpendicular to one another, whereby an individual can experience an autonomous-dependent behaviour (providing the values of this behaviour are congruent with their own) in the same way they can experience a heteronomous-dependent behaviour.

Competence is the need to feel environmental effectiveness in one's actions and having opportunities to demonstrate and enact on one's capabilities (Deci, 1975; Harter, 1983; White, 1959). This need drives people to undertake challenges suitable for their capabilities and continually maintain or increase their capabilities through repeated activity. This need is not an obtained capability or level of mastery, but instead is an individual's perceived sense of confidence and environmental effectiveness (Deci & Ryan, 2002).

Lastly, relatedness is the need to feel connected to other individuals or groups and to care and be cared for by these significant others (Baumeister & Leary, 1995; Bowlby, 1979; Harlow, 1958; Ryan, 1995). This need reflects the propensity of individuals to form interconnections with others (Angyal, 1963) and be accepted whilst acting in concordance with oneself (Deci & Ryan, 2002). These interconnections are not created in the pursuit of an outcome (e.g. sex) or specific status (e.g. becoming a spouse), but involve the psychological need to be with, and accepted by, others in a sense of secure community or unison (Deci & Ryan, 2002).

The basic psychological needs are seen by SDT as universal and are thus prevalent across all cultures and systems (Sheldon and colleagues, 2001; 2003), where people require these needs

to be satisfied in order to live and prosper (Jacob, 1973). The relationship between the basic psychological needs and wellbeing has briefly been described within the overview of SDT earlier. As well as high satisfaction of the needs being linked with positive wellbeing (Reis, et al., 2000; Sheldon, et al., 1996), dissatisfaction has been correlated to lower self-esteem, self-actualization, relationship quality, life satisfaction, and cooperative behaviour, in addition to greater depression, anxiety, prejudice, and social-dominant attitudes (Duriez, Vansteenkiste, Soenens, & De Witte, 2004; Kasser & Ryan, 1993, 1996; McHoskey, 1999; Sheldon & McGregor, 2000; Sheldon, Sheldon, & Osbaldiston, 2000).

In addition to an environment dissatisfying the basic psychological needs, it can also thwart them; where such a situation would see the active frustration of one or more of these needs (Bartholomew, Ntoumanis, Ryan, Bosch, & Thogersen-Ntoumani, 2011). This is to say that need dissatisfaction is not equivalent to need thwarting. Vansteenkiste and Ryan (2013) provide the analogy of a plant which is lacking the sun, soil, and water and therefore describes need dissatisfaction and may lead to the death of the plant. However, poisoning or applying saltwater to the plant will kill it more quickly, where this scenario describes need thwarting. If an environment is actively thwarting the basic psychology needs, this does not necessarily mean that an individual cannot adequately satisfy them; rather, the individual requires more than the typical amount of effort to achieve this (Bartholomew, et al., 2011). For example, during a smoking cessation attempt, an individual can still perceive their competence to be satisfied despite nicotine cravings actively thwarting this need. General symptoms and acute exacerbations have been described as thwarting stimuli in people with COPD (Toms & Harrison, 2002, Wortz, et al., 2012).

SDT describes the basic psychological needs as separate to motives, desires, or strivings; where, although such motives can be formulated to satisfy these needs, there are situations in which an individual strives toward a goal that is at odds with need satisfaction (Deci & Ryan,

2002). Such a situation would occur when the pursuit of an objective distracts an individual from a behaviour which would satisfy autonomy, competence, relatedness, or a combination of these three. It is also possible that such an objective actively thwarts these basic needs and thus detracts from an individual's overall wellbeing. Thus, effectively obtaining one's goals or desires is not necessarily equivalent to satisfying the basic psychological needs and achieving greater health or wellbeing (Deci, 1980; Ryan, Sheldon, Kasser, & Deci, 1996).

Dependent on the level to which a certain environment or activity satisfies or frustrates the basic psychological needs, is the amount of self-determined motivation an individual will experience toward that behaviour (Sheldon, et al., 2003). These three needs work simultaneously, whereby a behaviour that satisfies all three is more likely to be conducted in a self-determined manner than an activity that only satisfies one, or none (Hagger & Chatzisarantis, 2015). However, there is growing evidence to suggest that when an individual is dissatisfied in one or more of their needs, they have an increase in motivation to engage in satisfaction-supporting activities (Sheldon & Gunz, 2009). People also engage in restorative behaviours to overcome autonomy thwarting stimuli, however, only when they have high perceived competence in the task which is thwarting them (Radel, Pelletier, & Sarrazin, 2013). Cognitive evaluation theory (Deci, 1975; Deci & Ryan, 1980) distinguished between intrinsic and extrinsic motivation and identified contextual contingencies that influenced an individual between the two. Unlike other SCMs, SDT identified extrinsic motivation as a continuum as opposed to a dichotomy (Deci & Ryan, 2002), and this was fully explained with the incorporation of organismic integration theory (Deci & Ryan, 1985b; Ryan & Connell, 1989). This theory also saw the addition of the concept 'amotivation'. The relative positions between these different motivational or regulatory types is illustrated in Figure 3.4, with more self-determined versions found further to the left of this image (Ryan & Connell, 1989). This figure is the full version from Hagger and Chatzisarantis (2007), where this level

of detail was not needed for the overview section above and thus was not included in Figure 3.3.

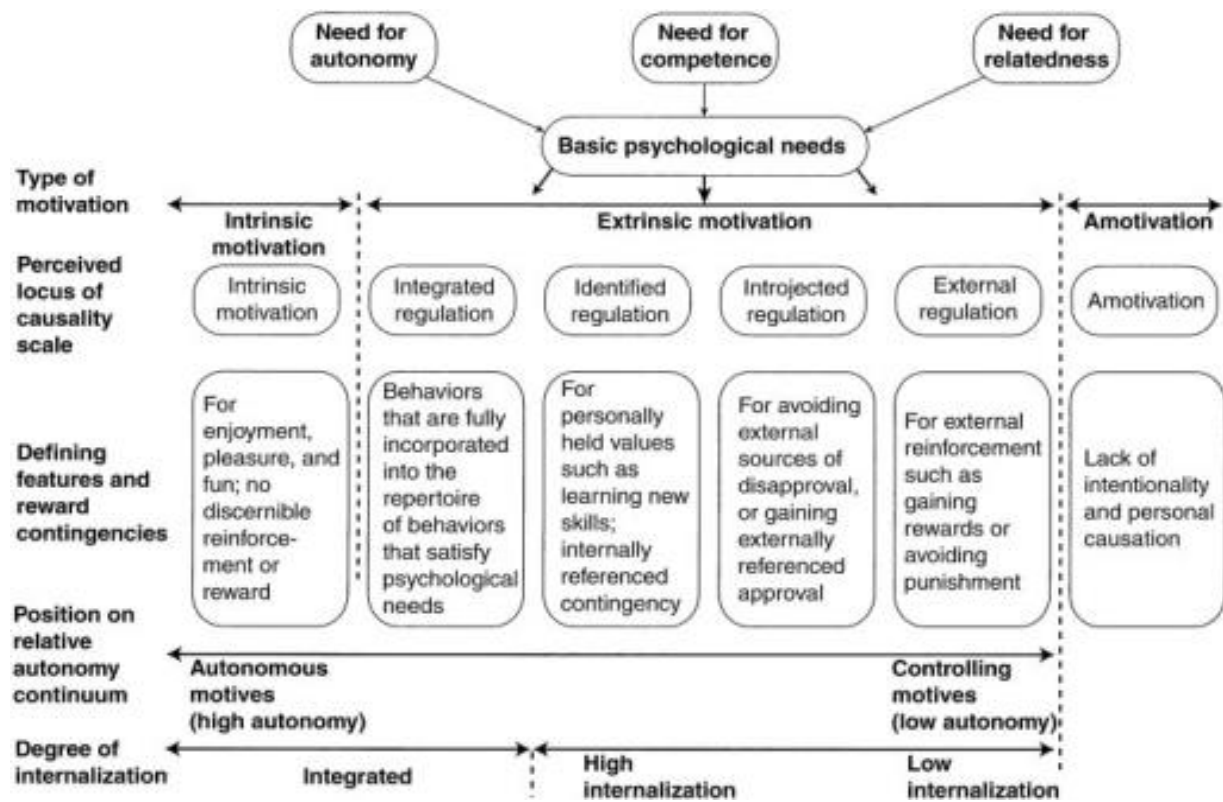


Figure 3.4. Self-determination theory (Deci & Ryan, 1985). From Hagger and Chatzisarantis, 2007.

An individual who is intrinsically motivated toward a behaviour engages with this activity for the sheer enjoyment, experience, and satisfaction; as opposed to any inherent reward or reinforcement (Ryan & Deci, 2000). Cognitive evaluation theory describes how the needs for autonomy and competence are instrumental for intrinsically motivated behaviours (Deci, 1975). Events which decrease the perceived locus of control, for example a monetary reward for performing physical exercise, will likely result in an undermining of an individual’s intrinsic motivation, due to a change in the perceived cause of that behaviour (Deci & Ryan, 1985b). However, an event which causes a more internal locus of control will likely increase intrinsic motivation (Deci & Ryan, 2002). Similar increases or decreases to this type of motivation are experienced within the need for competence; for example, a stimulus which

increases the perceived competence in an activity will likely be conducted in a more self-determined manner (Deci & Ryan, 1980). The importance of the need for relatedness within intrinsic motivation is still uncertain (Deci & Ryan, 2002).

Wortz, et al. (2012) found that people engaged in self-management behaviours because this enabled them to regain the ability to participate in enjoyable activities. This describes participating in an activity for an inherent reward and not for the sheer enjoyment and pleasure of the self-management behaviour. Therefore, another form of motivation is necessary to describe these individuals. For extrinsically motivated behaviours, individuals engage with such activities to receive a tangible reward or reinforcement (Ryan & Deci, 2000). Although previous authors have assumed that all extrinsically motivated behaviours have an external locus of causality (deCharms, 1968), Deci and Ryan (2002; 2008) differentiated between different forms of regulation by the level of autonomy satisfaction and internalisation an individual experienced toward an activity.

Integrated regulation occurs when an activity's goals and values have been fully aligned with one's sense of self and represents the most autonomous version of extrinsic motivation (Duncan, Hall, Wilson, & Jenny, 2010; Wilson, Rodgers, Loitz, & Scime, 2006). Although sharing aspects in common with intrinsic motivation, behaviour within this regulation type are still conducted to obtain separate, albeit fully integrated, outcomes (Deci & Ryan, 2002).

Identified regulation represents a slightly less self-determined form of motivation compared to that of integrated regulation; however, still incorporates a relatively high level of autonomy compared to the last two regulation types described below (Deci & Ryan, 2002). Individuals experiencing identified regulation consciously evaluate behavioural goals and determine the personal importance of these values (Ryan & Deci, 2000).

Integrated regulation describes the motivation toward an activity which is usually conducted to avoid guilt or shame, or to receive external reinforcements of worth (Deci & Ryan, 1995). Such behaviour is typically part-internalised; where, an individual does not consider the goals or values of the activity to be truly part of themselves. Therefore, this type of regulation can be considered quite controlling and thus less autonomous (Deci & Ryan, 2002).

External regulation is the form of extrinsic motivation described by operant theory, where behaviour is conducted to receive an external reward or avoid punishment (Skinner, 1953). Although these behaviours will be continued providing that the regulator remains consistent (e.g. continued monetary reward or threat of punishment), if these are withdrawn, the behaviour will likely be discontinued (Hagger & Chatzisarantis, 2015). Such activities are therefore conducted to fulfil an external demand and are lacking in autonomy and internalisation (Deci & Ryan, 2002).

Amotivation is defined as a behaviour conducted for no personally held rationale, where individuals within this type of motivation either do not engage with the activity at all or engage passively (Markland & Tobin, 2004). Such a state can result from individuals lacking a sense of causality or perceived competence to carry out the behaviour (Bandura, 1977; Deci, 1975; Seligman, 1975). Alternatively, individuals who do not value the activity, or the inherent outcomes, could also display amotivation toward the behaviour (Ryan, 1995).

As described within the overview of SDT, a behaviour is more likely to be conducted if an individual is either intrinsically motivated or extrinsically motivated with a high degree of internalisation, compared to one where the individual experiences amotivation. Additionally, a behaviour which satisfies both personally relevant, autonomous goals and the basic psychological needs is more likely to be conducted than a behaviour which satisfies only one or neither of these components. Through this increase in the conducting of a specific

behaviour, it becomes internalized and integrated into an individual's repertoire of behaviours (Hagger & Chatzisarantis, 2015).

As previously described, the satisfaction of the needs for autonomy and competence are central to intrinsically motivated behaviours (Deci, 1975). For extrinsic motivation, however, Deci and Ryan (2002) posit that relatedness is the core basic psychological need to be satisfied because behaviours within this domain are inherently uninteresting and therefore individuals need an original motivator to begin participating in the activity. This idea is supported by research which indicates that an individual, out of feeling related or wishing to be related to another group or person, begins a behaviour after receiving a request to engage from these significant others (Ryan, Stiller, & Lynch, 1994). Second to the importance of relatedness is the need of competence, because an individual must perceive themselves to be competent in the requested behaviour to engage, and subsequently internalise, the activity (Deci & Ryan, 2002). Lastly, as described above, the need for an internal locus of control, or autonomy, is required to fully integrate a behaviour; therefore, this need is also integral within extrinsic motivation (Sheldon, et al., 2003). Although some internalisation can occur toward an activity which is non-autonomous, more self-determined regulation will always occur in behaviour which supports this basic psychological need (Deci & Ryan, 2002). The relative importance of the basic psychological needs during behavioural initiation – as described above by Deci and Ryan (2002) and Sheldon, et al. (2003) – is supported by research conducted within cardiac and pulmonary rehabilitation (Whittaker, Matata, Midgley, & Levy, 2018). Using semi-structured interviews, Whittaker, et al. (2018) found that relatedness was the most salient need at referral and pre-rehabilitation assessment, all three needs during the programme, and autonomy and competence within long-term maintenance of behaviour. This represents the journey from relatedness satisfaction being the most

important need during behaviour initiation, through to the satisfaction of autonomy and competence after fully integrated regulation has been achieved.

Finally, causality orientations theory describes the individual differences inherent in the interpretation of situations where the extent of autonomy is ambiguous (Deci & Ryan, 1985). Although constituting one of the four mini-theories incorporated into SDT, these orientations are similar to personality traits (Deci & Ryan, 1985) and are therefore unlikely to be readily modified by an intervention (Haque, Abdullah, Rahaman, Kangas, & Jamsa, 2016). Research has found the relatively small albeit continuous effects of causality orientations across multiple contexts and domains (Deci & Ryan, 1985a; Ferguson, Kowalski, Mack, & Sabiston, 2014); however, despite the potential for being able to explain or predict self-management knowledge and HRQoL, such a finding would prove unhelpful if a healthcare intervention wishes to increase these factors. Therefore, causality orientations will not be assessed during the investigation into the applicability of SDT to a population with COPD, and thus will not be discussed further within this thesis.

3.2.2 SDT and self-management

As described within the overview of SDT, there is a wealth of evidence to support the schema proposed by the model (Edmunds, et al., 2007; Hagger, et al., 2006a; Standage, et al., 2007). This includes research which confirms the validity of basic needs theory (Ntoumanis, 2005; Standage, et al., 2005), organismic integration theory, and the perceived locus of causality (Deci, Eghrari, Patrick, & Leone, 1994; Grolnick & Ryan, 1989; Ryan & Connell, 1989; Williams & Deci, 1996). Although there is strong evidence for the satisfaction of the basic psychological needs predicting higher self-determined motivation, lower levels of these needs

are not always correlated to more controlled motivation (Ng, et al., 2012). Bartholomew, et al. (2011) have suggested the importance of assessing the thwarting of autonomy, competence, and relatedness in environments where optimal motivation cannot be achieved. Given the level of thwarting on daily activities exhibited by COPD (Toms & Harrison, 2002; Wortz, et al., 2012), the active undermining of these needs may prove important in explaining and predicting self-determined motivation to self-manage. However, to date little research has focused upon the thwarting of the basic psychological needs in any domain (Olafsen, et al., 2016).

Research has also found promising results when applying SDT to explain or predict activities pertinent to multiple self-management processes. Higher internalisation of behavioural values was found to positively predict long-term medication adherence, whereas less autonomy supporting regulation had no correlation with this factor (Williams, Rodin, Ryan, Grolnick, & Deci, 1998). This research also reported that clinicians' perceptions of their patients' motivation to adhere to the regimen was uncorrelated to actual medication compliance. Additionally, patients' perceptions of clinicians' support for their autonomy was found to increase internalisation and adherence (Williams, et al., 1998). SDT concepts can also explain multiple reasons for medication non-adherence in people with COPD given by George, et al. (2005).

Brooks, et al. (2018) investigated physical activity and exercise behaviour in people with chronic pain, finding that all SDT variables were associated with both factors; thus, supporting the ability of SDT to predict behaviours pertinent to COPD self-management. Other studies have also used SDT to predict physical activity (Fortier, Duda, Guerin, & Teixeira, 2012; Fortier, Sweet, O'Sullivan, & Williams, 2007), including post-PR. Cho, et al. (2017) found educational level, number of acute exacerbations, and identified regulation were predictors of continued exercise behaviour after PR. Additionally, Stewart, et al. (2014)

reported that competence satisfaction and autonomous motivation predicted the maintenance of physical activity post-PR. Although these results corroborate Whitaker, et al. (2018; described above), findings also showed that a level of non-autonomous regulation was important for maintaining these behaviours (Stewart, et al., 2014). This partially contradicts the idea that more self-determined motivation is always more beneficial to an individual (Deci & Ryan, 2002; Stewart, et al., 2014). This could also potentially explain the finding that living with someone positively predicts PR attendance (Hayton, et al., 2013), because sharing a living environment with someone could increase controlled regulation. However, the exact effect of this ‘living status’ – or other variables which involve close proximity to significant others (e.g. being in a relationship or medically caring for someone) – on SDT concepts is unknown.

Within smoking cessation, structural equation modelling showed that perceived autonomy-support predicted greater self-determined motivation, and this predicted cessation at 6, 12, and 30 months (Williams, et al., 2002). These results were later replicated, in addition to the finding that autonomy-support increased perceived competence satisfaction (Williams, et al., 2006).

Deci, Eghrari, Patrick, and Leone (1994) identified three factors which increased self-determined motivation; providing a meaningful rationale, acknowledging the individual’s feelings, and providing choice. Additionally, an environment which supports the individual’s autonomy in this way also facilitates the internalisation of behavioural regulation. This is further supported by Kaplan, Greenfield, and Ware (1989), who found that patients were more active during clinician appointments if a research assistant spent time helping them form their own questions beforehand. Williams and Deci (2001) later showed that the assistant helped support the patients’ autonomy, and this resulted in the beneficial effects.

The evidence shows that SDT can be used to explain and predict behaviours relevant to COPD self-management processes. The comprehensive review by Ng, et al. (2012) provides further support for the entirety of SDT in a health domain. Although the needs of autonomy and competence, in addition to higher self-determined motivation, were repeatedly found as positive predictors of healthy behaviours in the research described above, clinicians providing an autonomy-supportive environment was also shown to be effective. The importance of these factors is displayed in Figure 3.5, which illustrates the SDT model of health behaviour change (Ryan, et al., 2008).

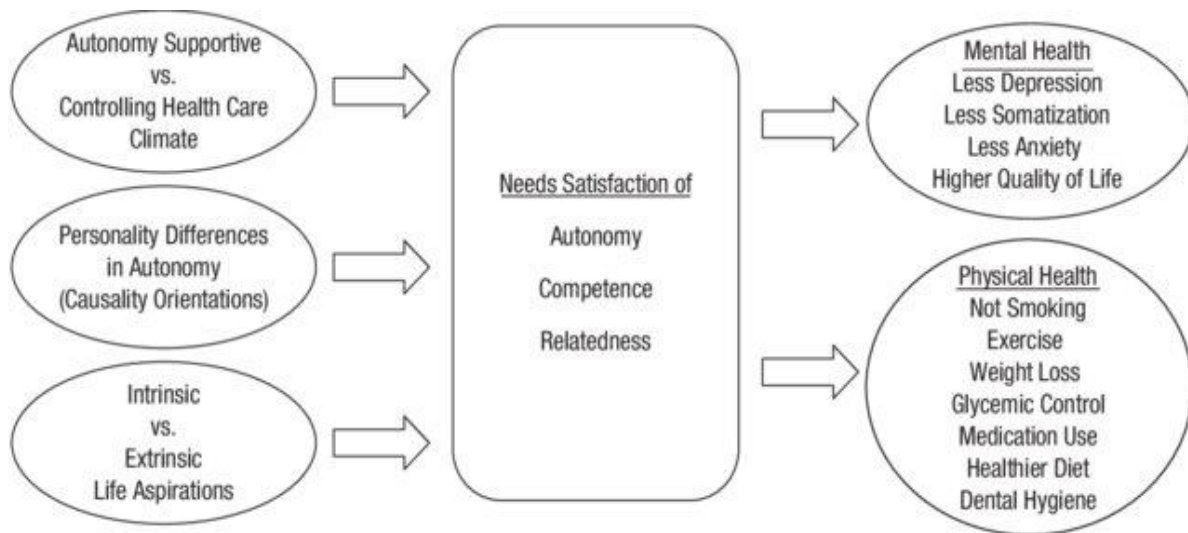


Figure 3.5. Self-determination theory model of health behaviour change (Ryan, et al., 2008).

Although causality orientations and life aspirations are depicted in Figure 3.5, as described earlier, these factors are trait-like variables and are therefore unlikely to be modifiable by a healthcare intervention. Other authors have also provided guidelines for interventions which only focus on autonomy support, the basic needs, and mental and physical health (Haque, et al., 2016).

In the examples of physical health behaviours given by Ryan, et al. (2008), all but glycaemic control and dental hygiene are relevant to COPD self-management knowledge described in the previous chapter (Schulman-Green, et al., 2012). Studies utilising this application of SDT

have shown positive results within dental hygiene (Halvari & Halvari, 2006), clinician self-management support (Kosmala-Anderson, Wallace, & Turner, 2010), and people with diabetes' glycaemic control (Liu, et al., 2018) and self-management behaviours (Rice, et al., 2017). The intervention described in the latter study used internet-delivered films designed to increase the basic needs and, through these, self-determined motivation to self-manage diabetes; where greater glycaemic control was reported for those who engaged with the films (Rice, et al., 2017). For self-management processes more pertinent to people with COPD, the SDT model of behaviour change has led interventions to positive outcomes in smoking cessation (Niemic, Ryan, Deci, & Williams, 2009; Williams, Niemic, Patrick, Ryan, & Deci, 2009) and physical activity (Fortier, et al., 2007; Sweet, Fortier, Strachan, & Blanchard, 2012; Sweet, Fortier, Strachan, Blanchard, & Boulay, 2014). Furthermore, PR – which incorporates autonomy support (NICE, 2011) – has been found to reduce the thwarting effects of COPD (Toms & Harrison, 2002) and create a sense of belonging amongst participants (i.e. relatedness satisfaction), encouraging adherence, knowledge sharing, self-confidence, and increased HRQoL (Halding, et al., 2010).

A recent meta-analysis found interventions utilising SDT-based behaviour change techniques resulted in significant positive effects on perceived autonomy support, self-determined motivation, and autonomy, competence, and relatedness satisfaction (Gillison, Rouse, Standage, Sebire, and Ryan, 2019). Furthermore, interventions delivered one-to-one compared to group, and to adults in comparison to children, resulted in greater benefits for participants' perceived competence satisfaction (Gillison, et al., 2019). This provides positive support for the use of interventions developed using SDT delivered one-to-one in a population with COPD (who are all adults). Interventions delivered to people with COPD have combined the use of behaviour change techniques based on SDT with other theories, such as TTM, finding positive results (Altenburg, et al., 2015; de Blok, et al., 2006; Hospes,

Bossenbroek, Hacken, van Hengel, & de Greef, 2009). Although promising, the lack of solely focussing on SDT concepts does create a gap in the literature for people with this condition.

All this research gives good evidence in support of the use of the SDT model of behaviour change to predict and influence self-management motivation and HRQoL. Indeed, Hagger and Chatzisarantis (2015) concluded that, within a health domain, SDT identifies motivational constructs, describes the mechanisms by which these constructs influence behaviour, and provides clear guidelines for each construct to allow interventions to be developed based upon its tenants.

3.3 Chapter summary

In summary, multiple authors have suggested the use of implementing psychological theory to explain health-related factors or to underpin healthcare interventions (Michie, et al., 2007; Painter, et al., 2008; Webb, et al., 2010). Despite these recommendations, current literature seldom utilises such models (Davies, et al., 2010; Prestwich, et al., 2014), where this is even rarer within self-management interventions designed for a population with COPD (McCullough, et al., 2016; Richardson, et al., 2014). Therefore, due to the definition of COPD self-management interventions specifying the need for the use of psychological theories and relevant behaviour change techniques (Effing, et al., 2016), research investigating COPD self-management may be smaller than previously reported (Kaptein, et al., 2014).

Following these recommendations and to help explain poor self-management motivation and HRQoL in people with COPD (Bourbeau & Bartlett, 2008; Kielmann, et al., 2010) four psychological theories were evaluated for their appropriateness. These theories were TTM

(Prochaska & DiClemente, 1983), TPB (Ajzen, 1991), SCT (Bandura, 1986), and SDT (Deci & Ryan, 1985). Although all four theories could explain or predict motivation toward behaviours relevant to COPD self-management processes or HRQoL to varying degrees, SDT was found to be the most suitable.

SDT posits that humans have a natural propensity to continually develop through creating interconnections both in and outside of oneself (Deci & Ryan, 2002). The level to which this can be enacted is dependent on the amount of perceived satisfaction for the needs of autonomy, competence, and relatedness (Ryan and Deci, 2000b). Also dependent on the level of satisfaction of these needs is the amount of self-determined motivation an individual will experience toward a given behaviour, where this is seen as a continuum between intrinsic motivation and amotivation (Deci & Ryan, 1985). The needs are universal and high and low satisfaction of these basic psychological needs has been linked with positive (Reis, et al., 2000) and negative (Sheldon & McGregor, 2000) wellbeing and HRQoL, respectively. An environment can also actively thwart these needs and COPD has been found to be a thwarting stimulus (Wortz, et al., 2012). This factor has been suggested as important in situations with sub-optimal motivation (Bartholomew, et al., 2011). Research has indicated that people with COPD are extrinsically motivated to conduct self-management behaviours and thus could be described as an activity with less than ideal motivation (Wortz, et al., 2012). However, there is currently little research which has investigated the effects of need thwarting in any domain (Olafsen, et al., 2016).

There is a wealth of literature supporting the model proposed by SDT (Edmunds, et al., 2007) and it has been applied to explain multiple behaviours relevant to self-management processes (Ng, et al., 2012). Several times throughout the literature review, the basic psychological needs, self-determined motivation, and clinician autonomy support were highlighted as important concepts (Brooks, et al., 2018; Deci, et al., 1994; Williams, et al., 2002; 2006). The

relevance of these factors is also evident in the SDT model of health behaviour change (Ryan, et al., 2008). Where, although the model includes the concepts of causality orientations and life aspirations, authors have suggested that the focus for interventions should be on the other variables present in the theory (Haque, et al., 2016). Interventions which positively influenced the factors identified in the model have reported beneficial outcomes on behaviours pertinent to self-management knowledge (Fortier, et al., 2007; Liu, et al., 2018; Rice, et al., 2017). Additionally, given the autonomy support present in PR (NICE, et al., 2011), this multidisciplinary intervention could also be described as built upon the tenants of SDT, where its positive effects have been reported in detail in the previous chapter.

The results from the literature review give strong evidence for the use of SDT to explain and predict self-management motivation and HRQoL. If valid in a population with COPD, the theory could be used to identify important concepts to improve motivation to self-manage and HRQoL (Hagger & Chatzisarantis, 2015). This follows the recommendation to implement ‘modelling’, which is promoted by various governing bodies and represents good practice (Craig, et al., 2008). However, although previous literature has partially applied SDT to people with COPD, this research largely aims to predict behaviours in individuals who have completed a PR programme (Cho, et al., 2017; Stewart, et al., 2014). It is estimated that less than 1.5% of the COPD population receive this each year (Yohannes & Connolly, 2004). Thus, the applicability of this theory to predict important factors before or during a multidisciplinary healthcare service is largely unknown. Additionally, the reviews which investigated the use of psychological models to design healthcare interventions for people with COPD, found none of the included studies used SDT (McCullough, et al., 2016; Richardson, et al., 2014).

This thesis aims to understand motivation to self-manage and HRQoL in people with COPD by utilising a SDT framework. Pertinent SDT concepts which have received limited research

attention, such as need thwarting (Olafsen, et al., 2016), will also be used to help explain relevant COPD variables. Thus, the research presented within this thesis is able to fill multiple gaps in current literature and report results which facilitated the building of knowledge within theory, research, and practice. The research questions and methodology which were used to meet the overarching aim are described within the following chapter.

Chapter Four: Thesis methodology

The two literature reviews provide a detailed overview of the current research conducted within the field. The second chapter, in addition to describing COPD, pharmacotherapy, self-management interventions, PR, and the use of technology, emphasised the low adherence rates observed across a range of behaviours in individuals with COPD. Therefore, there is a need to better understand the mechanisms that could help to explain this lack of motivation to adhere to self-management behaviours within this context. Additionally, the impact COPD and the accompanying co-morbidities have on HRQoL justifies the further need to consider the potential impact of such mechanisms of this important outcome.

The third chapter detailed how authors have recommended the use of psychological theory to explain various disease outcomes (Craig, et al., 2008). Despite a small amount of literature investigating this topic in populations with COPD (McCullough, et al., 2016), SDT was found to be the most appropriate model to explain the two outcomes of interest identified in chapter two; addressing both motivation to engage in behavioural outcomes and having corresponding relationships with wellbeing. The chapter identified a lack of literature considering the application of SDT in contexts such as COPD thus providing a relatively novel opportunity to utilise this framework to better understand self-management motivation and HRQoL in this underrepresented population.

The current chapter provides an overview of the thesis methodology and research questions which were used to meet the overarching aim. This aim is to understand motivation to self-manage and HRQoL in people with COPD from a SDT perspective. Three independent studies were conducted to answer specific research questions pertinent to this superordinate aim of the thesis.

4.1 Thesis overview

4.1.1 Study one

The second chapter highlighted the importance of motivation to self-manage and HRQoL for people with COPD. However, research indicates the relatively low level of these factors within this chronic condition (Bourbeau & Bartlett, 2008; Russell, et al., 2018), with behaviour change theories being recommended to explain health outcomes in general (Craig, et al., 2008). Although SDT can explain motivation to conduct multiple behaviours relevant to self-management processes and HRQoL (Deci & Ryan, 2002; Ng, et al., 2012), the theory has not been widely applied to people with COPD (Riley, et al., 2011). Studies which have applied the theory have focused on predicting health outcomes in people who have completed a PR programme (Cho, et al., 2017; Stewart, et al., 2014). Additionally, the effect of need thwarting remains uncertain (Bartholomew, et al., 2011; Olafsen, et al., 2016).

The first research study of this thesis aimed to address these gaps in the literature and investigate the ability of SDT concepts to predict motivation to self-manage and HRQoL in people with COPD who have not attended PR. Using a PR waiting-list population allowed this study to consider a group who have received a diagnosis but also little healthcare intervention previously; thus enabling the study to understand how the condition impacted psychological needs in order to better understand self-management motivations. This had the additional benefit where the historically low uptake of PR (Steiner, et al., 2015; 2016) could be explored using SDT concepts. This study was able to examine the relationships between the basic psychological needs, self-determined motivation, and HRQoL (incorporating the impact on both mental and physical health), as described by Ryan, et al. (2008; see Figure

3.5, page 62, Chapter Three). Although the motivation continuum is not included in the SDT behaviour change model (Ryan, et al., 2008), this concept logically resides between basic needs and the two health outcomes, due to this being a central tenet of SDT (Deci & Ryan, 1985; see Figure 3.4, page 55, Chapter Three). Analyses also included basic need thwarting variables to help build the knowledge regarding the role of this factor. Additionally, participant demographic variables were included in order to investigate if these had a positive or detrimental effect on the basic psychological needs.

This study used quantitative methodology to meet the research aims. Such methods were chosen because of their ability to statistically analyse variables and investigate the relationships between SDT and relevant health outcomes; where studies have used quantitative methods to meet similar aims previously (Sweet, et al., 2012; Kosmala-Anderson, et al., 2010).

Through these analyses, the first study was able to answer the question: *what are the relationships between SDT concepts, self-management motivation, and HRQoL in people with COPD?*

This was an important study to meet the superordinate aim of the thesis as it quantitatively tested aspects of the SDT behaviour change model (Ryan, et al., 2008) in people with COPD, before they attended an intensive, multidisciplinary intervention. To the author's knowledge, this represents a novel application of the theory to an underrepresented population within the literature with challenging issues of adherence. Additionally, measuring both need satisfaction and thwarting allowed a more complete understanding of SDT concepts on self-management motivation and HRQoL in people with COPD; thus, making a theoretical contribution to understand this debilitating condition.

4.1.2 Study two

Research has concluded that PR has a positive effect on a variety of health outcomes (McCarthy, et al., 2015) and participants have reported that some of the benefits of the programme include increased confidence and group belonging; where, these are conceptually similar to competence and relatedness satisfaction, respectively (Rapport, et al., 2015).

Additionally, Whittaker, et al. (2018) used qualitative methods and found the satisfaction of needs were present throughout various stages of pulmonary and cardiac rehabilitation, from invitation to long-term maintenance. Despite this, no study has investigated the potential mechanisms by which PR is effective by employing the theoretical principles of SDT. This is despite research concluding that, in the short-term, the positive effects of PR have a greater benefit on psychological, compared to physiological, factors (Ratneswaran, et al., 2015).

The GOLD COPD 2019 Report (Vogelmeier, et al., 2018) concluded that self-management interventions are effective at improving health status and reducing hospitalisations and emergency department visits. Additionally, positive increases in some measures can be explained from a SDT perspective; such as the role of the basic psychological need of relatedness explaining findings in a recent self-management intervention review (Baker & Fatoye, 2019). However, as described within Chapter Three, because the definition of COPD self-management interventions explicitly states the need for behaviour change techniques to be involved (Effing, et al., 2016), the limited use of theory within this condition (McCullough, et al., 2016) could have resulted in even less research within this topic than previously reported (Kaptein, et al., 2014). Two recent reviews found none of the included studies implemented a self-management intervention utilising solely SDT for people with COPD (McCullough, et al., 2016; Richardson, et al., 2014). Therefore, the ability of self-

management interventions which utilise psychological theory to increase SDT concepts is unknown.

Common barriers of attendance to respiratory healthcare programmes include a disruption to usual routine, programme timing, and travel and transport (Keating, et al., 2011); where, technology has been suggested as a method to overcome these problems (Wooton, 2012).

Research into such methods has reported positive results (Guo & Albright, 2017; Knox, et al., 2019; Steventon, et al., 2012; Vontetsianos, et al., 2005), in addition to high adherence (Gorst, et al., 2014). Furthermore, factors which predict low attendance in other programmes, such as current smoking in PR (Hayton, et al., 2013), are not evident in technology delivered interventions (Broendum, et al., 2016). However, there are fewer studies investigating the use of such technology for people with COPD compared to other chronic conditions (McKinstry, et al., 2009; Wooton, 2012) and the use of psychological theory within these interventions is low (Riley, et al., 2011; Webb, et al., 2010). Due to this, reviews have recommended more research within this area is warranted (Cruz, et al., 2014; McLean, et al., 2012).

Whereas the first research study examined the relationships between SDT concepts, self-management motivation, and HRQoL in people on a PR waiting-list, this study investigated the effect two healthcare interventions had on these variables. Specifically, these interventions were PR (the current gold standard) and a SDT-inspired, technology-delivered, self-management intervention, called PocketMedic. These were prescribed independently and in combination and enabled this research study to fill the gaps in the literature described above. Additionally, the ability of baseline SDT variables to predict PR adherence and PocketMedic attendance and adherence were also investigated.

Like the first study, quantitative methodology was implemented to meet the research aims. These methods were chosen due to their ability to directly compare participants across

multiple conditions in a variety of outcomes. Non-randomised clinical trial methodology was used where participants either received PR as standard best practice healthcare, a self-management intervention, or both of these simultaneously. Similar methods have been employed to good effect previously (Sweet, et al., 2014; Kosmala-Anderson, et al., 2010).

The analyses enabled the research study to conclusively answer the question: *what effect do PR and PocketMedic have on SDT concepts, self-management motivation, and HRQoL in people with COPD?*

This was an important research study to meet the overarching aim of the thesis. By investigating the effects of well-researched and novel interventions on SDT concepts, motivation to self-manage, and HRQoL, the mechanisms by which these interventions work and how components contribute to the positive outcomes seen were identified and explored. Furthermore, this study filled multiple gaps within the literature and increased the current evidence regarding the use of technology to deliver a self-management intervention to people with COPD. To the author's knowledge, no previous study has evaluated the use of a SDT-inspired, technology-based, self-management intervention within this population.

4.1.3 Study three

Multiple gaps within the current literature were highlighted in chapters two and three and throughout the descriptions of the first two research studies. These include the dearth of studies implementing SDT to explain health outcomes in people with COPD (Riley, et al., 2011); evaluating *actual* COPD self-management interventions (Kaptein, et al., 2014; McCullough, et al., 2016); examining the effects of such interventions, or PR, on SDT concepts (Richardson, et al., 2014); exploring the role of need thwarting (Olafsen, et al.,

2016); and investigating the efficacy of psychological theory-based, technology delivered, self-management interventions for people with COPD (McKinstry, et al., 2009; Riley, et al., 2011; Webb, et al., 2010; Wooton, 2012). Although the first studies in this thesis began to quantitatively address these gaps, given the lack of literature to understand COPD and intervention adherence, it was also important to use qualitative methodology to enable participants to discuss their subjective experiences on this subject (Howitt, 2010). Within a medical field, it is important to include such methods to help further understanding and knowledge (Murphy, Dingwall, Greatbatch, Parker & Watson, 1998). This positive of qualitative methods is also supported by Silverman (2000) who stated that interviews allow a deeper understanding of a topic to be obtained. A need to fully explain outcomes is also supported by regulatory agencies and other authors (Craig, et al., 2008).

Such methods have been used previously to examine the effects of lay-person led self-management programmes (Stevens, 2016) and evaluate self-management interventions in general (Apps, et al., 2017; Bourbeau, Nault, & Dang-Tang, 2004; Monninkhof, et al., 2004). The effects of PR have also been qualitatively studied by Rapport, et al. (2015), however, as described above, the authors did not consider their findings within a theoretical context. Other research has rectified this limitation, where Whittaker, et al. (2018) interviewed cardiac and pulmonary rehabilitation staff and participants to investigate which basic psychological needs were most salient throughout the duration of the programme. This study was conducted to gain a more thorough understanding of physical activity motivation. Although results corroborated the relative importance of the needs during the process of internalisation reported by previous authors (Deci & Ryan, 2002; Ryan, et al., 1994; Sheldon, et al., 2003), Whittaker, et al. (2018) did not investigate need thwarting, self-management motivation, or consider the experiences of living with COPD more broadly, outside of their intervention.

The third study employed qualitative methodology and used semi-structured interviews.

These were transcribed and analysed using thematic analysis to answer the research question:

How do people discuss their experiences of COPD and engaging with PR and PocketMedic?

Where this research involved recruiting participants who took part in the second research study described above.

This was an important study to answer the superordinate aim of this thesis because it enabled the collection and analysis of in-depth, rich, and contextual data relating to the key factors of interest. Additionally, a triangulated view was obtained of various gaps evident within the literature, which were initially quantitatively filled by the previous studies. Through this use of qualitative methodology, this study allowed a more thorough understanding of motivation to self-manage and the influential factors contributing to HRQoL in people with COPD.

The overarching aim of the thesis and how the separate studies were interlinked is illustrated in Figure 4.1.

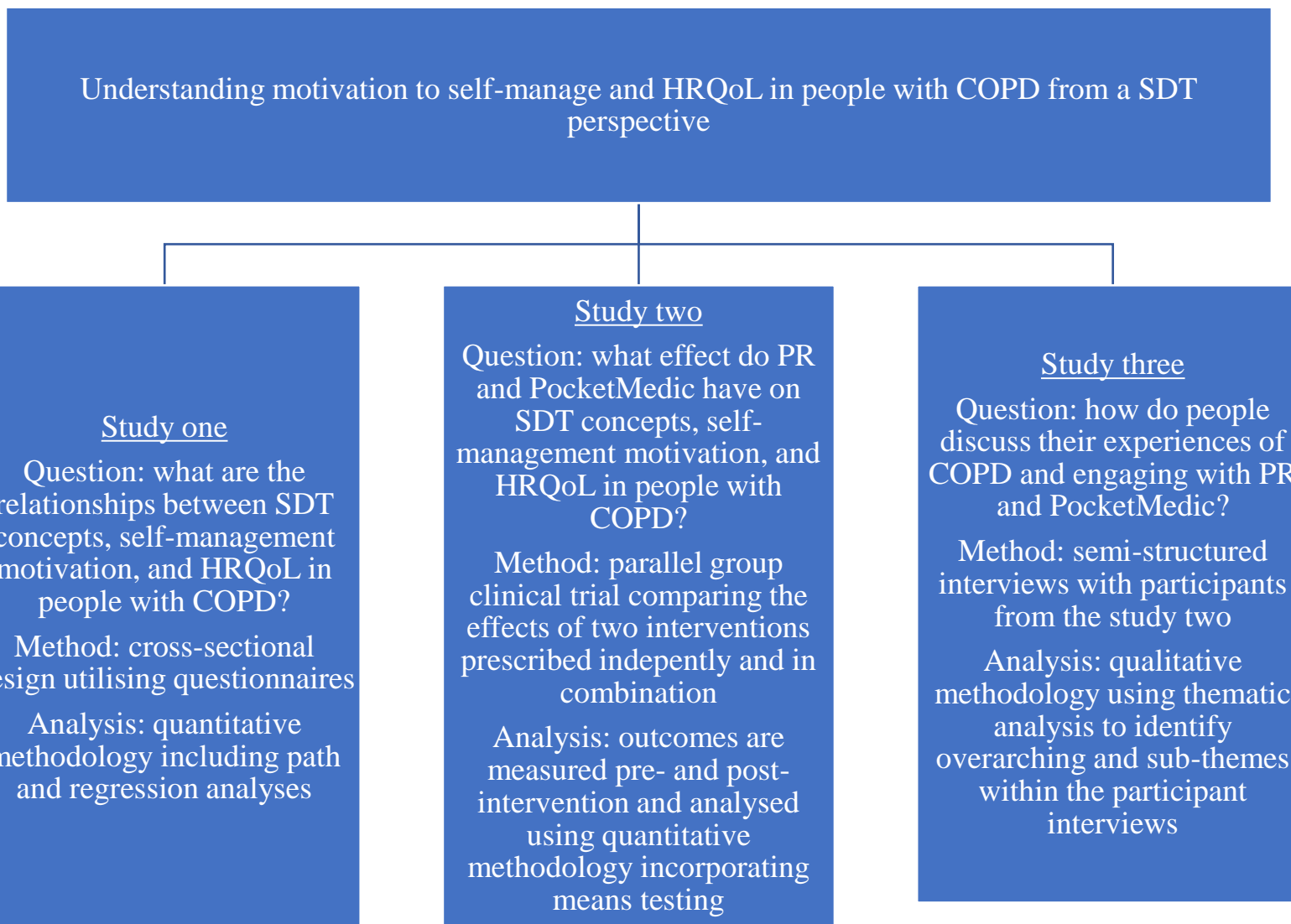


Figure 4.1. The superordinate aim and three independent research studies.

4.2 Mixed methodology

As described above, through a series of quantitative and qualitative research studies, the aim of the thesis is to gain a more triangulated understanding regarding this complex topic.

This is the integration of different methodologies to answer a research question to a level which could not be matched by the utilisation of one method alone (Cresswell & Clark, 2007). The term ‘mixed research’ is also used synonymously (Tariq & Woodman, 2013). The use of mixed methods in healthcare research has increased dramatically (O’Cathain, Murphy, & Nicholl, 2007). The benefits of employing such methodology are that the strengths of quantitative research – for example, objective, generalizable findings, and the minimization of confounding variables – can be combined with the strengths of qualitative methods – for example, providing rich description of views and the open-ended process – or vice versa.

Greene, Caracelli, and Graham (1989), together with Pope and Mays (1995) present a comprehensive list of reasons as to why researchers utilise mixed methods. Previous research states that the aggregated five reasons are equally valid when used as justifications; however, it is fundamental for researchers to explicitly state the reason for the utilisation of such methods (Cresswell & Clark, 2007; O’Cathain, et al., 2008). This allows other researchers to assess the appropriateness of using mixed methods to answer the research question. In keeping with these recommendations, this thesis used mixed methods for ‘expansion’ purposes. This is where research aims to examine different aspects of the research question, where each aspect requires different methodology (Tariq & Woodman, 2013). Applying this framework to the thesis studies, results in quantitative methods investigating the predictive ability of SDT and the impact of PR and PocketMedic on outcomes in people with COPD and the implementation of qualitative methods to allow individual experiences to be analysed.

Tariq and Woodman (2013) developed a typology of mixed methods research models, which describes when both the quantitative and qualitative aspects should be implemented. The model that best describes how the three thesis studies were integrated is ‘Explanatory Sequential’. This is where qualitative methods are used to answer questions generated from previous quantitative research.

Some philosophical authors have suggested that the use of both quantitative and qualitative methodology together is inappropriate, due to their irreconcilable epistemological underpinnings originating from two distinct paradigms (Smith, 1983a; 1983b, 1985).

These two paradigms are realism and relativism (Guba, 1990; Smith, 1983a); where, positivism and idealism are used as respective synonyms (Bilgrami, 2002; Crossain, 2003). Positivism holds the view that the world exists irrespective of anyone’s perception of it (Smith, 1983b) and that a theory describes an object which truly exists (Bhaskar, 1975; 1979). Relativism holds the view that the world is only made of representations which are created by the mind (Williams & May, 1996) and that, although agreeing that an object exists, *truly* knowing this object is an issue (Murphy, et al., 1998).

Although traditionally realists and relativists adopt quantitative and qualitative methodologies respectively (Hammersley, 1992), this is not always the situation (Hammersley, 1992; Harre, 1970; Lundberg, 1933). However, researchers who ardently adhere to either paradigm argue that the combination of methodologies should be completely avoided (Lincoln, 1990). Other authors have suggested that the ontological and epistemological dichotomies between the two methodologies described by some authors do not reflect a necessary or helpful distinction (Murphy, et al., 1998). This is supported by Waitzkin (1990) and Walker (1985) who, despite agreeing that philosophical differences exist between the two paradigms, suggest that these arguments should be ‘side-stepped’, and an eclectic choice of methods should be chosen on

pragmatic grounds. This is particularly relevant in a healthcare setting (Dingwall, 1992; Steckler, McLeroy, Goodman, Bird, & McCormick, 1992) where quantitative methods can measure impact (Walker, 1985) and qualitative methods can “interpret, illuminate, illustrate, or qualify quantitative findings” (Murphy, et al., 1998, p. 60).

Due to both naïve positivism and idealism being fundamentally flawed (Hammersley, 1992), and the need for mixed methodology research within healthcare settings (Dingwall, 1992; Steckler, et al., 1992), this thesis adopted the philosophical position of subtle realism (Hammersley, 1992). This perspective holds the idea that research observes independent, knowable objects; however, accepts that these objects rely on cultural assumptions.

Additionally, subtle realism disagrees with both naïve paradigms by rejecting their definitions of knowledge (Hammersley, 1992). The perspective argues that it is impossible to obtain beliefs of which the validity is known with certainty, which corresponds with the idealistic idea that multiple truths can exist simultaneously (Guba & Lincoln, 1989). However, the perspective also rejects the idealistic view that these truths can be contradictory (Hammersley & Atkinson, 1995). Lastly, subtle realism states that social research should not aim to reproduce reality but instead aim to simply represent it (Hammersley, 1992). Therefore, this approach rejects the belief that quantitative and qualitative research come from antagonistic philosophical backgrounds, as suggested by Smith (1983a; 1983b), and is equally appropriate for either methodology, or the mixture of the two (Hammersley, 1992).

4.3 Quantitative methodology considerations

Both the first and second research studies had similar aims and quantitative methods and therefore the strengths and limitations of this methodology as they relate to both studies are

described within this section. The methodology used for the third, qualitative study is described in the following section. Lastly, methodological issues which were pertinent to both quantitative and qualitative research are discussed within the last section of this chapter.

4.3.1 Self-report questionnaires

Within the first two research studies is the need to measure the concepts of SDT, motivation to self-manage, and HRQoL, alongside a range of other variables. These three concepts are all subjective and specific to every individual. For people with COPD, although measures such as spirometry are clinically useful, a multifaceted range of assessments is warranted within this population (Glaab, Vogelmeier, & Buhl, 2010). Therefore, to measure these concepts self-report questionnaires were employed.

Self-report measures are a major source of data in healthcare research (Del Boca & Noll, 2000; Schwarz, 1999). Benefits can include the ability to measure participants' subjective feelings, attitudes, and behaviour within a given topic, without the need for extensive observation (Schwarz, 1999). The widespread use of this methodology is partly due to the inadequacy of other measurement techniques for latent variables. Although clinical measures such as spirometry could have been used to determine disease severity and observational techniques used to measure the amount of self-management activities individuals conducted; these techniques do not have the same ability to measure concepts like the basic psychological needs or knowledge. Within these examples, using these methods would also have increased the number of medical tests individuals had to experience, in addition to relatively long-term, intrusive observation.

However, there are important issues of which researchers must be cognisant whilst using self-report measures. Although some of these issues relate to the validity of the measure, the first two research studies only employed previously created and validated questionnaires.

Therefore, aspects such as response acquiescence set (Coolican, 2004) or participant question comprehension (Grice, 1975) will not be discussed.

Respondent characteristics refer to a multitude of dimensions, including personality, attitudes, beliefs, intelligence, and cognitive impairment, which could influence the validity of responses by participants. This group of variables is less influential compared to other factors (Schwarz, Groves, & Schuman, 1998); however, studies have found that participants aim to present themselves positively, which could affect the validity of responses. This effect is called social-desirability bias (Chan, 2008). Continued smoking after a diagnosis of COPD is one such area where social-desirability bias could affect participant responses; however, Bradburn (1983) and Schwarz (1999) both describe how researchers and clinicians often assume this bias as present, rather than test for it. This factor can also be reduced if the questionnaires are administered via computer or web-based means (Turner, et al., 1998); where, one explanation of this could be due an increase in anonymity (Del Boca & Noll, 2000). Given the anonymity and confidentiality assured to all who are participating in research, such bias may also be generally less prevalent in this field. However, the increase in socially undesirable answers when self-report measures are implemented through web-based means may also be due to the ability for the participant to reflect on their behaviour and answer in their own time (Del Boca & Noll, 2000). Although such bias is present when the concept being measured is obvious to the participant or during high-stakes testing (e.g. at employment interviews), similar susceptibility to this factor is not universal across self-report measures (Chan, 2008). Social-desirability bias is also lowered when participants believe their answers will be verified through other sources (Becker & Colquitt, 1992; Cascio, 1975).

Therefore, participants who are given anonymity, are unaware of the concept being tested, are reassured that there is no 'right' answer, and believe their responses may be verified, may not experience any bias from respondent characteristics.

Motivation can also influence the veracity of respondents' answers. This factor can be affected by the perceived outcomes from responding, in addition to the level of embarrassment that may arise from answering a specific way (Del Boca & Noll, 2000).

Denial often falls under the heading of motivation. This variable could easily be linked to social desirability, as a respondent may not wish to categorise themselves in a manner which is socially undesirable. This could increase the perceived embarrassment of answering in a particular way. Thus, denial may have more of an effect on answers to questions that imply a personal defect (e.g. continued smoking), compared to questions about normative behaviours (e.g. drinking; Del Boca & Noll, 2000). Motivation can be affected by the physical and psychological state of the individual (Del Boca & Noll, 2000). For example, fatigue and negative psychological states (e.g. anxiety or depression) could bias respondents' answers. This could materialise through decreased effort expended by the respondent or through such states effecting the individuals' perceptions (Del Boca & Noll, 2000).

Lastly, research has been conducted on the validity of memory. Retrieval accuracy may be influenced by when the event being recalled occurred, in addition to the saliency and novelty of the memory (Loftus, 1979). To overcome issues of memory, several authors have recommended the use of multiple cues to aid recall accuracy during circumstances which require self-report (Belli, 1998; Del Boca & Noll, 2000). Conrad, Brown, and Cashman (1998) describe three strategies respondents implement to estimate behaviour frequency. Enumeration is the process of an individual recalling every occasion they conducted the behaviour in question; however, this method uses a relatively large amount of cognitive resources and takes longer. Recalling events and estimating a rate of occurrence will

generally be used for regular events (e.g. smoking on a Tuesday evening) or similar occurrences (e.g. smoking after an evening meal). Having a sense of frequency and converting this to a numerical value is the last strategy, and such a method may be used to recall the amount of high frequency events. Del Boca and Noll (2000) urge researchers to be cognisant of these recall strategies when implementing self-report methods. If enumeration is the likely strategy that will be implemented, a long time period to respond should be allowed; whereas, if estimates of event frequency is likely, a range of estimates could be provided to help recall. However, care should be taken when providing a choice of answers to participants as this could bias the respondent (Dell Boca & Noll, 2000). Ultimately, however, such recollection strategies can only be used if the information is stored in the respondents' memory (Conrad, et al., 1998).

Although there are multiple methods to administer self-report measures, questionnaires were used due to their ability to gather a large amount of data which is readily analysable using quantitative methodology, all for a low cost (Edwards, et al., 2007). These were important aspects for the first two research studies because they aimed to investigate the relationship between SDT concepts, motivation to self-manage, and HRQoL, in addition to the ability of two healthcare interventions to influence these factors. Questionnaires have been implemented to collect data over a very broad range of topics (Edwards, et al., 2007; Johnson & Turner, 2002). This includes SDT concepts, including self-determined motivation toward a variety of behaviours (Deci & Ryan, 2002; Hagger & Chatzisarantis, 2007; Sheldon, et al., 2003) and HRQoL; which has become an increasingly used outcome in research (Hendry & McVittie, 2004).

Johnson and Turner (2002) describe both the strengths and weaknesses of administering self-report measures via questionnaires. Among the strengths, the quick turnaround, high perceived anonymity, and ease of close-questioned data analysis are all important.

Additionally, as described earlier, less social desirability bias may be experienced from an increase in anonymity. Although questionnaires initially require extensive validation, once this has been conducted, they generally have high measurement validity (Johnson & Turner, 2002).

Limitations of questionnaires include the potential for missing data, as participants may choose not to answer specific items if these are perceived to be intrusive or socially undesirable. Additionally, especially with postal questionnaires, the low response rate is well documented, with rates as low as 20% being common (Roberts, Roberts, Sibbald, & Torgerson, 2002). Non-response of questionnaires will reduce the sample size of the study, and thus the power of statistical analysis, and could introduce bias (Armstrong, 1995).

Research has found that monetary incentives, short questionnaires, personalised accompanying letters, coloured ink, providing stamped return envelopes (rather than pre-paid envelopes), providing a second copy of the questionnaire at follow-up, and sending the questionnaires first class all increase response rate (Edwards, et al., 2002; 2007).

Additionally, contacting participants before and after a questionnaire is sent also has a beneficial effect (Edwards, et al., 2002; 2007). Response rates declined when questionnaires contained items which are considered sensitive in nature (Edwards, et al., 2002; 2007).

Although the finding that incentives increase response rates in postal questionnaires has been replicated in other studies, no statistically significant differences were found between 'lottery' incentives (where a participant has a chance to win) compared to no incentive (Roberts, et al., 2000). This suggests that researchers should either spend the additional money to provide incentives to all participants or forgo monetary incentives entirely.

4.3.2 Thesis questionnaires

As mentioned previously, there is a large range of validated questionnaires which have been designed to measure psychological need satisfaction, need thwarting, self-determined motivation, and HRQoL. The specific questionnaires that were included in the first and second research studies are described below, alongside research investigating the psychometric qualities of each. If guidance was available for how to compute missing values, this is also described below. In addition to these questionnaires, other measures were employed to fully meet the aims of the research and these are also described below. Unless otherwise specified, the questionnaires and measures were collected for both the first and second research studies. These questionnaires are presented in the Appendices one to seven.

4.3.2.1 Demographics

Several demographical variables were collected to help fully describe participants within the first two research studies. These were age, gender (male or female), smoking status (current, ex-smoker, non-smoker), average amount of cigarettes or tobacco smoked per day (if current or ex-smoker), carer for someone else (yes or no), relationship status (single, married, divorced, or widowed), and living alone (yes or no).

The first four variables are extremely common in research involving people with respiratory conditions and smoking cessation is an important aspect at all stages of the healthcare pathway (Vogelmeier, et al., 2018).

As described in Chapter Three, the effect of living, caring, and relationship status on SDT concepts is unknown. Therefore, these variables were included to enable statistical tests to

examine this relationship. For living alone and carer status, participants had two options where they could indicate that they either lived with someone else or alone and cared for someone else or do not. For relationship status, participants were able to indicate if they were single, married, divorced, or widowed.

4.3.2.2 Disease-specific health-related quality of life

The COPD Assessment Test (CAT; Jones, et al., 2009b) was used to measure participants' disease-specific HRQoL. This questionnaire involves eight questions rated on a six-point Likert Scale. Scores are totalled for the eight questions giving a result between 0 and 40, where 0 is indicative of low disease impact and 40 is indicative of high disease impact. When up to two scores are missing, these values can be set as the average of the non-missing scores; however, when more than two scores are missing, these values cannot be calculated (Jones, et al., 2009b). The questionnaire takes approximately three minutes to complete.

The CAT was chosen over the St. George's Respiratory Questionnaire (SGRQ; Jones, Quirk, Baveystock, & Littlejohns, 1992) due to the length of the latter measure. Although SGRQ correlates significantly with other disease specific (e.g. Six Minute Walk Test, FEV1) and generic health questionnaires (e.g. Short-Form 36), this measure has a total of 50 items and takes approximately fifteen minutes to complete. Validation studies have found similarities between the CAT and SGRQ and therefore the shorter questionnaire will be used (Jones, et al., 2009b).

Potential items were first identified using clinician interviews and focus groups with people with COPD (Jones, Harding, Wiklund, Berry, & Leidy, 2009). These items were then narrowed down to the current eight, using psychometric and Rasch analyses. The first

validation study showed good internal consistency (Cronbach's alpha = .88) and test re-test reliability (intra-class correlation coefficient; ICC = .8; Jones, et al., 2009b). Differences between people who were stable and experiencing an exacerbation were found to be five units on the 40-point scale (Jones, et al., 2009b). Other validation studies have found that the CAT is sensitive to health status changes in individuals following an exacerbation (Jones, et al., 2012) and PR attendance (Dodd, et al., 2011; Jones, et al., 2012). A systematic review of 36 studies supported the validity and reliability of the CAT and its sensitivity to interventions (Gupta, Pinto, Morogan, & Bourbeau, 2014).

4.3.2.3 Generic health-related quality of life

The EuroQol five-dimension, five-long questionnaire (EQ-5D-5L; Herdman, et al., 2011) was used to measure participants' generic HRQoL. This questionnaire incorporates two separate sections. The first section uses a five-point Likert scale on five different health states; mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. A total of 3,125 health states are possible and each health state is given a five-digit code. For example, a health state of 11111 indicates no problems on any of the dimensions, whereas 55555 indicates extreme problems on all five health state dimensions. Missing scores are given the value nine. Each of the 3,125 health states are computed to give an index score between 1 and -0.285. These index scores can document many different health states, including those considered worse than death (i.e. scores less than zero). The second section of the questionnaire uses a visual analogue scale (VAS) from 0 to 100, where 0 is indicative of "the worst health you can imagine" and 100 is indicative of "the best health you can imagine".

Participants are required to make a mark upon the scale to indicate how they feel that specific day. The entire questionnaire takes approximately three minutes to complete.

Due to the long data collection period to fully validate questionnaires, the EQ-5D-5L has fewer studies assessing its validity compared to the previous version (EuroQol five-dimension, three-long; EQ-5D-3L; The EuroQol Group, 1990); which is still widely used. The former version has been validated within multiple different countries; where the Europe validation included 82,910 participants, generating general population preference weights for each of the 243 possible health states (Greiner, et al., 2003). Additionally, all health states could be described by a common model (Greiner, et al., 2003). Studies comparing the two questionnaires have reported that the EQ-5D-5L displayed face-validity, in addition to less ceiling effects (20.2%, compared to 16%), and less health states being classified as “worse than death” (5.1%, compared to over 33%) in comparison with the EQ-5D-3L (Delvin, Shah, Feng, Mulhern, & van Hout, 2017; Janssen, et al., 2012). Janssen, et al. (2012) concluded that the 5L version was a valid extension to the 3L, improving measurement properties, discriminatory power, and establishing convergent and known-groups validity. van Hout, et al. (2012) developed ‘crosswalk value sets’ which accurately calculates EQ-5D-5L index values using EQ-5D-3L data sets; allowing researchers to access the wealth of published population norms for the earlier questionnaire. Both questionnaires have been used extensively in a variety of health contexts (Janssen, et al., 2012).

4.3.2.4 Self-management knowledge

The Understanding COPD Questionnaire (UCOPD; O’Neill, Cosgrove, MacMahon, McCrum-Gardner, & Bradley, 2012) has eighteen items scored using a Likert scale marked

0-10. Questions are divided into three sections; about COPD, managing symptoms of COPD, and accessing help and support. These sections have seven, seven and four items, respectively. These three sections all include questions relating to self-management knowledge (Schulman-Green, et al., 2012; see Chapter Two). A percentage of total understanding or confidence is calculated for each section. An overall score, also a percentage, can be calculated for the entire questionnaire. Low percentages are indicative of a participant's lack of understanding or confidence and high percentages indicate high levels of understanding or confidence. A single missing score from each section can be calculated by using baseline or follow-up data (baseline data used for a missing follow-up score and vice versa; O'Neill, et al., 2012). O'Neill, et al. (2012) offer no guidance on how to calculate missing values if more than one score is missing or if data is only collected at one time point. This questionnaire, which assesses self-management knowledge, will be used instead of simply asking participants how many self-management activities they conduct, due to the issues with memory described above.

In developing the questionnaire, focus groups involving both people with COPD and health care professionals were implemented to identify the key factors important in the delivery of COPD education (Wilson, O'Neill, Reilly, MacMahon, & Bradley, 2007). These factors were then used to develop the UCOPD questionnaire (O'Neill, et al., 2012). The UCOPD questionnaire has shown good test-retest reliability (ICC range: 0.87-0.96) and internal consistency (Cronbach's Alpha range: 0.78-0.95; O'Neill, et al., 2012). O'Neill, et al. (2012) additionally found that all three sections of the UCOPD questionnaire were sensitive to PR and overall scores moderately correlated with the Bristol COPD Knowledge Questionnaire (White, et al., 2006) both pre- and post-PR ($r = 0.41$ and 0.35 , respectively).

4.3.2.5 Basic psychological need thwarting

The Psychological Need Thwarting Scale (PNTS; Bartholomew, et al., 2011) involves twelve items rated on a seven-point Likert scale, measuring how an individual feels their basic psychological needs are being actively thwarted. Each basic need has four items. Each item score is aggregated to give a total level of thwarting for each of the basic psychological needs. Two modifications were made to the original questionnaire. First, the stem was modified to read as follows “Regarding your everyday experiences since being diagnosed with COPD, please indicate on a scale of 1 (disagree) to 7 (agree) how much you can relate to each of the following statements”. Second, individual PNTS items were modified to focus the questionnaire on how needs were being thwarted by COPD. For example, “Due to COPD, I feel prevented from making choices regarding the way I live”. These modifications were implemented to allow the questionnaire to measure if individuals perceived that COPD was thwarting their basic psychological needs.

Bartholomew, et al. (2011) conducted the original validation through three studies in a sport domain. Study one interviewed athletes and coaches to generate a preliminary list of items relating to psychological need thwarting. Study two implemented a confirmatory factor analysis using responses from 354 athletes; where the model ultimately demonstrated an excellent fit to the data. The third study aimed to utilise an independent sample to cross-validate the model generated from study two. 289 athletes were asked to complete the PNTS. The model again showed a good fit with the data and all three needs had good internal consistency (composite reliability coefficients: .77-.82). Bartholomew, et al. (2011) concluded that the PNTS provides a useful and robust tool for measuring psychological need thwarting. These findings of good validity and internal consistency have been replicated by other studies in a more general physical activity context (Gunnell, Crocker, Wilson, Mack, &

Zumbo, 2013) and after being translated into Spanish (Cuevas, Sanchez-Oliva, Bartholomew, Ntoumanis, & Garcia-Calvo, 2015). Additionally, Gunnell, et al. (2013) modified the PNTS in similar ways to the changes that will be made for the purposes of this thesis.

4.3.2.6 Basic psychological need satisfaction

The Psychological Need Satisfaction in Exercise Scale (PNSE; Wilson, Rogers, Rodgers, & Wild, 2006) consists of eighteen items; however, due to the repetition of items and the total length of all the questionnaires, the number of items was reduced to nine. These items are rated on a six-point Likert Scale with three questions relating to each of the three basic psychological needs. Scores are aggregated for each of the three needs. This questionnaire was also modified so that the items are specifically asking about the participants' basic psychological needs in relation to the self-management of their condition; for example, "I feel free to self-manage my condition in my own way". The questionnaire takes approximately three minutes to complete.

Wilson, et al. (2006) conducted two studies using a total of 426 participants. An exploratory factor analysis in the first study supported a 3-factor measurement model and a confirmatory factor analysis in the second study found similar results. Additionally, the second study showed high internal consistency (Cronbach Alpha > .90).

4.3.2.7 Motivation to self-manage

The Behavioural Regulation in Exercise Questionnaire-3 (BREQ-3; Wilson, Rodgers, Loitz, & Scime, 2006) involves 24 items rated on a five-point Likert Scale marked 0-4. Using the relative autonomy index, item responses are transformed to provide an overall score between -96 and 96. Higher scores are indicative of greater self-determined motivation.

The BREQ-1 was originally created by Mullan, Markland and Ingledew (1997) to measure external, introjected, identified and intrinsic forms motivation regulation to exercise.

Markland and Tobin (2004) published the BREQ-2 after the implementation of the amotivation items. Lastly, Wilson, et al. (2006) incorporated the integration subscale, publishing the BREQ-3.

The original BREQ-3 was modified to specifically measure participants' behavioural motivation to the self-management of their condition, rather than to exercise. For example, "I engage with activities that support the self-management of my symptoms because it's fun".

This questionnaire takes approximately four minutes to complete.

Validation of the BREQ-3 found that reported data from 207 participants showed a desirable model fit (Comparative fit index = .96) and differed significantly to the BREQ-2. Reliability estimates ranged from .78 to .93 (Wilson, et al., 2006).

4.3.2.8 Disease knowledge

The Bristol COPD Knowledge Questionnaire (BCKQ; White, et al., 2006) consists of thirteen topics relating to COPD. Each topic lists five statements where participants are instructed to

indicate if the statement is true, false, or that they don't know. Upon completion, a percentage of correct answers is calculated. For the purposes of marking, the "don't know" option is considered incorrect. The inclusion of a separate option other than true or false allows researchers to investigate the breadth of COPD knowledge, alongside areas where an individual may believe they know the answer but are incorrect. The "don't know" option additionally decreases the amount of correct answers due to guesses. An average score in subjects with no prior education is 54.7%, where a significant improvement of 18.3 percentage points was found in individuals after an eight-week intervention (White, et al., 2006). This improvement remained at the six-month follow-up without further education (White, et al., 2006). The questionnaire takes approximately twenty minutes to complete and score and was used in the second research study to investigate the ability of the two healthcare interventions to increase this factor.

Good internal consistency for all 65 items (Cronbach's Alpha = .73) and test re-test reliability ($r = .71$) has been found in validation studies (White, et al., 2006).

4.3.2.9 PR attendance

PR attendance was operationalised as whether a participant attends a PR assessment when invited. These assessments are standard practice to ensure everyone is clinically stable to participate in a PR programme. These assessments are conducted to ensure a high level of safety is maintained. This variable was collected within the first study to allow the investigation of SDT concepts to predict this factor.

Participants were categorised into one of three groups. ‘Yes’, the participant attended a PR assessment. ‘No’, the participant did not attend. ‘Unable’, the participant was still waiting for the opportunity to attend an assessment when the data was collected.

4.3.2.10 PR adherence

PR adherence was operationalised as the number of sessions attended by a participant. Within the health board where this research was conducted, the maximum number of sessions (i.e. full attendance) is fourteen. This variable was only collected for participants in the second research study.

4.3.2.11 PocketMedic attendance

PocketMedic attendance was operationalised as whether a participant chooses to watch one or more of the digital health films. Participants were categorised into two groups; ‘yes’ the participant watched a film and thus PocketMedic attendee; and ‘no’ the participant did not watch any films and thus did not attend. This variable was measured in the second study.

4.3.2.12 PocketMedic adherence

PocketMedic adherence is conceptually similar to PR adherence and is the number of sessions interacted with by the participant. The maximum number of sessions (i.e. full adherence) is ten. This variable was also only collected within the second research study.

4.3.2.13 Functional exercise capacity

The Six Minute Walk Test (6MWT; Balke, 1963) measures functional exercise capacity in respiratory or cardiology patients. The test measures the distance (in meters) an individual can walk along a flat, hard surface in six minutes. Participants can walk at the speed they wish and take breaks if necessary; where the aim is for the individual to walk as far as they can in the designated time.

Other lengths of walking time do exist; however, longer timed tests have problems with ease of administration (Butland, Pang, Gross, Woodcock, & Geddes, 1982), whereas shorter tests have been found to be less sensitive (Strijbos, Postma, van Altena, Gimeno, & Koeter, 1996; Du, Newton, Salamonson, Carrieri-Kohlman, & Davidson, 1999).

The 6MWT is taken as part of usual care at HDUHB PR programmes and this is measured before and after each programme to ensure safety and course quality is maintained. This variable was measured for participants enrolled in a PR programme within the second study.

4.4 Qualitative methodology considerations

4.4.1 Semi-structured interviews

As previously described, qualitative methodology enables participants to discuss their subjective experiences (Howitt, 2010), which is especially important within a medical field (Murphy, et al., 1998). There are a variety of methods to collect qualitative data (Gill,

Stewart, Treasure, & Chadwick, 2008), however, focus groups and interviews are the most common within healthcare research (Britten, 1999; Legard, Keegan, & Ward, 2003).

Focus groups have been previously used to good effect (Bloor, Frankland, Thomas, & Robson, 2001). However, participants within the third research study would already know each other from PR and therefore may be reluctant to divulge information regarding how they experienced this group programme. Focus groups which are likely to restrict the flow of discussion is one criterion of when to avoid conducting this method suggested by Morgan (1998).

Interviews can be divided into three distinct types; structured, unstructured, and semi-structured (Corbetta, 2003). Structured interviews are similar to questionnaires, primarily do not allow the participant to expand, and are therefore less used when depth is required (Gill, et al., 2008). Unstructured interviews can be considered the opposite and significant depth can be acquired; however, they are usually very time-consuming and problematic for both the researcher and participant due to their unrestrictive nature (Gill, et al., 2008; May, 1991). Semi-structured interviews involve the researcher preparing several key questions of interest but also allow the participant to expand if they wish (Britten, 1999) and this format is the most commonly used within healthcare research (Gill, et al., 2008). Interviews allow for a deeper understanding of a topic to be obtained (Gray, 2004; Silverman, 2000) and are useful in situations where there is little pre-existing knowledge surrounding this topic (Gill, et al., 2008). The aim of the third study was to *understand* the experiences of people with COPD. Additionally, little research has applied SDT to people with COPD (McCullough, et al., 2016; Riley, et al., 2011). Therefore, semi-structured interviews could constitute a valuable method to collect data for the third research study.

Spradley (1979) provides a detailed description on the process of rapport which is the development of the relationship between the interviewer and interviewee. This is a four-stage process where the first stage is apprehension. This is the initial feeling of uncertainty experienced by both parties involved in the interview and the interviewee may be reluctant to give much detail to any questions. This can be overcome by using descriptive questions, as these can lead to more flowing and in-depth responses. This stage is quickly followed by exploration, where the interviewer and interviewee both begin to test the growing relationship between them and gain more of an understanding of what is expected from the other party. Within this stage making repeated explanations, restating what participants say, and avoiding asking for meaning can facilitate the transition to the next stage. Cooperation is defined as the active engagement and cooperation between the two parties. Within this stage, the interviewee knows what to expect from the interview process and actively tries to provide in-depth, sometimes personal, information regarding the topic. The last stage is participation, this is where the interviewee takes a more assertive role and begins to provide information and possible analysis of their own experiences without encouragement from the interviewer. During the design phase of the third research study, the aspects described above were considered and used to facilitate the progression to the later stages of the interviewer-interviewee relationship. Due to the qualitative research recruiting participants directly from the second research study, the researcher already met all the interviewees, which also helped progress the relationship and provided more fruitful discourse.

4.4.2 Thematic analysis

There are multiple methods which researchers can utilise to analyse qualitative semi-structured interviews (Howitt & Cramer, 2008; Nolen & Talbert, 2011); however, reviewing the strengths and limitations of each individual method is beyond the scope of this thesis.

Thematic analysis (TA) is the process of identifying, analysing, and reporting of themes that are present within qualitative data (Braun & Clarke, 2006). These aspects are evident in other qualitative data analytical techniques and have led some authors to claim that this is not an independent method (Boyatzis, 1998; Holloway & Todres, 2003). However, other authors argue that this view is incorrect (Braun & Clarke, 2006; King, 2004; Leiniger, 1992).

TA has multiple strengths that has led it to become increasingly adopted as a method for analysing interviews conducted in medical domains (Braun & Clarke, 2006; Castleberry & Nolen, 2018; Nowell, Norris, White, & Moules, 2017). The main strength of TA is the flexibility it possesses which enables the method to be conducted alongside other analytical methodologies, such as quantitative statistics (Vaismoradi, Turunen, & Bondas, 2013). This strength is primarily as a result of the method not being tied to any specific theory, philosophy, or epistemology (Nowell, et al., 2017). As a result of this flexibility, this technique can be modified to suit a range of different situations, helping to further understanding and provide complete and in-depth data (Braun & Clarke, 2006; King, 2004). Furthermore, due to TA being accessible, less experienced qualitative researchers can utilise the technique, whilst still obtaining the views and experiences of the participant and identify similarities and differences within the data (Braun & Clarke, 2006; King, 2004).

However, the method has been ‘poorly branded’ and is seldom considered to be of the same rigor and value as grounded theory or interpretive phenomenological analysis (Braun &

Clarke, 2006; Nowell, et al., 2017). Additionally, due to researchers not fully describing their methods, the appropriateness of the techniques employed are often difficult to assess (Braun & Clarke, 2006). As a result, novice researchers may find it difficult to utilise because of the relatively limited literature describing the necessary processes that need to be undertaken (Nowell, et al., 2017). Authors have also suggested that the flexibility in the approach can lead to less cohesion during the development of themes (Holloway & Todres, 2003); although methods can be used to improve this aspect (Nowell, et al., 2017), such as those described by Yardley (2000) below. Lastly, TA cannot make claims about the use of language, whereas other analytical techniques do possess this ability (Braun & Clarke, 2006).

TA was used to analyse the semi-structured interviews within the third research study due to its ability to be theoretically flexible and not tied to a specific philosophy or epistemology.

Through this method, the views and experiences of individuals who received the two healthcare interventions as part of the second research study could be assessed. Although there is less literature which describes how to conduct a TA, both Braun and Clarke (2006) and Howitt and Cramer (2008) do provide detailed accounts to overcome this issue.

Furthermore, techniques were used to ensure analytical rigor and cohesiveness are maintained during the analysis. These methods are discussed within the next section.

4.4.3 Principles for ensuring good qualitative methodology

Authors have agreed that factors which constitute good quantitative research are not necessarily appropriate markers for qualitative methodology (Charmaz, 1990; Swanson & Chapman, 1994). Yardley (2000) sets out four characteristics to ensuring good quality qualitative research in a health domain; sensitivity to context, commitment and rigor,

transparency and coherence, and impact and importance. These characteristics have become accepted criteria to assess the validity of research (Robinson, 2014; Smith, Flowers, & Larkin, 2009).

The sensitivity to context criteria refers to multiple different contexts. The context of theory, and of previous researchers' findings, is generally well accepted across both quantitative and qualitative methodologies. However, qualitative research focuses on 'vertical generalisation', where a researcher may aim to connect their data to the abstract and others work (Johnson, 1997). Through this, the improvement of theory can be facilitated and thus a background knowledge of the theory being used to examine the data is needed (Yardley, 2000). For some types of analysis, such as discourse or phenomenology, an even greater knowledge of theory is needed to identify and test common-sense concepts and assumptions (Harding & Gantley, 1998). Yardley (2000), however, is quick to note that the sensitivity to a theory and past research should not be at the expense of the sensitivity to the data. In other words, the themes being identified should be evident within the data and not solely the theory. The combination of sensitivity to theory and to the data can be shown by a researcher looking for findings which don't corroborate their theory, examining these, and then accounting for them. A sensitivity to the socio-cultural setting of the study is also needed (Yardley, 2000). The multiple characteristics that affect both participants and the researcher need to be considered. This includes the relationship between the researcher and the participant, as maintaining a completely neutral stance when conducting an observation or interview is impossible (Potter & Wetherell, 1995).

Meeting this criterion was facilitated by keeping a diary of the researcher's opinions and beliefs toward the subject area and ensuring that these did not impact the interview or data analytical process. Participants within the qualitative study were recruited from the second research study, therefore the researcher met these participants and formed a relationship prior

to the interview being conducted. Although such a relationship could help the interviewing process to obtain more rich and valid data on the topic (Spradley, 1979), it was important not to let this influence the analytical process.

Commitment, rigor, transparency, and coherence are all quite standard concepts within both quantitative and qualitative research (Yardley, 2000). Commitment refers to the researcher engaging at length with their chosen topic, methods, and data to build their level of competency and understanding of the data. This aspect was already facilitated through the long process of doctoral level research; however, was also benefited from the comprehensive literature reviews regarding the chronic condition the participants have and SDT.

Rigor is defined by a researcher ensuring a high level of precision when undertaking data collection and analysis. Data collection includes obtaining a suitable sample, which does not have to be large but does have to supply enough data to saturate an analysis. The analysis should interpret all the data and provide a description and explanation for all the variation found. This can be conducted through several means, such as triangulation; which can provide a “rounded, multi-layered understanding of the research topic” (Yardley, 2000, p 222). This aspect was achieved by the researcher practicing the interview process with an experienced qualitative member of staff from the Psychology Department at Aberystwyth University. This individual then offered advice on how to improve the interviewing technique. Furthermore, the researcher had previously conducted qualitative semi-structured interviews and TA and therefore already had experience of these techniques.

Transparency can be displayed by thoroughly describing all aspects of the research, including data collection, how data was coded, and by providing excerpts so that the reader may examine the themes the researcher has identified (Yardley, 2000). Providing audiotapes or transcripts to other analysts can also increase transparency (Huberman & Miles, 1994);

however, it is important not to provide any sensitive information due to ethical considerations of anonymity and confidentiality. Transparency is also increased when a researcher accurately details their own assumptions, intentions and actions, throughout the research process and reflects how these factors may have affected or biased the analysis. This has been termed “reflexivity”. Although previous research conducting a TA has failed to disclose all information relating to their method (Braun & Clarke, 2006), this research followed the recommendations by Yardley (2000) and provided complete transparency across all aspects of the research. Anonymised transcriptions for all interviews and thematic tables are provided within the appendix.

Coherence describes how appropriate the research question, philosophical approach, and method of investigation and analysis are to one another (Yardley, 2000). It is important to note that this is a different coherence to that described by Holloway & Todres (2003), which is regarding the development of themes. Several authors describe how the purpose of qualitative research is to provide greater understanding toward a given topic (Gray, 2004; Howitt & Cramer, 2008; Silverman, 2000). The aim of this thesis was also to achieve a greater understanding. Additionally, the flexibility of TA provides greater coherence between the philosophical approach and the methodology (Nowell, et al., 2017). Therefore, within the third research study, there was relatively good coherence between the aspects required for good quality qualitative research (Yardley, 2000).

Ultimately, any piece of research should be assessed on its impact and importance (Yardley, 2000). Even if a study highly conforms to the characteristics described above, if this research does not provide useful insight or explanation of a process, then it has very limited worth. Research findings do not need to conform to past literature to gain impact or importance and can describe a novel way of viewing a process (Yardley, 2000). Researchers have additionally become concerned with the socio-cultural impact of their findings because if

research can alter the discourse surrounding a topic, then attitudes or beliefs may change as a result (Oliver, 1990; Swain, Finkelstein, French, & Oliver, 1993). The third research study aimed to meet all the characteristics given by Yardley (2000), in addition to providing meaningful insight into how people with COPD experience two healthcare interventions.

4.5 Quantitative and qualitative methodology considerations

There are some methodological considerations that are relevant for both the quantitative and qualitative components of this thesis and therefore these are discussed within this section. Specifically, these relate to sampling and ethics.

4.5.1 Sampling

Both the quantitative and qualitative aspects of this thesis required a sample to be recruited in order to collect data. Robinson (2014) developed a four-point approach regarding sampling; defining a sample universe, deciding upon a sample size, selecting a sample strategy, and sample sourcing.

Defining a sample universe, or target population, is conducted by creating a set of inclusion and exclusion criteria (Luborsky & Rubinstein, 1995; Patton, 1990). This is a set of characteristics that a potential participant must have (inclusion) or not have (exclusion) in order to be invited to take part in the study. However, simply meeting the inclusion criteria and not processing any traits on the exclusion criteria does not guarantee that an individual will be invited to participate in the study; this also depends upon the chosen size, strategy,

and sourcing of the sample. For example, if the inclusion criteria for a study incorporated needing to live in Wales, this does not necessarily mean that everyone in Wales would be recruited and participate in the study.

Increasing the amount of inclusion and exclusion criteria increases the sample universe homogeneity; which is made up of five separate domains (Robinson, 2014). Demographic homogeneity describes a sample which all possess similar demographic characteristics such as age, gender, or socio-economic background. Geographical homogeneity refers to a sample obtained from the same physical area, such as a local health board. Physical homogeneity is where a sample all possess a similar physical characteristic, such as COPD. Psychological homogeneity is similar to this concept, where the sample possesses a similar psychological characteristic; for example, a high IQ. Lastly, life history homogeneity describes where the sample have all shared a similar experience, such as attending PR.

The level of sample universe homogeneity that a study sets is dependent on theoretical and practical factors (Robinson, 2014). Interpretative Phenomenological Analysis (IPA), for example, aims to have high sample homogeneity to fit its philosophical underpinning and analytical processes (Smith, et al., 2009). Whereas, Grounded Theory intentionally aims for a heterogeneous sample (Strauss & Corbin, 1998). There is a balance to meet between the homogeneity and heterogeneity of a sample universe. Describing the extremes of this continuum sees results obtained from a highly homogenous sample hard to generalise outside the strictly defined setting; whereas a highly heterogeneous sample would increase the heterogeneity of data to a level where meaningful trends or patterns may not be found during the analysis (Robinson, 2014).

Deciding upon a sample size is often influenced by theoretical and practical reasons (Robinson, 2014). For example, studies with idiographic aims only require a small sample; a

general guideline of IPA is three to sixteen subjects (Smith, et al., 2009). Practical reasons such as time or funding also need to be considered when deciding on a sample size. Although an element of this decision is made a priori to conducting the study, Mason (2002) describes the skill of 'organic' sampling as the ability of a researcher to respond to practical realities, which are unable to be foreseen at the beginning of a project. Silverman (2010) states that there are several theoretical and practical justifications for altering the target sample size; for example, Grounded Theory analysis should be conducted simultaneously with data collection, so that judgements on whether additional interviews will create extra meaningful data can occur (Strauss & Corbin, 1998). Due to these reasons, steadfastly continuing with the a priori sample size decision may not be appropriate, and multiple authors advocate the ceasing of further data collection after theoretical saturation has been met (Guest, Bunce, & Johnson, 2006; Strauss & Corbin, 1998).

Selecting a sample strategy determines how the study will recruit participants which meet the inclusion and exclusion criteria up to the required sample size. Robinson (2014) categorises the strategic options into random, convenience, and purposive sampling strategies.

Random sampling is simply where everyone in the sample universe population has an equal chance of being included in the study. Quantitative studies often use this technique as statistics processes the assumption that included samples are random (Robinson, 2014).

Convenience sampling is where a convenient group of individuals, often defined by proximity, that meet the participant criteria are selected to take part in the study until the required sample size is recruited. Although such a method is expedient, in qualitative research if the sample universe is diverse generalisations from such a sample may not be valid. This limitation can be somewhat removed by defining the study universe less broadly and thus restricting the generalisation of results to this less diverse population (Robinson,

2014). Within the first two quantitative research studies convenience sampling was used as the sample strategy.

Purposive sampling is a non-random strategy to guarantee the obtaining of specific sub-groups in the study universe. Such methods are often employed when there is a theoretical rationale that certain individuals possess a unique insight on the topic in question, and thus should be represented in the sample (Mason, 2002; Trost, 1986). There are four types of purposive sampling for non-case studies; stratified, cell, quota, and theoretical sampling. However, the third qualitative research study used stratified sampling and thus is the only non-random strategy discussed.

Stratified sampling is where a researcher selects specific categories that they wish to be included in the final sample and then allocates a target number for each category. These stratification categories can take the form of almost any characteristic; however, there needs to be a theoretical justification as to why these categories will differ (Robinson, 2014). For example, research could wish to recruit equal numbers of people who did and did not engage in a self-management intervention.

The last point is sourcing the sample. As well as practical and organisational skills, this point requires sensitivity and ethical skills (Robinson, 2014). Especially within a healthcare context, fully informed consent is essential for every participant and thus every person has volunteered to take part. One limitation to voluntary participation is self-selection bias (Costigan & Cox, 2001). As interviews require the disclosure of extensive, sensitive information, individuals who volunteer may be different to those that do not. Previous research has found that females have a higher tendency to volunteer for research than males (Dindia & Allen, 1992). This could have been a confounding variable for all three research studies because COPD is more predominant in men (Buist, et al., 2007). Due to ethical

considerations, it was not possible to avoid self-selection bias; however, it was an important factor to be cognisant of during the analysis of data (Robinson, 2014).

Like the issues described within the quantitative section, monetary incentives to take part in qualitative research have strengths and limitations. The benefits include increased participation and retention in longitudinal studies (Yancey, Ortega, & Kumanyika, 2006). However, limitations include participants fabricating information to receive the money and ethical concerns that they will participate despite not intrinsically wishing to (Robinson, 2014). Robinson (2014) concluded that if a sample can be obtained without the use of monetary incentives, it is better to not use them. Additionally, highlighting that the research may be beneficial to other people with the condition can act as a non-monetary incentive (Robinson, 2014).

The four-points suggested by Robinson (2014) described above can have a direct influence on Yardley's (2000) criteria to ensure research validity. For example, sensitivity to context can be facilitated by a well-defined sample universe preventing unjustified generalisations. Additionally, choosing sampling processes which complement research aims, analyses, and theoretical underpinnings can enhance coherence.

4.5.2 Ethical considerations

There are several ethical considerations pertinent to all three research studies which are discussed within this section. All three studies received a favourable ethical opinion from the Seventh Wales Research Ethics Committee (REC7) and the local health board research and development department.

Due to the researcher not being an employee of the NHS, specific processes needed to be put in place to avoid personal information being distributed to non-health board organisations. Therefore, individuals who were eligible for the first two research studies were identified by NHS staff collaborators and initially approached by these employees. For the first study, this involved sending out invitation letters. For the second study, a face-to-face approach was used during PR assessments. If an individual was interested in participating, they could either return a signed consent form via post (study one) or could agree to speak to the researcher who took them through the informed consent process (study two).

Although telephone calls to potential participants before or after an invitation to take part in research has been found to increase response and recruitment rates (Edwards, et al., 2002; 2007), this was prohibited by the REC7. However, for the first study, reminder letters were posted by NHS employees if no response is received after a month of sending the initial invitation.

NHS employees were not used to help recruit individuals for the third research study. This is because everyone who was eligible for this study was already known to the researcher and had provided their permission to be contacted regarding the possibility of participating in the third study.

All participants were given the option as to whether they wished for a summary of their clinical data (e.g. healthcare utilisation) to be provided to the researcher. If this aspect was declined, they could still participate in the research but without clinical data being collected. If consent was given, NHS employees accessed clinical records and only provided the researcher with a summary of measures. For example, the researcher was informed that a participant was hospitalised; however, a detailed account of this hospitalisation including test results and prescribed medication was not provided. During the second study, to prevent

follow-up questionnaires being sent to participants who had died, NHS employees accessed the health board electronic database to confirm the live status of every participant.

Lastly, due to dyspnoea being a common symptom of COPD (WHO), the researcher introduced methods as to not exacerbate this further. During consent, questionnaire completion, PocketMedic and PR, and the interviews, participants were reminded that, in case they get breathless, they should take a short break, or they could stop altogether if they wish. This was additionally written in the participant information sheet for all three research studies.

Chapter Five: What are the relationships between SDT concepts, self-management motivation, and HRQoL in people with COPD on a PR waiting-list?

5.1 Introduction

The most recent GOLD COPD report highlighted the importance of self-management knowledge for increasing multiple health outcomes in people with COPD (Vogelmeier, et al., 2018); including HRQoL (Majothi, et al., 2015; Zwerink, et al., 2014). However, poor attendance and adherence to pharmacotherapy and PR has been repeatedly reported (Bourbeau & Bartlett, 2008; Steiner, et al., 2015; 2016), which demonstrates poor self-management in this population (Schulman-Green, et al., 2012). Although there are multiple explanations for this, one important factor is motivation (Restrepo, et al., 2008; Sheldon, et al., 2003). Thus, understanding motivation to self-manage may be instrumental in explaining poor adherence to COPD treatment. Additionally, research has shown that HRQoL is adversely affected by this condition (Esteban, et al., 2009), where Russell, et al. (2018) describe the particularly negative state and outlook of this population. Therefore, it is unsurprising that improving HRQoL has been deemed as a crucial component to support people with COPD (Kaptein, et al., 2014; Kielmann, et al., 2010).

Research has recommended the use of employing psychological models to explain target behaviours in chronic conditions (Craig, et al., 2008) and the importance of implementing behaviour change theory in populations with COPD (Effing, et al., 2016; Restrepo, et al., 2008; Vogelmeier, et al., 2018). Following these recommendations, Chapter Three concluded

that SDT provides a convincing theoretical underpinning to explore motivation to self-manage, and the influence on HRQoL, in people with COPD. However, there is a sparsity of research that has considered the application of this theory within this context (McCullough, et al., 2016; Richardson, et al., 2014; Riley, et al., 2011).

The limited literature which has applied SDT to a population with COPD has left several gaps in the current state of knowledge. For example, research has primarily focused on identifying factors that are important in the maintenance of healthy behaviours in people who have completed a PR programme (Cho, et al., 2017; Stewart, et al., 2014). Thus, populations which have not received such a programme remain underutilised and the relationships between motivational factors and poor PR attendance are unexplored. Research has found that people with COPD are extrinsically motivated to self-manage (Wortz, et al., 2012) and that in such situations, where optimal motivation cannot be achieved, need thwarting may be more influential on self-determined motivation, compared to need satisfaction (Bartholomew, et al., 2011). Although COPD has been found to be a thwarting stimulus (Wortz, et al., 2012), the effects of need thwarting remain uncertain (Bartholomew, et al., 2011; Olafsen, et al., 2016).

Research has reported that PR attendance is greater in people who are living with someone else (Hayton, et al., 2013). From a SDT perspective, this could be explained through an increased sense of relatedness gained from living in close proximity with another (Deci & Ryan, 2002). However, an individual urging someone with COPD to attend PR could alter their behavioural control. This would help explain why controlled regulation may initially be beneficial in people with COPD (Stewart, et al., 2014). However, the exact role of 'living status' on SDT concepts is unknown. Additionally, other demographic variables which could affect the basic psychological needs or self-determined motivation in the same way, such as

being in a relationship or medically caring for someone else, have not been previously considered.

This study aimed to fill these gaps in the literature and answer the research question: *what are the relationships between SDT concepts, self-management motivation, and HRQoL in people with COPD on a PR waiting-list?*

From the above literature several hypotheses were formed. 1) That SDT concepts will be able to predict motivation to self-manage and HRQoL in a population with COPD. 2) That need thwarting will have more of an association with self-management motivation, compared to need satisfaction. 3) That greater self-management knowledge will predict positive disease-specific HRQoL. 4) That participants who go on to attend PR will have higher levels of need satisfaction, lower need thwarting, and higher levels of self-determined motivation compared to PR non-attendees. 5) That living, caring, and relationship status affect the basic psychological needs and self-determined motivation to self-manage COPD.

5.2 Methods

5.2.1 Design

This study used a cross-sectional questionnaire-based design to consider the predictive relationships between psychological need satisfaction, psychological need thwarting, behaviour regulation to self-manage, and HRQoL in a sample with COPD. A PR waiting-list population was used for this study because it allowed for the exploration into a group who had a COPD diagnosis but no intensive intervention to date. Additionally, this afforded the

opportunity to explore why the uptake of PR is historically low, using SDT concepts (Steiner, et al., 2015; 2016).

Similar designs have been used previously to assess the validity of applying SDT to predict factors determining engagement in physical exercise in university students (Sweet, et al., 2012) and self-management support practices in clinicians working in chronic conditions (Kosmala-Anderson, et al., 2010). Questionnaires were used to measure need satisfaction and thwarting, self-determined motivation to self-manage, disease-specific and generic HRQoL, and self-management knowledge. Additionally, PR attendance data was collected.

5.2.2 Participants

People with COPD on a Hywel Dda University Health Board (HDUHB) waiting-list to attend PR during the time period October 2016 – May 2018 were invited to participate in this study. To be referred to PR for COPD treatment within this health region everyone must conform to the GOLD definition of COPD; be 50 years or older, have at least 10 pack-years smoking history, and post-bronchodilator spirometry of FEV₁/FVC ratio less than 70% and FEV₁ less than 80% predicted.

All participants had to be willing and able to give informed consent. No exclusion criteria were imposed.

A total of 226 individuals were on the waiting-list and were invited to participate in the study, of these 78 consented, representing a 35% acceptance rate. To recruit this sample, 226 initial invitation letters and 115 reminder letters were sent, thus representing a 23% response rate for all 341 letters. Of the questionnaires returned, 11 were returned with completed questionnaires but without an accompanying consent form. In this situation the completion of

the questionnaires was considered to imply consent and as such contributed to the research; however, no clinical measures were able to be obtained for this group. An additional 6 people returned a consent form without a questionnaire. Although these 6 were contacted, no questionnaire was returned, and this group was thus excluded from the study. The demographics of the remaining 72 responders are presented in Table 5.1.

	N	Mean (SD)
Age (Years)		67.9 (9.25)
Gender		
<i>Male</i>	35	
<i>Female</i>	34	
<i>Missing</i>	3	
Living Status		
<i>With someone</i>	44	
<i>Alone</i>	24	
<i>Missing</i>	4	
Caring Status		
<i>Carer</i>	7	
<i>Not a carer</i>	60	
<i>Missing</i>	5	
Relationship Status		
<i>Single</i>	7	
<i>Married</i>	37	
<i>Divorced</i>	12	
<i>Widowed</i>	12	
<i>Missing</i>	4	
Smoking Status		
<i>Current smoker</i>	5	
<i>Non-smoker</i>	7	
<i>Ex-smoker</i>	57	
<i>Missing</i>	3	
Amount smoked per day (Cigarettes)		21.4 (11.3)

Table 5.1. Summary of participant characteristics for study one responders.

5.2.3 Measures

A questionnaire booklet was developed with seven sections. The first section contained demographical questions about the participants' age, gender, living, carer, and relationship

status, smoking status, and amount smoked per day (if current or ex-smoker). These questions are explained and justified in section 4.3.2.1.

The CAT (Jones, et al., 2009b), EQ-5D-5L (Herdman, et al., 2011), UCOPD (O'Neill, et al., 2012), PNTS (Bartholomew, et al., 2011), PNSE (Wilson, et al., 2006), and BREQ-3 (Wilson, et al., 2006) questionnaires made up the remaining six sections. For a full description of these questionnaires alongside a summary of their psychometric qualities, see Chapter Four from section 4.3.2.2 onwards.

The clinical measure of PR attendance was collected from HDUHB electronic databases, Myrddin and Welsh Clinical Portal and this variable is explained in section 4.3.2.9. Although guidelines state that people should be invited to attend a PR programme within three months (Steiner, et al., 2016), within HDUHB the average waiting-time ranged between 6 and 12 months. Therefore, electronic databases were accessed 12 months after consent was given to collect this data.

5.2.4 Procedure

People conforming to the eligibility criteria were identified from HDUHB PR waiting-lists by NHS employees and sent a study invitation letter, participant information sheet (PIS), consent form, questionnaire booklet, and return prepaid envelope (appendices 8 to 10). Individuals who wished to participate were instructed to complete the consent form and questionnaire and return these in the prepaid envelope. Alternatively, participants could follow a website address displayed on the front of the questionnaire booklet to an online version. This version was designed using the Bristol Online Survey and required participants to use tick boxes to indicate consent before they could complete the questionnaires. Participants were asked to

complete the questionnaires using only one of these methods. Altogether, the questionnaire booklet took a maximum of 15 minutes to complete.

If individuals did not wish to participate, no further action was required. Some, however, decided to utilise the contact details displayed on the PIS to inform the study team that they did not wish to participate. If the individual did not respond within one month of the original posting (returning a paper/online questionnaire or an indication of declining participation), a reminder letter (Appendix 11:) was posted to them. This reminder letter was attached to the same documents as the original letter. If nothing was received from the invited individual after this second attempt, no further documentation for this study was sent and participation was assumed to have been declined.

Consenting participants were given identification codes to anonymise responses. For participants who had consented to accessing their clinical data, NHS employees collated this information from electronic databases using participant names and ages and subsequently provided this information to the researcher.

5.2.5 Analysis

All data was extracted from the paper copy questionnaires, online questionnaires, and medical records and entered into SPSS. All analyses and path analyses were conducted through SPSS and AMOS, respectively.

With exception of some of the demographic information, all questionnaire and clinical measures generated either interval or ratio data. All variables met the parametric assumptions of normality and homogeneity of variance except for generic HRQoL, self-management knowledge, relatedness thwarting, and autonomy satisfaction, (see Appendix 12:). This was

tested using the Kolmogorov-Smirnov test with the Lilliefors significance correction because of the relatively large sample size in this study making it the more appropriate test. Despite these violations, parametric tests were still conducted. The issue of the validity of using parametric tests despite assumption violations is a divisive issue (Games, 1983; 1984; Levine & Dunlap, 1982; 1983). Multiple studies support the robustness of multiple different parametric tests when assumptions are violated (Glass, Peckham, & Sanders, 1972). F tests are particularly unaffected by multiple violations (Donaldson, 1968; Glass, et al., 1972; Lunney, 1970); however, when group sizes are largely varied, violations to homogeneity of variance do affect validity (Field, 2009). Options for correcting violations to parametric assumptions in regression analyses are limited, where transforming raw data won't necessarily affect residuals (Field, 2009). Although, t-tests can be biased for non-normally distributed data (Wilcox, 2005), studies have found that the Type I error probability for Wilcoxon or Mann-Whitney tests is greater than the t-test (Zimmerman, 1987). Other authors suggest that, providing that data does not depart severely from normality, parametric tests can still be implemented (Hubbard, 1978). Due to this, parametric tests were conducted despite minor violations; where, in such situations type I error may have been increased.

Following recommendations from Streiner (2003), to measure the internal consistency of the study data, Cronbach's Alpha was calculated individually for all self-report questionnaires. Following guidelines from published literature, a coefficient between 0.70 and 0.95 was considered acceptable (Bland & Altman, 1997; DeVellis, 2003; Nunnally & Bernstein, 1994).

To test the first three hypotheses, a path analysis was used to examine: if SDT concepts predicted self-management motivation and HRQoL (hypothesis one), the relative association between need satisfaction and thwarting with motivation to self-manage (hypothesis two), and if self-management knowledge positively predicted disease-specific HRQoL (hypothesis three). The analysis used maximum likelihood and estimated means and intercepts due to

small amounts of missing data. Chi-square tests compared over- and just-identified models for each analysis. For testing incremental, absolute and parsimonious fit, the comparative fit index (CFI), the root mean squared approximation of error (RMSEA), and the CMIN/DF (minimum discrepancy divided by degrees of freedom) were used, respectively. These three fit indices are resilient against sample size effects (Bentler, 1990; Hoe, 2008; Joreskog & Sorbom, 1993). CFI of 0.90 or greater, CMIN/DF ratio of 3 or less, and RMSEA of 0.05 or less, represent a good fit between the model and the data (Bentler, 1990; Hoe, 2008; Kline, 1998). RMSEA of 0.08 or less is considered an acceptable fit (Awang, 2012).

To analyse whether SDT concepts could predict PR attendance, an independent t-test was conducted using need satisfaction, need thwarting, and motivation to self-manage as dependent variables and whether an individual had attended PR or not as the independent variable. Participants who had not yet had the opportunity to attend PR after twelve months were excluded from this analysis.

Lastly, to examine whether living, caring, or relationship status had a detrimental impact on positive levels of the basic psychological needs or self-determined motivation, independent t-tests were used on living and caring status and a one-way ANOVA for relationship status. The dependent variables consisted of three psychological need satisfaction variables, three psychological need thwarting variables and self-determined motivation. For the ANOVA, in case of significant findings, post-hoc analyses would consist of independent t-tests, using the Bonferroni correction.

5.2.6 Statistical power analysis

Required sample size was calculated using G Power 3.0.10. All calculations used a medium effect size, an alpha level of 0.05 and power set at 0.80.

Although an increasing amount of published papers tackle the issue of sample size requirements for structural equation models and confirmatory factor analyses, there is still limited literature of path analysis sample size requirements. Lacking a better option, recommendations from Kline (1998) were used, where the sample size should be 10 times the number of parameters. The Chi-square test examining differences between the just- and over-identified models required a total sample of 84 to achieve 80% power. This was computed with 20 degrees of freedom (the highest amount of the three path analyses).

For the independent t-tests the required sample size was 102. This assumes that the two groups included within the analyses were equal.

The only planned ANOVA had four groups (single, married, divorced, and widowed), where the required sample size for this analysis was 48.

5.3 Results

Descriptive statistics, including Cronbach's Alpha, for all measured variables are displayed in Table 5.2

	N	Mean (SD)	Cronbach's Alpha
Disease specific HRQoL	71	27.8 (5.73)	0.84
Generic HRQoL			
<i>Index score</i>	71	0.48 (0.29)	0.87
<i>VAS task</i>	70	46.4 (20)	-
Self-management knowledge (%)			
<i>About COPD</i>	71	68.1 (21.5)	0.92
<i>Managing symptoms of COPD</i>	68	60.4 (18.6)	0.72
<i>Accessing help and support</i>	70	47.3 (23.9)	0.84
<i>Overall</i>	67	60.5 (17.7)	0.90
BPN thwarting			0.92
<i>Autonomy thwarting</i>	69	13.6 (7.47)	0.93
<i>Competence thwarting</i>	68	16.5 (6.94)	0.88
<i>Relatedness thwarting</i>	69	9.62 (5.74)	0.82
BPN Satisfaction			0.85
<i>Autonomy satisfaction</i>	68	13.6 (3.66)	0.79
<i>Competence satisfaction</i>	67	10.8 (4.24)	0.90
<i>Relatedness satisfaction</i>	64	11.1 (4.02)	0.73
Self-management motivation	67	31.3 (27.8)	0.85
PR attendance	46	-	-
<i>Attended</i>	25		
<i>Did not attend</i>	17		
<i>Unable</i>	4		

Table 5.2. Descriptive statistics for questionnaire responders. BPN = basic psychological needs.

5.3.1 Hypotheses one, two, and three

To investigate if SDT concepts predicted motivation to self-manage and HRQoL, if need thwarting or need satisfaction had a greater effect on self-management motivation, and if self-management knowledge positively predicted disease-specific HRQoL (i.e. hypotheses one, two, and three), a path analysis was used.

Constructs were entered into the model and relationships drawn between these constructs, based on previous authors' detailed descriptions of SDT (Deci & Ryan, 1985; Ng, et al., 2012; Ryan, et al., 2008; Standage, et al., 2005). Standage, et al. (2005) reported the high correlation between need satisfaction variables. This was assumed to be similar for need

thwarting variables, despite a sparsity of research being conducted on these concepts (Bartholomew, et al., 2011). Both organismic integration theory (Deci & Ryan, 1985b; Ryan & Connell, 1989) and cognitive evaluation theory (Deci, 1975; Deci & Ryan, 1980) describe how the basic psychological needs predict self-determined motivation (see section 3.2.1). The SDT model of health behaviour change (Ryan, et al., 2008) also defines the relationships between SDT constructs, behaviours pertinent to self-management knowledge, and HRQoL. Both disease-specific and generic HRQoL were included in the path analysis. Lastly, literature has reported the positive relationship between self-management knowledge and HRQoL (Majothi, et al., 2015; Zwerink, et al., 2014), therefore this relationship was also replicated within the model. This model is illustrated in Figure 5.1 and was tested for goodness of fit.

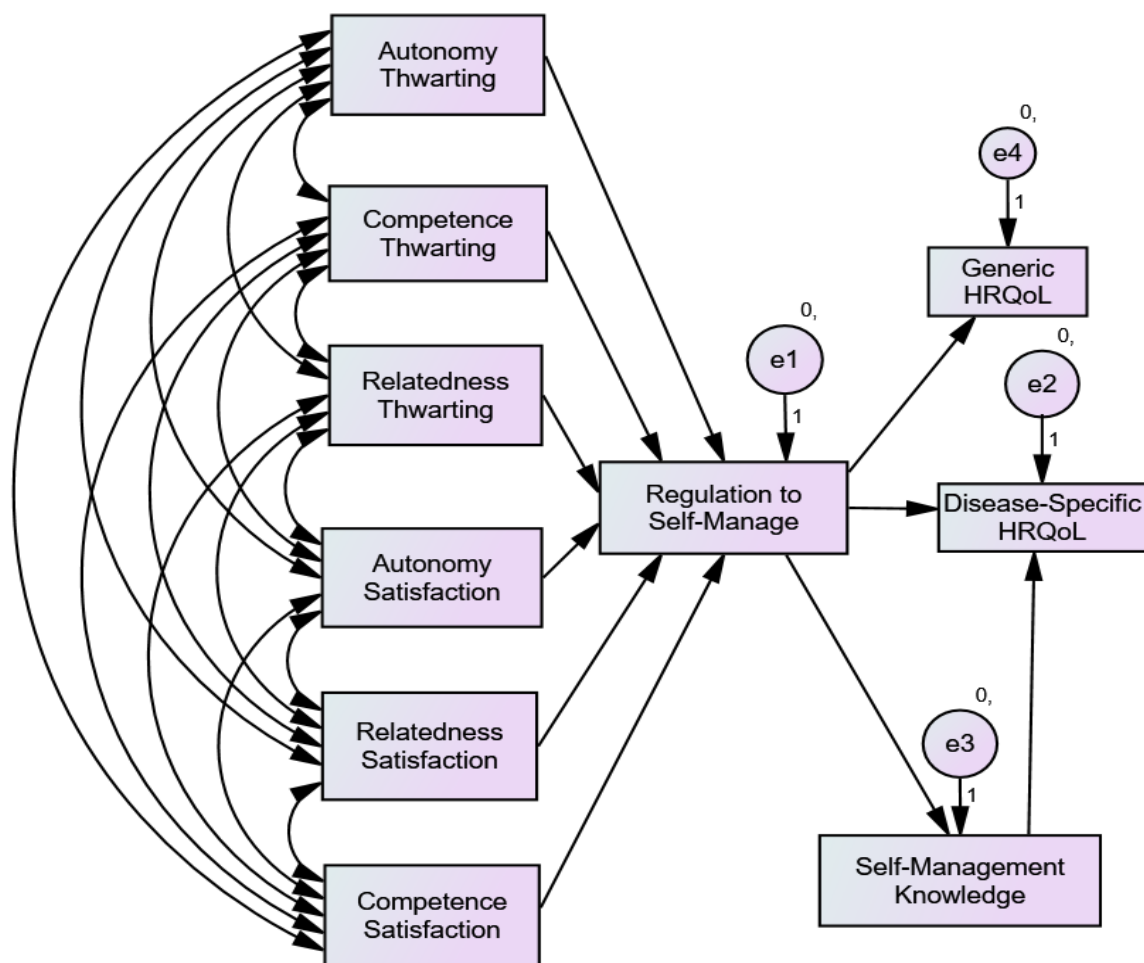


Figure 5.1. First path analysis investigating hypotheses one, two, and three in the first study.

A Chi-square test found that there were statistically significant differences between the over-identified model (i.e. Figure 5.1) and the just-identified model ($\chi^2(20, N = 72) = 75.4, p < 0.05$). Additionally, CMIN/DF, CFI, and RMSEA all indicated the proposed model's poor fit to the data. Furthermore, this model includes ten different parameters and thus previous research recommends a total of 100 participants to test the model (Kline, 1998).

To achieve a parsimonious model and improve the power of the proposed model, generic HRQoL – which represented the least statistically significant concept in the first model – was removed and analyses were conducted again.

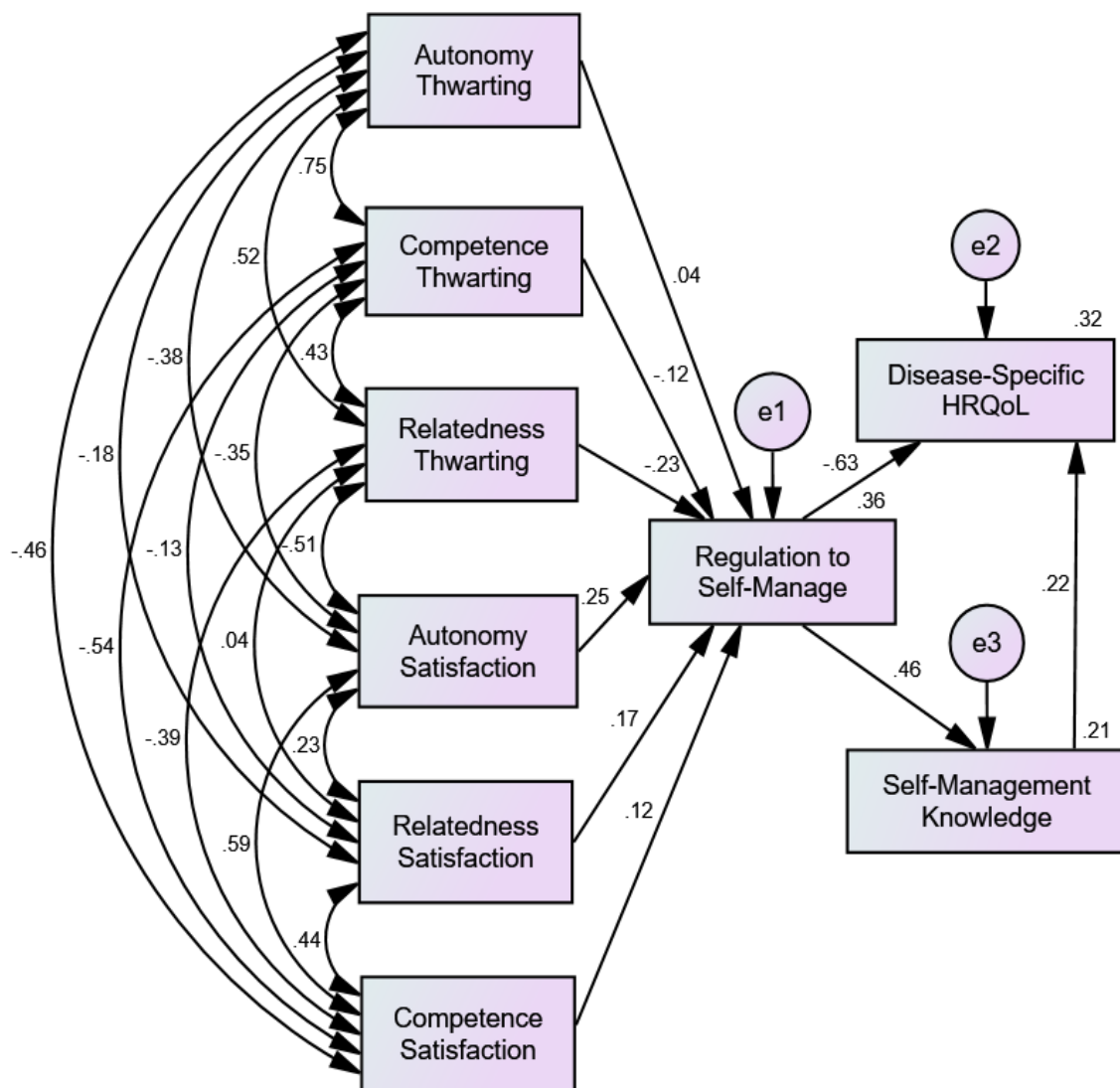


Figure 5.2. Second path analysis investigating hypotheses one, two, and three in the first study.

A Chi-square test found no statistically significant differences between the proposed model (Figure 5.2) and the just-identified model ($\chi^2 (12, N = 72) = 16.9, p > 0.05$). Additionally, CMIN/DF, CFI, and RMSEA were 1.41, 0.98, and 0.76, respectively. Thus, representing an acceptable fit to the data (Awang, 2012; Bentler, 1990; Hoe, 2008; Kline, 1998).

Finally, to explore whether this model could be improved, the least statistically significant pathways were individually removed until the model represented the best fit to the data.

These included the pathways between autonomy and competence thwarting and regulation to self-manage, and relatedness thwarting and relatedness satisfaction. This model is illustrated in Figure 5.3.

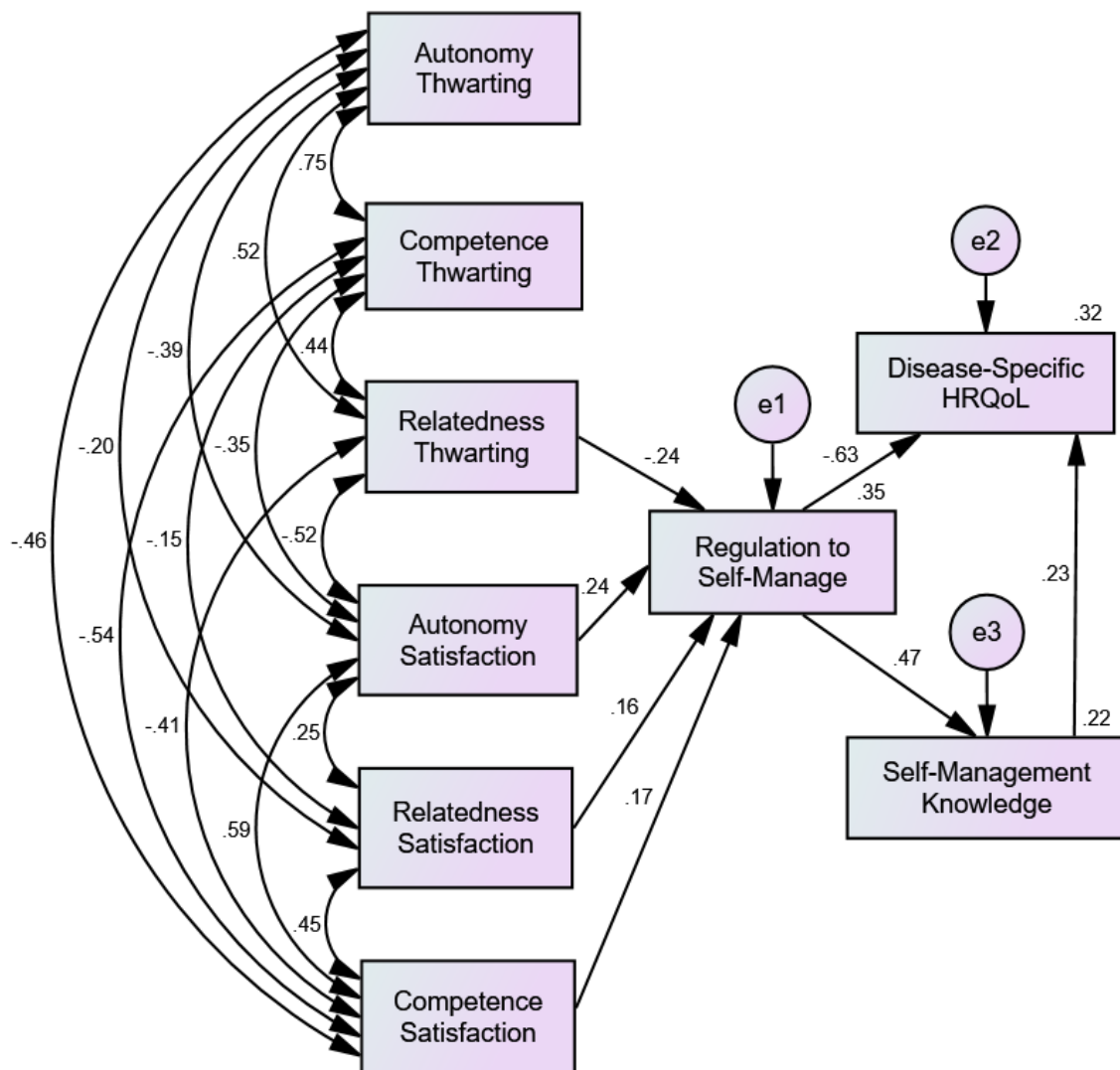


Figure 5.3. Third path analysis investigating hypotheses one, two, and three in the first study.

A Chi-square test found no statistically significant difference between the over- and just-identified models ($\chi^2 (15, N = 72) = 17.6, p > 0.05$). CMIN/DF was 1.17, CFI was 0.987, and RMSEA was 0.049; thus, representing a good fit to the data.

All the relationships between the basic psychological needs were in their predicted direction. For example, need satisfaction variables positively correlated with one another and negative correlations were found between need satisfaction and need thwarting variables. The four needs predicting regulation to self-manage explained 35% of the variance and aligned with expected patterns; with need satisfaction and need thwarting positively and negatively predicting this factor, respectively. Relatedness thwarting and autonomy satisfaction had the greatest predictive power compared to the satisfaction of the other two basic needs. However, autonomy and competence thwarting did not directly predict regulation to self-manage.

Regulation to self-manage had strong predictive power, in the expected directions, on disease-specific HRQoL and self-management knowledge. It is important to remember that lower levels on the disease-specific HRQoL measure (the CAT) are indicative of higher levels of quality of life. Lastly, self-management knowledge was also found to directly predict disease-specific HRQoL; however, unexpectedly, this relationship was found to be positive and therefore greater self-management knowledge predicted worse disease-specific HRQoL.

5.3.2 Hypothesis four

Independent t-tests were used to investigate if there were any significant differences between those who did and did not attend a PR assessment for the variables of basic psychological need thwarting, need satisfaction, and self-determined motivation. Descriptive statistics are

presented Table 5.3. Participants still on the waiting-list, or those who had died, at twelve months were excluded from this analysis.

	PR attendee (n = 25)	PR non-attendee (n = 17)
BPN thwarting		
<i>Autonomy thwarting</i>	13.68 (6.99)	13.81 (9.57)
<i>Competence thwarting</i>	16.92 (7.45)	17.69 (7.60)
<i>Relatedness thwarting</i>	11.28 (6.18)	8.94 (6.62)
BPN satisfaction		
<i>Autonomy satisfaction</i>	13.08 (3.76)	14.82 (3.34)
<i>Competence satisfaction</i>	10.68 (4.27)	10.56 (3.35)
<i>Relatedness satisfaction</i>	11.96 (3.97)	9.93 (3.71)
Self-determined motivation	31.8 (31.4)	26.5 (27.8)

Table 5.3. Descriptive statistics for SDT concepts for PR attendees and non-attendees.

Despite differences between average levels of SDT concepts between the two groups, there were no statistically significant differences in any of the analysed variables ($p > 0.05$). The power analysis conducted in section 5.2.6 indicated that a sample size of 102 was needed. The total sample for these analyses was 42; however, none of the statistics were even approaching close to the 0.05 significance level selected for this study. Therefore, it is unlikely that a lack of statistical significance was solely as a result of low power.

5.3.3 Hypothesis five

To examine whether living or caring status had a detrimental impact on need satisfaction or self-determined motivation, or increased need thwarting, independent t-tests were used.

Descriptive statistics for these analyses are presented Table 5.4.

	Living status		Caring status	
	Living alone (n = 23)	Living with someone (n = 42)	Carer (n = 7)	Not a carer (n = 57)
BPN thwarting				
<i>Autonomy thwarting</i>	14.0 (7.14)	14.1 (7.74)	14.6 (8.24)	13.8 (7.19)
<i>Competence thwarting</i>	16.9 (6.32)	16.9 (7.24)	18.4 (6.73)	16.7 (6.61)
<i>Relatedness thwarting</i>	10.3 (6.10)	9.3 (5.60)	10.9 (7.11)	9.8 (5.61)
BPN satisfaction				
<i>Autonomy satisfaction</i>	13.65 (3.61)	13.5 (3.85)	13.4 (2.82)	13.4 (3.80)
<i>Competence satisfaction</i>	11.1 (3.30)	10.5 (4.82)	11.0 (3.37)	10.5 (4.41)
<i>Relatedness satisfaction</i>	10.8 (4.21)	11.2 (3.94)	11.0 (4.86)	10.9 (3.86)
Self-determined motivation	39.6 (25.6)	26.0 (28.0)	31.1 (31.9)	30.6 (27.3)

Table 5.4. Descriptive statistics of SDT variables for living and caring status.

Despite differences in average scores between the groups, neither living nor caring status had a significant effect on any of the SDT variables analysed ($p > 0.05$). However, the difference between living status groups for the variable of self-determined motivation were approaching statistical significance ($p = 0.06$), where the average score for those living alone was higher than those living with someone.

To investigate if relationship status influenced the same variables as the above analyses, a one-way ANOVA was employed. Descriptive statistics for SDT concepts by relationship status are presented in Table 5.5.

	Single (n = 7)	Married (n = 37)	Divorced (n = 11)	Widowed (n = 12)
BPN thwarting				
<i>Autonomy thwarting</i>	16.0 (5.97)	13.3 (7.60)	14.7 (8.91)	13.6 (6.95)
<i>Competence thwarting</i>	17.2 (3.11)	17.2 (7.32)	14.7 (7.98)	17.3 (5.48)
<i>Relatedness thwarting</i>	12.8 (5.31)	8.92 (5.86)	9.10 (5.63)	10.42 (5.40)
BPN satisfaction				
<i>Autonomy satisfaction</i>	12.9 (4.06)	14.0 (3.75)	12.3 (4.74)	13.8 (2.73)
<i>Competence satisfaction</i>	9.33 (5.13)	11.3 (4.54)	10.7 (2.45)	9.50 (4.48)
<i>Relatedness satisfaction</i>	9.50 (4.68)	11.6 (3.89)	10.9 (4.86)	10.8 (3.64)
Self-determined motivation	26.6 (28.6)	26.3 (28.7)	48.7 (25.2)	33.3 (24.2)

Table 5.5. Descriptive statistics of SDT variables for relationship status.

Like the above analyses, no statistically significant differences were detected by the one-way ANOVA in any of the SDT variables measured between any of the four groups. Therefore, no post-hoc t-tests were conducted.

5.4 Discussion

Within the current sample, average generic HRQoL was less than half of someone considered healthy and the average score on the VAS measuring HRQoL that specific day was 46.4 out of 100. Jones, Jenkins, and Bauerle (2012) describe the symptoms of people with scores above 20 on the disease-specific HRQoL measure (CAT):

COPD stops them doing most things that they want to do. They are breathless walking around the home and when getting washed or dressed. They may be breathless when they talk. Their cough makes them tired and their chest symptoms disturb their sleep on most nights. They feel that exercise is not safe for them and everything they do seems too much effort. They are afraid and panic and do not feel in control of their chest problems. (p. 6)

Participants in this sample on average scored 27.8. These findings corroborate previous research which has also reported the large detrimental effect COPD has on HRQoL (Esteban, et al., 2009; Russell, et al., 2018) and it is not surprising that increasing this factor has been highlighted as crucial within this population (Kielmann, et al., 2010). Although this sample was on a waiting-list to receive PR, where the positive effects of this intervention are widely recognised (McCarthy, et al., 2015), HRQoL had already been significantly decreased. Therefore, earlier intervention could prove beneficial to, at least, slow down disease progression and its negative impact on HRQoL.

The aim of this study was to fill several gaps in the literature described during the introduction (section 5.1), and several analyses were conducted to investigate the ability of SDT to predict motivation to self-manage and HRQoL.

Analyses showed that the original model was a poor fit to the data; however, research would recommend that 100 participants would be needed due to the number of parameters and the analysis only had 72 (Kline, 1998). Generic HRQoL was removed from the model as this represented the only variable that was not specific to people with COPD and thus the other constructs may more readily predict one another. The second model showed an acceptable fit to the data; however, some relationships were largely non-significant and could have been making the model less valid. After the removal of these pathways, the final model showed good fit to the data; therefore, supporting the acceptance of the first hypothesis (that SDT concepts can predict motivation to self-manage and HRQoL).

Increasing self-management knowledge and HRQoL has been identified as crucial to support people with COPD (Kaptein, et al., 2014; Kielmann, et al., 2010) and the path analysis shows that regulation to self-manage is a key variable to consider in this endeavour. Previous research has suggested the importance of self-determined motivation to explain self-management knowledge in other conditions (Sheldon, et al., 2003). The direct effect regulation to self-manage exhibited on disease-specific HRQoL was especially strong, and 32% of the variance of this variable was explained by self-management motivation and knowledge. The strength of the relationships between the SDT variables and health outcomes highlights the importance to target motivational factors when developing interventions for people with COPD. These pathways also explain the relative ineffectiveness of education only interventions (Harris, et al., 2008). SDT provides clear guidelines for each construct to allow interventions to be developed based upon its tenants (Hagger & Chatzisarantis, 2015); therefore, future research should utilise this theory as a theoretical underpinning. If done so

correctly, a number of important variables could be targeted and improved, all for the benefit of people with COPD.

The model also supports the assumption that autonomy, competence, and relatedness thwarting would correlate to one another, as research has found for need satisfaction variables (Standage, et al., 2005). Additionally, the need thwarting and need satisfaction measures negatively correlated with one another as expected, apart from relatedness thwarting and satisfaction where no significant relationship was found. Previous research has stated that even in environments with a high degree of thwarting, needs can still be satisfied (Bartholomew, et al., 2011) and that need dissatisfaction is not equivalent to need thwarting (Vansteenkiste & Ryan, 2013). Therefore, the lack of relationship between the two measures of relatedness does conform to this literature. However, the small to medium strength pathways between the other need thwarting and satisfaction variables does disagree with Bartholomew, et al. (2011), and that in people with COPD, high levels of need thwarting may limit the satisfaction of needs individuals can experience.

This study corroborates findings that people with COPD are, on average, extrinsically motivated to self-manage COPD (Wortz, et al., 2012). Previous research has suggested that need thwarting may play a larger role in situations where optimal motivation cannot be achieved (i.e. extrinsic motivation; Bartholomew, et al., 2011). However, out of the three psychological needs only relatedness thwarting predicted regulation to self-manage but was one of the strongest predictors. Due to this, the second hypothesis (that need thwarting will have a larger association than need satisfaction with self-management motivation) can only be partially accepted. Relatedness, in comparison to the other two needs, was also found to be the least thwarted by COPD (see Table 5.2); therefore, this indicates that even low levels of relatedness thwarting have a negative impact on self-determined motivation. This is an important finding to consider, because limited literature has focused on need thwarting

(Bartholomew, et al., 2011; Olafsen, et al., 2016). Additionally, the lowest scored section on the self-management knowledge questionnaire related to confidence to access help and support. Therefore, people with COPD may need an external agent (i.e. a healthcare intervention) to overcome the thwarting of relatedness. As described within Chapter Three (section 3.2.1), for extrinsically motivated activities, relatedness is posited as the core basic psychological need and behaviours are initiated due to a request from someone an individual feels related to, or desires to be related to. (Deci & Ryan, 2002; Ryan, et al., 1994).

Therefore, if people with COPD are having their relatedness thwarted, this could explain the poor attendance rate seen at programmes such as PR (Steiner, et al., 2015; 2016). Qualitative research has reported that participants' engagement was increased during PR and self-management interventions with a strong group-exercise component (Baker & Fatoye, 2018; Rapport, et al., 2015). These positive findings can be explained by the programmes helping people overcome the thwarting of their need for relatedness; however, future research should investigate the effects such interventions have on this need, in addition to the other needs which have a direct effect on regulation to self-manage. Due to the detrimental effect of relatedness thwarting, one conclusion from this study would be that interventions delivered individually should be avoided, unless they have an effective mechanism to overcome the thwarting of this need.

In line with a plethora of previous literature, the path analyses found that the satisfaction of autonomy, competence, and relatedness positively predicted self-management regulation (Deci & Ryan, 1985; 2002; Ng, et al., 2012; Ryan, et al., 2008). As expected, these needs were also highly correlated with one another (Ntoumanis, 2005). The relative strengths of the three needs (i.e. autonomy and relatedness representing the strongest and weakest predictors, respectively) also conforms to past literature (Deci & Ryan, 1985) and suggests that

participants require agency and confidence to self-manage their COPD more than relatedness with others.

In an unexpected finding, the path analysis found that greater self-management knowledge negatively predicted disease-specific HRQoL. This represents the opposite of previous research (Benzo, et al., 2015; Zwerink, et al., 2014), and thus, the third hypothesis (that self-management knowledge would positively predict disease-specific HRQoL) was rejected. One interpretation could be that participants with greater self-management knowledge were aware of the poor outlook associated with COPD and thus the negative symptoms could have been associated with this potential decline. However, path analyses cannot make causal inferences (Streiner, 2005). Therefore, it is possible that this relationship should be reversed and lower disease-specific HRQoL predicts higher self-management knowledge. Although previous research has not investigated this relationship, it is conceivable that in instances of high disease-impact (i.e. low HRQoL), more self-management knowledge is needed to cope with the burden caused by COPD symptoms. Although future research could investigate whether this theory is valid, time and resources would likely be better spent increasing self-management knowledge at the beginning of the COPD pathway, rather than investigating its effects at the end.

In concordance with previous literature, the satisfaction of the basic psychological needs positively predicted self-determined motivation to self-manage COPD and the three needs were correlated with one another (Deci & Ryan, 1985; 2002; Ng, et al., 2012; Ntoumanis, 2005; Standage, et al., 2005). During behaviour initiation for activities which are not inherently interesting (i.e. extrinsic motivation), the satisfaction of relatedness has been posited as the most important need, followed by competence and autonomy (Deci & Ryan, 2002). However, after the behaviour has been adopted, autonomy and competence satisfaction become important psychological needs to fully internalise the activity into the

repertoire of behaviours regularly conducted (Ryan & Deci, 2000). Therefore, the findings of the path analysis suggest that people with COPD have not recently adopted self-management behaviours and thus the ability of SDT to predict these behaviours during the initial adoption of them is still unknown.

Using a population on a waiting-list for PR allowed this study to investigate whether SDT concepts could predict PR attendance. Additionally, the limited literature which has applied SDT to a population with COPD has largely focused on post-PR samples (Stewart, et al., 2014); therefore, this represented an even more novel application of the theory. Although the path analyses showed that SDT could be validly applied to people with COPD, no differences between those who did and did not attend PR were found in any of the SDT variables.

Therefore, the fourth hypothesis was rejected. This represented a surprising finding because of the ability of SDT concepts to predict other disease relevant outcomes; such as HRQoL and self-management knowledge. Additionally, qualitative research has highlighted that relatedness was a particularly salient need at the start of PR (Whittaker, et al., 2018); yet the analysis detected no increase. One explanation is that the average time to PR enrolment was twelve months and therefore these variables could have changed by the time participants were invited to attend. This represents a problematic theory to test because data would likely have to be collected longitudinally or people recruited as soon as they decline PR to ascertain its veracity. Alternatively, if an intervention was implemented which improves attendance whilst increasing basic psychological need satisfaction, and lowering relatedness thwarting, this could also support the explanation posited above.

Previous research has found that PR attendance is higher in people who live with someone else (Hayton, et al., 2013). From a SDT perspective, this could be explained by relatedness being a core basic psychologic need in behaviour initiation (Deci & Ryan, 2002) and satisfaction of this need being higher in people who live with someone else. If this individual

urges someone to attend PR, autonomy satisfaction may be lowered, or a more controlled regulation type may be experienced. Similar effects could also be seen in people who are married. Furthermore, less autonomy could be experienced if an individual is a carer for someone else, as they may have to put other people's needs before their own. To investigate this possibility, several tests were employed; however, no differences were seen in any SDT variable for living, caring, or relationship status. For the variable of motivation to self-manage, the difference between those living alone and living with someone else was approaching statistical significance. The average scores indicated that those who lived alone had greater self-determined motivation to self-manage COPD, which does align with hypothesis five. However, the p-value was still greater than that set for this study and thus the experimental hypothesis was rejected. Future research could investigate this factor further as low sample size and high variances may have affected the result.

This study replicates most postal questionnaire response rates of approximately 20% (Roberts, et al., 2002). Although the method was employed to increase the rate of response, only four participants completed the questionnaire online. Therefore, such methods may not be the most appropriate for people with COPD.

In conclusion, this study demonstrates that SDT concepts can be applied to a PR waiting-list with COPD to predict motivation to self-manage and HRQoL. This research begins to fill a gap in the literature; where, to the author's knowledge, no previous studies have applied SDT to this population before. The novel application of this theory has allowed for an increased understanding into the role of need thwarting in extrinsically motivated behaviours, in addition to the relationship between basic psychological need thwarting and satisfaction variables. The findings also provide interesting and novel contributions pertinent to interventions aiming to increase self-management knowledge or HRQoL. Specifically, the importance of targeting motivation to self-manage and developing mechanisms to overcome

the effects of relatedness thwarting. Although this study fills multiple gaps within the literature, it has left some questions unanswered. For example, how relatedness thwarting can be influenced to increase intervention attendance, the ability of SDT concepts to predict adherence to PR or self-management programmes, or the effectiveness of a self-management intervention utilising SDT as a theoretical underpinning.

Finally, this study has made a positive contribution to meet the overarching aim of this thesis. By utilising SDT in a novel setting, a greater understanding of motivation to self-manage and HRQoL in people with COPD has started to be achieved. The next chapter will describe the justification, methodology, and results for the second study; which will investigate the effectiveness of two healthcare interventions to increase SDT concepts. The findings of this chapter are discussed, alongside those of the following two studies, within the general discussion presented in Chapter Eight.

Chapter Six: What effect do PR and PocketMedic have on SDT

concepts, self-management motivation, and HRQoL in people with COPD?

6.1 Introduction

The first study concluded that SDT could be used to predict motivation to self-manage and HRQoL in people with COPD on a PR waiting-list. However, the study also highlighted topics in which future research was needed to further examine the role of SDT in this condition; such as the effectiveness of self-management interventions or PR to increase theory concepts.

COPD self-management interventions have been found to benefit multiple health outcomes; such as self-management knowledge and HRQoL (Bringsvor, et al., 2018; Zwerink, et al., 2014). Additionally, a recent review of nurse-led self-management interventions found that the increase in social and psychological support, alongside social interaction during group exercise, improved the wellbeing of participants (Baker & Fatoye, 2018). From a SDT perspective, these interventions could be increasing the satisfaction of relatedness and thus resulted in greater wellbeing and HRQoL. However, the definition of COPD self-management interventions explicitly states the need for behaviour change theory to be used (Effing, et al., 2016) but the use of theory within this condition is limited (McCullough, et al., 2016). Therefore, there could be fewer studies evaluating *actual* self-management interventions than has been previously reported; where this number was already relatively low (Kaptein, et al., 2014). Chapter Three concluded that SDT could be an applicable theory

to utilise within a population with COPD; however, there was a dearth of studies evaluating this application of the model (Riley, et al., 2011). The few studies which have employed SDT within this condition have also used other psychological theories (Altenburg, et al., 2015; Hospes, et al., 2009). Two recent reviews found none of the included studies implemented a self-management intervention utilising solely SDT for people with COPD (McCullough, et al., 2016; Richardson, et al., 2014).

There is also a wealth of previous literature which reports the wide-ranging benefits of PR on various participant outcomes, including functional exercise capacity, HRQoL, and disease knowledge (Corhay, et al., 2014; McCarthy, et al., 2015; Puhan, et al., 2011 White, et al., 2006). Additionally, interviews with people attending PR reported an increase in confidence and group belonging (Rapport, et al., 2015). These outcomes are conceptually similar to the needs of competence and relatedness, respectively. However, no study has quantitatively analysed the effects of PR on SDT concepts to date. This is despite research suggesting that PR has a greater benefit on psychological factors, as opposed to physiological, in the short-term (Ratneswaran, et al, 2015).

Although research has investigated barriers to performing behaviours relevant to self-management knowledge (Bourbeau & Bartlett, 2008; Restrepo, et al., 2008), barriers to self-management intervention adherence have largely remained unexplored. PR attendance and adherence, however, has been thoroughly researched; where a disruption to usual routine, programme timing, travel and transport, and smoking status have all been identified as relevant factors (Hayton, et al., 2013; Keating, et al., 2011). Although research has qualitatively examined the salient basic psychological needs at each stage of pulmonary rehabilitation (Whittaker, et al., 2018), no studies have used quantitative measures to investigate the ability of SDT concepts to predict PR adherence. One method which has been suggested to overcome the aforementioned barriers is the use of technology (Wooton, 2012).

Research investigating the effectiveness of self-management interventions or PR delivered through technology has shown promising results (Guo & Albright, 2017; Knox, et al., 2019; Rice, et al., 2017; Stickland, et al., 2011). Additionally, such programmes have reported high adherence (Gorst, et al., 2014) and factors which predict low attendance in other programmes are not evident in technology delivered interventions (Broendum, et al., 2016). However, there are relatively few studies evaluating the use of technology to support people with COPD compared to other chronic conditions (McKinstry, et al., 2009; Wooton, 2012) and the use of psychological theory within these interventions is low (Riley, et al., 2011; Webb, et al., 2010). Although research has investigated the use of technology to deliver PR programmes (Knox, et al., 2019; Stickland, et al., 2011), there is a paucity of studies examining technology-delivered, theory-based self-management interventions. Multiple authors have recommended that more research should be conducted upon this topic (Cruz, et al., 2014; McLean, et al., 2012).

This study aimed to fill the gaps in the literature described above and answer the research question: *what effect do PR and PocketMedic have on SDT concepts, self-management motivation, and HRQoL in people with COPD?* This study implemented two interventions, prescribed independently and together; PR and a technology-delivered, SDT-based self-management intervention. Measures which have been employed previously, alongside SDT concepts, were used within this study to evaluate the interventions. Lastly, the ability of SDT concepts to predict attendance and adherence to a technology-delivered self-management intervention, and PR adherence was investigated.

In line with the study aims and previous literature, several experimental hypotheses were developed. 1) That the self-management intervention and PR (both separately and together) will have a positive effect on basic psychological need satisfaction and thwarting and self-determined motivation to self-manage. 2) That the self-management intervention and PR

(both separately and together) will have a positive effect on functional exercise capacity (PR participants only), HRQoL, self-management knowledge, and disease knowledge. 3) That the combination of interventions will have a greater beneficial effect on all the above measures, compared to either intervention prescribed independently. 4) That baseline need satisfaction, need thwarting, and self-determined motivation will be able to predict self-management intervention attendance and adherence. 5) That baseline need satisfaction, need thwarting, and self-determined motivation will be able to predict PR adherence.

6.2 Method

6.2.1 Design

This study used a questionnaire-based parallel group design to investigate the ability of the two healthcare interventions to increase psychological need satisfaction, psychological need thwarting, self-determined motivation to self-manage, and HRQoL in a sample with COPD. Additionally, measures which have been previously used to evaluate self-management interventions and PR were used to facilitate the comparison of the interventions presented in this study to previous programmes. The study comprised of three separate research arms. Participants in condition one received a web-delivered SDT-based self-management intervention alongside PR. Participants in condition two received a link-delivered SDT-based self-management intervention. Participants in condition three received PR.

Similar designs have been used previously to assess the ability of SDT to predict physical exercise in university students (Sweet, et al., 2014) and self-management support practices in clinicians working in chronic conditions (Kosmala-Anderson, et al., 2010). Questionnaires

were used to measure need satisfaction and thwarting, self-determined motivation to self-manage, disease-specific and generic HRQoL, self-management knowledge, and disease knowledge. Additionally, functional exercise capacity, self-management attendance and adherence, and PR adherence data were collected.

6.2.2 Participants

All participants were recruited within HDUHB and were eligible to attend PR, even if they did not receive this as part of their treatment. To attend PR for COPD treatment within this health region, everyone must conform to the GOLD definition of COPD; be 50 years or older, have at least 10 pack-years smoking history, and post-bronchodilator spirometry of FEV1/FVC ratio less than 70% and FEV1 less than 80% of predicted. All participants had to be willing and able to give informed consent.

Exclusion criteria included individuals who were unwilling or unable to give informed consent, those with a life-expectancy of less than six months, unstable cardiovascular disease, dementia, cancers other than non-melanoma skin cancer, and any condition that prevents the use of laptops or mobile phones (e.g. being blind or deaf).

A total of 199 individuals were invited to participate in this study, of these 55 consented, representing a 28% acceptance rate. 29, 7, and 19 participants were recruited into condition one, two, and three, respectively. The method of allocation is explained in detail in section 6.2.5. Two participants, one from condition one and three, withdrew from the study. The demographics of the remaining 53 participants are displayed in Table 6.1. There were no statistically significant differences between the three conditions.

	Condition one (n = 28)	Condition two (n = 7)	Condition three (n = 18)
Age	66.0 (5.54)	68.1 (10.9)	65.3 (7.10)
Gender, n			
<i>Male</i>	15	6	11
<i>Female</i>	13	1	7
Living Status, n			
<i>With someone</i>	15	4	7
<i>Alone</i>	6	3	8
<i>Missing</i>	7	0	3
Caring Status, n			
<i>Carer</i>	3	1	1
<i>Non-Carer</i>	18	6	13
<i>Missing</i>	7	0	4
Relationship Status, n			
<i>Single</i>	2	1	3
<i>Married</i>	9	3	5
<i>Divorced</i>	6	1	3
<i>Widowed</i>	3	2	3
<i>Missing</i>	8	0	4
Smoking Status, n			
<i>Current smoker</i>	3	2	1
<i>Non-smoker</i>	3	0	0
<i>Ex-smoker</i>	15	5	14
<i>Missing</i>	7	0	3
Amount smoked per day (cigarettes)	20.3 (18.2)	26.4 (17.0)	25.4 (10.2)

Table 6.1. Summary of study two participant characteristics. Data are presented as mean and standard deviation (SD) in parenthesis unless otherwise stated. All differences between groups were non-statistically significant ($p > 0.05$).

6.2.3 Healthcare interventions

6.2.3.1 Technology-delivered SDT-based self-management

PocketMedic is a technology-delivered, SDT-based self-management intervention designed for multiple chronic conditions including COPD, diabetes, and heart failure. PocketMedic was developed by eHealth Digital Media Ltd. The aim of this intervention is to help improve

health outcomes in people with chronic illness by increasing self-management motivation and knowledge. This is accomplished by being autonomy supportive, using SDT concepts to effect behaviour change, and increasing self-determined motivation, alongside delivering educational components. Digital health films lasting approximately five minutes each can be prescribed by clinicians and watched by individuals at a time and place which suits them, using a smart phone, tablet, or computer. The films show a mix of clinicians and people with the conditions discussing the illness and providing information on how to effectively self-manage. A separate series of films is created for each chronic condition; where, the topics covered by the films prescribed as part of this study included breathlessness, physical activity, and information on PR. Additionally, there were three films directly designed to target and increase participants' wellbeing. The specific films which were delivered to participants in condition one and two, alongside a short description, are given in Appendix 13:

PocketMedic could be prescribed by one of two delivery systems. Web-delivered PocketMedic used a log-in system, whereby individuals had a PocketMedic account and password and received one digital health film per week. Automatic messages were sent to users' email accounts when a new film was available. Link-delivered PocketMedic used a website URL – or link – to navigate an individual to a webpage with all the digital health films available at once. The link could be given out either by email, text, hand, or post. Both methods allowed the individual to re-watch the digital health films at their leisure. After this research was completed, eHealth Digital Media, Ltd. no longer provided the web-delivered system and now only use the link-delivered PocketMedic system.

6.2.3.2 Pulmonary rehabilitation

PR and its effects have been described in detail within 2.2.3. Specifically, within HDUHB, PR consists of twice weekly sessions lasting seven weeks, located at an outpatient, hospital cardio-pulmonary centre. Safety and quality assessments are taken before and after the fourteen sessions. Approximately seven to ten participants attend each seven-week programme. The course is delivered by an Occupational Therapist, Physiotherapist, and a Respiratory Technician. A supervised, personalised aerobic exercise session lasting 1-1.5 hours is followed by a 20-40-minute talk delivered by the standard PR staff, or guest speakers. The guest speakers are all specialists and consist of Respiratory Nurses, Dieticians, or Respiratory Physicians. The Occupational Therapist also offers 1:1 sessions and additional advice on anxiety management, breathlessness control, and breathing exercises for those that want this. Both exercise and educational components are delivered according to best practice and current guidelines (Bolton, et al., 2013; Griffiths et al., 2000).

6.2.4 Measures

A questionnaire booklet was developed with eight sections. The first section contained demographical questions about the participants' age, gender, living, carer, and relationship status, smoking status, and amount smoked per day (if current or ex-smoker). These questions are explained and justified in section 4.3.2.1.

The CAT (Jones, et al., 2009b), EQ-5D-5L (Herdman, et al., 2011), UCOPD (O'Neill, et al., 2012), PNTS (Bartholomew, et al., 2011), PNSE (Wilson, et al., 2006), BREQ-3 (Wilson, et al., 2006), and BCKQ (White, et al., 2006) questionnaires made up the remaining seven

sections. This booklet took approximately 30 minutes to complete. For a full description of these questionnaires alongside a summary of their psychometric qualities, see chapter four from section 4.3.2.2 onwards.

For participants receiving PR (conditions one and three), the clinical measures of PR adherence and 6MWT were collected from HDUHB electronic databases, Myrddin and Welsh Clinical Portal, and these variables are explained in section 4.3.2.10 and 4.3.2.13, respectively. 6MWT is not collected as part of usual care outside of PR and therefore was not available for participants in condition two. For condition one participants, web-delivered PocketMedic attendance and adherence data were automatically collected by the electronic system. The electronic system used for condition two (link-delivered PocketMedic) was unable to collect this data; therefore, a self-report measure was incorporated into the follow-up questionnaire for participants in this group.

These measures were taken at baseline and again at seven-weeks.

6.2.5 Procedure

6.2.5.1 Conditions one and three

Participants who received PR as part of their care (conditions one and three) were recruited from two sites in the county of Carmarthenshire; Glangwili Hospital (GGH), Carmarthen and Prince Philip Hospital (PPH), Llanelli. Upon the request of the REC, to avoid individuals within the same PR programme being allocated to different research groups, for the first cohort all consenting participants at GGH received PocketMedic and PR (condition one),

whereas PPH consenters only received PR (control three). To reduce geographical bias being introduced, this allocation was alternated with each PR cohort (see Figure 6.1).

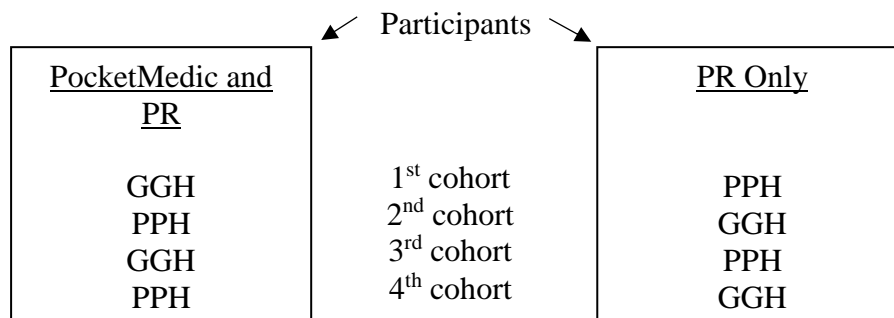


Figure 6.1. Recruitment location cross-over design.

Participants in condition one and three were recruited during the pre-PR assessment session and were provided with a PIS (Appendix 14:), consent form (Appendix 15:), and questionnaire booklet. After fully informed consent was received and a questionnaire booklet completed, participants were allocated to a study condition in accordance with Figure 6.1.

Participants in condition one had a web-delivered PocketMedic user account created and log-in details were sent out via automatic emails. They were also reminded to check their email junk folders if they had not received an email after a few days. Participants in condition three were not prescribed any form of PocketMedic. People in both conditions were instructed to attend PR as normal.

Consenting participants were given identification codes to anonymise responses. Clinical data was collated by NHS employees from electronic databases using participant names and ages and subsequently provided this information to the researcher. For follow-up at seven weeks, questionnaire booklets and return prepaid envelopes were posted to participants.

6.2.5.2 Condition two

Participants in condition two were recruited exclusively from the counties of Pembrokeshire and Ceredigion. PR is not regularly available in these counties and thus PocketMedic represented the best alternative to overcome this disparity in care. People conforming to the eligibility criteria were identified from general practitioners' lists by NHS employees and sent a study invitation letter (Appendix 16:), PIS, consent form, baseline questionnaire booklet, and a prepaid return envelope. All these documents are included within the appendix. Individuals who wished to participate were instructed to complete the consent form and questionnaire booklet and return these in the prepaid envelope. Alternatively, participants could follow a website address displayed on the front of the questionnaire booklet to an online version. This version was designed using the Bristol Online Survey and required participants to use tick boxes to indicate consent before they could complete the questionnaires. Participants were asked to complete the questionnaires using only one of these methods.

If individuals did not wish to participate, no further action was required. If the individual did not respond within one month of the original posting (by returning a paper/online questionnaire), a reminder letter (Appendix 17:) was posted to them. This reminder letter was attached to the same documents as the original letter. If nothing was received from the invited individual after this second attempt, no further documentation for this study was sent and participation was assumed to have been declined.

Once signed consent was received, a letter was posted containing instructions on how to access the link-delivered PocketMedic films, alongside simple picture-based instructions to help those less computer-literate (Appendix 18:). Consenting participants were given

identification codes to anonymise responses. No clinical data was collected for people within this group. For follow-up at seven weeks, questionnaire booklets and return prepaid envelopes were posted to participants.

Figure 6.2 shows a flow chart displaying the number of participants within the three study groups at each stage of the study.

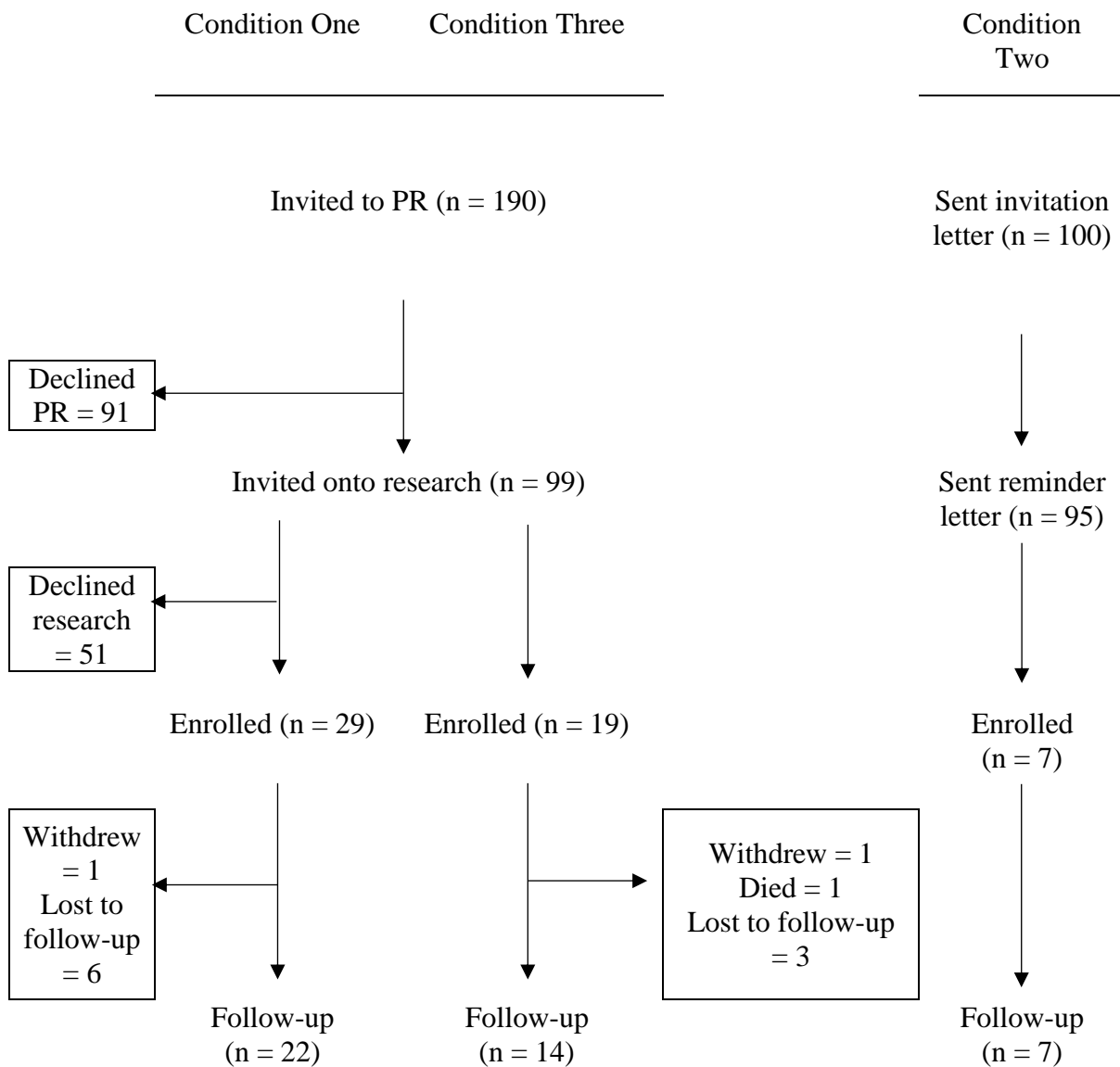


Figure 6.2. Number of participants at each stage of the study

6.2.6 Analysis

All data was extracted from the paper copy questionnaires, online questionnaires, and medical records (for conditions one and three) and entered into SPSS. All analyses were additionally conducted through SPSS.

With exception of some of the demographical information, all questionnaire and clinical measures generated either interval or ratio data. A few of the variables across the two time-points violated the assumption of normality (see Appendix 19:). The Shapiro-Wilk test was used to test for violations of normality due to the relatively small sample size of this study making this the most appropriate test.

To analyse the effects of PocketMedic and PR on the variables of basic psychological need satisfaction, need thwarting, and self-determined motivation to self-manage (i.e. hypothesis one), a repeated measures MANOVA was conducted.

To analyse the effects of PocketMedic and PR on the variables of disease-specific and generic HRQoL, self-management knowledge, and disease knowledge (i.e. hypothesis two), another repeated measures MANOVA was conducted.

Separate MANOVAs were conducted for hypothesis one and two due to previous research recommending that fewer than ten dependent variables are inputted into a MANOVA unless sample sizes are large (Stevens, 1980). Both MANOVAs can also investigate whether the combination of interventions (i.e. condition one) is more effective compared to either intervention prescribed independently (i.e. conditions two and three) at providing a greater beneficial effect on the above outcomes (i.e. hypothesis three). Therefore, the only additional analyses that were conducted to meet this hypothesis were post-hoc pairwise t-tests.

Due to the small sample sizes of this research study, the MANOVA test statistic was chosen based on which would offer the best statistical power for each analysis; providing that the test statistic was not contraindicated due to the violation of an assumption. However, for small sample sizes, observed power does not differ to a large degree (Olson, 1974) and the four most common test statistics are all relatively robust to violations of multivariate normality (Olson, 1976). In case of equal power between test statistics, Pillau's trace was reported. For each MANOVA reported within the results section, the test statistic used is clearly noted.

A MANOVA was the more appropriate statistical test because running multiple separate ANOVAs would inflate Type I error rates. In the case of a statistically significant MANOVA result, separate ANOVAs for each dependent variable were implemented. The following ANOVAs were protected against inflated Type I error rates by the initial MANOVA (Bock, 1975). Pairwise t-tests were selected for post-hoc analyses in the event of a statistically significant finding in either of the following ANOVAs. Providing that the assumption of independence of the post-hoc tests was not violated, the Sidak correction was implemented for these post-hoc tests to avoid unnecessary loss of statistical power. In the event of the assumption of homogeneity of variances being violated (as determined by a significant Levene's test), the Games-Howell correction was used instead.

To analyse whether the two healthcare interventions significantly increased functional exercise capacity within conditions one and three, a repeated-measures ANOVA was used. This ANOVA additionally met hypothesis three and compared whether the combination of interventions was more beneficial than solely PR.

Due to only 51.4% of participants who were prescribed PocketMedic watched one or more of the films, sub-group analyses were conducted excluding those who did not watch any of the digital health films. These analyses were conducted to remove any concealing effects the

non-engaging participants' data may have had on the results; where similar techniques have been employed previously (Bucknall, et al., 2012).

To investigate whether baseline basic need satisfaction, need thwarting, and self-determined motivation could predict PocketMedic attendance and adherence, a separate analysis was conducted for each variable. For attendance, participants within conditions one and two were categorised into those who did and did not engage with the intervention. Engaging in PocketMedic was operationalised as a participant who watched one or more of the digital health films. Non-engagement was defined by a participant not watching any films. An independent t-test was then used to investigate if there were any differences in SDT concepts between these two groups. For adherence, a multiple regression analysis was conducted inputting the number of films watched as the criterion variable and all SDT concepts as the predictor variables. To control for any effects the included variables could have on PocketMedic attendance, only participants who watched one or more of the films were included. Backwards elimination was used in order to identify the best variable, or variables, which could predict PocketMedic adherence.

To investigate whether baseline basic need satisfaction, need thwarting, and self-determined motivation could predict PR adherence (hypothesis five), a multiple regression analysis was conducted inputting the number of PR sessions participants attended as the criterion variable and all the SDT concepts as the predictor variables. Backwards elimination was used in order to identify the best variable, or variables, which could predict PR adherence.

To test for the problem of multicollinearity within the two multiple regression analyses, SPSS calculated tolerance and variance inflation factor (VIF). Following recommendations from previous authors, no collinearity is evident in the data if the largest VIF is smaller than 10

(Bowerman & O'Connell, 1990; Myers, 1990) and tolerance is greater than 0.2 (Menard, 1995).

6.2.7 Statistical power analysis

Power analyses were calculated using G*Power 3.0.1.0. For the MANOVAs to detect a significant difference between the three conditions, using a small-medium effect size, alpha error probability of 0.05, and at 80% power, a total sample of 42 was needed. Statistical power for post-hoc tests will be calculated during their computation, due to the unknown nature of what specific tests will be conducted and the correction used to be dependent on whether the assumption of homogeneity of variance was violated.

The repeated measures ANOVA required a total sample of 21 using the same effect size, alpha error probability, and power as above.

For the two planned multiple regression analyses, a total of fourteen predictors were inputted; therefore, a total sample of 65 was needed.

For the independent t-test investigating PocketMedic attendance the required sample size was 102. This assumes that the two groups included within the analyses were equal.

6.3 Results

One-way ANOVAs were conducted on all baseline variables to identify any differences between the three research conditions (Table 6.2). Only the variable of disease knowledge, measured by the BCKQ, showed a significant difference between groups ($F(2, 38) = 3.53, p$

< 0.05). Post-hoc pairwise t-tests were implemented using the Sidak correction, finding statistically significant differences between participants in condition two (PocketMedic only) and the other two conditions ($p < 0.05$), indicating that this group had, on average, lower disease knowledge.

Measure	Condition one (n = 28)	Condition two (n = 7)	Condition three (n = 18)
Disease-specific HRQoL	27.7 (6.21)	28.6 (3.60)	27.1 (5.15)
Generic HRQoL			
<i>EQ Index</i>	0.47 (0.32)	0.52 (0.17)	0.54 (0.20)
<i>EQ VAS</i>	49.0 (22.4)	46.3 (20.3)	52.5 (20.4)
Self-management knowledge			
<i>About COPD</i>	69.6 (14.8)	59.0 (24.1)	66.1 (14.3)
<i>Managing symptoms of COPD</i>	63.1 (14.2)	53.5 (21.7)	53.7 (22.0)
<i>Accessing help and support</i>	43.2 (18.5)	38.2 (20.8)	44.4 (18.9)
<i>Total</i>	61.2 (10.3)	52.2 (17.0)	56.5 (15.2)
BPN thwarting			
<i>Autonomy thwarting</i>	13.1 (6.90)	15.6 (5.53)	12.5 (5.52)
<i>Competence thwarting</i>	16.1 (6.49)	17.4 (3.36)	12.0 (6.29)
<i>Relatedness thwarting</i>	8.98 (4.77)	8.86 (4.71)	11.2 (4.48)
BPN satisfaction			
<i>Autonomy satisfaction</i>	13.4 (3.01)	15.6 (1.62)	13.5 (3.50)
<i>Competence satisfaction</i>	10.6 (3.96)	10.9 (2.73)	10.7 (3.43)
<i>Relatedness satisfaction</i>	11.2 (4.19)	10.1 (3.34)	10.2 (3.69)
Self-management motivation	30.8 (27.9)	24.3 (23.8)	27.0 (19.2)
Disease knowledge	47.9 (14.9) * ¹	35.7 (8.50) * ¹ * ²	50.3 (9.59) * ²
Functional exercise	167 (102)	-	135 (78.9)

Table 6.2. Descriptive statistics for all measures at baseline. *¹ and *² denote statistically significant interactions at $p < 0.05$.

Table 6.3 shows average participant PocketMedic and PR adherence per condition. Due to only 51.4% of participants in conditions one and two watching one or more of the digital health films (i.e. PocketMedic attendance), average PocketMedic adherence whilst excluding non-engagers was also calculated.

	Condition one (n = 28)	Condition two (n = 7)	Condition three (n = 18)
PocketMedic adherence	2.93 (4.06)	7.0 (4.12)	-
PocketMedic adherence (only engagers)	n = 12, 6.83 (3.35)	n = 6, 8.17 (2.99)	-
PR adherence	10.33 (4.76)	-	9 (4.40)

Table 6.3. Descriptive statistics for PocketMedic and PR adherence.

6.3.1 Hypotheses one and three

To investigate whether the self-management intervention and PR – prescribed independently and together – had a positive effect on need satisfaction, need thwarting, and self-determined motivation to self-manage (i.e. hypothesis one), a repeated measures MANOVA was conducted. This analysis also enabled the interventions to be directly compared and thus contributed to answering the third hypothesis.

Using Pillai's trace, there was no significant effect between the three research conditions ($V = 0.46$, $F(14, 62) = 1.31$, $p > 0.05$); however, when keeping the research condition constant, time was found to be a significant within group factor ($V = 0.53$, $F(7, 30) = 4.76$, $p < 0.001$). Bartlett's test of sphericity found a significant effect ($p < 0.001$), therefore indicating the violation of this assumption. Univariate tests using the Greenhouse-Geisser correction found significant improvements in competence satisfaction ($F(1, 36) = 19.6$, $p < 0.001$), relatedness satisfaction ($F(1, 36) = 11.3$, $p < 0.05$), autonomy thwarting ($F(1, 36) = 27.6$, $p < 0.001$), competence thwarting ($F(1, 36) = 4.84$, $p < 0.05$), and motivation to self-manage ($F(1, 36) = 7.29$, $p < 0.05$), and were identified from baseline to follow-up. Descriptive statistics for all variables across the three research groups at both time points are displayed within Table 6.4.

Measure	Condition one		Condition two		Condition three	
	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up
Disease-specific HRQoL	27.7 (6.43)	23.6 (4.99)	28.2 (4.32)	21.4 (3.91)	26.2 (5.57)	24.7 (6.75)
Generic HRQoL						
<i>EQ index</i>	0.51 (0.32)	0.56 (0.31)	0.54 (0.20)	0.70 (0.12)	0.54 (0.22)	0.63 (0.24)
<i>EQ VAS</i>	49.0 (22.4)	61.84 (18.78)	46.3 (20.3)	50.43 (11.67)	52.5 (20.4)	63.31 (18.33)
Self-management knowledge						
<i>About COPD</i>	66.8 (13.9)	76.5 (14.6)	65.1 (23.9)	72.9 (21.4)	65.3 (13.6)	68.6 (7.77)
<i>Managing symptoms of COPD</i>	60.3 (15.2)	66.5 (24.6)	47.4 (23.4)	66.7 (23.6)	54.4 (12.59)	62.5 (13.2)
<i>Accessing help and support</i>	49.5 (16.4)	56.7 (21.9)	34.0 (23.9)	62.5 (20.4)	41.8 (14.0)	59.8 (9.89)
<i>Total</i>	60.4 (11.3)	68.1 (17.1)	51.3 (20.2)	68.5 (21.3)	55.8 (6.93)	64.3 (7.53)
BPN thwarting						
<i>Autonomy thwarting</i>	12.5 (7.00)	10.3 (5.37)	15.6 (5.53)	10.1 (3.89)	12.6 (5.83)	10.2 (5.18)
<i>Competence thwarting</i>	14.9 (5.43)	12.63 (5.26)	17.43 (3.36)	14.86 (4.45)	12.58 (6.45)	12.77 (5.92)
<i>Relatedness thwarting</i>	8.4 (3.91)	8.53 (5.29)	8.86 (4.71)	7.71 (3.99)	10.89 (4.32)	11.69 (5.84)
BPN satisfaction						
<i>Autonomy satisfaction</i>	13.5 (3.12)	15.3 (2.36)	15.6 (1.62)	15.7 (2.22)	13.5 (3.31)	13.6 (3.12)
<i>Competence satisfaction</i>	10.53 (3.73)	12.5 (3.55)	10.9 (2.73)	12.7 (1.98)	10.31 (3.5)	12.9 (3.45)
<i>Relatedness satisfaction</i>	11.0 (4.08)	13.3 (3.65)	10.1 (3.34)	13.1 (3.39)	10.5 (3.78)	13.0 (1.99)
Self-management motivation	30.8 (28.5)	37.2 (29.3)	24.3 (23.8)	41.4 (14.3)	29.4 (19.1)	32.7 (23.3)
Disease knowledge	46.8 (15.2)	60.8 (19.0)	38.4 (8.74)	70.9 (6.22)	52.2 (8.68)	60.6 (9.04)
Functional exercise	172 (107)	237 (150)	-	-	133 (75.3)	191 (115)

Table 6.4. Descriptive statistics for the three research groups and time-points.

6.3.1.1 Hypothesis one and three sub-group analysis

A second MANOVA was conducted utilising the same between and within group variables (i.e. the three conditions, need satisfaction, need thwarting, and self-determined motivation) whilst excluding participants who did not attend PocketMedic (i.e. watched zero films).

Similar to the original analysis, no significant differences were detected between the three research conditions ($V = 0.50$, $F(14, 42) = 1.00$, $p > 0.05$); however, time had a significant effect when research condition was held constant ($V = 0.61$, $F(7, 20) = 4.37$, $p < 0.05$).

Univariate tests utilising the Greenhouse-Geisser correction found competence and relatedness satisfaction and autonomy thwarting all significantly improved between the two time points ($p < 0.05$); however, competence thwarting and motivation to self-manage were no longer showing significant differences between the two time-points ($p > 0.05$).

6.3.2 Hypotheses two and three

To investigate whether the self-management intervention and PR – prescribed independently and together – had a positive effect on disease-specific and generic HRQoL, self-management knowledge, and disease-knowledge (i.e. hypothesis two), a repeated measures MANOVA was conducted. This analysis also enabled the interventions to be directly compared and thus contributed to answering the third hypothesis.

Using Pillai's trace, there was no significant effect between the three research conditions in any of the variables between baseline and follow-up ($V = 0.77$, $F(14, 42) = 1.89$, $p > 0.05$). However, when research condition was held constant, there was a significant effect for the within group variable ($V = 0.81$, $F(7, 20) = 0.81$, $p < 0.001$). Bartlett's test of sphericity was

again significant ($p < 0.001$) and therefore the following ANOVAs used the Greenhouse-Geisser correction. The univariate tests found a significant effect of time for all the included variables at the alpha level of 0.001, apart from the managing symptoms of COPD section of the self-management questionnaire which was significant at the alpha level of 0.05. All average scores at follow-up indicated more beneficial health states compared to those at baseline. Unexpectedly, despite the original MANOVA indicating that there were no significant differences between the conditions, these ANOVAs showed a significant difference for the variable of disease knowledge ($F(2, 26) = 0.14, p < 0.05$). However, pairwise post-hoc t-tests using the Sidak correction found no significant differences between the research conditions.

A repeated measures ANOVA was used to examine the variable of functional exercise capacity between condition one and three and the two time-points. Bartlett's test of sphericity found a significant effect ($p < 0.001$) and the resulting ANOVA using the Greenhouse-Geisser correction found no significant effect of research condition ($F(1, 27) = 0.08, p > 0.05$). However, the within-group variable of time was significant when research condition was held constant ($F(1, 27) = 19.8, p < 0.001$). Descriptive statistics show that average follow-up scores were higher than those at baseline for both condition one and three.

6.3.2.1 Hypothesis two and three sub-group analysis

The sub-group analysis excluding participants who did not watch any of the PocketMedic digital health films repeated the original MANOVA and ANOVA described above.

Using Roy's largest root, significant effects were found for both time ($\theta = 9.50, F(7, 12) = 16.3, p < 0.001$) and research condition ($\theta = 1.79, F(7, 13) = 3.33, p < 0.05$). Bartlett's test of

sphericity was found to be significant ($p < 0.001$); therefore, the following ANOVAs used the Greenhouse-Geisser correction. Univariate analyses found significant differences between the two time-points for all the included variables ($p < 0.001$). Only for the variable of disease knowledge was there a significant difference between the three conditions ($F(2, 18) = 6.02, p < 0.05$); however, the variables of disease-specific HRQoL and self-management knowledge were narrowly non-significant ($F(2, 18) = 3.31, p = 0.06$ and $F(2, 18) = 3.37, p = 0.057$, respectively). Post-hoc pairwise t-tests using the Sidak correction again found no significant differences between the three research conditions ($p > 0.05$).

The ANOVA investigating the dependent variable of functional exercise capacity found the same results as the original analysis including all participants across conditions one and three.

6.3.3 Hypothesis four

An independent t-test was conducted to investigate whether there were statistically significant differences for need thwarting, need satisfaction, or self-determined motivation between participants who did and did not watch any of the PocketMedic films. Table 6.5 displays the descriptive statistics for the two groups.

	PocketMedic attendee (n = 12)	PocketMedic non-attendee (n = 9)
Need thwarting		
Autonomy thwarting	13.2 (6.03)	12.9 (8.31)
Competence thwarting	17.7 (7.18)	14.0 (5.05)
Relatedness thwarting	8.89 (4.90)	9.11 (4.89)
Need satisfaction		
Autonomy satisfaction	13.5 (3.23)	13.2 (2.86)
Competence satisfaction	11.5 (4.40)	9.44 (3.13)
Relatedness satisfaction	11.0 (4.13)	11.6 (4.50)
Self-determined motivation	42.4 (25.0)	15.3 (24.8)

Table 6.5. Descriptive statistics of SDT variables for PocketMedic attendees and non-attendees.

Self-determined motivation to self-manage was found to be statistically significantly different between the two groups ($t(19) = 2.47, p < 0.05$). An accompanying effect size for this significant difference was also calculated ($g = 0.04$); where this this is less than a small effect (Cohen, 1988). No other variables were found to be statistically significant between those who did and did not attend PocketMedic.

A multiple regression analysis was also conducted to investigate if SDT variables could predict PocketMedic adherence. This analysis was only conducted with participants who watched one or more of the digital health films to control for any effects the included variables could have had on PocketMedic attendance. Need thwarting, need satisfaction, and self-determined motivation were inputted as predictor variables and the number of digital health films watched as the criterion variable.

After the elimination of non-contributory variables, a significant regression equation was found ($F(2, 15) = 4.77, p < 0.05$), with an adjusted R^2 of 31%. PocketMedic adherence was equal to a constant $- 0.42$ relatedness thwarting $+ 0.38$ autonomy satisfaction. However, both variables were narrowly non-statistically significant ($p = 0.06$ and 0.09 , respectively). This equation indicates that higher baseline relatedness thwarting negatively predicts the number of films a participant watched. Additionally, the role of autonomy satisfaction was in the expected direction and was positively correlated to PocketMedic adherence.

6.3.4 Hypothesis five

A multiple regression analysis was also conducted to investigate if SDT variables could predict PR adherence. The same predictor variables were used as hypothesis four and the criterion variable was PR adherence. After the elimination of non-contributory variables, a

significant regression equation was found ($F(2, 27) = 5.86, p < 0.05$), with an adjusted R^2 of 25%. PR adherence was equal to a constant + 0.29 autonomy thwarting + 0.54 autonomy satisfaction. Although the latter variable was a statistically significant predictor ($p < 0.05$), the former variable was not ($p > 0.05$). Autonomy satisfaction positively predicting PR adherence reflects a similar result within hypothesis four. Although non-significant, the positive relationship between baseline autonomy thwarting and PR adherence could also be explained by participants with greater thwarting actively engaging with an intervention to overcome this negative factor.

6.4 Discussion

The aim of this study was to fill several gaps in the literature described during the introduction (section 6.1), and answer the research question; *what effect do PR and PocketMedic have on SDT concepts, self-management motivation, and HRQoL in people with COPD?* This included investigating the effects of two healthcare interventions – prescribed independently and in combination – across multiple outcomes, in addition to directly comparing them. Lastly, the ability of SDT concepts to predict PocketMedic attendance and adherence and PR adherence was explored.

The analyses investigating hypothesis one (that the interventions would positively effect SDT variables and motivation to self-manage) found that PR and PocketMedic had significant positive effects on multiple SDT concepts. Motivation to self-manage COPD, competence and relatedness satisfaction, and autonomy and competence thwarting were all significantly improved by the two healthcare interventions in all three conditions. The possible effects of relatedness satisfaction in self-management interventions and competence and relatedness

satisfaction in PR programmes have previously been discussed (Baker & Fatoye, 2018; Rapport, et al., 2015). The results of this study corroborate these findings and highlight the need for future research to investigate the effect interventions have on psychological theory constructs. Indeed, there is a wealth of literature detailing the positive effects of PR (McCarthy, et al., 2015); however, the theoretical mechanisms by which these occur have largely been overlooked by previous research. Authors have suggested that such programmes have more of an effect on psychological factors in the short-term (Ratneswaran, et al., 2015); therefore, it is surprising that research has not focused on psychological concepts which could help explain the effectiveness of PR.

Previous interventions have been shown to increase basic psychological need satisfaction and self-determined motivation in multiple chronic conditions (Hagger & Chatzisarantis, 2015); therefore, although this research seldom uses a sample with COPD, it is not surprising to see increases in competence and relatedness satisfaction and self-management regulation. The definition of PR includes a statement that it should support the autonomy of participants (NICE, 2011) and PocketMedic was additionally designed with this aspect in mind, as suggested within the SDT model of health behaviour change (Ryan, et al., 2008). However, unexpectedly, autonomy satisfaction did not increase to a statistically significant degree; where Deci and Ryan (1985) have thoroughly described how the satisfaction of this need is crucial for more self-determined regulation. Whittaker, et al. (2018) found that autonomy was a salient psychological need throughout PR. Therefore, the findings of Whittaker et al. (2018) and the current study are antagonistic to one another. More research is needed to investigate the role of autonomy satisfaction within effective PR programmes and whether this need is more dependent on how the intervention is organised and conducted in different localities.

As described previously, the role of basic psychological need thwarting may be more prevalent in extrinsically motivated behaviours (Bartholomew, et al., 2011; Wortz, et al.,

2012); however, this has received little attention in the literature (Bartholomew, et al., 2011). This study has increased the knowledge on this topic and has demonstrated that two healthcare interventions can decrease autonomy and competence thwarting to a statistically significant degree. This is a particularly important finding because previous authors have described the thwarting effects of COPD and the negative consequences these have on HRQoL (Russell, et al., 2018; Wortz, et al., 2012). Additionally, the role of autonomy thwarting could help explain the unexpected inability of two interventions to increase autonomy satisfaction. Although both interventions can be defined as autonomy supportive, in people with COPD, this may have more of an effect at lowering the relatively high level of autonomy thwarting evident throughout the samples in the first and second research studies. Future research could investigate this possibility further, potentially using interviews to understand this phenomenon from the perspective of the participant. Due to the ability of the two healthcare interventions to positively affect self-determined motivation to self-manage and two of the three need satisfaction and need thwarting concepts, the first hypothesis was accepted.

Previous research has reported the positive effects of self-management interventions and PR on self-management knowledge, HRQoL, functional exercise capacity, and disease knowledge (Bringsvor, et al., 2018; McCarthy, et al., 2015; White, et al., 2006; Zwerink, et al., 2014). The results of this study corroborate this previous literature, which indicates the two healthcare interventions were effective, as defined by these commonly measured variables. This additionally increases the generalisability of the rest of the findings and the effect these interventions have on SDT concepts, as described above, can be assumed to be evident in other similar self-management interventions or PR programmes. The analysis aimed at testing the second hypothesis reported significant benefits in all measured variables between time-points, when the condition was held constant; therefore, this hypothesis was

also accepted. There were some conflicting statistics associated with the variable of disease-knowledge, with an original MANOVA in addition to post-hoc t-tests indicating no statistically significant differences between groups and an ANOVA reporting the reverse. However, the between group analysis of baseline variables did indicate a significant difference between the groups for this variable; where, participants in condition two had considerably lower levels than the other two conditions. Therefore, it is possible that the contradictory statistics could be as a result of this baseline difference.

The analyses used to investigate the first two hypotheses also had the ability to answer the third hypothesis (that the combination of interventions would improve measured variables compared to either prescribed independently). Results showed that there were no statistically significant differences between the three conditions and thus the hypothesis had to be rejected. This is an interesting finding to consider because the within group variable of time was significant, indicating that all three research conditions positively affected the aforementioned variables to a similar degree. Therefore, despite the positive results found when PocketMedic and PR were prescribed independently of one another, the combination of the two interventions did not have an accumulative effect. This would indicate that either there is a maximum level that these variables can be affected over a seven-week period, or the two interventions were similar to one another and the repetition was not beneficial. Although narrowly non-significant, the descriptive statistics for the sub-group analysis investigating the differences between research conditions for the variables of disease-specific HRQoL and self-management knowledge, did show a beneficial effect for the combination of interventions. Given that these differences were approaching statistical significance, it is important to consider the effect the low sample size had on the analysis. In any event, travel and transport in addition to a disruption in usual routine have been highlighted as barriers to PR adherence (Keating, et al., 2011). Therefore, the ability of a technology-delivered

intervention, which can overcome these barriers, to deliver significant benefits on par with PR could prove beneficial (Wooton, 2012). This is supported by one of the key principles of Prudent Healthcare being a reduction in geographical heterogeneity in the services provided (Drakeford, 2015); where, due to rurality and low staffing preventing PR being delivered fully across HDUHB, PocketMedic may be a viable, effective, and suitable alternative. A recent review into technology-delivered self-management interventions also showed positive results (Guo & Albright, 2017); however, future research would be needed to further assess the safety and effectiveness of PocketMedic.

Analyses were conducted to investigate if any of the SDT variables were statistically different between participants who did and did not attend PocketMedic. Results indicated that those with less self-determined motivation to self-manage were less likely to watch even one of the digital health films. This finding is unsurprising because previous research has described similar results in other health domains (Ng, et al., 2012); however, it is also unfortunate, because people with low self-management motivation is the precise group that would most likely gain the most from an intervention targeting that specific area. Previous research has found that the referring doctor's attitude toward PR has an impact on attendance and adherence (Keating, et al., 2011). Although the current research study cannot confirm whether this effect is also present for PocketMedic, if the digital health films were prescribed by a respiratory clinician – as opposed to a doctoral researcher – attendance may be increased.

The multiple regression analysis investigating SDT predictors on the number of PocketMedic films watched found a significant regression equation. A constant, alongside relatedness thwarting and autonomy satisfaction could predict 31% of the variance in the number of PocketMedic films watched. As described above, need thwarting may have more of an influence for extrinsically motivated behaviours (Bartholomew, et al., 2011); where, the

results from this analysis support this statement. Importantly, however, relatedness thwarting was one of the only basic psychological needs that was not significantly changed by any of the research conditions. Thus, the thwarting of this need currently represents a negative predictor of intervention adherence, in addition to a variable on which two well-structured interventions do not have an effect. Therefore, future research investigating the role of relatedness thwarting in people with COPD could lead to more positive interventions and increased treatment adherence. The fourth hypothesis can only partially be accepted, because although SDT concepts could predict PocketMedic attendance and adherence, relatively few significant predictors were actually identified. This supports previous research which describes the problem of attendance and adherence in people with COPD as multifaceted (Restrepo, et al., 2008). A similar analysis was used to investigate if baseline SDT concepts could predict PR adherence (hypothesis five). Autonomy satisfaction and autonomy thwarting could both positively predict a greater number of PR sessions. Like the PocketMedic adherence analysis, the ability of autonomy satisfaction to predict adherence was unsurprising and this has also been found in other health domains (Ng, et al., 2011). Although somewhat counterintuitive, the role of autonomy thwarting could be explained by participants who had this variable most thwarted at baseline being more likely to attend a programme in an attempt to overcome the thwarting effects. This conforms with previous literature which has found that participants are motivated to overcome the thwarting of autonomy providing that their need for competence is satisfied (Radel, et al., 2013). As previously stated, however, there is a sparsity of literature investigating the thwarting of the basic psychological needs (Bartholomew, et al., 2011) and more research is needed to fully understand the role of this concept in people with chronic conditions. Nevertheless, due to these findings the fifth hypothesis was partially accepted.

The flow diagram illustrating the number of participants at each stage of the research shows the lack of response demonstrated by individuals who were invited to PR. A recent UK review found that 31% of people invited to PR will not attend the assessment (Steiner, et al., 2015). However, in this research study 48% of people invited did not attend. HDUHB serves a wide, rural geographical area; where, only one out of its three counties regularly deliver PR. Therefore, given that travel and transport are both negative predictors of PR attendance and adherence (Keating, et al., 2011), this could explain the heightened non-attendance rate. The acceptance rate for the research was also relatively low and of the 199 individuals invited to participate, only 28% of them accepted. The response rate was even lower for condition two which used a postal consent process. Of the 100 initial invitation letters and the 95 reminder letters, only 7 people signed the consent form, representing less than a 4% response rate. This is significantly worse than the average of 20% reported widely in other studies utilising similar methods (Roberts, et al., 2002). Although several strategies were implemented to increase the acceptance rate across the three research conditions – such as a six-month extension – these did little to alleviate the issues. Other methods which have been shown to aid recruitment, such as first-contact or follow-up telephone calls (Edwards, et al., 2002; 2007), were not permitted by the REC. However, one of the justifications for conducting this research in people with COPD is that self-management motivation in this condition is poor, evidenced by low adherence to treatment (Bourbeau & Bartlett, 2008; Sheldon, et al., 2003). Therefore, although unfortunate, it is not exactly surprising that there were recruitment issues within this study, because such issues are also evident throughout other areas of care for people with COPD (Restrepo, et al., 2008).

In conclusion, this study demonstrates the ability of two healthcare interventions to significantly benefit SDT concepts, self-management motivation, and HRQoL in a population with COPD. The study begins to fill several gaps within current literature; where, to the

author's knowledge, no previous research has quantitatively examined the ability of these interventions to increase SDT concepts in people with COPD before. The novel investigation into this model has allowed further understanding into the role of SDT constructs during disease management programmes; especially the under-researched concept of need thwarting. The significant baseline need thwarting variables predicting attendance and adherence lends support to the need for further research examining their influence. The study also provides novel contributions relevant to the care of people with COPD; such as, the finding that although the interventions were effective separately, there were no cumulative benefits when the interventions were prescribed together. However, the lack of differences between the research groups does support the prescription of a technology-delivered, SDT-based, COPD self-management intervention; especially where environments prevent traditional programmes from functioning fully. Additionally, to the author's knowledge, the examination of a self-management intervention which brings together technology, SDT, and people with COPD, has not been previously conducted. Several questions, however, have not been fully answered and future research should investigate these areas further. For example, the effect autonomy-supportive interventions have on autonomy thwarting, the effects of PocketMedic when prescribed outside of traditional disease-management programmes, how the thwarting of relatedness can be overcome in people with COPD, and what are peoples' experiences of these two healthcare interventions.

Finally, this study made a positive contribution to the overarching aim of this thesis, by examining traditional and novel interventions a greater understanding of how to increase SDT concepts, self-management motivation, and HRQoL in people with COPD has started to be obtained. The next chapter describes the justification, methodology, and results for the third study; which explored the lived experiences of the people who received the two interventions

as part of the current study. The findings and conclusions from this study are discussed again, alongside those from the preceding and following research studies, within Chapter Eight.

Chapter Seven: How do people discuss their experiences of COPD and engaging with PR and PocketMedic?

7.1 Introduction

Chapter Six investigated the ability of two healthcare interventions to increase SDT concepts, motivation to self-manage, and HRQoL in people with COPD. Both PocketMedic and PR, prescribed independently and in combination, demonstrated an ability to positively effect these measured variables. The study concluded that SDT concepts could help explain the historical positive effects of self-management interventions and PR found by previous reviews (McCarthy, et al., 2015; Zwerink, et al., 2014). However, the study did leave questions unanswered, including how people with COPD experienced the two healthcare interventions.

Quantitative methodology can directly compare participants receiving different treatments and investigate the predictive power of variables (Howitt, 2010); however, qualitative methods can help understand social phenomena in natural settings; giving emphasis on the meanings, experiences, and views of the participant (Mays & Pope, 1995). Additionally, previous authors have attested to the use of qualitative methodology within a medical field to help further understanding and knowledge (Murphy, et al., 1998). Therefore, to build upon the results of the second study and respond to the questions it was unable to answer, qualitative methodology needed to be employed.

Research applying qualitative methodology to investigate the effectiveness of COPD self-management interventions have repeatedly reported the enthusiasm of participants during

programmes (Apps, et al., 2017; Baker & Fatoye, 2018). However, these studies and reviews have failed to make the connection between their findings and the psychological theories which could explain them. For example, Monninkhof, et al. (2004) found that participants valued the increase in autonomy and perceived exercise capacity, in addition to the social aspect of group training, during a multi-component, COPD self-management programme. However, the authors do not suggest the ability of SDT to provide further understanding to these results; where the concepts of autonomy, competence, and relatedness satisfaction, respectively, could explain their findings. Other authors have also reported results in which further understanding could be gained by the acknowledgement of the SDT concepts of autonomy (Baker & Fatoye, 2018), competence (Bourbeau, Nault, & Dang-Tan, 2004), and relatedness (Apps, et al., 2017; Baker & Fatoye, 2018). A recent review concluded that the psychosocial needs of people with COPD need to be considered (Russell, et al., 2018); therefore, where appropriate, the psychological literature needs to be drawn upon to fully understand and explain qualitative results.

Qualitative research has also been employed to investigate the experiences of participants attending PR. One study which holistically examined the experiences of PR participants, their significant others, and healthcare professions found enthusiasm, less anxiety, and an appreciation of their work by the three groups, respectively (Rapport, et al., 2015). Research upon PR has begun to utilise psychological theories to bring further understanding to their findings. For example, Whittaker, et al. (2018) applied SDT to people attending pulmonary and cardiac rehabilitation, concluding the most salient basic psychological needs at each stage of the programme. This study, however, only reported the satisfaction of the needs; where, given the level of thwarting displayed over the studies within this thesis, it is surprising that the thwarting of needs was not also present within the interviews. As a result,

the role of need thwarting remains uncertain (Bartholomew, et al., 2011; Olafsen, et al., 2016).

Although research has employed qualitative methodology to understand the experiences of participants who have received either a self-management intervention or PR, such methods have not been employed for participants who have received both interventions simultaneously. Admittedly, this could be as a result of few interventions prescribing such interventions in combination with one another in the first place. Nevertheless, this has left a gap in the literature where it is currently unknown as to how participants experience two healthcare interventions which are received simultaneously. Additionally, the studies described above have focused on the period during the intervention (Apps, et al., 2017; Baker & Fatoye, 2018; Rapport, et al., 2015) and therefore how participants experienced the time before or after remains unexplored.

To obtain a more thorough understanding of the two healthcare interventions which were prescribed in the previous study, qualitative methodology was employed to answer the research question: *How do people discuss their experiences of COPD and engaging with PR and PocketMedic?*

7.2 Method

7.2.1 Design

This study used qualitative methodology and semi-structured interviews with participants who received PocketMedic as part of their treatment described in Chapter Six. The interviews

ranged from 46 to 75 minutes in length. The strengths and weaknesses of this approach have been discussed in Chapter Four.

7.2.2 Participants

A purposive sample was originally planned to continue recruiting participants who received PocketMedic within Chapter Six, until data saturation had occurred (Fusch & Ness, 2015).

Sampling selection was designed to ensure representation from the two recruiting hospitals (Prince Philip and Glangwili), those who did and did not engage with the intervention, and both delivery systems of PocketMedic (web- and link-delivered). However, due to the low recruitment in Chapter Six, the current study had a limited sample universe from which to recruit.

Although 33 people indicated that they would like to be contacted with the opportunity to participate in an interview after the intervention had finished, only ten people consented when they were invited. Of these ten, only seven arranged a time and location for the interview to take place. For this reason, all participants who consented and arranged an interview were included in this study.

Table 7.1 shows key demographical information for the seven participants. Six of the participants received PocketMedic alongside PR (web-delivered), and one received PocketMedic only (link-delivered). Despite including everyone who consented and arranged an interview, the sample included a good representation from the two hospitals, delivery method, PocketMedic adherence, age, and gender. Therefore, this study possessed the ability to gain a meaningful understanding of a range of participants' experiences.

Participant indicator	PR location	PocketMedic delivery method	Number of films watched	Age (years)	Gender
RC	GGH	Web-delivered	5	63	Female
MJ	GGH	Web-delivered	0	69	Male
RR	GGH	Web-delivered	4	57	Female
AB	GGH	Web-delivered	10	58	Male
FS	PPH	Web-delivered	3	69	Female
KT	PPH	Web-delivered	8	70	Female
PM	N/A	Link-delivered	10	76	Male

Table 7.1. Demographics of Chapter Seven participants.

7.2.3 Procedure

During the consenting process of Chapter Six, participants were asked to indicate whether they would like to be given more information about future research relating to PocketMedic and PR.

Participants who had received PocketMedic in Chapter Six and who indicated consent to be contacted were sent a further study invitation letter (Appendix 20:). This letter was sent alongside a PIS (Appendix 21:), a consent form (Appendix 22:), the follow-up questionnaires described in Chapter Six, and a prepaid return envelope. All study documentation is presented within the appendix. Participants with questions were encouraged to call the researcher. If willing, participants were asked to fully initial and sign the consent form, provide a contact telephone number, and return this with the follow-up questionnaire in the prepaid envelope.

Once this had been received the researcher contacted the participant to arrange a mutually beneficial date, time, and location for the interview to take place. As payment or reimbursement was not able to be provided in exchange for participation, the researcher took care to be as flexible as possible to the participants' availability. Interviews either took place within the Clinical Research Centre in Prince Philip Hospital or at the participants' homes. In the latter case, HDUHB lone worker policies were followed to ensure the researcher's safety. Two Dictaphones were used to record all the interviews.

At the beginning of the interview, participants were provided with a copy of the signed consent form for their own records and reminded that they could pause or stop the interview at any time if they wished. At the end of the interview, they were thanked for their time and reminded of their right to withdraw by contacting the researcher. In such an event, their data would be removed from the analysis.

7.2.4 Data collection

Individual semi-structured interviews were conducted with each participant. The strengths and limitations of these methods have been discussed previously in Chapter Four, section 4.4.

The interview schedule (see Appendix 23:) was created following a review of relevant literature (see Chapter Two). This was separated into four interrelated sections; beginning with an introductory section, and then dividing questions into groups relating to before, during, and after the two healthcare interventions.

The inclusion of an introductory section was to help foster a positive relationship with the participant. This method is supported by Spradley's (1979) model of interviewer-interviewee rapport (see Chapter Four, section 4.4.1) and helps progress through the apprehension and

exploration stages. This process was further aided by the fact the researcher had previously met most of the participants during the recruitment process of Chapter Six. Thus, the stages of cooperation and participation could be achieved more quickly. This section also asked the participant to describe their feelings at the time of their diagnosis of COPD. This question was included to give participants the opportunity to discuss how they were diagnosed and their initial feelings and perceptions of this diagnosis. Chapters Five and Six had both quantitatively shown the thwarting effects COPD had on the basic psychological needs, and the current study could qualitatively investigate this topic further and provide a greater understanding of these results.

The second section focused on asking questions relating to the time before attending PR and/or PocketMedic. This section featured predominantly descriptive questions to ascertain the participants' understanding of COPD, whether and how they self-managed their condition, and how they were first referred to PR. As described within the introduction, previous literature which has employed qualitative methodology has primarily focused on the experiences of participants during an intervention. Therefore, these questions were included to gain an understanding of the experiences and views of participants before they had received any major healthcare intervention. Additionally, because these questions were focused upon a period which was quantitatively investigated within Chapter Five, answers could provide greater understanding for the results from this study. For example, the novel findings regarding the role of need thwarting variables could be discussed by participants to get a more rounded interpretation surrounding this topic.

The third section included questions about the experience of PR and/or PocketMedic. Questions focused on participants' overall feelings towards PocketMedic, with specific prompts on what they liked and disliked. Other questions were included to ascertain the participants' viewing habits, including at what time and with whom they watched the films.

These were included to investigate whether participants used the ability to engage with PocketMedic at a time and place that they chose; alongside views on how PocketMedic delivered information and whether this was useful. Questions relating to PR were also incorporated into the interview schedule to gain a similar understanding of how participants engaged and experienced this intervention in addition to PocketMedic. Given the non-accumulative quantitative effects when the interventions were jointly prescribed described in Chapter Six, answers to these questions could provide an explanation for these findings from a participant's point of view.

The final section focused on the time after the two interventions had concluded and asked questions relating to how participants had been experiencing the need for continued self-management. Questions in this section were personalised to the participant; for example, if they had indicated that they had begun to self-manage during the interventions, they would be asked if they thought they would continue these techniques. Participants were also questioned regarding their current level of social support, as the role of relatedness thwarting has been highlighted in Chapters Five and Six. All the interviews were concluded by asking participants to sum up the entirety of their experiences with COPD into three phrases or sentences and were then invited to add anything that they felt had not been included in the interview. This enabled participants to highlight what they felt were the most important aspects of their COPD journey and add further explanation of their feelings if necessary.

For participant PM, questions relating to his experiences of PR were omitted due to this service not being available within the region where he lived.

7.2.5 Data analysis

All seven interviews were transcribed using the play script method which provides an account of what the participant spoke rather than being unnecessarily filtered by the person transcribing (Oliver, Serovich, & Mason, 2005). A verbatim account of the interview was produced for each, with line numberings and symbols denoting important expressions of emotion, such as laughter, added. Each interviewee was given a pseudonym to maintain their anonymity, and where locations of their homes, or any other identifiable information were discussed during the interview, these were removed during transcription to ensure anonymity.

Although an inductive thematic procedure was originally planned to analyse the interviews – which does not actively try to fit themes to pre-specified theories – themes were interpreted and contextualised according to current literature on SDT. Thus, whilst the initial coding remained data-driven, the analysis adopted a more theoretically driven approach. This allowed the study to actively test SDT and explore if participants experienced the two healthcare interventions in terms of theory constructs. Other authors have adopted similar methods within a health context (Bell, Deighton-Smith, & Hurst, 2019).

Latent, as opposed to semantic, themes were focused upon during the analysis in an aim to identify underlying ideas, assumptions, and conceptualisations (Braun & Clarke, 2006). A particular strength of thematic analysis is that it does not rely on a particular philosophical underpinning (Braun & Clarke, 2006) and thus can be conducted without violating the epistemological or ontological assumptions of the previous two quantitative research studies or subtle realism.

The main processes in thematic analysis are transcription, analytical effort, and theme identification (Howitt & Cramer, 2008); however, this process is not necessarily linear and

often researchers perform these processes simultaneously (Howitt, 2010). Indeed, after identifying themes, it is advisable for a researcher to review their transcriptions to investigate how well these themes fit the data (Braun & Clark, 2006; Howitt, 2010). Authors conducting a thematic analysis have previously been criticised for not providing a thorough account of how they implemented this method (Attride-Stirling, 2001, Howitt, 2010). Therefore, in an aim to provide a good scientific account and avoid this criticism, alongside Howitt and Cramer's (2008) generic processes, the six phases of thematic analysis were also followed (Braun & Clarke, 2006). These phases are presented in Table 7.2.

Phase	Description of the process
Familiarising yourself with your data	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.
Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
Reviewing themes	Checking the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Table 7.2. Braun and Clarke (2006) – Steps to completing a thematic analysis.

As detailed above, the researcher transcribed all the interviews and thus data familiarisation begun immediately. Following this, transcripts were reread, initial ideas noted, and then further developed into initial codes; thus, organising the data into meaningful groups (Tuckett, 2005).

Progressing to phase three, potential themes were identified and the relationships between these patterns explored. These themes were conceptualised through SDT concepts through the deductive approach, however, these groupings were still reworked multiple times to ensure that they represented the best true fit to the data possible. As encouraged by Braun and Clarke (2006), codes and themes directly corresponding with interview questions or the four interrelated sections of the interview schedule were avoided. A list of possible themes was created as a result of this phase.

This list of themes was then considered collectively, and a process of refinement begun. All themes had their internal homogeneity and external heterogeneity judged to ensure all codes cohered to one another in each theme but were suitably different to data represented within other themes (Patton, 1990). All transcripts were again reread to ensure that the produced list of themes effectively reflected the discourse throughout all the interviews. As per phase five, themes were named and defined according to concepts and terminology evident in SDT and the final analysis is presented in the findings below. Phase six occurred simultaneously and compelling codes were chosen that effectively describe each theme and the story of all the interviews. All overarching and subthemes, alongside extracts and codes, are presented in the thematic tables in Appendix 24:.

7.3 Analysis and discussion

Using a deductive thematic analysis, two prominent overarching themes were found within the interviews. These were labelled *experiencing and adapting to psychological need thwarting* and *facilitating basic psychological need satisfaction*. The former overarching theme comprised of the sub-themes: *COPD thwarting the basic psychological needs*, *controlling environments pre-intervention*, and *recalibrating psychological need thwarting*. The latter overarching theme comprised of the sub-themes: *supporting agency and homonomy*, and *redefining challenge*.

7.3.1 Experiencing and adapting to psychological need thwarting

The thwarting of the basic psychological needs became a central theme throughout the interviews and many participants described how COPD was restricting their ability to be a causal agent within their environment, effective in their environment, and fully relate to other individuals. The healthcare services were also perceived as not being as supportive of the needs for autonomy and competence as participants thought they could be; however, their discussions regarding PR and PocketMedic reflected an antonymic point of view. Lastly, participants described how they physically employed methods to overcome situations where their needs were being thwarted. Figure 7.1 illustrates the formation of this theme.

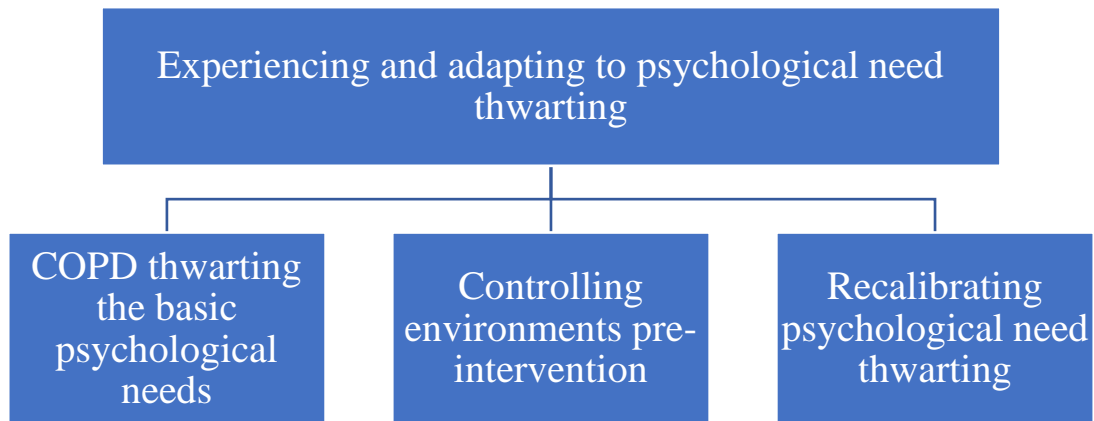


Figure 7.1. Experiencing and adapting to psychological need thwarting.

7.3.1.1 COPD thwarting the basic psychological needs

Within this sub-theme, participants discussed how COPD was actively obstructing their ability to engage with activities, feel effective in their environment, and fully relate to others. The complex interaction between autonomy and competence needs were evident in this theme. The physical decline in lung function negatively influenced their ability to engage in tasks, emphasising the thwarting of competence, but equally this thwarted their need for autonomy through limiting their volitional control over the activities with which they could engage.

For the thwarting of autonomy, this would often manifest in activities which were previously taken for granted, becoming either out of their control or a foreign entity altogether.

“My mother was ill in hospital, and she lived down on the south coast, and she had pneumonia and daren’t go near because of what I had, so I never even got a chance to say goodbye to my mum, and that was like a really hard thing for me to accept”. RC, line 96.

Approximately 80% of exacerbations are caused by infections (Senthil, 2000) and as a result many people with COPD avoid situations where they may be more at risk. This concern appeared to affect their ability to engage in activities they would normally be able, and would be wanting, to engage with. This restriction on their abilities to engage in tasks often resulted in frustrations or resentment in relation to the resulting negative outcomes. For others the autonomy thwarting was less to do with the environmental choices available, but perceived control of their own physicality; such as losing control of their breathing. The quote “getting my breathing under control”, or similar, was discussed multiple times by five of the seven participants. These quotes show how the participants felt COPD had undermined the perceived autonomy they had in relation to the volitional control of their own physical health. Participants also discussed how even after they had received PR and PocketMedic they still felt this need was being thwarted, despite some improvements. This active barrier to a basic psychological need caused several of the participants anguish.

*“I’m working nights but I do find I get a bit tired during the day so that’s given me some limitations. One time, I used to keep myself reasonably fit, I used to go walking for miles, and out on a bike, but basically I can’t do it now. So fully-fledged temper tantrums *laughs*”.*

AB, line 20.

This quote demonstrates how the thwarting of their volitional actions to participate in the activities they once previously enjoyed resulted in feelings of frustration. Although behaviours are often initiated by a request from a significant other within extrinsically motivated activities (Ryan, et al., 1994), to fully integrate behaviour, an element of self-determination is required (Sheldon, et al., 2003). Therefore, the need for autonomy being thwarted, particularly in relation to their engagement with usual activities and control of their own physical health, is likely to have undermined the internalisation process to engage with

interventions such as PR; where, regaining control of breathing and physical activity are key components.

Participants also described active thwarting of competence needs described through the gradual decline in their abilities. In the initial stages of diagnoses, individuals saw less evident changes to their physical abilities despite the knowledge that their condition was relatively severe.

“within the first two or three years nothing really changed very greatly, from being told I only have 42, 43% lung function, nothing really changed really greatly. I could still do most things, maybe a bit slower, maybe having to stop a little more frequently”. RC, line 90.

However, this gradual deterioration in their condition became actively thwarting of their competence needs, when engagement in previous activities created a realisation that they were no longer able to perform to the same functional ability.

*“it was distressing when I got to hills. When I knew I could do things, I thought I could do things. But when I would do them, *pants heavily* I was out of breath. That was the only time I thought like it had got me you know”. MJ, line 65.*

This quote from MJ describes his moment of realisation that the condition had stopped him from taking part in an activity which he used to find easy. This is something which is mentioned by most of the other participants and one interpretation is that due to the *slow* loss of ability, this moment of realisation was one of surprise. The result is a sudden undermining of perceived competence and through this now thwarted need, the participants suffered from lower wellbeing and distress in situations that brought this realisation home. The gradual onset of symptoms could explain the low adherence and poor self-management in people with COPD (Bourbeau & Bartlett, 2008). As the participants described that nothing overtly changed in their lives immediately after diagnosis, they could perceive the need to engage

with self-management behaviours as unnecessary or lacking in urgency. Subsequently, later in the progression of COPD, the distress from the sudden realisation of their inability to conduct an activity, could make engaging with a behaviour such as physical exercise be perceived as unsafe (Jones, et al., 2012). Previous research has identified fear of increased dyspnoea as a barrier to PR attendance (Harris, et al., 2008) and this could also be interpreted as COPD thwarting the need for competence, resulting in the decreased likelihood of engaging in a behaviour (Deci & Ryan, 1985). Authors suggest that a lack of perceived competence to conduct a behaviour which is inherently not enjoyable (i.e. extrinsically motivated), could result in an individual avoiding the behaviour altogether (Deci & Ryan, 2002). Therefore, the thwarting of competence by COPD could explain why self-management behaviours, even ones which do not increase dyspnoea, are not performed. Previous research has described how individuals can become motivated to overcome the thwarting of autonomy, but only in situations where their need for competence is satisfied (Radel, et al., 2013). Given that participants describe how both these needs are thwarted, this could explain why people with COPD struggle to overcome the effects of their condition and do not engage in self-management behaviours; suggesting that future interventions should consider the role of competence needs.

The quotes within this subtheme can also be described by general adaptation syndrome (GAS; Selye, 1950). This theory posits that when a stressful stimulus is encountered an alarm reaction stage is triggered. This could be represented in the above quotes when the participants were surprised that they no longer possessed the ability to engage in certain activities. The next stage is the called resistance and is where the body tries to reverse some of the physiological mechanisms which were triggered within the first stage. However, if the stressful stimulus has not been overcome, an individual can become irritable (Selye, 1950). This can be shown by the quote provided by AB who becomes distressed at the new lack of

abilities. Exhaustion is the final stage, where, in situations of prolonged exposure to stressful stimuli, the body depletes its resources which can cause depression, anxiety, and an inability to cope. Such outcomes have been described as common in people with COPD previously (Jones, et al., 2012). Research linking GAS to SDT has shown that autonomy restorative activities are engaged with in the alarm stage, however, if the thwarting stimuli is not overcome (i.e. prolonged exposure and progression to the exhaustion stage), individuals are likely to disengage with the behaviour (Radel, Pelletier, Sarrazin, & Milyavskaya, 2011). This could help why in some situations people with COPD are motivated to self-manage and overcome the thwarting effects of the condition, however, in others disengage with helpful behaviours.

Participants discussed how friends, family, and the general public didn't understand how COPD affected them, resulting in their basic psychological need of relatedness being thwarted.

“I was with the kids and they'd say there is nothing wrong with you, I used to go for a walk with them. You try going up a hill with COPD. They'd say you're really unfit. I'd say no I'm fit, but my lungs. I couldn't do it...I told my girls listen, I'm not unfit I have COPD, my lungs are unfit, you go on walks and they take the dogs, 3 or 4 miles. But I can't do the hills anymore”. RR, line 57.

RR described how she disliked being labelled as physically unfit and felt that it was unjustified given her respiratory condition. Additionally, participants felt that they either physically couldn't join others due to their condition – as illustrated by RR – or were psychologically reluctant to be in a situation where COPD thwarted their ability to relate to others in the same environment.

“I couldn’t imagine going to gym, I’m not a swimmer. I hate water. Apart from the wailing, I couldn’t go to a gym because they’d all be looking at me after five minutes when I’m wheezing and coughing because I can’t get my breath”. RC, line 253.

Relatedness has been identified as the core need during behavioural initiation of extrinsically motivated behaviours such as self-management (Deci & Ryan, 2002; Wortz, et al., 2012).

Therefore, the findings that participants perceive this basic psychological need to be thwarted could explain why self-management behaviours are not conducted within this population (Bourbeau & Bartlett, 2008).

Additionally, this last quote fully illustrates how the thwarting of the three psychological needs are interconnected and how this was described throughout most of the interviews.

Dyspnoea and coughing are common symptoms of COPD (WHO) and this was described above as a thwarting stimulus for the need of competence. The resulting influence this had on the thwarting of autonomy and relatedness is demonstrated in the quotes by AB, who can no longer engage in the physical activities he used to enjoy, and RC, who disliked the idea of being looked at whilst breathless at the gym, respectively. Research has found that the satisfaction of the three basic psychological needs are strongly correlated with one another (Ntoumanis, 2005; Standage, et al., 2005). The findings within this sub-theme help to illustrate the way in which the three psychological needs are interconnected through their influence on outcome behaviours and overlapping influences and implications. Lastly, past literature has found that the low satisfaction of the basic needs is linked with lower wellbeing and greater depression and anxiety (Kasser, & Ryan, 1999; Sheldon, et al., 2000). Although need thwarting is not necessarily equivalent to need dissatisfaction (Bartholomew, et al., 2011), the thwarting of autonomy, competence, and relatedness discussed throughout the interviews could explain the low HRQoL (Russell, et al., 2018) and high rates of anxiety and depression (Schane, et al., 2008) observed in people with COPD.

7.3.1.2 Controlling environments pre-intervention

Several authors and policies have described the need for healthcare to adopt a partnership model between clinicians and patients, to allow the latter to be involved in their own care and promote engagement (Drakeford, 2015; Coulter, et al., 2013; Goodwin, et al., 2012). From a SDT perspective, the recommendation to move toward a more autonomy-supportive model of care is backed by a wealth of evidence, which describes the relationships between such a model and various positive health outcomes; including HRQoL and behaviours pertinent to COPD self-management (Deci, et al., 1994; Ng, et al., 2012; Ryan, et al., 2008; Williams, et al., 1998; 2006). However, during the interviews, participants discussed how they did not perceive healthcare to be as autonomy-supportive as they believed it could be. When asked how the conversation with the doctor who referred them to PR went, one participant replied:

“Yeah pretty well I think, he didn’t say that much, they don’t have time to tell you. You know a nurse does most of it but she pretty much says blow in this, blow in that and when there is something wrong she’ll go round and see the doctor and get more medication for you. Or a different medication.”. MJ, line 90.

MJ discusses how during a healthcare appointment he had little option but to follow the nurse’s instructions and didn’t receive much information regarding PR. This is unlikely to support the participants’ needs for autonomy or competence and therefore could result in a decreased likelihood of attendance at the programme (Deci & Ryan, 2002). Throughout the interviews, participants felt there was little ability for them to satisfy their need for autonomy during these appointments. A similar description is offered by another participant:

“...you went along, you saw your doctor, you got your medication and that was that...I suffer with blood pressure where they’ve been messing around my tablets ever since I started rehab

trying to get that right. So, I never really thought about [COPD] being ‘managed’ in any particular terms, like you got your medication and that was that and you’d jump through hoops as you were told to turn up for appointments”. RC, line 80.

Similar to the quote from MJ, RC illustrated how participants perceived that their ability to experience agency has been inhibited by the healthcare services and that they have to take medication or attend appointments as instructed. This suggests that although healthcare services are adopting strategies to become more autonomy-supportive, participants are not perceiving an increase in their autonomy but rather a thwarting of it. The negative impact that this has on the participants is illustrated in the quote below.

“That’s what they don’t do see, they assume they’ve got all the answers to your illness without you having to come there, so why bother?” PM, line 89.

In extrinsically motivated behaviours, the perceived locus of control can have an influence on the level of internalisation toward a behaviour (Sheldon, et al., 2003). Therefore, as illustrated above, although likely unintended, the perception of a non-autonomy-supportive healthcare service is likely to have a negative effect on participants’ psychological need satisfaction and motivation to attend appointments or engage with interventions (Deci & Ryan, 1985). This could help to explain the findings that for every 100 people referred to PR, 41 of them either do not attend the original assessment or do not enrol in the programme (Steiner, et al., 2015; 2016). Deci and Ryan (2002) explain that autonomy is not a synonym of independence; thus, healthcare appointments have the potential to be perceived as autonomy-supportive, even whilst prescribing medication which have strict dosing schedules. An individual can perceive a highly dependent behaviour as autonomous, providing that the values of this behaviour are congruent with their own (Ryan & Deci, 2000b). Therefore, healthcare services should clearly illustrate why they are prescribing medication or requesting appointments, alongside

providing greater opportunity for decision making; for example, by giving individuals a choice of inhaler (but not the medication dispensed) or the time and date of their appointment. Through these methods, the perception of the autonomy-supportive environments that the healthcare system provide could be increased and through this, greater HRQoL, attendance, and self-management (Ng, et al., 2012; Ryan, et al., 2008; Williams, et al., 2006).

Participants also described how they were given very little information when they were diagnosed. This, combined with the gradual loss of ability, resulted in greater distress and, for some participants, anger.

“yeah it was the sort of feeling about going into the unknown because obviously you were feeling a little unsure and so forth there. But you sort of curtailed frustration basically and into the unknown. Because at the time it was basically ‘get on with it’. ‘You have COPD, get on with it, alter your life cycle’, well what am I meant to do basically? I think it rammed home, my dog died basically so I was digging a hole and I failed to dig the hole. So you know, fully fledged temper tantrum, what the hell was going on?”. AB, line 44.

AB described how he was told to change his lifestyle but felt that he had been given little support to help him make this change. Before PR and PocketMedic, participants repeatedly discussed how they perceived they didn’t possess enough knowledge regarding COPD, and this thwarted their competence to self-manage their condition. The lasting impact this original lack of knowledge exerts on the health of people with COPD is evident in this next quote:

“I think nobody had actually explained to me that certainly with doing things and exercising that it’s normal to get out of breath whether you’re suffering from lung function problems or not. And because of my lung function I found myself stopping doing certain things, I was thinking ‘this isn’t good’ when I was breathing hard and if I was told that I could perhaps

push myself more than I had been, I wish I had been told this five years ago. You know, in the first year of having it, it might have caused me to not lose quite so much lung function had I been told at the outset". RC, line 65.

Here, RC described how being given little information resulted in her stopping activities when she became breathless. Although already a negative outcome, the relationship between dyspnoea and increased inactivity has been identified as one explanation for the discontinuation of behaviours, such as physical exercise, in people with COPD (Donaldson, Maddocks, Martolini, Polkey, & Man, 2012). This quote also illustrated how the participants did not feel able to push themselves. One conclusion that could be drawn from this is that a lack of knowledge thwarted the need for competence and thus self-determined motivation to persevere whilst exercising (Deci & Ryan, 1995). As described previously, lacking competence satisfaction also stops an individuals' ability to overcome autonomy thwarting effects (Radel, et al., 2013); therefore, the lack of information at diagnosis could have long and far-reaching implications. The resulting feeling is one of regret at the loss of abilities that could have potentially been avoided with the timely implementation of educational support.

7.3.1.3 Recalibrating psychological need thwarting

Within this sub-theme participants talked about how PR and PocketMedic helped them to overcome the thwarting effects of COPD and enable them to regain some agency and effectiveness in their daily lives. When asked how she found managing her symptoms, one of the participants responded:

“well until I did the rehab’ I didn’t manage it very well at all. But from the rehab’ on, first rehab’, learnt how to breathe how to control and it put me back in the driving seat. Made such a difference just knowing how to. The one thing it taught me was ‘look, you’re not that ill, you’re still living, you can get up and do things’ you know? It was like a tonic really, it made such a difference”. FS, line 44.

Both Jones, et al. (2012) and Russell, et al. (2018) describe the losses and limitations to the lifestyles of people with COPD; however, FS demonstrated here the ability of PR to give her back some of the agency that was lost. Most of the participants discussed how they felt they had lost control of their breathing, and thus, the ability of PR to educate and support them to the point that gave them back control was one of the key features underlying the positive effect of PR for participants. Participants described how regaining agency made them realise that there was life after COPD and to appreciate the tangible benefits that could be realised through effective self-management. PR as a motivating factor to engage in behaviours which participants thought were lost to them, was a topic discussed within most of the interviews and one interpretation could be that the removal of the autonomy thwarting effects has additionally increased the satisfaction of their competence to participate in other activities. Several authors have described the relationships between the satisfaction of the three psychological needs (Ntoumanis, 2005; Standage, et al., 2005) and the first sub-theme also discusses how the thwarting of the three needs may have similar relationships. Here, however, participants seem to describe the relationship between the thwarting of autonomy and the satisfaction of competence; thus, suggesting that there is a link between the undermining and facilitation of these needs. Previous research has also described how autonomy thwarting may be overcome if the need for competence is satisfied (Radel, et al., 2013). This study concurs and furthers Radel, et al. (2013), by suggesting that people can overcome autonomy thwarting stimuli even if their competence is initially low. Although

individuals may initially disengage with such a situation, when the needs are necessarily satisfied the same individuals can reengage and attempt to overcome the autonomy thwarting effects. In combination with the earlier discussion on GAS (Selye 1950), this finding could suggest that, even when exhausted, people can overcome the stressful stimuli when they have the necessary requirements.

In addition to PR helping participants overcome the thwarting of autonomy, the programme also enabled them to regain a lot of the abilities that were lost as a result of their COPD. Although several of the participants also found PocketMedic beneficial, this was often overshadowed by the effectiveness of PR.

“Because I had stopped walking and I drove, if we were going to [welsh city] [my husband] would drop me by the shop and he’d go to park the car and I’d meet him by the café. I wouldn’t walk. Or if I went up on the train I’d get off and then take a taxi to the shop when you can see it from the station, I wouldn’t walk. And [the PR occupational therapist] told me that if I don’t walk I won’t be able to walk. So she said you’ll just have to do 100 yards one night, well 50 or 100, and I did exactly what she said and I am walking a lot better. I learnt so much to be honest and I think that was on one of the films but it was [the PR staff] who emphasised it”. KT, line 128.

This is one of many positive quotes which described the benefits of PR and the effectiveness of the staff because of their ability to help participants overcome the competence thwarting effects of COPD. Previous research has also reported the positive opinions PR participants had towards staff members (Rapport, et al., 2015) and how this can promote PR adherence (Halding, et al., 2010).

The beginning of this quote describes the thwarting effects of COPD on KT’s abilities to walk and as a result of her low competence she avoided walking altogether. As KT describes,

the PR staff and the films both gave information on how this avoidance will further compound the problem; however, it was the PR staff who made KT see the benefits of walking and stopping the avoidance of the behaviour. As described previously, the lack of self-management knowledge was perceived to be a thwarting factor and therefore, as both interventions provided this information, participants should have felt that both decreased the amount of thwarting relatively equally. This could be interpreted as the PR staff helping participants overcome the thwarting of COPD by providing information and although education was provided through PocketMedic, this was not perceived as beneficial by participants. There is a sparsity of literature which could explain why participants perceived PR had more of an effect at decreasing the thwarting of competence compared to PocketMedic. Rapport, et al. (2015) described how PR increased participants' confidence. Although the authors did not consider their findings through the utilisation of a framework for a psychological theory, the concept of confidence could be considered conceptually similar to competence. Therefore, it is possible that PR increased participants' competence satisfaction which enabled them to overcome the thwarting effects of COPD; whereas, PocketMedic may not have accomplished this as effectively. Other authors have found the satisfaction of the needs for autonomy and competence are prevalent during PR (Whittaker, et al., 2018); however, these authors, and the wider literature, fail to investigate the role of the thwarting of these needs (Bartholomew, et al., 2011; Olafsen, et al., 2016). Throughout the interviews, participants considered that their competence was synonymous with their physical abilities, and previous research has reported the positive effects of PR to increase exercise capacity (McCarthy, et al., 2015). Therefore, another interpretation could be that due to PR combining both self-management knowledge and supervised exercise (Wagg, 2012), these two components in combination helped decrease the thwarting of competence, compared to PocketMedic which provided the information only.

In addition to the interventions decreasing the thwarting of autonomy and competence, participants employed physical solutions to overcome the thwarting of their basic psychological needs. Some of these solutions were physical changes they made to their environment or daily routines, which enabled them to reduce, or avoid, the number of situations in which they perceived their needs to be thwarted.

*“The only thing I struggle with is changing the beds and hoovering as it’s a massive struggle...I can’t I struggle to hoover so I put laminate flooring down. I can cope with that
laughs I’m doing it that way”. RR, line 200.*

This quote is just one example of the simple yet effective methods the participants employed to overcome some of the thwarting effects of COPD. With the apparent acknowledgement that the thwarting effects of COPD were not necessarily going to go away, participants discussed ways in which they were identifying physical solutions or modifications to circumvent the thwarting of competency.

“I had a nice garden then, I could dig without any problem at all, as soon as I had [COPD] I knew I had to change the whole garden to suit an elderly person, that’s me okay, that’s what I’ve done. So there’s hardly any work to do here unless it’s with a power washer or paint brush. And all the flower beds are at waist level”. PM, line 70.

In a similar vein to the quote above, here PM described how he has limited the amount of physical work that is needed in the garden and modified the nature of maintenance required so that the work required is easier to conduct. This change was as a result of knowing that COPD would thwart his physical abilities and competence to maintain his garden. Thus, in previous themes individuals discussed how prior to interventions like PR their competence was thwarted through a realisation of their inability to perform activities. In turn, this thwarting of competence needs contributed to a thwarted of autonomy through a lack of

volitional choice to engage in activities that they enjoyed or valued. Here we can see that post PR, individuals no longer experienced this knock-on effect between the two needs. Whilst acknowledging that competence needs remained thwarted, they had identified ways to ensure that this no longer reduced their feelings of choice. Instead, the modifications helped to ensure that those choices remained available to them in modified ways. Whereas previous research has found that individuals can become motivated to satisfy their needs in situations where they are unsatisfied (Sheldon & Gunz, 2009) and overcome autonomy thwarting (Radel, et al., 2013), this study provides support for the possibility that individuals can become motivated to overcome competence thwarting through the adaptation of the activity or environment and ensure their competence is satisfied. This is interesting to consider in combination with GAS (Selye, 1950), as the finding suggests that even when individuals are in the later stages of the model as they have not overcome a thwarting stimulus, a simple modification to an environment can help rectify suboptimal levels of needs and lower stress. Whereas the other quotes demonstrate the physical adaptations to the environment, this extract illustrates how participants would either modify their routines, or think ahead, in order to reduce the number of times they would have to conduct an activity in which their needs were thwarted.

*“I normally have my shower and dress, because I don’t come down in the morning until I’m dressed. Because if I’m to go back up [the stairs] *laughs*. So that’s something I’ve learnt to do as well is to pace myself if you like and try and think ahead so when I do come down in the morning having showered and I’ve probably cleaned the bathroom as well before I come down and I bring the washing down as well so I don’t have to go up [the stairs] for a few hours”. FS, line 163.*

Stairs were often described within the interviews as a barrier and an additional two participants moved into a bungalow to avoid having to use stairs daily. Previous research has described how low need satisfaction or high need thwarting can result in the avoidance of a behaviour (Deci & Ryan, 1985; 2002; Sheldon, et al., 2003). However, this demonstrates the ingenuity of people with COPD to avoid their psychological thwarting, by employing changes to their physical environment or routines. Although reducing the thwarting effects of COPD would likely have more of a positive influence on HRQoL, these practical measures could be an effective method to reduce the negative influence of need thwarting (Bartholomew, et al., 2011).

7.3.2 Facilitating basic psychological need satisfaction

In addition to participants discussing how COPD thwarted their basic psychological needs, they also described how the health interventions helped the satisfaction of these needs. Specifically, participants talked about how being able to engage with PocketMedic when they chose supported their ability to be causal agents within their environment and how meeting other people during PR was an important positive of the programme. Participants also described how improved relatedness satisfaction made them feel more confident in situations which had previously made them feel self-conscious or embarrassed. Another outcome from the two interventions was the participants accepting that their abilities were permanently reduced as a result of COPD. Rather than this being perceived negatively, their competence satisfaction seemed to be benefited, due to participants redefining what challenged them; where, before the interventions, they would compare and unfairly judge their current abilities with their past selves. The overarching and sub-themes are visually displayed in Figure 7.2.

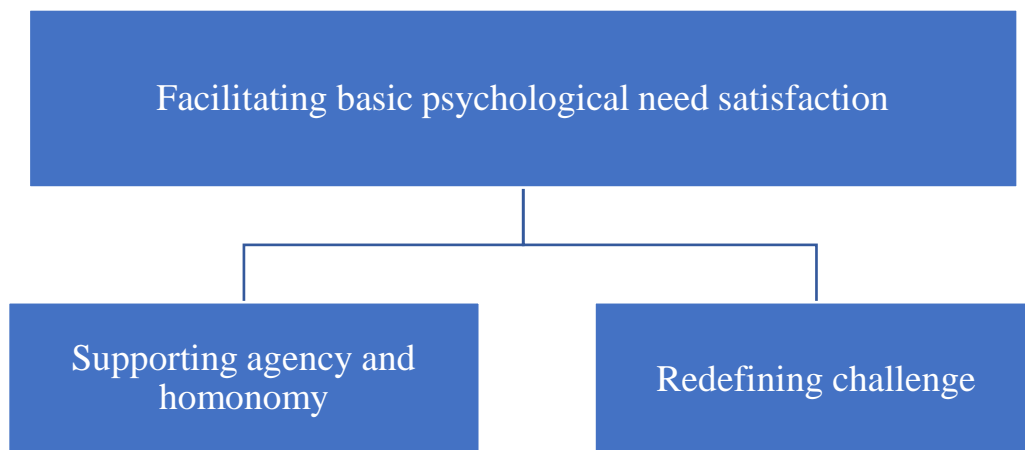


Figure 7.2. Facilitating basic psychological need satisfaction.

7.3.2.1 Supporting agency and homonomy

Within this sub-theme, participants discussed how their needs for autonomy and relatedness were supported by PocketMedic and PR, respectively. For the former need, the flexibility that the technology-delivered intervention provided facilitated this satisfaction.

“Sometimes I’d go through emails and see there was a new film available so I’d want to have time to watch this properly. Normally with my emails I’d be going through either deleting or quickly replying to things so if I saw an email from the films I may not watch it for a day or two. So I’d have time to sit down and actually be able to digest what I was watching. And then occasionally I would go back to it if I thought I’d missed something or I got disturbed I’d go back then”. RC, line 161.

RC describes how PocketMedic enabled her the choice to decide when and where to engage with the intervention, in addition to stop or re-watch any of the films should the need arise. PocketMedic’s ability to facilitate autonomy satisfaction is advantageous as a more internal locus of control is likely to increase the amount of internalisation individuals experience

(Deci & Ryan, 1985). Additionally, disruption to usual routine, programme timing, integration, and travel and transport are all factors which negatively influence PR attendance and adherence (Halding, et al., 2010; Keating, et al., 2011). Due to the technology-delivery system, PocketMedic can overcome these factors and enable participants to engage with the intervention at a time which is most suitable to them; therefore, increasing autonomy satisfaction and adherence.

“I’d suggest for certain people it would be good for them to go back [to PocketMedic].

Particularly if they haven’t taken part in rehab’ or whatever. To go back and remind yourself. Because I know after the first rehab’ I had all this documentation and quite a few times I went back to it so I could imagine someone in possession of the films, particularly if it was their first time of rehab’, I think they’d find it useful”. FS, line 98.

FS illustrates here how participants felt that the ability to re-watch PocketMedic was an advantage, especially to recap on information discussed during PR, or if this programme had not yet been attended. Several participants additionally stated that the film format of PocketMedic was more beneficial than being provided written information. As described earlier, a lack of knowledge was perceived to thwart participants’ competence; however, being provided education overcame these effects. Multiple participants discussed how PocketMedic was beneficial at delivering this education, and the positives of the ability to have this information available when needed is effectively described by FS, above. However, the repetition between PocketMedic and PR was experienced by some participants as a negative, as they were not gaining anything new.

“yeah well I found them quite boring because, well if I hadn’t done PR I would imagine they’d be quite interesting. You know they were good at explaining at what COPD was, but because I’d done the course I was flicking through like there’s nothing new to tell me here.

Learnt it on the course. But if someone hadn't done the course, I think they'd be good.

Explains pretty good about COPD". RR, line 125.

RR explains how due to PocketMedic lacking any new material she did not feel engaged with the intervention. Later in the interview, RR also discussed some technical problems in accessing the films. As a result of these difficulties and repetition she chose not to watch anymore. The basic psychological need of competence explains that people are driven to undertake challenges suitable for their capabilities (Deci, 1975); therefore, this loss of motivation could be as a result of participants not feeling challenged when engaging with PocketMedic, due to the repetitive information. Due to the overlap between the two interventions being discussed within several of the interviews, a couple of participants suggested that the digital health films should be prescribed independent of PR. When asked whether PocketMedic should be given before or after this programme, the next quote illustrates the consensus amongst the participants.

"I'd say before. Yes I think for somebody who hadn't done rehab' and was a bit, what's the word? Not reluctant. Unsure, apprehensive, I think they'd be good. Because then the rehab' comes along and together with the exercises it would just reinforce on what's on the film".

FS, line 107.

FS discusses how people may be worried about attending PR; where, fears of increased dyspnoea and exercise have been found previously as barriers to attendance (Harris, et al., 2008). Throughout the interviews, participants described how they felt they had no control over their breathing and COPD thwarted their need for competence for activities, such as exercising. Therefore, it is perhaps unsurprising that people are apprehensive to engage in a behaviour in which they have low competence to complete. One interpretation of most participants suggesting that PocketMedic should be prescribed before PR is that they are

acknowledging the dearth of information available to them before this programme and the thwarting effect this is having on their basic psychological needs. Although participants felt that PocketMedic added little to the positive effects of PR, prescribing this intervention independently could see increased disease knowledge and reduced need thwarting; therefore, an increase in self-management behaviours such as attendance and adherence to PR.

For the participants who were enrolled in PR, meeting other people with COPD was a large positive of the course. This directly relates to the need of homonomy (tending toward integration of oneself with others; Angyal, 1963). Participants described how satisfaction of relatedness needs gained from these introductions benefited both their motivation to adhere to the programme and continue self-managing after the course finished, and several participants kept in contact with the people they met.

“You got to talk with people with the same problems. And you got to know what helped them and what they were struggling with. Which your kids and friends don’t understand because they haven’t got it you know? The girls I met [at PR], and I made friends there, and they were going to gym now. My life was changed by other people having it as well. Walk and talk, and we’d whinge to each other. How red faced we were that day, the weather. All same thing in common and that’s what keeps me going”. RR, line 70.

RR describes in detail the benefits she received from meeting other people with COPD who knew about the experience of living with the condition. Most of the participants discussed similar experiences and some felt like they were the only one with the condition. The positive effects on relatedness satisfaction, or similar concepts, that are gained from group interventions is described by a wealth of previous literature, which includes the resulting impact on motivation (Baker & Fatoye, 2019; Rapport, et al., 2015; Stevens, 2016). The ability to learn from others’ experiences has also been highlighted as a beneficial component

of such programmes (Stevens, 2016). Additionally, Deci & Ryan (2002) state that relatedness is a pivotal need at the beginning of behaviour acquisition for extrinsically motivated activities and recent research has reported that this is a salient need within participants at the beginning of PR (Whittaker, et al., 2018). Therefore, increasing the satisfaction of relatedness at the beginning of interventions could result in higher levels of adherence, which could potentially then lead to further increases for this basic psychological need.

*“Whereas in rehab, when you go into a fitness room you’re all in the same boat, everyone is there. Some were a lot better off and some were a lot worse off and nobody minded because it was very social and the first week or couple times everyone went and were surprised going ‘oh they expect us to do this?’ *laughs*”. RC, line 252.*

RC discusses that despite being at different levels of physical ability, she still felt a sense of relatedness satisfaction with other people at PR. Several participants also talked about how they noticed that some of the PR attendees had a different severity of COPD to them; however, like RC, this was not described in terms of less relatedness satisfaction. This was in notable contrast to how some participants had described the thwarting of their relatedness needs outside of PR. In earlier themes, participants described how their COPD made them conscious of being different and unaccepted in society due to the noticeable symptoms of their illness drawing unwanted attention. Following PR participants described how having their relatedness needs satisfied by peers in the group had increased their confidence which helped them when they were in different environments.

“before I was really embarrassed because people look at you thinking you’re odd because you can’t breathe and puffing when you go shopping...people don’t understand, I don’t like them looking when I’m stopping and panting and you gain more confidence because of PR. And now if they don’t like it then tough”. RR, line 190.

As described earlier, the symptoms of COPD thwarted several of the participants and made them avoid situations, such as the gym. Participants did not describe PR in terms of removing the thwarting of their relatedness external to the group; however, their increase in relatedness satisfaction from a different context appeared to help buffer the negative effects of this. This is an interesting theoretical observation, in that many authors emphasise the inherent need to satisfy needs in all contexts for well-being (Deci & Ryan, 2002); however, it does appear that in situations where that is not possible, that satisfying a need in one context may go some way to alleviating the negative impact of its thwarting or dissatisfaction elsewhere.

7.3.2.2 Redefining challenge

Throughout the interviews the participants described how COPD thwarted their competence needs and the sudden realisation that they couldn't conduct a behaviour they used to be able to had a negative effect on their wellbeing. Within this sub-theme, however, participants discussed how through engaging in interventions such as PR and PocketMedic they had learnt to accept their current abilities. This is conceptually different to *Recalibrating psychological need thwarting* because participants in that sub-theme discussed the techniques they employed to avoid thwarting situations entirely; whereas, this sub-theme describes the acceptance of their reduced abilities and the thwarting effects of COPD, and how they continued to conduct behaviours in which their needs were thwarted.

“I think [self-managing] helps you know, before I couldn't accept that I couldn't do things as I used to, now this its taught me you have to accept it and there are things you can't do that you did before”. RR, line 224.

The description of self-management knowledge given by Schulman-Green, et al. (2012) also refers to the process of accepting a loss of physical functioning. Whereas, when reflecting on their time before PR, participants discussed how the loss of ability had a negative impact, when discussing life after the intervention, there were no references to this negativity. One interpretation could be that participants have accepted that they have a new level of physical ability which is lower than it was before; however, this has either also lowered the perceived thwarting of COPD or increased their satisfaction. Instead of mourning this loss, participants talked about how they used methods such as pacing to enable them to still engage with behaviours, albeit slower than before they had COPD.

“So I know what I can do now. I know if I walk up steps I get knackered by the time I get to the top. So I go up slowly. Going downhill, nothing, on the flat, nothing. I’m fine. It’s just slight hill, stairs, or if I’m doing the gardening, mowing the lawn, I’ve got to sit down every ten to fifteen minutes”. MJ, line 44.

Both PR and PocketMedic included materials on how participants should pace themselves during physical activities; although, there was no discussion on whether one of the interventions was better at purveying this information compared to the other. The deliberate pacing of activities did not remove the competence thwarting effects of COPD; however, the self-management method seemed to provide participants with the belief that they could still conduct activities despite them being thwarted.

“I painted the bathroom this week, its not very big...but I felt really good about it, I don’t think I would have been able to do that before rehab. Last year I would have just ‘I can’t do this’. I’m already thinking I can do this but when we move on from bathroom I’m already thinking ‘one wall [to paint] a day’. If I start on a room and do one wall a day, one coat, I’ve done something and it will get done. A few years ago I would have moved all the furniture

and gone all round the room and then I would hope that it dried for a second coat. Now I pace myself for one wall and it'll get there eventually". RC, line 274.

RC describes her ability pre-COPD and that this had decreased to a state where she could not paint a bathroom. However, by using pacing, she was confident that the entire house would get painted eventually. From a SDT perspective, the increase in competence satisfaction could be as a result of participants redefining what they perceive as a challenge, in line with their new reduced abilities (Deci & Ryan, 2002). Using the example of painting, RC can no longer paint an entire room twice in one day due to her COPD. This could normally be interpreted through a loss of competence satisfaction or increased competence thwarting (Deci & Ryan, 1985; Bartholomew, et al., 2011); however, RC has accepted her reduced abilities and challenges herself to paint just one wall a day. Therefore, when this is achieved, RC could still feel her competence satisfied, because she no longer compares her current achievements to her previous abilities. The beginning of the quote by RC illustrates the positive effects this redefining of challenge had for participants.

7.4 Conclusion

This study shows that participants discuss their condition in terms of the thwarting of the three basic psychological needs and extracts indicate that these concepts have a relationship with one another similar to those found between the need satisfaction constructs (Ntoumanis, 2005; Standage, et al., 2005). The thwarting of all the needs appeared to have a detrimental effect on wellbeing and caused participants distress, or to avoid situations in which they perceived this would be increased; for example, physical activities. This could explain the low adherence to medication and disease-management programmes, including PR. Previous

research has found that those living alone are less likely to attend PR (Hayton, et al., 2013). Additionally, fears of increased dyspnoea (Harris, et al., 2008), a disruption to usual routine, and programme timing (Keating, et al., 2011) have also been found to be barriers to PR attendance and adherence. The findings from Hayton, et al. (2013), Harris, et al. (2008), and Keating, et al. (2011) can be explained from a SDT perspective through the concepts of relatedness, competence, and autonomy thwarting, respectively. As participants feel their relatedness is thwarted by COPD, they may not accept a request from another to begin an activity, due to not feeling related to them enough (Ryan, et al., 1994). Due to COPD thwarting their competence, participants could feel that they are unable to engage in physical activities and avoid situations in which they must do so (Deci & Ryan, 2002). This could also explain the cyclical relationship between increased dyspnoea and decreased exercise (Donaldson, et al., 2012). Lastly, because COPD thwarts their autonomy, participants may not engage in activities in which they do not feel they have an internal locus of control; for example, healthcare appointments or an intensive PR programme (Sheldon, et al., 2003). This latter point could be especially relevant for adherence to healthcare services because participants described how they did not perceive such services to support their needs for autonomy.

Most of the quotes describing the effects of COPD could be explained by GAS (Selye, 1950) where, due to the incurable nature of COPD, participants ultimately ended in the exhaustion stage and had resulting feelings of anxiety, depression, and an inability to cope. As described above, the same quotes also described the thwarting and dissatisfaction of needs and therefore the psychological needs may have physiological antecedents or consequences. However, participants were still able to overcome the thwarting effects of COPD and the exhaustion stage through the two interventions. Although Radel, et al. (2011) found that in the alarm stage individuals are motivated to overcome need dissatisfaction and thwarting, this study

highlighted that if perceived competence is increased – even in the exhaustion stage – people with COPD can reengage with behaviours such as self-management.

Physical solutions were adopted to overcome some of the thwarting effects of COPD. These solutions included methods such as a change of routine to avoid regularly using the stairs or adapting the environment to reduce the amount of physical work it required to maintain.

Although the simple, yet effective, methods helped participants avoid situations in which they felt their basic psychological needs were being thwarted, the solutions did not reduce the amount of thwarting they experienced. Thus, the avoidance of situations in which participants felt distress could be a positive factor. However, it is equally possible that such methods are used to avoid the necessity to ‘treat’ the thwarting; for example, by physically exercising. In this latter situation, participants may adopt the use of physical solutions to adapt an environment in which they are being thwarted when they do not have enough satisfaction of needs or the knowledge required to conduct behaviours which would reduce the thwarting stimulus directly. This could be supported by Raden, et al. (2013) who found that autonomy thwarting environments are overcome only if perceived competence is high. Therefore, to increase competence satisfaction, people with COPD may alter their environments and enable themselves to overcome thwarting stimuli. However, there is still limited literature on need thwarting (Olafsen, et al., 2016); thus, it is difficult to evaluate the validity of this theory by comparing it to other possible explanations presented in past research. Therefore, future studies could investigate when and why people with COPD adopt physical solutions to psychological barriers, and whether these represent a positive or negative coping mechanism.

Participants also described how PR and PocketMedic lessened the effects of autonomy and competence thwarting caused by COPD. The ability to regain some of the activities that they had lost was especially beneficial and participants discussed how this increased their motivation to persevere through symptoms such as dyspnoea. Research has found that PR

increases individuals' physical activity, control, confidence, and willingness to self-manage (Rapport, et al., 2015); where, these results could be explained by this programme decreasing the thwarting effects of COPD. Despite the interventions not helping participants to revert to a non-COPD health-state, they discussed how they had accepted their new abilities, and this is one of the processes involved in effective self-management (Schulman-Green, et al., 2011). The positivity of this acceptance was interpreted as participants redefining what challenged them and thus saw an increase to their competence satisfaction and the activities in which they would engage. For example, participants discussed how they could now walk up the stairs or mow the lawn and employed methods such as taking breaks to reduce the physical exertion they experienced. This would be in contrast to the physical solutions employed to *avoid* thwarting situations, as methods such as pacing were used to enable the participant to engage in activities which COPD had thwarted. This could be due to participants perceiving their competence to be higher whilst using such methods and thus being motivated to try and overcome the thwarting situations (Radel, et al., 2013). Greater satisfaction of the basic psychological needs has also been linked with higher wellbeing (Ng, et al., 2012). Therefore, it is possible that the mechanism in which PR and self-management behaviours and interventions effect HRQoL (Majothi, et al., 2015; McCarthy, et al., 2015; Zwerink, et al., 2014), is through the level of acceptance, and thus competence satisfaction, these programmes and behaviours provide. However, due to the limited literature regarding this topic, future research could be developed to further explore this theory.

Despite participants expressing that meeting other people with COPD was a motivator to adhering to PR, which has been reported previously (Baker & Fatoye, 2019; Rapport, et al., 2015), their relatedness appeared to continue to be thwarted in other situations. Research has found that the positive effects of PR are not maintained longitudinally (Bestall, et al., 2003; Foglio, et al., 2007). One interpretation, using the findings of this study, could be that these

effects are not maintained due to participants still having their relatedness thwarted, and thus do not continue self-managing their condition because they do not adequately relate to other individuals in their environment. However, it has been suggested that even in extrinsically motivated behaviours, the need of relatedness may not play a large role long-term (Deci & Ryan, 2002; Whittaker, et al., 2018); therefore, it is equally possible that PR's positive effects are not maintained due to the progressive nature of COPD which gradually increases the thwarting of needs over time.

Several participants described that there was a lot of repetition between PR and PocketMedic and this negatively affected participants' motivation to adhere to the latter intervention. This was interpreted as the digital health films not providing enough challenge to the individual and therefore lowered their competence satisfaction. Due to this, multiple participants suggested that the two interventions should be prescribed separately and that receiving PocketMedic before PR would be most beneficial. A lack of knowledge was perceived to thwart competence and although the interventions lowered the amount of thwarting and provided education, participants described their feelings of regret that this was not received sooner. Therefore, future research could investigate the effectiveness of prescribing PocketMedic to people pre-PR to increase self-management motivation and knowledge and decrease apprehensiveness toward PR in this sample. Barriers to PR include a lack of travel and transport and the programme not fitting into participants' lives (Keating, et al., 2011); therefore, given that PocketMedic can overcome these barriers, this intervention could be prescribed and provide benefits to people with COPD earlier. Future research could investigate whether this is a safe, feasible, and effective intervention.

Although poor recruitment prevented the originally planned purposive sampling method, the original justification was to allow participants from both hospitals to be interviewed in addition to those who did and did not engage with PocketMedic. By chance, the participants

who were interviewed were recruited from both Glangwili and Prince Philip hospital. Only one participant who did not engage with the intervention was recruited; where, a technical error in the PocketMedic system was at fault. Therefore, unfortunately no information could be obtained from participants who chose not to watch the films and future research should consider investigating this aspect further.

In summary, this study provides an increased understanding into the experiences of COPD and how participants engage with PR and PocketMedic. This research also overcomes the limitations of past literature which have not considered the role of need thwarting in people with COPD. Using thematic analysis, themes were identified which provide greater knowledge on the mechanisms by which healthcare interventions have been shown to be effective. Additionally, the perceptions of healthcare appointments were obtained, which could have a direct benefit for services that implement changes based on these findings. The themes have identified topics in which further research is required. For example, when and why do people implement physical solutions to overcome need thwarting and the safety, feasibility, and effectiveness of PocketMedic prescribed independently of PR. Finally, this study made a positive contribution to meet the overarching aim of this thesis. By using qualitative methods, a greater understanding of self-management motivation and HRQoL could be obtained from the perspective of individuals with COPD; where, these findings compliment the quantitative research described in Chapters Five and Six. All three research chapters are discussed in greater detail within the next chapter.

Chapter Eight: Overall discussion

8.1 Discussion of main findings

The aim of this thesis was to understand motivation to self-manage and HRQoL in people with COPD from a SDT perspective. To accomplish this, three independent studies were conducted.

The first study (Chapter Five) used a PR waiting-list population to answer the research question: *what are the relationships between SDT concepts, self-management motivation, and HRQoL in people with COPD?* Results showed that need satisfaction and thwarting variables can predict motivation to self-manage, which in turn predicts disease-specific HRQoL and self-management knowledge; specifically, autonomy satisfaction and relatedness thwarting were the strongest predictors. This study contributed to the overarching aim of this thesis by investigating and finding that SDT concepts can be used to predict self-management motivation and HRQoL in people with COPD. This is an important, novel finding because previous research has not used a PR waiting-list population, which has led to a limited understanding of factors which affect self-management motivation and HRQoL in people who have not received any significant healthcare intervention. Additionally, although research has qualitatively investigated the applicability of SDT in people with COPD (Whittaker, et al., 2018), to the author's knowledge, this is the first study to quantitatively examine the validity of using this theory to predict health outcomes in this condition. Lastly, the measuring of need thwarting concepts helped to gain a much-needed, greater understanding of these variables more generally and specifically to people with COPD; where, the condition was found to be a highly thwarting stimulus.

The second study (Chapter Six) implemented PR and a SDT-based, technology-delivered, self-management intervention, both independently and in combination, to answer the research question: *what effect do PR and PocketMedic have on SDT concepts, self-management motivation, and HRQoL in people with COPD?* Results showed that both interventions could significantly increase both self-management motivation and HRQoL and improve most of the basic psychological needs. These findings contribute to the aim of the thesis by helping to understand the mechanisms behind the positive results found in previous studies evaluating PR and self-management interventions (McCarthy, et al., 2015; Zwerink, et al., 2014). Specifically, the significant benefits to competence and relatedness satisfaction and autonomy and competence thwarting were identified in both interventions. Surprisingly, despite the assumed autonomy-supportive nature of PR and PocketMedic, the satisfaction of autonomy did not significantly increase. Additionally, the thwarting of relatedness was not reduced despite both interventions introducing participants to other people with COPD (one in person and the other through peer led stories on film). Lastly, the use of SDT helped gain a greater understanding of how the basic psychological needs influence PR adherence and PocketMedic attendance and adherence, showing that methods to increase these variables should consider applying SDT.

The third study (Chapter Seven) used qualitative methodology to answer the research question: *how do people discuss their experiences of COPD and engaging with PR and PocketMedic?* Results showed that participants discussed COPD in terms of basic psychological need thwarting. The two interventions appeared to help decrease the negative effects of autonomy and competence thwarting and also benefited the satisfaction of all three need satisfaction concepts. This was an important study to contribute to the overarching aim of this thesis as it allowed a greater understanding of the effects of COPD and healthcare interventions, from the perspective of the participant. The diverse interview schedule helped

gain a greater knowledge regarding the results from the previous two studies through triangulation. Specifically, the perception of healthcare environments on the need of autonomy, the benefit of the interventions to help reduce competence thwarting, and the role of acceptance to increase competence satisfaction. Lastly, the participants' recommendations regarding the timing of PocketMedic could also help people newly diagnosed with COPD, which may not have been considered without this study.

This chapter will consider all these findings across the three research studies to give a triangulated understanding of motivation to self-manage and HRQoL in people with COPD, whilst simultaneously giving suggestions for future research. Findings were discussed by the contribution they made to theory and the contribution they made to clinical practice.

The chapter will then discuss the strengths and limitations of the research before progressing to detail the possible implications of the thesis.

8.2 Contribution to theory

Previous literature has highlighted the importance of basic psychological need satisfaction and the positive relationship these concepts have with self-determined motivation (Deci & Ryan, 1985; 2000; 2002; Ng, et al., 2012). However, research has suggested that people are extrinsically motivated to self-manage COPD (Wortz, et al., 2012) and in such situations where the chronic disease has such a profound impact on an individual's lifestyle it is feasible to understand how need thwarting may have a larger influence on self-determined motivation compared to need satisfaction (Bartholomew, et al., 2011). Results from Chapter Five found that autonomy, competence, and relatedness satisfaction positively predicted COPD self-management regulation; thus, conforming to the findings from past literature (Deci & Ryan,

2002). However, relatedness thwarting was the joint largest predictor of COPD self-management regulation, and this provides support for the suggestions from Bartholomew, et al. (2011) for the important role that need thwarting may also play. Deci and Ryan (2002) explain how in behaviours which are not inherently interesting (i.e. extrinsically motivated behaviours), the need for relatedness is pivotal, as these activities are first conducted due to a request from a significant other an individual feels, or would like to feel, related to (Ryan, et al., 1994). Therefore, the poor attendance and adherence to medication and disease management programmes (Bourbeau & Bartlett, 2008) could be explained by the results describing COPD as actively thwarting this need. This was further supported by Chapter Six finding that baseline relatedness thwarting and autonomy satisfaction predicted adherence to PocketMedic; corroborating the results from Chapter Five and further highlighting the role of thwarting in people with COPD. Throughout the interviews conducted for Chapter Seven, participants described how their friends and family did not understand the condition and that they avoided situations where they felt they would get judged for being breathless; for example, the gym or walking any distance in public. These extracts were interpreted as describing how COPD was actively thwarting the participants' need for relatedness and provides yet further evidence to the saliency of this concept within people with this chronic condition.

The interviews also highlighted how COPD thwarts the needs for competence and autonomy. Participants discussed how the gradual reduction in their abilities led them to decrease the amount of physical activities they engaged in and some avoided walking altogether. Research has described the perpetual, cyclical relationship between dyspnoea and a reduction in physical activity (Donaldson, et al., 2012). It appears that this can in part be explained by breathlessness increasing the thwarting of competence needs, which leads to increased likelihood of inactivity in order to avoid these need thwarting activities. Similarly, fear of

increased dyspnoea is one predictor of PR non-attendance (Harris, et al., 2008) and this could also be explained by participants being worried that their competence will be further thwarted at the programme and thus do not attend. Although relatedness is an important need in extrinsic behaviour initiation, perceptions of competence is also necessary, because without the fulfilment of this need an individual will likely avoid the activity (Deci & Ryan, 2002). The loss of ability was also talked about in terms of how this thwarted the participants' need for autonomy through removal of their choices about daily behaviours that they wanted to engage with. This led participants to become distressed when they no longer perceived themselves as causal agents in their own lives. To fully integrate the behaviour, an internal locus of control is required (Sheldon, et al., 2003) and although some internalisation can occur toward non-autonomous activities, more self-determined regulation will always occur in situations which satisfy autonomy (Deci & Ryan, 2002). Thus, individuals with COPD may be less likely to fully internalise self-management behaviours due to their condition thwarting this basic psychological need. Therefore, the thwarting of competence and autonomy could also explain the poor attendance and adherence to healthcare services (Bourbeau & Bartlett, 2008), because as COPD is actively thwarting these needs, individuals may not feel competent to engage in physically active behaviours or that they have any agency in these activities.

There is a dearth of literature which investigates the role of need thwarting in general (Olafsen, et al., 2016) and research applying SDT to populations with COPD is sparse (McCullough, et al., 2016; Riley, et al., 2014). As a result, previous studies have failed to examine the role of need thwarting in people with COPD; however, across all three study chapters within this thesis the thwarting of the basic psychological needs was evident.

Therefore, not considering this concept and the corresponding implication of need thwarting

could be limiting the current understanding of how COPD effects people and their health-related behaviours and decisions.

In addition to highlighting the importance of considering need thwarting when investigating the effects of COPD, the studies within this thesis also contribute to furthering the current knowledge relating to this concept. Firstly, previous research has described how the satisfaction of the basic psychological needs are strongly correlated (Ntoumanis, 2005; Standage, et al., 2005) and the path analyses conducted in Chapter Five show that the thwarting of needs are also similarly correlated with one another. Additionally, the correlations between need thwarting constructs were stronger than those between need satisfaction constructs. During the interviews in Chapter Seven, participants related their physical fitness with their perceived competence and discussed how COPD actively thwarted their ability to engage in activities. This loss of ability was also described as frustrating their agency and relatedness. Therefore, these findings support the results from Chapter Five and suggest that the competence thwarting effects of COPD facilitate the thwarting of the other basic needs. Furthermore, past literature has described that the basic psychological needs can be satisfied in environments where they are also being actively thwarted (Bartholomew, et al., 2011); however, the negative correlations between the two types of needs would indicate the detrimental effect the active frustration of needs can have on fulfilment. Although the bidirectional relationships described in the path analyses cannot infer causality and thus it is plausible that high need satisfaction diminishes the perception of need thwarting, the results from Chapter Seven would refute this interpretation. During the interviews, participants described PR in terms of decreasing the thwarting of their autonomy which resulted in them persevering in other physical activities which they would have previously avoided. The interpretation of these extracts was that the reduction of autonomy thwarting may have increased the satisfaction of competence; however, future research would need to investigate

this topic further to examine whether such relationships are present between the thwarting and satisfaction of all the basic psychological needs. Additionally, past research has described the reverse, where competence satisfaction can support the overcoming of autonomy thwarting stimuli (Radel, et al., 2013) and this future research could investigate whether just one or both of these situations can occur in people with COPD. Lastly, physical solutions were employed to overcome the active frustration of the basic needs. Throughout the interviews, participants described how they physically modified their environment to require less work or altered their routines to avoid situations in which their needs were thwarted; such as climbing the stairs. Although these modifications allowed them to avoid situations in which their needs were thwarted, this could be interpreted as a negative factor if such methods are being used instead of performing self-management behaviours such as physical exercise. Therefore, future research should investigate when and why these physical modifications are being implemented, the corresponding effect on outcome measures such as HRQoL and whether interventions should encourage the avoidance of need thwarting environments or equip people to tackle them.

The studies presented in this thesis also help develop the understanding regarding the mechanisms by which PR and self-management interventions work, and through this the use of SDT within a population with COPD. This directly addresses suggestions from the latest GOLD COPD report which states more studies are needed to investigate the beneficial components of these interventions (Vogelmeier, et al., 2018). Previous research has reported that PR and self-management interventions have positive effects on disease knowledge, functional exercise, dyspnoea, and HRQoL (McCarthy, et al., 2015; White, et al., 2006; Zwerink, et al., 2014). Although it is unsurprising that interventions which provide disease education and encourage participants to engage in physical activity benefit the former three outcomes, the mechanism by which these interventions exert this effect may not be as

straightforward. There is a wealth of literature which describes how high and low need satisfaction correlates with positive and negative wellbeing and HRQoL, respectively (Kasser & Ryan, 1993; 1996; Reis, et al., 2000; Sheldon, et al., 1996; Sheldon & McGregor, 2000). However, the role of need thwarting on wellbeing and HRQoL is not as well documented. Chapter Six found that PR and PocketMedic had significant positive effects on competence and relatedness satisfaction, autonomy and competence thwarting, and HRQoL. Therefore, one interpretation could be that these SDT constructs are one of the mechanisms by which the interventions have positive effects on HRQoL. This theory is supported by the SDT model of health behaviour change, although, once again, this model does not consider the role of basic psychological need thwarting (Ryan, et al., 2008). The results from this study suggest that this model could be updated to accommodate the new understanding regarding need thwarting in the context of chronic disease. Additionally, because both interventions can be defined as autonomy-supportive, this thesis can also help further the model, by concluding that such interventions can have positive effects on need thwarting constructs. Lastly, despite the autonomy-supportive nature of PR and PocketMedic, these services failed to significantly increase autonomy satisfaction thus contradicting past literature (Deci, et al., 1994; Ryan, et al., 2008; Williams, et al., 2002; 2006). However, autonomy thwarting was significantly decreased which does suggest that, at least in people with COPD, autonomy-supportive environments may have more of an effect at reducing the negative effects of autonomy thwarting compared to increasing the satisfaction of this need. Future research should investigate the effects of autonomy-supportive services on need thwarting and potentially provide a revision to the current SDT health behaviour change model (Ryan, et al., 2008) to accommodate need thwarting constructs where appropriate.

During the interviews of Chapter Seven, one of the benefits of the healthcare interventions was that participants re-evaluated their physical inabilities as a result of COPD. Rather than

being perceived negatively, participants described developing an acceptance that they were not going to fully recover their abilities, and this seemed to result in positivity. Thus, it appeared that the acceptance helped participants to redefine what they perceived as a challenge, which stopped them unfairly comparing their current abilities with their past selves. Such a re-evaluation could help increase competence satisfaction because participants perceive that they are undertaking challenges suitable to their current capabilities (Deci & Ryan, 2002). Alternatively, the re-evaluation could have beneficial effects by decreasing the level of competence thwarting because participants have accepted their new physical abilities and thus may perceive that COPD is not further thwarting their capabilities. However, Chapter Six found that although competence satisfaction and thwarting were significantly benefited by the two interventions, the satisfaction of this need was on average only two thirds of the maximum score and the thwarting of this need was still relatively high at follow-up. Therefore, the positive effects of acceptance are unable to be explained just from the perspective of a re-evaluation of challenge. The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) describes how a shift to a Wellness in the Foreground perspective includes a revisioning of what is possible and normal. Additionally, the shift has been described as a movement from “a victim of circumstances to creator of circumstances” (Barroso, 1995, p. 44) and a focus on social aspects of life and appreciation of loved ones (Patterson, Thorne, Crawford, & Tarko, 1999). These descriptions of the Wellness in the Foreground perspective align well with the basic psychological needs of competence, autonomy, and relatedness, respectively. Therefore, the acceptance described in Chapter Seven could be one example of participants shifting illness perspectives. Instead of this directly effecting psychological needs, this change could be interpreted as participants focusing on the way they could seek out opportunities to satisfy their needs rather than focusing on how COPD was thwarting them. Paterson (2001) states that little research exists

relating to how healthcare professionals can facilitate a shift to a Wellness in the Foreground perspective. This thesis highlights that PR and PocketMedic may be ways to assist in this shift; however, future research should investigate the exact components of these interventions and the SDT mechanisms which enable this to occur.

8.3 Contribution to clinical practice and policy

The studies presented within this thesis also provide valuable contributions to COPD clinical practice. There is a wealth of literature reporting the poor attendance and adherence by people with COPD to medication and disease management programmes (Bourbeau & Bartlett, 2008; Restrepo, et al., 2008; Steiner, et al., 2015; 2016; Vogelmeier, et al., 2018). Taking prescribed medication and attending healthcare appointments and services are considered good self-management behaviours (Schulman-Green, et al., 2012); therefore, the lack of these behaviours represents poor COPD self-management. Supporting self-management processes have been identified as crucial for people with this condition (Kaptein, et al., 2014; Kielmann, et al., 2010); additionally, due to the detrimental impact of COPD (Russell, et al., 2018), supporting HRQoL is equally as important (Kielmann, et al., 2010). Although motivation has been suggested as a possible explanation for poor self-management behaviours (Sheldon, et al., 2003), limited research has been conducted investigating the role of motivation in this condition. Chapter Five started to address this gap in the literature, finding that self-management regulation can positively predict both self-management knowledge and HRQoL in people with COPD; thus, supporting the explanation posited by Sheldon, et al. (2003). This is an important finding because it not only highlights the role of motivation in poor self-management but also provides useful mechanisms by

which to increase this factor (Hagger & Chatisarantis, 2015). Participants in Chapter Seven described how a lack of knowledge thwarted their competence to conduct self-management behaviours; however, PR and PocketMedic helped provide education which lessened the effect of this factor. Therefore, in addition to highlighting that future healthcare interventions should target self-determined motivation, self-management education could also help increase motivation by reducing the thwarting of participants' competence. Both previous literature and the path analyses presented in section 5.3.1, reported that increasing self-management motivation positively effects HRQoL (Ng, et al., 2012) and Majorthi, et al. (2015) have also reported similar relationships between self-management knowledge and HRQoL. Therefore, such programmes could prove beneficial at increasing self-management motivation, knowledge, and HRQoL in people with COPD and healthcare services should be cognisant of these findings to improve these factors in future interventions.

Chapter Six found that PR and PocketMedic are two interventions which can increase self-management motivation, knowledge, and HRQoL. Although the positive effects of PR are well documented (McCarthy, et al., 2015), no study has quantitatively investigated the mechanisms by which this programme works using a SDT framework. As described above, the study showed that one of the variables positively affected by the two interventions was relatedness satisfaction. In Chapter Seven, participants described how meeting other people with COPD during PR was a positive factor and this gave them motivation to adhere to the programme. Previous research has found the group component of healthcare programmes to be beneficial (Baker & Fotaye, 2018; Halding, et al., 2010; Rapport, et al., 2015; Stevens, 2016); however, these authors did not consider the concept of relatedness when analysing their results. This research adds to the current knowledge surrounding these programmes by utilising a SDT framework to explain why group programmes have a positive effect on motivation and health interventions should strive to include group components in the future.

This is also supported by findings from Chapter Five which showed that relatedness satisfaction was one of the basic psychological needs which predicted self-management regulation. As described above, the need for relatedness is pivotal during behaviour acquisition (Deci & Ryan, 2002) and this was also qualitatively found in pulmonary and cardiac rehabilitation participants (Whittaker, et al., 2018). Given the significant number of people who do not attend PR (Steiner, et al., 2015; 2016), future programmes should fully advertise group components because this could potentially increase the uptake of the service.

Despite the positive effects of PR and PocketMedic to significantly benefit several of the antecedents of self-management knowledge and HRQoL, both interventions were unable to influence autonomy satisfaction and relatedness thwarting. These basic psychological needs represent the largest predictors of self-management regulation found in Chapter Five and also predicted PocketMedic adherence in Chapter Six. PR has been found to benefit HRQoL and functional exercise capacity (McCarthy, et al., 2015); however, because the programme does not target the main predictors of self-management regulation, ultimately participants may regress back to not conducting these behaviours once the structured component of the rehabilitation has ended. Thus, the inability of PR to influence autonomy satisfaction and relatedness thwarting could explain why the positive effects of the programme are not maintained long-term (Foglio, et al., 2007; Spruit, et al., 2004). Although the need of relatedness is pivotal in behaviour initiation (Deci & Ryan, 2002), research suggests that the needs for autonomy and competence are more important in behaviour maintenance (Sheldon, et al., 2003; Whittaker, et al., 2018). Past literature describes that an internal locus of control is required to fully integrate behaviours (Sheldon, et al., 2003) and thus the lack of satisfaction of autonomy could explain why individuals do not conduct self-management activities long-term having failed to fully internalise them during the structured interventions. This research did not explore long-term engagement beyond the PR scheme and as such

future research is needed to investigate the most effective methods at influencing these basic psychological needs and the longer-term implications that this has on the maintenance of desired behaviour change.

Although both interventions were found to not significantly increase autonomy satisfaction, participants in Chapter Seven did describe PocketMedic in terms of providing agency which they were not receiving from other healthcare services. Some of the justifications for PocketMedic employing a technology delivery system was to overcome the common barriers to respiratory disease management programmes; such as travel and transport and a disruption to daily routine (Keating, et al., 2014). Participants discussed how the ability to engage with this intervention at a time and place which suited them was a significant benefit, and future programmes should consider similar methods if possible and relevant. The ability to support the need for autonomy was perhaps more influential due to participants perceiving healthcare to not facilitate the satisfaction of this need during routine appointments. For some participants, this had a detrimental impact on motivation and this finding is further supported by the results of Chapter Five highlighting that autonomy satisfaction was the joint highest predictor of self-management regulation. Healthcare services have been encouraged to move toward a partnership model; where, patients are provided choice in their own care (Coulter, et al., 2013; Goodwin, et al., 2010). The findings of this thesis suggest that the autonomy-support being offered by healthcare is not being positively perceived by service users, and future research should investigate how this can be facilitated in the future. Autonomy is not a synonym of independence (Deci & Ryan, 2002); therefore, clinicians prescribing medication with strict regimens or stating the need for smoking cessation will not necessarily thwart autonomy. Ryan and Deci (2000b) explain that a behaviour can be dependent and perceived as autonomous, providing that the values of this activity are congruent with their own. As a result, when prescribing medication, ensuring the individual knows the reasons for why this

is necessary may decrease the thwarting of, or better satisfy the needs for, autonomy. This is supported by previous research finding that providing choice and a meaningful rationale increased self-determined motivation (Deci, et al., 1994), which could be interpreted as clinicians articulating the values of why disease management decisions are required.

Studies are also needed to investigate the most appropriate time to prescribe PocketMedic, or similar interventions. During the interviews, participants described that there was a lot of repetition between PR and PocketMedic, and due to the films not providing anything new they were not adhered to. Several of the participants suggested that prescribing the two interventions independently of one another could be beneficial and the consensus was that PocketMedic should precede PR. One of the justifications for this was that the digital health films could reduce the apprehension felt by participants before they began PR; where, fears of increased dyspnoea has been found as a barrier to the programme previously (Harris, et al., 2008). The UK PR audit highlighted that out of every 100 people referred to the programme, 31 failed to even attend the assessment (Steiner, et al., 2015; 2016). This represents the highest dropout throughout the process of PR. Therefore, prescribing an intervention to decrease this non-uptake could see positive benefits. In addition, prescribing PocketMedic pre-PR could help to overcome some of the lack of understanding surrounding the referrals to PR by healthcare professionals thus going some way to reducing the perceived controlling environments created during this stage of diagnosis. Prescribing the films after PR, however, could also prove beneficial, as literature widely reports that the positive outcomes of this multidisciplinary programme return to baseline after approximately twelve months (Bestall, et al., 2003; Vogelmeier, et al., 2018). Therefore, a widely accessible, relatively inexpensive self-management intervention delivered at, or slightly before, one year could elongate the benefits of PR and reemphasise the benefits accrued during the programme. Due to literature and the results from Chapter Six reporting the effectiveness of PR to increase self-

management motivation and knowledge (Rapport, et al., 2015) engagement with the digital health films may also be increased by a post-PR prescription. Nevertheless, Chapter Six represents a novel contribution to the literature because it is the first to investigate a technology-delivered, SDT-based, self-management intervention, and the results for PocketMedic do support its wider application. The policy of Prudent Healthcare states that reducing the inappropriate geographic variation in health services is required (Drakeford, 2015). In the health region where this thesis conducted the research, HDUHB, structured PR is only available in one out of three counties and the referral of eligible people is the lowest in Wales (Baxter, et al., 2016). Therefore, to overcome environmental heterogeneity in the services provided, technology-delivered interventions could be prescribed, and such innovations have also been recommended within the Welsh Government Health Delivery Plan (2018-2020). A recent review concluded that technology is an effective method in supporting self-management across multiple chronic conditions, including COPD (Guo & Albright, 2017). The findings of Chapter Six corroborate these findings and promote the prescription of an intervention such as PocketMedic, particularly to environments where traditional PR cannot be provided.

Care must be taken, however, not to increase or compound the current inequalities present within healthcare interventions. Two current barriers to PR attendance and adherence are travel and transport (Keating, et al., 2011); where, these could be more prevalent in people from less affluent backgrounds. As previously stated, PocketMedic has the ability to overcome such limitations, however, requires recipients to own a smart phone, computer, or tablet. Therefore, it is possible that, again, people from a less affluent background are unable to engage with the intervention. Thus, innovative yet simple methods may have to be employed to overcome such barriers which do not exacerbate already present healthcare inequalities. As described above, this is a key aspect of Prudent Healthcare (Drakeford,

2015). Future research should investigate this possibility further, potentially by offering PR in the community by using technology (which doesn't have to be owned by the healthcare user; Knox, et al., 2019) or through providing an intervention such as PocketMedic on a DVD. In any situation, new methods should be investigated to ensure that those who are most vulnerable or have least access to routine care are not forgotten or ignored.

8.4 Strengths and limitations

Although SDT has been applied to explain a wide range of behaviours relevant to self-management (Ng, et al., 2012), there is a dearth of research applying the theory to populations with COPD. Additionally, the knowledge regarding basic psychological need thwarting is limited (Olafsen, et al., 2016). Psychological theory has been recommended to be used to fully explain health processes (Craig, et al., 2008) and although SDT has been qualitatively applied to PR participants (Whittaker, et al., 2018), research has not quantitatively investigated the use of the model during this programme or in people on a waiting-list. One of the major strengths of this thesis is the addressing of several gaps in current knowledge, both for the literature relating to SDT and COPD healthcare services. The studies thoroughly investigate the applicability of SDT to explain self-management motivation and HRQoL in people with COPD both before and during PR and Chapter Six represents the first use of SDT to explain mechanisms by which PR and self-management interventions work. The measuring of psychological need thwarting concepts has allowed the research to examine the effects of COPD and provide meaningful contributions to the knowledge on the role of these needs. Additionally, PocketMedic represents the first intervention to incorporate a technology delivery system and a self-management intervention

based upon SDT concepts for people with COPD, and the research described in Chapter Six and Seven provide evidence to support the efficacy of this intervention.

Another strength of this thesis is the utilisation of mixed methods to provide a triangulated view which helped to understand motivation to self-manage and HRQoL in people with COPD. Both quantitative studies allowed for statistical tests to be used to investigate the applicability of SDT to a population with COPD and predictive relationships between model constructs and disease outcomes to be identified. The qualitative study helped gain a more in-depth understanding of these factors from the perspective of the participants and further examined how people with COPD experienced PR and PocketMedic. The broad interview schedule allowed questions to be asked relating to the entire COPD journey, from diagnosis to post-PR, and the semi-structured format provided participants the opportunity to expand on specific topics. Quantitative methodology has commonly been used to investigate SDT (Deci & Ryan, 2002); however, qualitative studies have also found important findings (Whittaker, et al., 2018). This thesis brought together both of these components and thus achieved a thorough, well-rounded understanding of motivation to self-manage and HRQoL in people with COPD from a SDT perspective.

A limitation of the research described in Chapter Six, which has been discussed previously, is the low sample size recruited for the study. Although during the design phase the clinical team deemed the recruitment target as feasible; unfortunately, due to staff shortages, low funding, and poor attendance, recruitment was lower than anticipated. Techniques designed to increase the sample were ultimately ineffective; where, even a six-month extension to the research did little to increase the final number. Unfortunately, techniques such as first-contact or follow-up telephone calls, which have been shown to increase recruitment (Edwards, et al., 2002; 2007), were not permitted by the research ethics committee providing approval for the studies. Due to the large positive effects associated with PR (McCarthy, et al., 2015), any

intervention prescribed as an adjunct to this programme would either have to possess a big sample or relatively large positive effects of its own. Therefore, it is plausible that some of the non-significant findings are Type II errors, caused as a result of low statistical power due to the poor recruited sample size. However, a main justification for the need of this thesis was due to the historically low attendance and adherence displayed by people with COPD (Bourbeau & Bartlett, 2008). Therefore, it is somewhat unsurprising that the thesis experienced problems to recruit participants, because a similar lack of engagement is displayed to healthcare services which have been shown to have positive benefits. The issues described above stemmed from problems with one recruitment site and despite valiant efforts by staff, the team struggle to provide enough sessions to combat the increasing waiting-list. Therefore, due to the low number of sessions provided, there were less opportunities for participants to be recruited. One possible solution could have been to utilise other PR programmes available within other health boards. However, employing more programmes would have introduced an increased heterogeneity between participants, as different PR services provide different components over different periods of time and intensity (NICE, 2016). Thus, the recruitment of participants attending one PR programme represents a strength of the research because of the increased reliability that this provided. Furthermore, the participant acceptance rates for Chapter Five and Six were comparable to previous research (Edward, et al., 2002). Lastly, the low recruitment in Chapter Six lowered the number of eligible participants available for Chapter Seven. Originally, this study aimed to recruit a mix of participants from both recruiting hospitals and those who did and did not engage with PocketMedic. However, the study had to adapt to the low recruitment and thus included everyone who consented and arranged an interview. Fortunately, the seven participants were representative of the wider population with COPD and featured a mixture of PocketMedic engagement. Furthermore, data saturation was achieved which additionally

suggested that the analysis represented the group's experiences and therefore this is a further strength of the study and thesis.

One factor which could have been taken as both a strength and a limitation was the technology problems; where, some participants had difficulties logging onto the PocketMedic system and viewing the films. Although the actual problems are clearly a negative for the intervention and further development is needed to remove them, these issues did allow the research to investigate the real-world effectiveness of PocketMedic, rather than a non-ecologically valid laboratory-based study. This real-world research also allowed for the average number of engagers to be found and enabled the possibility of investigating why some people chose not to watch any of the digital health films. Although this was accomplished quantitatively within the study described in Chapter Six, unfortunately more in-depth analysis could not be completed because only one person who did not engage with PocketMedic consented to be interviewed. However, the reason for non-engagement was due to technological problems and therefore this remains an unexplored area. Future research should qualitatively investigate why only approximately 50% of people engage with digital health films.

Lastly, due to all participant sheets having the author's name on them and being present during all the consenting sessions for Chapter Six, it is possible that participants believed that the researcher was an advocate for PocketMedic. This belief would be a limitation of the qualitative study because participants may have altered their answers to present the digital health films more positively (Chan, 2008). However, throughout the interviews several negative views were raised regarding PocketMedic, especially by the recipient of the link-delivered films. Therefore, although this limitation is still possible, it is unlikely that the validity of this study was detrimentally affected to a large degree.

8.5 Conclusion

In conclusion, this thesis has investigated motivation to self-manage and HRQoL in people with COPD from a SDT perspective. Kaptein, et al. (2014) report that there are relatively few studies researching self-management in COPD compared to other conditions. Additionally, the use of psychological theory within healthcare interventions is low (Davies, et al., 2010); where, in COPD this is even less (McCullough, et al., 2016). Therefore, although SDT has been applied to self-management in multiple chronic conditions, such as chronic pain (Murray, et al., 2015) and diabetes (Gourlan, Trouilloud, & Boiche, 2015; Trief, Cibula, Delahanty, & Weinstock, 2017), the theory has not been widely used in populations with COPD (Richardson, et al., 2014; Riley, et al., 2011; Webb, et al., 2010). This thesis addresses this gap in the literature by being one of the first studies to explore the application of SDT within people with COPD, and by doing so has advanced theory and practice.

Advances in theory refer to the application of Deci and Ryan's (1985) SDT to a population with COPD, and the thorough investigation of the ability of this model to explain motivation to self-manage and HRQoL across the three studies. Research has found that people with COPD are extrinsically motivated to self-manage their condition (Wortz, et al., 2012) and that in such situations need thwarting may have more of an effect on self-determined motivation relative to need satisfaction (Bartholomew, et al., 2011). However, research applying SDT to populations with chronic conditions primarily focus on need satisfaction (Fortier, et al., 2007; Gillson, et al., 2019; Kosmala-Anderson, et al., 2010; Ng, et al., 2012; Sweet, et al., 2012; 2014; Whittaker, et al., 2018). As a result, throughout most of the literature, the thwarting of the basic psychological needs has gone unresearched (Olafsen, et al., 2016). This thesis has rectified this problem and has highlighted how, within a population with COPD, the neglect of need thwarting facilitates a limited understanding of the effects

of the condition and the mechanisms by which healthcare interventions work. Furthermore, the three studies have described the relationships between need thwarting constructs and has recommended that the existing SDT model of health behaviour change (Ryan, et al., 2008) be updated to accommodate these constructs.

Advances to practice refer to the use of SDT to investigate the mechanisms by which PR and a technology-delivered, SDT-based, self-management intervention work. The findings show that both interventions have significant positive effects on the basic psychological needs, motivation to self-manage, self-management knowledge, and HRQoL. Additionally, the ability to facilitate a change to a Wellness in the Foreground perspective was positively viewed by participants. The group component of PR increased motivation and promoted adherence to the programme. However, both interventions failed to influence autonomy satisfaction and relatedness thwarting, which were found to be the strongest predictors of self-management regulation and could explain why the benefits of PR are not continued long-term. Future research is needed to investigate how these basic psychological needs can be influenced, as this could result in increased self-management motivation and long-term behaviour change. Lastly, findings show that PocketMedic is an effective self-management intervention which can overcome common barriers to other respiratory disease-management programmes (Keating, et al., 2012) and is viewed positively by people with COPD. Based on recommendations from participants, this intervention should be prescribed before PR to decrease apprehension towards this programme and help increase self-management motivation and knowledge earlier in the COPD pathway.

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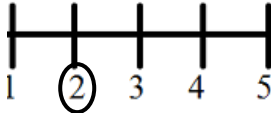
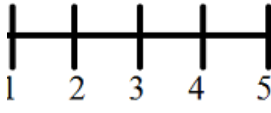
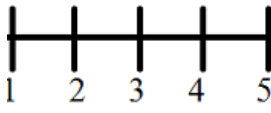
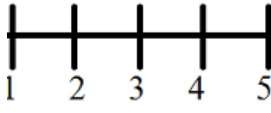
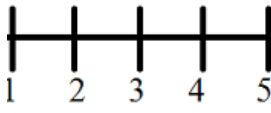
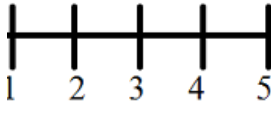
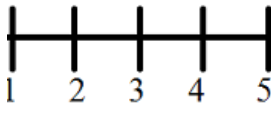
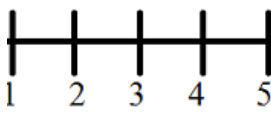
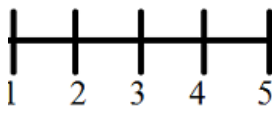
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Appendices

Appendix 1: COPD Assessment Test

For each item below, circle the score that best describes you currently. Be sure to only select one response for each question.

	Example: I am very happy		I am sad
A1)	I never cough		I cough all the time
A2)	I have no phlegm (mucus) in my chest at all		My chest is completely full of phlegm (mucus)
A3)	My chest does not feel tight at all		My chest feels very tight
A4)	When I walk up a hill or one flight of stairs I am not breathless		When I walk up a hill or one flight of stairs I am very breathless
A5)	I am not limited doing any activities at home		I am very limited doing activities at home
A6)	I am confident leaving my home despite my lung condition		I am not at all confident leaving my home because of my lung condition
A7)	I sleep soundly		I don't sleep soundly because of my lung condition
A8)	I have lots of energy		I have no energy at all

Appendix 2: EuroQoL 5D-5L

Under each heading, please tick the **ONE** box that best describes your health **TODAY**

B1) MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

B2) SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

B3) USUAL ACTIVITIES (*e.g. work, study, housework, family or leisure activities*)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

B4) PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

B5) ANXIETY / DEPRESSION

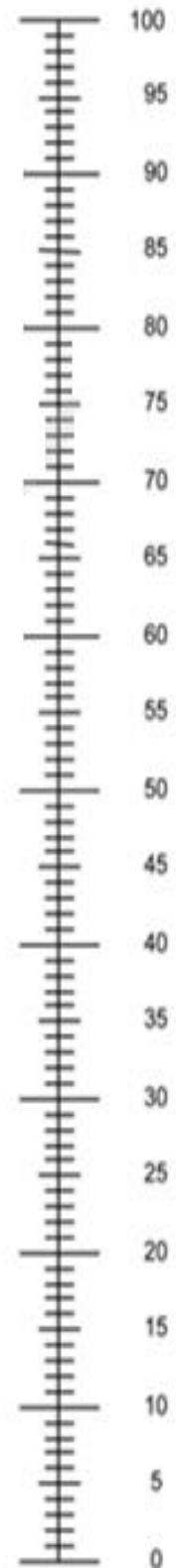
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

B6) We would like to know how good or bad your health is **TODAY**.

- This scale is numbered from **0** to **100**.
- **100** means the best health you can imagine.
- **0** means the worst health you can imagine.
- Mark an **X** on the scale to indicate how your health is **TODAY**.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health you can imagine

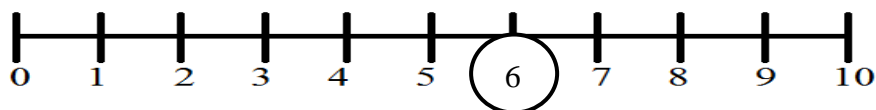


The worst health you can imagine

Appendix 3: Understanding COPD

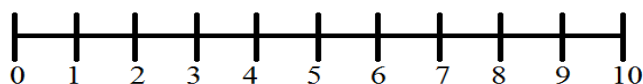
For each question please **circle the number** on the scale to show your understanding, confidence or use with each topic. If there are topics you do not know much about, feel less confident with or don't use often, then you should circle a low score. If there are topics you know more about, feel more confident with or use often then you should circle a higher score.

Example:



ABOUT COPD

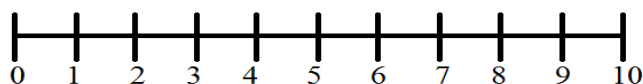
C1) How well do you understand what COPD is?



No understanding

Full understanding

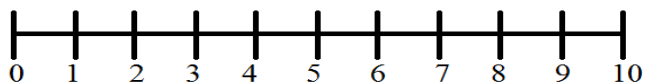
C2) How well do you understand how COPD changes over time?



No understanding

Full understanding

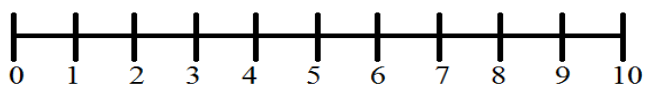
C3) How confident are you that you can recognise an exacerbation (a significant worsening of your usual symptoms)?



Not confident

Very confident

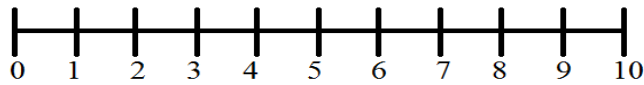
C4) How confident are you that you know how to alter your therapy during an exacerbation (a significant worsening of your usual symptoms)?



Not confident

Very confident

C5) How confident are you that you know when to seek help during an exacerbation (a significant worsening of your usual symptoms)?



Not confident

Very confident

C6) How confident are you that you know **how** to use your COPD medication (e.g. inhaler, nebuliser, and tablets)?



Not confident

Very confident

C7) How confident are you that you know **why** you use your COPD medication?

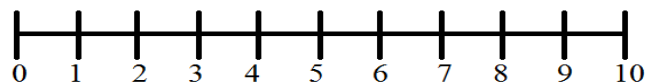


Not confident

Very confident

MANAGING SYMPTOMS OF COPD

C8) How often do you use breathing techniques to manage your symptoms (e.g. slowing your breathing down and pursed lip breathing)?



Never

Always

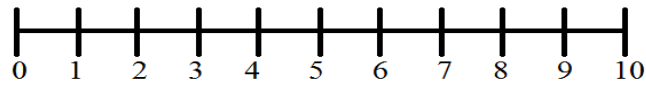
C9) How often do you pace yourself to conserve energy (e.g. plan activities, alternate light and heavy tasks)?



Never

Always

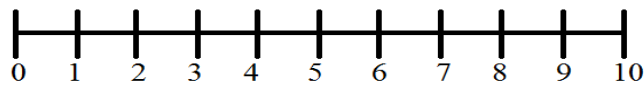
C10) How often do you use positions of ease (e.g. body positions to reduce shortness of breath)?



Never

Always

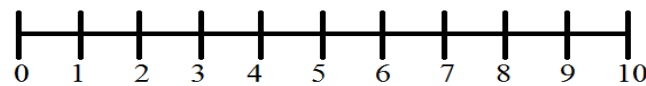
C11) How well do you understand the benefits of exercise?



No understanding

Full understanding

C12) How confident are you that you can take part in exercise?



Not confident

Very confident

C13) How confident are you that you can manage the low mood or depression sometimes associated with COPD?



Not confident

Very confident

C14) How confident are you that you can manage the anxiety and panic sometimes associated with COPD?

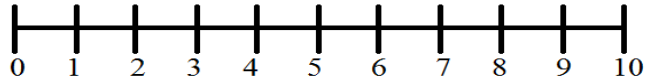


Not confident

Very confident

ACCESSING HELP AND SUPPORT

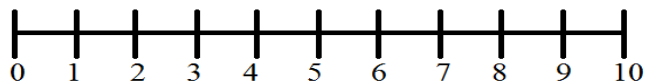
C15) How confident are you that you know how to get aids and appliances if you need them (e.g. shoe horn, shower seat)?



Not confident

Very confident

C16) How confident are you that you know how to get information about welfare and benefits that you might be entitled to?



Not confident

Very confident

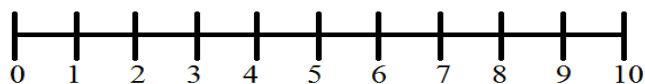
C17) How confident are you that you know how to access facilities for exercise (e.g. gym, pool, walking clubs)?



Not confident

Very confident

C18) How confident are you that you know how to get information about local support groups for people with respiratory conditions?



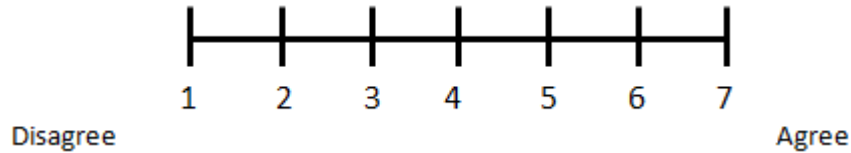
Not confident

Very confident

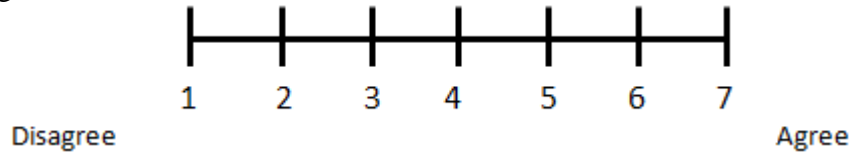
Appendix 4: Psychological Need Thwarting Scale

In regards to your *everyday experiences since being diagnosed with COPD*, please indicate on a scale of 1 (**disagree**) to 7 (**agree**) how much you can relate to each of the following statements. Please circle **one** number.

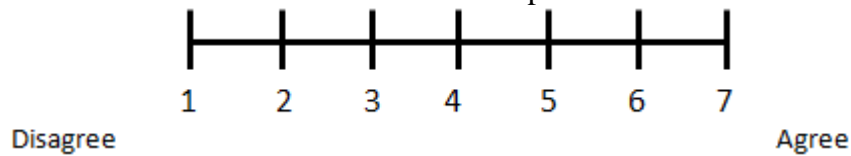
D1) There are situations where I am made to feel inadequate to complete everyday activities



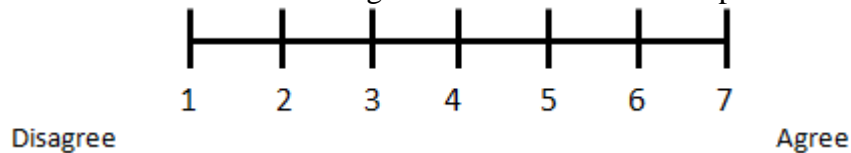
D2) I feel inadequate because I am no longer given the same opportunities as I had before my diagnosis



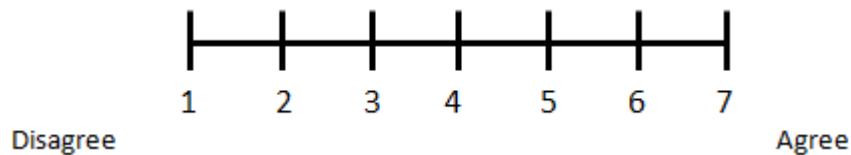
D3) Situations occur in which I am made to feel incapable



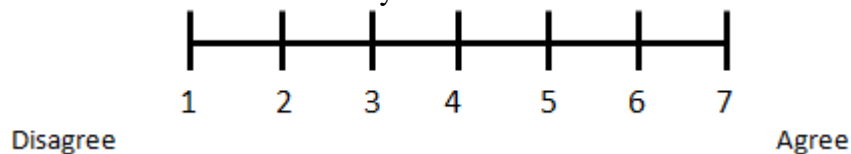
D4) There are times when I am told things that make me feel incompetent



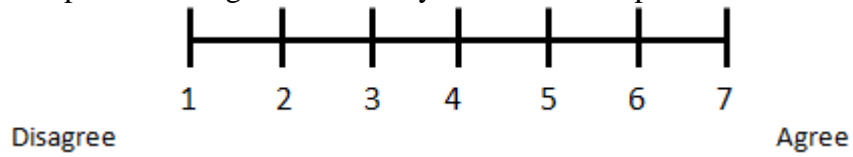
D5) I feel prevented from making choices with regard to the way I engage in everyday activities



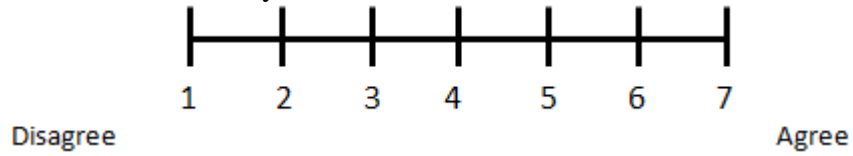
D6) I feel pushed to behave in certain ways



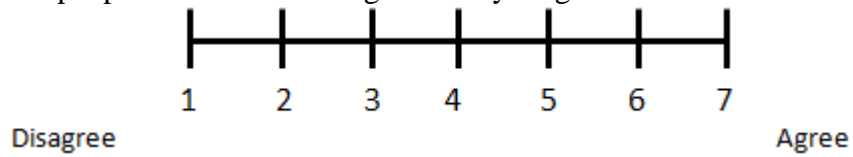
D7) I feel under pressure to agree with lifestyle choices I am provided



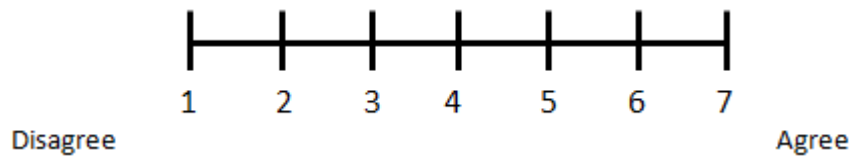
D8) I feel forced to follow lifestyle choices made for me



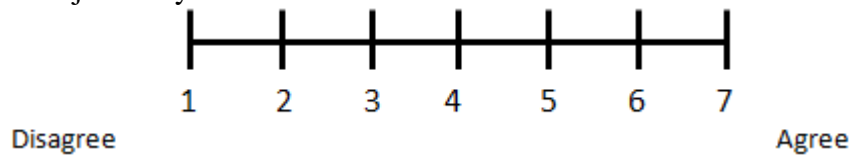
D9) I feel other people dislike me talking about my diagnosis



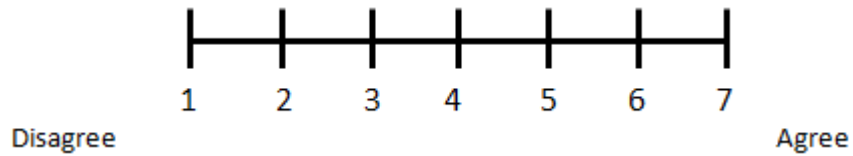
D10) I feel others can be dismissive of me



D11) I feel I am rejected by those around me



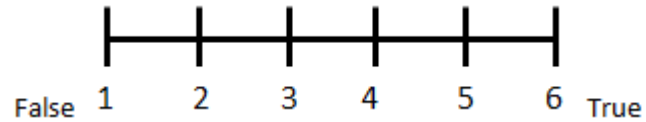
D12) I feel that other people are envious when I overcome my diagnosis and do well



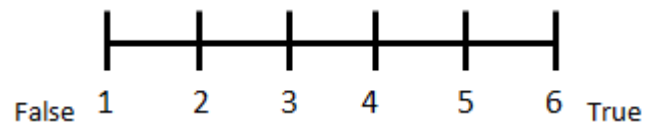
Appendix 5: Psychological Need Satisfaction in Exercise

Thinking about the self-management of your condition, please indicate on scale of 1 (false) to 6 (true) how applicable each of the following statements is to you by circling **one** number.

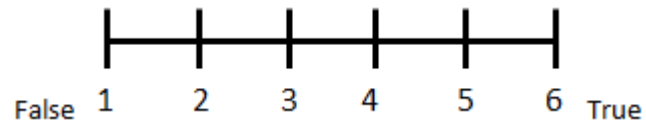
E1) I feel like I am the one who decides what self-management tasks I do



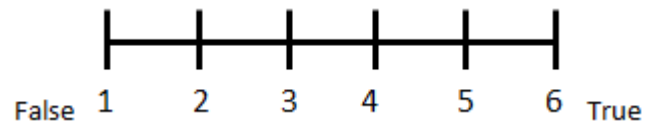
E2) I feel confident I can do even the most challenging self-management regimes



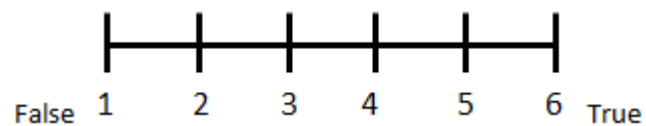
E3) I feel close to people supporting me as they appreciate how difficult the self-management of my condition can be



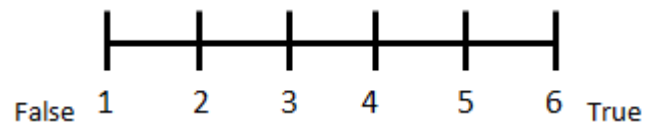
E4) I feel like I have a say in choosing how I self-manage my condition



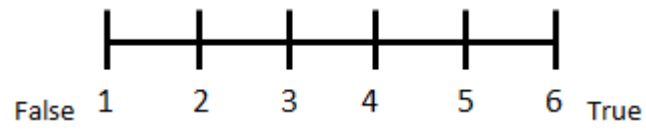
E5) I feel like I am capable of doing even the most challenging self-management tasks



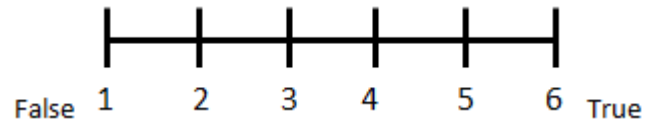
E6) I feel a sense of camaraderie with other COPD patients because we do the same self-management regimes



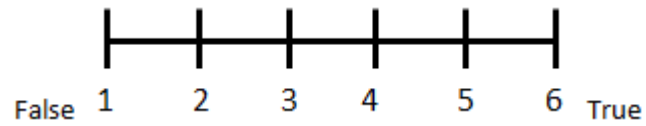
E7) I feel free to self-manage my condition in my own way



E8) I feel capable of completing self-management tasks that are challenging to me



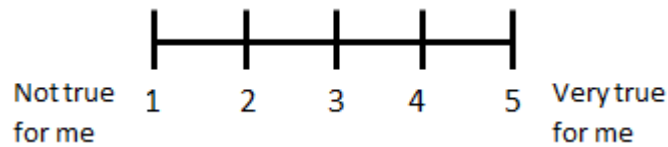
E9) I feel connected to other people with COPD in the knowledge that they are doing the same self-management regimes as me



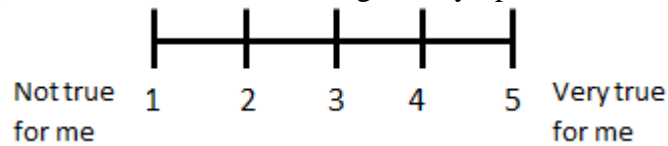
Appendix 6: Behavioural Regulation in Exercise Questionnaire - 3

This section is interested in your reasons for self-managing your COPD.

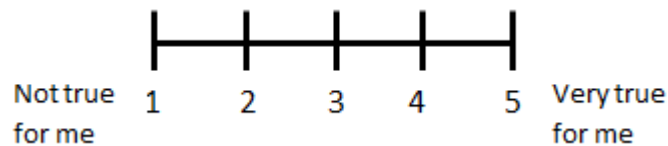
F1) It's important to me to self-manage the symptoms of COPD regularly



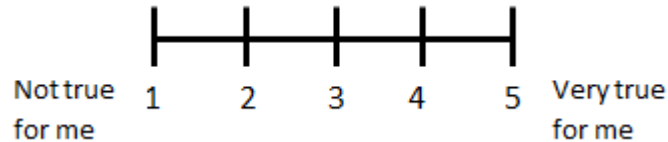
F2) I don't see why I should have to self-manage the symptoms of COPD



F3) I engage activities that support the self-management of my symptoms (e.g., exercise, relaxation) because it is fun



F4) I feel guilty when I don't manage my condition



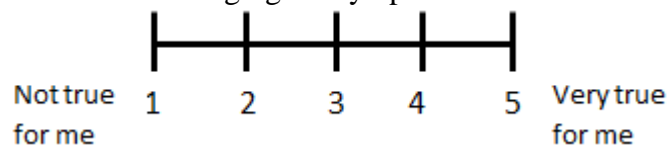
F5) I self-manage the symptoms of COPD because it supports me to achieve my life goals



F6) I self-manage the symptoms of COPD because other people say I should



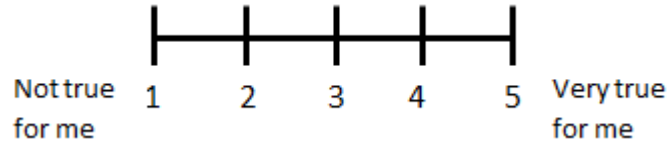
F7) I value the benefits of self-managing the symptoms of COPD



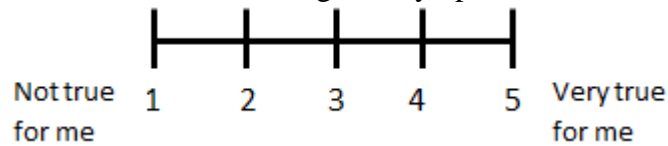
F8) I can't see why I should bother to self-manage the symptoms of COPD



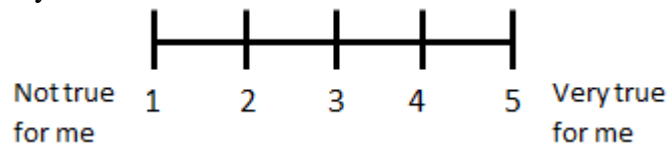
F9) I enjoy some elements of self-managing the symptoms of COPD



F10) I feel ashamed when I do not self-manage the symptoms of COPD



F11) I consider being someone who self-manages their symptoms effectively as forming part of my identity



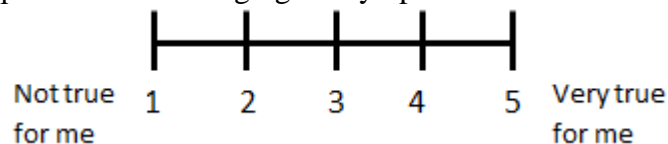
F12) I take part in self-management of the symptoms of COPD because my friends/family/doctor say I should



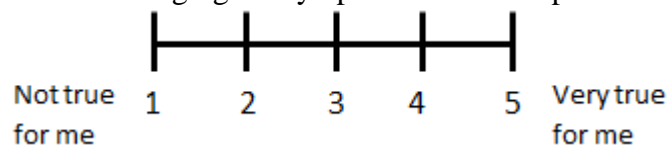
F13) I think it is important to make the effort to self-manage the symptoms of COPD



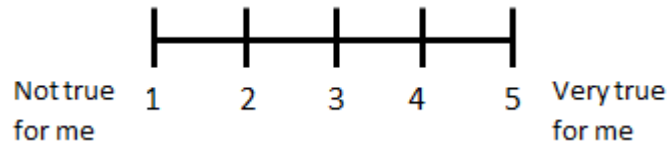
F14) I don't see the point in self-managing the symptoms of COPD



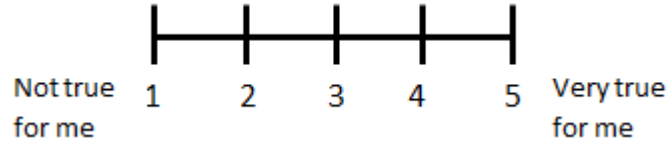
F15) I find elements of self-managing the symptoms of COPD pleasurable



F16) I feel like a failure when I haven't performed activities to self-manage the symptoms of COPD in a while



F17) I consider COPD self-management a fundamental part of who I am



F18) I self-manage the symptoms of COPD because others will not be pleased with me if I don't



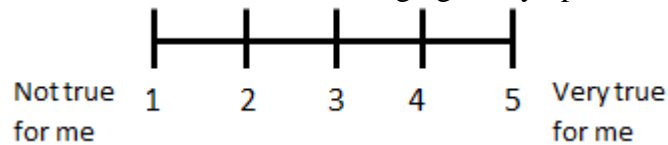
F19) I get restless if I don't perform activities to self-manage the symptoms of COPD regularly



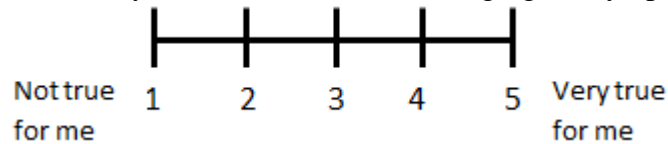
F20) I think self-managing the symptoms of COPD is a waste of time



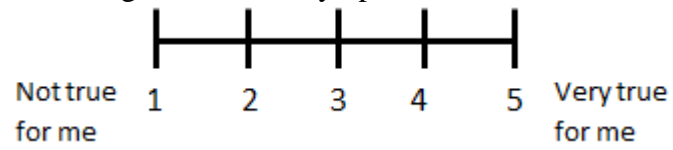
F21) I get pleasure and satisfaction from self-managing the symptoms of my COPD



F22) I would feel bad about myself if I was not self-managing the symptoms of COPD



F23) I consider the self-management of the symptoms of COPD consistent with my values



F24) I feel under pressure from my friends/family/doctor to self-manage the symptoms of COPD



Appendix 7: Bristol COPD Knowledge Questionnaire

Under each heading, please circle **one** answer for each of the 5 statements.

G1. In COPD:

a. In COPD the word “chronic” means it is severe.	True	False	Don't Know
b. COPD can only be confirmed by breathing tests.	True	False	Don't Know
c. In COPD there is usually gradual worsening over time.	True	False	Don't Know
d. In COPD oxygen levels in the blood are always low.	True	False	Don't Know
e. COPD is unusual in people less than 40 years old.	True	False	Don't Know

G2. COPD:

a. More than 80% of COPD cases are caused by cigarette smoking.	True	False	Don't Know
b. COPD can be caused by occupational dust exposure.	True	False	Don't Know
c. Longstanding asthma can develop into COPD.	True	False	Don't Know
d. COPD is commonly an inherited disease.	True	False	Don't Know
e. Women are less vulnerable to the effects of cigarette smoke than men.	True	False	Don't Know

G3. The following symptoms are common in COPD:

a. Swelling of ankles	True	False	Don't Know
b. Fatigue (tiredness)	True	False	Don't Know
c. Wheezing	True	False	Don't Know
d. Crushing chest pain	True	False	Don't Know
e. Rapid weight loss	True	False	Don't Know

G4. Breathlessness in COPD:

a. Severe breathlessness prevents travel by air.	True	False	Don't Know
b. Breathlessness can be worsened by eating large meals.	True	False	Don't Know
c. Breathlessness means that your oxygen levels are low.	True	False	Don't Know
d. Breathlessness is a normal response to exercise.	True	False	Don't Know
e. Breathlessness is primarily caused by a narrowing of the bronchial tubes.	True	False	Don't Know

G5. Phlegm (sputum):

a. Coughing phlegm is a common symptom in COPD.	True	False	Don't Know
b. Clearing phlegm is more difficult if you get dehydrated.	True	False	Don't Know
c. Bronchodilator inhalers can help clear phlegm.	True	False	Don't Know
d. Phlegm causes harm if swallowed.	True	False	Don't Know
e. Clearing phlegm can be assisted by breathing exercises.	True	False	Don't Know

G6. Chest infections/Exacerbations:

a. Chest infections often cause coughing of blood.	True	False	Don't Know
b. With chest infections phlegm usually becomes coloured (yellow or green).	True	False	Don't Know
c. Exacerbations (episodes of worsening) can occur in the absence of a chest infection.	True	False	Don't Know
d. Chest infections are always associated with a high temperature.	True	False	Don't Know
e. Steroid tablets should be taken whenever there is an exacerbation.	True	False	Don't Know

G7. Exercise in COPD:

a. Walking is better exercise than breathing exercises to improve fitness.	True	False	Don't Know
b. Exercise should be avoided as it strains the lungs.	True	False	Don't Know
c. Exercise can help maintain bone density.	True	False	Don't Know
d. Exercise helps relieve depression.	True	False	Don't Know
e. Exercise should be stopped if it makes you breathless.	True	False	Don't Know

G8. Smoking:

a. Stopping smoking will reduce the risk of heart disease.	True	False	Don't Know
b. Stopping smoking will slow down further lung damage.	True	False	Don't Know
c. Stopping smoking is pointless as the damage is done.	True	False	Don't Know
d. Stopping smoking usually results in improved lung function.	True	False	Don't Know
e. Nicotine replacement therapy is only available on prescription.	True	False	Don't Know

G9. Vaccination:

a. A flu jab is recommended every year.	True	False	Don't Know
b. You can get flu from having a flu jab.	True	False	Don't Know
c. You can only have a flu jab if you are 65 or over.	True	False	Don't Know
d. A pneumonia jab protects against all forms of pneumonia.	True	False	Don't Know
e. You can have a pneumonia jab and a flu jab on the same day.	True	False	Don't Know

G10. Inhaled Bronchodilators:

a. All bronchodilators act quickly (within 10 minutes).	True	False	Don't Know
b. Both short and long acting bronchodilators can be taken on the same day.	True	False	Don't Know
c. Spacers (e.g. nebulizer, aerochamber) should be dried with a towel after washing.	True	False	Don't Know
d. Using a spacer device will increase the amount of drug deposited in the lungs.	True	False	Don't Know
e. Tremor may be a side effect of bronchodilators.	True	False	Don't Know

G11. Antibiotic treatment in COPD:

a. To be effective, the course should last at least 10 days.	True	False	Don't Know
b. Excessive use of antibiotics can cause resistant bacteria (germs).	True	False	Don't Know
c. Antibiotics will clear all chest infections.	True	False	Don't Know
d. Antibiotic treatment is necessary for an exacerbation (worsening) however mild.	True	False	Don't Know
e. You should seek advice if antibiotics cause severe diarrhoea.	True	False	Don't Know

G12. Steroid tablets given for COPD (e.g. prednisolone):

a. Steroid tablets help strengthen muscles.	True	False	Don't Know
b. Steroid tablets should be avoided if there is a chest infection.	True	False	Don't Know
c. The risk of long-term side effects due to steroids is less with short courses than with continuous treatment.	True	False	Don't Know
d. Indigestion is a common side effect from using steroid tablets.	True	False	Don't Know
e. Steroid tablets can increase your appetite.	True	False	Don't Know

G13. Inhaled Steroids. (brown, red or orange):

a. Inhaled steroids should be stopped if you are given steroid tablets.	True	False	Don't Know
b. Steroid inhalers can be used for rapid relief of breathlessness.	True	False	Don't Know
c. Spacer devices reduce the risk of getting thrush in the mouth.	True	False	Don't Know
d. Steroid inhaler should be taken before your bronchodilator.	True	False	Don't Know
e. Inhaled steroids improve lung function in COPD.	True	False	Don't Know

Appendix 8: Study one invitation letter

Date:

Dear

This letter has been sent on behalf of Aberystwyth University by the NHS clinical team, to avoid your personal data being shared without consent. If you have any questions, please do not hesitate to get in contact using the details below, or provided on the participation information sheet attached.

Aberystwyth University are working in conjunction with Hywel Dda University Health Board to explore the health-related status and service utilisation of patients with Chronic Obstructive Pulmonary Disease on a waiting-list for Pulmonary Rehabilitation. This study seeks to identify how patients are currently living with their condition, as well as how they access healthcare; this will help decisions to be made about whether or not the current service is working and how it could be improved for patients. This research will also form part of a PhD thesis in Health Psychology.

We would therefore like to invite you to participate in completing a series of short questionnaires which are provided with this letter; these can either be completed in hard copy or online. Provided with this letter is a participant information sheet which we encourage you to read. It contains information about what would be involved with this study to help you decide whether or not this is something that you would like to do. Your decision about whether or not to participate in this study will have no influence on the care that you are receiving or your ability to participate in any future projects.

Many thanks for your time and consideration.

Mr Liam Knox
Adran Seicoleg/ Psychology Department
Penbryn 5,
Campws Penglais Campus,
Prifysgol Aberystwyth University
SY23 3UX
01970 628619.

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: The health-related status and healthcare utilisation of patients on a waiting-list for Pulmonary Rehabilitation.

You are being invited to take part in a research study. Before you make a decision it is important to explain why the research is conducted and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Do not hesitate to ask us if there is anything that is not clear or if you would like additional information.

What is the purpose of the research study?

We are interested in:

- 1) how much understanding individuals have of their condition and how their condition affects their daily lives and well-being in the period before they receive pulmonary rehabilitation, and
- 2) Whether any of these factors determines how likely people are to visit their GPs, be admitted to hospital or to take part in pulmonary rehabilitation.

This research programme may help discover why people choose to attend pulmonary rehabilitation and help improve care for patients on a waiting-list in the near future. This research will also form part of a PhD thesis in Health Psychology.

Why have I been chosen to participate?

You have been invited to participate as someone who has Chronic Obstructive Pulmonary Disease (COPD) and is currently on a waiting list for pulmonary rehabilitation. We would like your help by providing us with answers to some questionnaires.

Do I have to participate?

Participation in this study is completely voluntary. If you wish to take part you will be asked to complete the attached consent form. You are free to withdraw from the study after you have returned the questionnaires without providing us with a reason and without any detriment to your on-going care. In the event of you withdrawing, your data will be destroyed and removed from any analysis. It is possible for us to retrieve your data up to the point that the data is published. After this, your data will have been included and we will no longer be able to remove your data from the group analysis. To do this you simply need to contact the chief-investigator (details at the end of this information sheet).

What will happen to me if I agree to participate in the research?

If you decide to take part in this study, you will be asked to complete a series of questionnaires. These questionnaires will take approximately 30 minutes of your time to complete and can either be filled out in hard copy and mail returned in the prepaid envelope provided, or online using the web address given on the front of the questionnaire packet. Please use only one of these methods.

As this study also aims to explore service utilisation (number of GP visits, hospitalisations) along with the waiting time and uptake of pulmonary rehabilitation, you will be asked to consent for the Aberystwyth Research Team to have access to a summary of this data.

The questionnaires will ask you about socio-demographic data such as; your age, gender and marital / living status. Alongside this, specific questionnaires will measure information such as your health related quality of life, the extent to which COPD affects your daily life and well-being, your reasons for engaging in self-management practices and your understanding of COPD.

This will allow us to better understand 1) how different factors contribute to service utilisation such as hospital or GP visits and quality of life, and 2) to explore whether specific factors can be identified as predictors of uptake of pulmonary rehabilitation so that sufficient support and information is provided for people in the period prior to attending pulmonary rehabilitation.

Data will be analysed by the research team from Aberystwyth University and the findings will be fed back to Hywel Dda University Health Board via a final report as well as disseminated in academic conferences and journal articles.

What will I have to do?

There are no lifestyle restrictions if you help. We will want you to continue your normal activities and all usual health treatments and medications will be unchanged as a result of taking part in this study.

What are the side effects of participating in this study?

There are no known risks to the participant, other than the potential for you to feel tired during completing the questionnaires. To avoid this as much as possible, you will not have to complete the questionnaires in one sitting and will be free to take a breaks at any point or stop altogether if you feel that this is necessary.

What are the benefits associated with me taking part in this research study?

We hope that should you decide to take part that you will find this a rewarding experience. People often enjoy the opportunity to answer questions about their condition and will be contributing useful information about how services can be improved for future patients. Unfortunately, we cannot pay you for participating in this study. Upon taking part, you also have the option of receiving a summary of the findings via email, which you can opt into by checking the relevant box and providing an email address on the consent form.

What will happen if something goes wrong?

If you feel that you have any reason to complain about any aspect of the way you have been approached in the hospital or further treated during the course of the study, the normal National Health Service complaints mechanisms are available to you.

Will my participation in this study be kept confidential?

All personal data will remain confidential between the participants and the research team and any data that you provide will be stored securely at Aberystwyth University. All personal data will be kept separate to your questionnaire responses and a coding system will be used to ensure that only the researcher is able to identify which set of answers belongs to each participant.

All participants' answers will be pooled into one data set and only group results will be used in any publications so that no one individual will be identifiable.

What will happen with the results generated by this research programme?

The findings from our study may be published in scientific journals and presented at conferences in a fully anonymized way.

Who is organizing and funding this research?

This research is the result of collaboration between Hywel Dda University Health Board and Aberystwyth University.

Who has reviewed the study?

Our research study has undergone review by medical doctors and scientific researchers within Hywel Dda University Health Board and across Wales As well as an NHS Research Ethics Committee (WALES REC 7).

If you have any further queries please do not hesitate to contact:

Mr Liam Knox

Chief Investigator

Department of Psychology, Aberystwyth University.

Telephone – 01970 628619

E-Mail – lik2@aber.ac.uk

Dr Rachel Rahman

PhD Postgraduate Supervisor

Department of Psychology, Aberystwyth University.

Telephone - 01970 621749

E-mail – rjr@aber.ac.uk

Prof. Keir Lewis

Hon. Consultant, Hywel Dda University Health Board &

Professor of Respiratory Medicine, Swansea University

Telephone – 01554 783133

Email – k.e.lewis@swansea.ac.uk

Contacts for further information:

For independent advice, please contact Mr Chris Tattersall, R&D Department, Withybush Hospital, Tel: 01437 773813.

Email: chris.tattersall@wales.nhs.uk

Appendix 10: Study one consent form

REC reference: 16/WA/0068

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: The health-related status of COPD patients on a waiting-list for PR.

Name of Researchers: Mr Liam Knox, Dr Rachel Rahman, Professor Keir Lewis

Contact Telephone Number: 01970 628619.

Please
initial box

1. I confirm that I have read the information sheet S1 V4 dated 04/03/2016 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of the data collected during the study, may be looked at by individuals from Aberystwyth University, from regulatory authorities or from the NHS organisation, where it is relevant to my taking part in this research.
4. I consent for the Aberystwyth Research team to be allowed access my clinical records alongside the clinical teams that will be looking after me.
5. I understand that any use of the results will be anonymised so that my identity, questionnaire answers and clinical data cannot be connected.
6. Please tick the box if you would like to receive a summary of the results for this study and please provide an email address you would like us to send this to:

7. I agree to take part in the above study.

Name of Participant

Date

Signature

Appendix 11: Study one reminder letter

Date:

Please note that this letter has been sent on behalf of Aberystwyth University by Hywel Dda clinical staff, to avoid your personal data being shared without consent. If you have any questions, please do not hesitate to get in contact using the details below, or provided on the participation information sheet attached.

Dear

We recently contacted you to invite you to take part in a piece of research that Aberystwyth University are conducting in conjunction with Hywel Dda University Health Board. The research explores the health-related status and service utilisation of patients with Chronic Obstructive Pulmonary Disease on a waiting-list for Pulmonary Rehabilitation. This study seeks to identify how patients are currently living with their condition, as well as how they access healthcare. This will help decisions to be made about whether or not the current service is working and how it could be improved for patients. This research will also form part of a PhD thesis in Health Psychology.

If you have decided that you would not like to take part in this research then please ignore this letter; no further action is required and we will not send any further letters concerning this research project. We would however like to thank you for your time and consideration.

If you are still interested to participate in the research then this is a gentle reminder and we have included a second pack of information about the research for your convenience. In summary, the research involves completing a series of short questionnaires which are provided with this letter; these can either be completed in hard copy or online. Provided with this letter is a participant information sheet which we encourage you to read. It contains more detailed information about what would be involved to help you decide whether or not this is something that you would like to do. Your decision about whether or not to participate in this study will have no influence on the care that you are receiving or your ability to participate in any future projects.

If you would like to take part in this research please read through the accompanying information and return a signed consent form along with your completed questionnaire in the prepaid envelope provided.

Many thanks for your time and consideration.

Mr Liam Knox
Adran Seicoleg/ Psychology Department
Penbryn 5,
Campws Penglais Campus,
Prifysgol Aberystwyth University
SY23 3UX

Appendix 12: Study one non-normal distributions

Measure	Statistic	Significance
EQ index score	0.139	$P < 0.05$
UCOPD: About COPD	0.154	$P < 0.05$
Relatedness thwarting	0.196	$P < 0.01$
Autonomy satisfaction	0.126	$P < 0.05$

Table 0.1. Significant non-normal measures as determined by Kolmogorov-Smirnov tests in study one.

Appendix 13: PocketMedic digital health film titles and descriptions

Film title	Description
Introducing COPD	GP Dr Jane Gilbert explains COPD with the help of a sponge! Significant health improvements can be gained by making lifestyle changes, taking medication, and performing self-management.
Managing things yourself	Lawrence and Sandra share their experiences of living with COPD. Lawrence demonstrates some breathing exercises and shares practical advice.
Don't talk to me about fitness	On the sofa, walking down the garden, or out with the dog – there are lots of ways to start exercising. Derrick and Alwyn know what it's like to feel breathless and share their experiences, but the bottom line is that anything you can do will help.
Understanding breathlessness	“Breathlessness is the number one complaint and fear of those with COPD”. Dr Jane Gilbert acknowledges the anxiety among people with COPD. Susie remembers how she used to panic when she

	felt breathless but is pleased to report that she can now control it herself.
Welcome to pulmonary rehabilitation	A gentle introduction to a PR course and why it is so important.
Coping with COPD	“Half of the battle is your mental attitude”. People living with COPD share their strategies for coping with the ups and downs of daily life, from getting out in the car, to seeing friends, and surfing the internet.
Sleep	Alwyn, Susie, Derrick, and Lawrence talk about their experiences of sleeping and what works for them.
The proof is in the pudding	People with COPD and their families describe how a PR course has changed their lives.
COPD and medication	A whole armoury of medication is available to those affected by COPD. Dr Jane Gilbert talks about what is on offer and people living with COPD share their experiences.
Pace yourself	It can be hard to adjust to a new pace of life. Susie found that a PR course really made a difference to her everyday life.

Appendix 14: Study two participant information sheet

PARTICIPANT INFORMATION SHEET

REC reference: 16/WA/0130

PROJECT TITLE: Are outcomes for patients with COPD improved after receipt of educational films?

You are being invited to take part in a research study. Before you make a decision it is important to explain why the research is conducted and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Do not hesitate to ask us if there is anything that is not clear or if you would like additional information.

1. What is the purpose of the research study?

Pulmonary rehabilitation (PR) has been shown to help patients with Chronic Obstructive Pulmonary Disease (COPD) improve their exercise tolerance, dyspnoea and health-related quality of life. Attendance at these PR programmes, however, is extremely low. We believe that empowering patients through increased education and specific disease knowledge may have a positive effect on patients' engagement with PR. This study aims to compare patients receiving standard PR with patients receiving educational digital films in addition to standard PR. This will provide valuable information about how we could enhance support of patients with COPD in the near future. This research will also form part of a PhD thesis in Health Psychology.

2. Why have I been chosen to participate?

You have been invited to participate as someone who has Chronic Obstructive Pulmonary Disease (COPD) and is about to commence PR. We are specifically working with patients from Hywel Dda UHB catchment area and are seeking to engage with a wide range of the population.

3. Do I have to participate?

Participation in this study is completely voluntary. Should you decide to take part, you will be asked to complete a consent form to indicate your willingness to take part and to consent to the Aberystwyth research team accessing information about your hospital and GP visits. You are free to withdraw from the study at any time without providing us with a reason and without any detriment to your on-going care. Your decision about whether or not to participate in this study will have no influence on the care that you are receiving or your ability to participate in any future projects or the standard PR programme.

4. What will happen to me if I agree to participate in the research?

You will have a minimum of 24 hours to decide if this is something you wish to participate in, so we encourage you to take your time to consider. If you wish for more information please get in contact with us using the details at the bottom of this information sheet. Alternatively, a member of the Aberystwyth research team will be available during your assessment appointment to answer any questions that you may have. We will, however, need

to know 4 weeks ahead of your pulmonary rehabilitation start date so that the relevant information can be sent to you.

If you would like to take part in the study, you can provide informed consent either by signing the attached consent form and returning this in the prepaid envelope provided or you can give your consent form to a member of the Aberystwyth research team, who will be available at your assessment appointment, should you wish to ask any questions.

Once you have provided us with a signed consent form you will be allocated to one of 2 groups. Group 1 will receive the usual PR programme. Group 2 will receive the usual PR programme alongside 10 educational digital films. It is important to randomize participants into groups so you will not be able to choose which group you are placed.

You may have recently taken part in a study titled “The health-related status and healthcare utilisation of patients on a waiting-list for Pulmonary Rehabilitation.” If you have completed the questionnaires of this study within the last month, there is no need to recomplete them. Instead, you can consent to allow us to use the results from that study in lei of completing the same questionnaires again.

If you did not take part in the above study, or did not take part within the last month, this is not a problem. We ask that you complete the questionnaire booklet provided and send this back to us when you send the signed consent form. If you prefer, you may fill out these questionnaires online, following the web address given in the letter. We ask that you fill out the questionnaires using only one of these methods. The questionnaires should take no longer than 30 minutes to complete.

Only following the completion of these questionnaires will you be told which group you have been assigned to.

For standard PR: you will be given details for your local PR programme which you should attend weekly. After 7 weeks this programme will be complete and you will be asked to complete the same questionnaires you were given at the start of the study.

For educational digital films and PR: you will be sent a weekly email which contains a link to an online digital film. The digital films show health care professionals and other COPD patients talking about the self-management of their condition and their personal wellbeing. After each digital film there is a feedback page asking several questions, designed to remind and encourage you to use your newly gained knowledge to improve your health and behaviour. Each time you watch a digital film an electronic file will be created and sent, notifying the research team of what time and which film you watched. After week 3, you will also be given details for your local PR programme, which you should attend alongside watching the films, as you ordinarily would have. After week 10, both the weekly digital films and the PR will be complete and you will be given the same questionnaires you were asked to complete at the start of the study.

Whichever group you are assigned to, you will be contacted again 6 months after the end of PR and asked if you would complete the same questionnaires you were given at the start of the study. This is to enable us to explore any long term effects that there may or may not be. There may be the possibility for you to take part in a further research linked with this study. If you would like to be contacted regarding further opportunities of participation, please tick the box on the consent form.

5. What are the positives and negatives of participating in this study?

We hope that should you decide to take part that you will find this a rewarding experience. People often enjoy the opportunity to take part in research studies designed to enhance clinical care and provide information regarding COPD. You would also be contributing useful information about how services can be improved for future patients.

People who contribute to the research will also be offered the opportunity to receive a summary report of the findings which you may find interesting. Unfortunately, we cannot pay you for participating in this study.

There are no known risks to the participant, other than the potential for you to feel tired watching the digital films or completing the questionnaires. You are free to take a break from watching the digital films or answering the questions, or stop altogether should you wish.

6. What will happen if something goes wrong?

If you feel that you have any reason to complain about any aspect of the way you have been approached or treated during the course of the study, the normal National Health Service complaints mechanisms are available to you.

7. Will my participation in this study be kept confidential?

All personal data will remain confidential and will only be made available to the research team. Any data that you provide will be stored securely at Aberystwyth University. All personal data (e.g. name, address) will be kept separate to your questionnaire responses and clinical data and a coding system will be used to ensure that only the researcher is able to identify which set of answers belongs to each participant. This code is kept to enable us to look at your data from different timepoints and in the event of you wishing to withdraw Every participant's answers will be pooled into one data set and only group results will be used in any publications so that no one individual will be identifiable.

8. What will happen with the results generated by this research programme?

The findings from our study may be published in scientific journals and presented at conferences in a fully anonymized way.

9. Who is organizing and funding this research?

This research is the result of collaboration between Hywel Dda University Health Board and Aberystwyth University. This research will also form part of a PhD thesis in Health Psychology.

10. Who has reviewed the study?

Our research study has been approved by the NHS Research Ethics Committee.

If you have any further queries please do not hesitate to contact:

Mr Liam Knox

Chief Investigator

Department of Psychology, Aberystwyth University.

Telephone – 01970 628619

E-Mail – lik2@aber.ac.uk

Dr Rachel Rahman

PhD Postgraduate Supervisor

Department of Psychology, Aberystwyth University.

Telephone - 01970 621749

E-mail – rjr@aber.ac.uk

Prof. Keir Lewis

Hon. Consultant, Hywel Dda University Health Board &

Professor of Respiratory Medicine, Swansea University

Telephone – 01554 783133

Email – k.e.lewis@swansea.ac.uk

Contacts for further information:

For independent advice, please contact Mr Chris Tattersall, R&D Department, Withybush Hospital, Tel: 01437 773813.

Email: chris.tattersall@wales.nhs.uk

Appendix 15: Study two consent form

Participant reply slip

If you would like to participate in this study please return this reply slip along with a signed consent form in the prepaid envelope you have been provided. Alternatively, a member of the Aberystwyth research team will be available during your assessment, to answer any questions you may have and you can return your reply slip and consent form to them directly if you would prefer.

It would be helpful if you could supply us with an address and postcode so that we may send you the appropriate follow up questionnaires, as well as a current email address so that if you're allocated to group 2 you may be sent the digital films.

Name:

Address:

Email address:

Alternatively you may contact Liam Knox directly using the contact details below:

Mr Liam Knox

Chief Investigator

Telephone – 01970 628619

E-Mail – lik2@aber.ac.uk

REC reference: 16/WA/0130

Study Number: 200905

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: Are outcomes for patients with COPD improved after receipt of educational films?

Name of Researchers: Mr Liam Knox, Dr Rachel Rahman, Professor Keir Lewis

Please
initial box

1. I confirm that I have read the information sheet S2 v4.1 dated 03/09/2017 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of the data collected during the study, may be looked at by individuals from Aberystwyth University, from regulatory authorities or from the NHS organisation, where it is relevant to my taking part in this research.
4. I consent for the Aberystwyth research team to be allowed access to my clinical records alongside the clinical teams that will be looking after me
5. I understand that any use of the results will be anonymised so that my identity, questionnaire answers and clinical data cannot be connected.
6. I have taken part in the first study within the last month and consent that my results given in that study may be used in lei of the first set of questionnaires usually given at the start of the current study.
7. I consent for the Aberystwyth research team to contact me about further related studies
8. Please tick the box if you would like to receive a summary of the results of this study.
9. I agree to take part in the above study.

Name of Participant Date Signature

Appendix 16: Study two invitation letter

REC reference: 16/WA/0130

Date:

Dear

Aberystwyth University are working in conjunction with Hywel Dda University Health Board to investigate whether a series of educational films about Chronic Obstructive Pulmonary Disease (COPD), improve health-related outcomes for patients with COPD. This will help decisions to be made about how the current standard care could be improved for future patients. This research will also form part of a PhD thesis in Health Psychology.

We would therefore like to invite you to participate in a controlled trial research study. Details about the study are included in the participant information sheet attached to this letter. Your decision about whether or not to participate in this study will have no influence on the care that you are receiving or your ability to participate in any future projects.

Please note that this letter has been sent on behalf of Aberystwyth University by the NHS clinical team to avoid your personal data being shared without consent.

Therefore, if you decide that you would like to get involved then please contact the research team, either by using the contact details below or by returning the reply slip at the end of the participant information sheet, at which point the research team will be able to contact you directly. We encourage you to take time to consider and discuss this with your relatives or GP, should you wish.

Many thanks for your time and consideration.

Mr Liam Knox
Adran Seicoleg/ Psychology Department
Penbryn 5,
Campws Penglais Campus,
Prifysgol Aberystwyth University
SY23 3UX
01970 628619.

Appendix 17: Study two reminder letter

REC reference: WA/16/0130

Date:

Dear

We recently contacted you to invite you to take part in a piece of research that Aberystwyth University are conducting in conjunction with Hywel Dda University Health Board. As we have not heard back from you, we thought we would send this invitation pack to make sure that all the relevant information got to you. If you would like to take part in this research please read through the accompanying information and return a signed consent form in the prepaid envelope provided. If, however, you do not wish to take part in the research you do not need to do anything, as we will not send any further letters concerning this research. We do thank you for your time and consideration.

We wish to investigate whether a series of educational films about COPD, improve health-related outcomes for patients with Chronic Obstructive Pulmonary Disease. This will help decisions to be made about how the current standard care could be improved for future patients. This research will also form part of a PhD thesis in Health Psychology.

We would therefore like to invite you to participate in a controlled trial research study. Details about the study are included in the participant information sheet attached to this letter. Your decision about whether or not to participate in this study will have no influence on the care that you are receiving or your ability to participate in any future projects.

Please note that this letter has been sent on behalf of Aberystwyth University by the clinical team to avoid your personal data being shared without consent. Therefore, if you decide that you would like to get involved then please contact the research team, either by using the contact details below or by returning the reply slip at the end of the participant information sheet, at which point the research team will be able to contact you directly. We would encourage you to take time to consider, however, we will need to know 4 weeks ahead of your pulmonary rehabilitation start date so that the relevant information can be sent to you.

Many thanks for your time and consideration.

Mr Liam Knox
Adran Seicoleg/ Psychology Department
Penbryn 5,
Campws Penglais Campus,
Prifysgol Aberystwyth University
SY23 3UX
01970 628619.

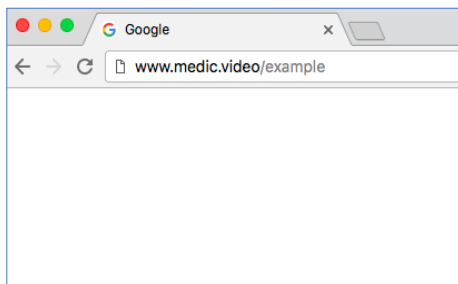
Are outcomes for patients with COPD improved after receipt of educational films?

Many thanks for agreeing to participate in this research study and for completing a questionnaire booklet. Below is the link to the short digital films.

Each film has been created by NHS healthcare professionals and people living with long term conditions to help you to understand and manage your health.

To watch these films, please type the web address below into your PC, tablet or smart phone browser and click enter:

<http://www.medic.video/y1-copd>



Please ensure that you type the link into the address bar at the top of your browser – NOT the search box in the middle of the screen.

Please watch these films in your own time. You can watch them all at once or over a few weeks, but most importantly, you can watch each film as many times as you like.

In approximately 7 weeks we will post you another questionnaire booklet. We really hope that you find these films useful, but even if you did not like them, please take the time to fill out the questionnaire we send. This helps us understand the effects the films have. Even if you did not watch them, all this information is useful to improve them for future patients.

If you have any questions regarding the study, please contact Liam Knox using the details on your participant information sheet.

If you have any difficulties accessing the films or have any comments, please email the team at patient@pocketmedic.org.

Appendix 19: Study two non-normal distributions

Measure	Condition one		Condition two		Condition three	
	Statistic	Significance	Statistic	Significance	Statistic	Significance
Disease-specific HRQoL			0.804	$P<0.05$		
EQ index	0.871	$P<0.05$	0.743	$P<0.05$		
UCOPD: Managing symptoms of COPD			0.757	$P<0.05$		
UCOPD: Total					0.856	$P<0.05$
Relatedness satisfaction	0.862	$P<0.05$				

Table 0.2. Significant non-normal baseline measures as determined by Shapiro-Wilk tests in study two.

Measure	Condition one		Condition two		Condition three	
	Statistic	Significance	Statistic	Significance	Statistic	Significance
EQ index	0.842	$P<0.05$	0.755	$P<0.05$		
EQ VAS	0.898	$P<0.05$				
UCOPD: Managing symptoms of COPD	0.841	$P<0.05$				
UCOPD: Total	0.895	$P<0.05$				
Autonomy thwarting	0.887	$P<0.05$			0.809	$P<0.05$
Autonomy satisfaction			0.739	$P<0.05$		
Competence satisfaction			0.799	$P<0.05$		
Relatedness satisfaction			0.770	$P<0.05$		

Table 0.3. Significant non-normal follow-up measures as determined by Shapiro-Wilk tests in study two.

Appendix 20: Study three invitation letter

REC reference: 16/WA/0134

Dear

Thank you very much for your participation in the trial of the Chronic Obstructive Pulmonary Disease educational digital films; the data you have provided will be extremely useful for informing whether this new intervention can help patients with COPD. In addition to the information that you have already provided us with, we are interested to explore how they have been used in practice and to receive any feedback, positive or negative that you may have about the films themselves.

We are therefore interested to interview a sub-sample of individuals who experienced the educational film arm of the trial and would therefore like to invite you to participate in an interview. The interviews will take approximately 30-60 minutes, in a place of your choosing. Please note that we are interested in hearing from you even if you did not watch the films, and would like to understand why and hear your feedback.

Please read the attached information sheet for more details and if this is something that you would like to participate in, please sign and return the attached consent form and reply slip using the prepaid envelope provided or by contacting the chief-investigator, Liam Knox, directly using the details provided. Your decision about whether or not to participate in this study will have no influence on the care that you are receiving or your ability to participate in any future projects.

Many thanks for your time and consideration.

Mr Liam Knox
Adran Seicoleg/ Psychology Department
Penbryn 5,
Campws Penglais Campus,
Prifysgol Aberystwyth University
SY23 3UX
01970 628619.

Appendix 21: Study three participant information sheet

PARTICIPANT INFORMATION SHEET

REC reference: 16/WA/0134

PROJECT TITLE: How do patients with Chronic Obstructive Pulmonary Disease experience a series of educational films to support Pulmonary Rehabilitation?

You are being invited to take part in a research study. Before you make a decision it is important to explain why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Do not hesitate to ask us if there is anything that is not clear or if you would like additional information.

1. What is the purpose of the research study?

We would like to understand patients' opinions and experiences of the digital films that you have recently been prescribed. We would therefore like to interview a selection of people who received the films alongside pulmonary rehabilitation (PR) in order to gather information about what you liked/disliked, found useful/unnecessary, etc. If you were prescribed the films but chose not to watch them we would still be interested to hear from you to better understand why. All of this information will help us to consider how to improve the films for future use. This research will also form part of a PhD thesis in Health Psychology.

2. Why have I been chosen to participate?

You have been invited to participate as someone who has Chronic Obstructive Pulmonary Disease (COPD) and has just completed a research study exploring the use of educational digital films alongside PR.

3. Do I have to participate?

Participation in this study is completely voluntary. If you do not wish to participate then we are grateful for your contribution to the research thus far. There is no need for you to do anything else. If you do wish to take part you will be asked to complete the attached consent form and reply slip and return it to the researcher in charge who will then contact you to arrange a suitable time for the interview. You are also free to withdraw from the study after you have completed the interview, without providing us with a reason and without any detriment to your on-going care. In the event of you withdrawing, your data will be destroyed and removed from any analysis. It is possible for us to retrieve your data up to the point that

the data is published. After this, your data will have been included and we will no longer be able to remove your data from the group analysis. To do this you simply need to contact the chief-investigator (details at the end of this information sheet).

4. What will happen to me if I agree to participate in the research?

You have at least 1 week to decide whether you would like to take part and so please feel able to take time to consider whether this is something that you would like to do. If you would like to take part we ask that you return a signed consent form and reply slip to us in the prepaid envelope provided, or contact the chief-investigator, Liam Knox, directly if you have any additional questions.

Although we would like to interview everyone who expresses interest in taking part in this research, we can only include a total of 20 people for this study. As such, even if you return a signed consent form, there is a slight possibility that we will not be able to interview you about your experiences.

If you are interested in participating in this study, you will be contacted to arrange a mutually convenient time to conduct the interview which can be organised to take place in the most convenient place for you; this could be at your local hospital or at your home if you would prefer. You are welcome to have someone with you during the interview, if you would like. The interview should take no longer than 30-60 minutes of your time (depending on how long you are willing and able to discuss the topic).

The interview will ask you about how you used the educational films and your experiences of watching them and to consider if and how the films contributed to your COPD management. Questions will also be asked about your opinions on the films and any feedback you would like to provide from the 10-week intervention.

This interview will be recorded and then transcribed (a script made of the interview) to allow for an accurate analysis of the content of the interviews. The recording and transcription will be stored securely at Aberystwyth University.

5. What are the benefits and limitations of participating in this study?

There are no known risks to the participant, other than the potential for you to feel tired during the interview. To avoid this as much as possible, you will not have to complete the interview in one sitting and will be free to take breaks at any point or stop altogether if you feel that this is necessary.

We hope that should you decide to take part that you will find this a rewarding experience. People often enjoy the opportunity to talk about their experiences and will be contributing useful information about how services can be improved for future patients.

People who contribute to the research will also be offered the opportunity to receive a summary report of the findings which you may find interesting. Unfortunately, we cannot pay you for participating in this study.

6. What will happen if something goes wrong?

If you feel that you have any reason to complain about any aspect of the way you have been treated during the course of the study, the normal National Health Service complaints mechanisms are available to you.

7. Will my participation in this study be kept confidential?

All personal data will remain confidential between the participants and the research team and any data that you provide will be stored securely at Aberystwyth University. All personal data will be kept separately to your interview transcript and a coding system will be used to ensure that only the researcher is able to identify which interview belongs to each participant.

Any information that could be used to identify you (name, address, etc.) will be taken out of the transcript. Your data will be pooled together and any quotes used for the publication of this research will be completely anonymised.

8. What will happen with the results generated by this research programme?

The findings from our study may be published in scientific journals and presented at conferences. Any verbatim quotes used from the interview will be completely anonymised.

9. Who is organizing and funding this research?

This research is the result of collaboration between Hywel Dda University Health Board and Aberystwyth University and forms part of a programme of PhD study.

10. Who has reviewed the study?

Our research study has undergone review by medical doctors from Hywel Dda UHB and scientific researchers from Aberystwyth University. The study has also been approved by a NHS Research Ethics Committee (WALES REC 7).

If you have any further queries please do not hesitate to contact:

Mr Liam Knox

Chief Investigator

Department of Psychology, Aberystwyth University.

Telephone – 01970 628619

E-Mail – lik2@aber.ac.uk

Dr Rachel Rahman

PhD Postgraduate Supervisor

Department of Psychology, Aberystwyth University.

Telephone - 01970 621749

E-mail – rjr@aber.ac.uk

Prof. Keir Lewis

Hon. Consultant, Hywel Dda University Health Board &

Professor of Respiratory Medicine, Swansea University

Telephone – 01554 783133

Email – k.e.lewis@swansea.ac.uk

Contacts for further information:

For independent advice, please contact Mr Chris Tattersall, R&D Department, Withybush Hospital, Tel: 01437 773813.

Email: chris.tattersall@wales.nhs.uk

Appendix 22: Study three consent form

Participant reply slip

If you would like to participate in this study please return this reply slip along with a signed consent form in the prepaid envelope you have been provided. It would be helpful if you could supply us with a contact number so that we may get in touch to arrange interviews.

Name:

Contact number:

For the next 2 questions there are no right or wrong answers, we just want to include a representative sample from both locations as well as people who fully engaged with the digital films and those who didn't. This will give us a better understanding and help us consider how to improve the films for future use.

Where are you registered to receive pulmonary rehabilitation?

- Glangwili Hospital, Carmarthen
 Prince Philip Hospital, Llanelli

How much would you say you engaged with the digital films?

- Not at all Moderately Completely

Alternatively you may contact LIAM KNOX directly using the contact details below:

Mr Liam Knox

Chief Investigator

Department of Psychology, Aberystwyth University.

Telephone – 01970 628619

E-Mail – lik2@aber.ac.uk

REC reference:16/WA/0134

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: How do patients with Chronic Obstructive Pulmonary Disease experience a series of educational films to support Pulmonary rehabilitation?

Name of Researchers: Mr Liam Knox, Dr Rachel Rahman, Professor Keir Lewis

Contact Telephone Number: 01970 628619.

Please
initial box

1. I confirm that I have read the information sheet S3 V5 dated 05/05/2016 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of the data collected during the study, may be looked at by individuals from Aberystwyth University (including researchers and transcription services), from regulatory authorities or from the NHS organisation, where it is relevant to my taking part in this research.

4. I understand that the interview will be recorded to ensure an accurate account of the topics discussed.

5. I understand that anonymised verbatim quotes will be used in any dissemination of the results.

6. Please tick the box if you would like to receive a summary of the results of this study and please provide an email address you would like us to send this to:

7. I agree to take part in the above study.

Name of Participant

Date

Signature

Appendix 23: Study three interview schedule

Interview Schedule

- 1) Greetings
- 2) Explain purpose of the interview
- 3) Explain format of the interview (semi-structured, questions grouped into sections)

Just to begin...

- 4) Can you tell me about yourself and your diagnoses of COPD?
 - a. Age, education, demographics, job (if applicable)...
 - b. When were you diagnosed?
 - c. What sort of feelings did you have after hearing this diagnosis?

Moving onto the time you spent before starting Pulmonary Rehabilitation

- 5) What was your understanding of COPD?
 - a. What did you know about the disease?
 - b. How serious did you think it was?
 - c. What research did you do, how and where?
- 6) Who did you think was responsible for managing your COPD?
 - a. You/Doctor/Nurse?
- 7) How did you find coping/managing your symptoms between appointments?
- 8) How did you find self-managing the symptoms of your COPD during this time?
 - a. Was there anything you found particularly difficult or did you pick up things quite naturally?
 - b. How often did you get medical help at any point, go see your GP, things like that?
 - i. What for?
 - ii. How did you find this medical help?
 - iii. How did you find the information you received? Were your questions answered?
- 9) So the conversation you had with your doctor about PR, how did that go?
 - a. How did the conversation make you feel?
 - i. About COPD as a whole
 - ii. Specifically about PR
 1. Was there anything in particular that made you want to attend?
 - b. When you heard about the digital films what were your initial thoughts?
 - i. How did you feel about receiving something alongside PR?

These next questions are on the digital films themselves

- 10) Tell me about your overall feelings towards the digital films.
 - a. What did you like?
 - b. What did you dislike?
 - c. Did you watch many of the films?
 - i. How many?
 - d. What was it like to have the information in film form? Rather than written?
 - e. Tell me about when you watched the films.
 - i. Specific time? Spare 5 minutes?
 - ii. Were they in the background or were you just focused on the films?
 - iii. Did you change at all how you watched them?
 1. If yes, how did you change?
 - iv. Did you find the feedback form useful for you in any way?
 1. If so, how?
 - v. How important do you think it is to have a feedback form connected with each film?
- 11) Did you watch any with your family/carers?
 - i. How did your family find them?
 - ii. What was their understanding of COPD after watching them? Had this changed?
- 12) How did you find the things discussed on the digital films?
 - a. Was the information useful?
- 13) How did the patients featured in the films make you feel?
- 14) Did your feelings about your ability to manage your diagnosis change at all during the intervention? If so, how?
- 15) Tell me about your self-confidence completing everyday activities during this time.
 - a. Did it change or stay the same?
 - b. Did you ever feel the need to contact your GP for anything?
 - i. If yes, tell me more about this.
 1. What sort of things did you talk about? Why?
 - ii. If no,
 1. Was there a particular reason why not?
- 16) Before starting PR, how did the films make you feel about rehabilitation?
 - a. Made you enthusiastic?
 - b. Put off?
- 17) Ideally, how often would you like to watch the films? And would you revisit any of them?
 - a. All in once go?
 - b. Daily/weekly?
 - c. Revisit any?

The next questions focus on both the digital films and Pulmonary Rehabilitation

- 18) Can you tell me how you experienced the digital films and pulmonary rehabilitation side by side?
- a. Contradicting information?
 - b. Behaviour reinforcement?
 - c. Repetition?
 - i. Did this effect how you felt about either digital films or PR?
 - d. What did the healthcare professionals do?
 - i. Supporting?
 - e. How did you feel meeting other people with COPD?
 - f. How would you feel if you missed a PR session?
 - g. Difference between *going* to PR and *watching* digital films online?
- 19) Did you use your GP at all during this time?
- a. Tell me more about this.
 - i. What sort of things did you go for?

The last questions are just about after the intervention ended

- 20) How has your self-management been going since the intervention ended?
- a. Have you used the digital films since the end of the intervention? If yes, how often?
 - i. Do you see yourself using them/continuing to use them? If yes, how often?
 - b. Have you used any different healthcare services since the intervention has ended?
 - i. If yes, how often?
 - ii. Have you been able to get everything you needed?
 - c. Tell me about your confidence at this present time?
 - d. What are your thoughts about your current level of social support?
 - i. Has this been affected by the intervention?
 1. If yes, tell me more.
 - e. Do you use the techniques you learned during your intervention?
 - i. In what ways do you use them?
 - ii. Do you see yourself using them/continuing to use them?
 1. How would you use them and how often?
- 21) Could you sum up all experiences in three words, phrases, or sentences?

Appendix 24: Study three thematic tables

	Experiencing and adapting to psychological need thwarting	
Sub-theme	Extracts	Codes
1) COPD thwarting the basic psychological needs	<p>Extract 1: I know at the end of 2014 I wasn't well and my mother was ill in hospital, and she lived down on the south coast, and she had pneumonia and daren't go near because of what I had, so I never even got a chance to say goodbye to my mum, and that was like a really hard thing for me to accept. After that I got two of three more bugs, so year it was probably 2015 and that really knocked my function right back and the last time I actually had a lung function test it was</p>	<p>COPD stopped her from saying goodbye</p> <p>Difficult to accept</p> <p>Gradual decline in ability</p> <p>Knowledgeable about respiratory tests results</p>

	<p>down to 33%. I found over that period I was doing less and less and less. P1.</p> <p>Extract 2: Up until then I was reasonably good I could do almost anything and I very rarely had to call for help because I was short of breath. But after that, that first chest infection, it affected me badly then. I had to have help to do any really physical tasks and I was living here at that time, well before then with my first wife. And I had a nice garden then I could dig without any problem at all as soon as I had this I knew I had to change the whole garden to suit an elderly person, that's me okay, that's what I've done. P7.</p>	<p>Originally diagnosis did not affect him</p> <p>Lived independently</p> <p>After chest infection required more help</p> <p>Enjoyed gardening</p> <p>No problems before infection</p> <p>Had to modify environment to help</p>
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	<p>Extract 3: I was only in for three days and I think from that point I've noticed, I don't know if deterioration is the right word, but its worse than it was. I'm much more breathless than I used to be and to attempt most tasks is much more difficult than it used to be, much more difficult. P5.</p> <p>Extract 4: yeah, when I, it was distressing when I got to hills. When I knew I could do things, I thought I could do things. But when I would do them, *pants* I was out of breath. That was the only time I thought like it had got me, you know. P2.</p> <p>Extract 5: I was with the kids and they'd say there is nothing wrong with you, I</p>	<p>Even short times in hospital result in loss of abilities</p> <p>Found it harder after a hospitalization</p> <p>More breathless</p> <p>Activities are more difficult than they used to be</p> <p>Low competence</p> <p>Found it hard dealing with the loss of ability</p> <p>Belief and ability didn't match</p> <p>Felt like COPD was 'winning'</p> <p>Children didn't believe their mother was ill</p>
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	<p>used to go for a walk with them. You try going up a hill with COPD. They'd say you're really unfit. I'd say no I'm fit, but my lungs. I couldn't do it. My friend was so pushing and so out of breath, I just thought I can't do this. I told my girls listen, I'm not unfit I have COPD, my lungs are unfit, you go on walks and they take the dogs, 3 or 4 miles. But I can't do the hills anymore. They had to accept it in the end. And we go for walks on flat. But if they go up hills I just don't go with them. P3.</p> <p>Extract 6: I couldn't imagine going to gym, I'm not a swimmer. I hate water. Apart from wailing, I couldn't go to a gym</p>	<p>Found hills difficult</p> <p>Perceives a difference between physical and lung fitness</p> <p>Didn't have ability to continue walking the hills</p> <p>Had to discuss condition within children to make them understand and accept her abilities</p> <p>COPD restricts where she can go</p> <p>Does not like the gym or swimming</p>
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	<p>because they'd all be looking at me after five minutes when I'm wheezing and coughing because I can't get my breath.</p> <p>Whereas in rehab, when you go into a fitness room you're all in the same boat, everyone is there. P1.</p>	<p>Dislikes the idea of others looking at her whilst she is out of breath due to COPD</p> <p>Lack of relatedness with others at gym</p> <p>High relatedness with people at PR, helps motivation</p>
<p>2) Controlling environments pre-intervention</p>	<p>Extract 1: (so the conversation you had with your doctor, how did that go?) yeah pretty well I think, he didn't say that much, they don't have time to tell you.</p> <p>You know a nurse does most of it but she pretty much says blow in this, blow in that and when there is something wrong she'll go round and see the Dr and get more medication for you. Or a different medication. P2.</p>	<p>Conversation about PR went well</p> <p>Doctors do not have much time</p> <p>Nurses do most of the appointments</p> <p>Told exactly what to do</p> <p>Problems discussed between nurse and doctor – patient excluded</p>

	<p>Extract 2: I never really thought about [COPD] being “managed”, it was more like you went along, you saw your doctor, you got your medication and that was that. No one ever talked in terms of managing it... I suffer with blood pressure where they’ve been messing around my tablets ever since I started rehab trying to get that right. So I never really thought about it being ‘managed’ in any particular terms, like you got your medication and that was that and you’d jump through hoops as you were told to turn up for appointments.</p> <p>P1.</p>	<p>Problems dealt with medication</p> <p>Doesn’t like the term self-management</p> <p>Went to doctor just to receive medication</p> <p>No mention of how to self-manage</p> <p>Altering medication to help blood pressure – treating symptom not patient</p> <p>Healthcare appointments don’t support autonomy</p>
<p>3) Recalibrating psychological need thwarting</p>	<p>Extract 1: well until I did the rehab I didn’t manage [COPD] very well at all. But from the rehab on, first</p>	<p>Didn’t manage COPD well</p> <p>PR taught her how to breathe again</p>

	<p>rehab, I learnt how to breathe how to control and it put me back in the driving seat. Made such a difference just knowing how to...the one thing it taught me was 'look you're not that ill'. You're still living, you can get up and do things you know. It was like a tonic really, it made such a difference. P5.</p> <p>Extract 2: by the end of the course I felt a lot better.</p> <p>Incidentally all my friends said oh my gosh we can see the difference and it was really interesting that other people said this without me saying anything. 'you just look marvellous after that' and because of all the upheaval with moving I perhaps haven't managed it</p>	<p>Regained control</p> <p>Realisation that she is capable of more</p> <p>PR helped a lot</p> <p>PR made her feel a lot better</p> <p>Friends noticed the difference without her mentioning anything</p> <p>Moving to a new house has caused her to not be able to self-manage as well as she may have wanted</p>
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	<p>as well as I should however, I have the knowledge to do that which I haven't done before. P1</p> <p>Extract 3: So I sleep [on the top floor], so I had a chair on the first floor landing, I would go half way, absolutely dead. Then I'd do the rest and I have a sofa up there and I would just flop on that sofa. I found it very difficult and then they taught me how to breathe to up the stairs and I can now go top to bottom. So there were a whole load of little hints and wrinkles but they might seem trivial to anyone else but to someone with COPD they did make a big difference, like to breathe. P6.</p>	<p>Has more self-management knowledge now</p> <p>Regained physical abilities</p> <p>Made resting points up the stairs</p> <p>Stairs were more difficult due to her physical abilities</p> <p>Interventions significantly helped</p> <p>Now doesn't need resting stations</p> <p>Re-learning to breathe was a large benefit</p>
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	<p>Extract 4: I normally have my shower and dress, because I don't come down in the morning until I'm dressed. Because if I'm to go back up [the stairs] *laughs*. So that's something I've learnt to do as well is to pace myself if you like and try and think ahead so when I do come down in the morning having showered and I've probably cleaned the bathroom as well before I come down and I bring the washing down as well so I don't have to go up [the stairs] for a few hours. P5.</p>	<p>Stairs are an obstacle</p> <p>Has to plan day to avoid the stairs</p> <p>Avoids situations where her physical abilities make the activity harder</p> <p>Simple routine to avoid these situations</p>

	Facilitating basic psychological need satisfaction	
Sub-theme	Extracts	Codes
1) Supporting agency and homonomy	<p>Extract 1: I think it was rehab which really did it for me because yes it was rehab. (and did your self-confidence in your ability to complete everyday activities change?)</p> <p>Absolutely, really soled. Really soled. And [PR staff] on one questionnaire at the beginning was are you depressed and I thought absolutely not. But you know that I realised the fitter I got the less this low feeling I had. Just dissipated I was just really *sound of relief* which was really good. P6.</p>	<p>Found PR had positive effect on self-management</p> <p>Confidence increased a lot</p> <p>Didn't believe she was originally depressed but after getting fitter realised that she may have been</p> <p>PR caused increase in physical fitness competence</p> <p>PR decreased a low feeling</p>

	<p>Extract 2: Sometimes I'd go through emails and see there was a new film available so I'd want to have time to watch this properly.</p> <p>Normally with my emails I'd be going through either deleting or quickly replying to things so if I saw an email from the films I may not watch it for a day or two. So I'd have time to sit down and actually be able to digest what I was watching.</p> <p>And then occasionally I would go back to it if I thought I'd missed something or I got disturbed I'd go back then. P1.</p> <p>Extract 3: Some were a lot better off and some were a lot worse of and no body minded because it was very social and the first week or</p>	<p>Wanted to have time to digest information</p> <p>Could delay watching the films if it suited her</p> <p>Could re-watch the films if wanted</p> <p>Films fit into her life</p> <p>Different physical abilities at PR</p> <p>PR became a social event</p>
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	<p>couple times everyone went and were surprised going ‘oh they expect us to do this?’ *laughs*. But by the half way through everyone accepted and just got on with it and after each exercise we’d be asked to assess our breathing and it’d be made note of to see if we improved. P1.</p> <p>Extract 4: (what were your overall feelings towards the films after you had watched them?) I suppose the first thing was that you’re not alone. But I knew that anyway but I don’t think I gained an awful lot from them because I already had most of the information if like that was in, in the videos if you like.</p> <p>Nutrition, breathing</p>	<p>PR attendees were surprised at what they were expected to do</p> <p>Everyone accepted the exercises</p> <p>Focus on breathing improvement</p> <p>PocketMedic helped her realise she wasn’t alone</p> <p>Although did know this already from previous PR course</p> <p>Didn’t gain lots from PocketMedic films as she knew most of the information – repetitive</p>
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	<p>exercises, physio exercises, you know it wasn't anything I didn't know put it that way. P5.</p> <p>Extract 5: you got to talk with people with the same problems. And you got to know what helped them and what they were struggling with. Which your kids and friends don't understand because they haven't got it. You know. The girls I met there, and I made friends there, and they were going to gym now. My life was changed by other people having it as well. Walk and talk, and we'd whinge to each other. How red faced we were that day, the weather. All same thing in common and that's what keeps me going. P3.</p>	<p>PocketMedic covered wide range, however, previous course also covered these topics</p> <p>Enjoyed discussing condition with others who had COPD</p> <p>Swapped hints and tips</p> <p>Friends and family don't understand COPD – lack of relatedness</p> <p>PR became a social event</p> <p>Has continued exercising at gym with friends due to high relatedness</p> <p>Feels relief that she is not the only one with COPD</p>
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		High relatedness with others with COPD
2) Redefining challenge	<p>Extract 1: I painted the bathroom this week, it's not very big but when we took the tiles off there was some hideous pink, so it took three coats of white undercoat and 2 coats of bathroom paint to cover it. But I felt really good about it I don't think I would have been able to do that before rehab. P1.</p> <p>Extract 2: So I know what I can do now I know if I walk up steps I get knackered by the time I get to the top. So I go up slowly. Going downhill, nothing, on the flat, nothing, I'm fine. Its just slight hill, stairs, or if I'm doing the gardening, mowing the lawn, I've got to</p>	<p>Proud of achievement</p> <p>Could change colour due to abilities</p> <p>PR helped abilities and knowledge increase</p> <p>Pacing</p> <p>Understands his own abilities</p> <p>Pacing helps</p> <p>Only inclines cause problems</p> <p>Struggles to do physical activities</p>

	<p>sit down every ten to fifteen minutes. P2.</p> <p>Extract 3: I think it helps you know, before I couldn't accept that I couldn't do things as I used to, now this its taught me you have to accept it and there are things you can't do that you did before. P3.</p>	<p>COPD forces him to take breaks</p> <p>Original non-acceptance/denial</p> <p>Acceptance has come post-intervention</p> <p>Made her aware of current capabilities</p>
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