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OPTIMISING MANAGEMENT AND CARE DELIVERY IN PEOPLE LIVING WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

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Doctor of Philosophy (Nursing)

2014

CERTIFICATE OF AUTHORSHIP AND ORIGINALITY

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Student

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ACKNOWLEDGMENTS

Only infrequently do we have the opportunity to publicly honour thanks on those who influence our life and journey, and so you will have to forgive me for taking liberties with the length of this acknowledgement – in truth, there are so many people to thank.

Thankyou firstly to my wonderful supervisors, Professor Trish Davidson for your sage guidance, your vision, and your ability to transform the 'respectable' into something meaningful and important to the broader context – you have such foresight, I have much to learn! Thankyou also for your kindness, warmth and patience. Thankyou also for guiding me to transform my thinking and helping me to understand the systems and broader influences that challenge and facilitate care delivery, I am so blessed to have been mentored by you.

To the ever lovely Associate Professor Sally Inglis, you are equally such an amazing guide and scholar, a steadying hand and true support. Your patience and encouragement were ever present and appreciated. Thankyou for believing in me and helping me to find presence in the work. I so look forward to working with you as a colleague.

Thankyou to Professor David Currow for your sharp perspective, focus on the person and caregiver, and for all your ongoing support and encouragement. You are ever generous with your time and intellect, a rare and appreciated quality indeed. Your approach and viewpoint have markedly influenced my own perspective and understanding and I thankyou for this.

Thankyou to all three of my supervisors for their generosity and support. It has been a privilege to have worked with such prolific leaders and to have been guided by you.

Thankyou also to Professor Robyn Gallagher and Dean John Daly, for helping me to start this process and helping me to frame where I was going, an incredibly important step in my doctoral journey. Thankyou.

Thankyou to all those who have contributed to the articles in this thesis: my supervisors of course, Dr Tim Luckett, Anna Green, Assoc. Prof Doranne Donesky, Prof Virginia Carrieri-Kohlman, Dr Phillip Newton, Prof Robyn Gallagher, Dr Tracy Smith, Prof Jane Philips, Prof Miriam Johnson, Nick Spiliopoulos, Margaret Collins, Prof Peter Macdonald, and Prof Allan Glanville. Thankyou to Hiba Deek and Sabine Allida for your help and assistance. Thankyou Michelle Nankervis and Darrin Penola from St Vincent's Hospital. Thankyou also to Jane Van Balen from the UTS Library and Priya Nair from the Faculty of Health. Thanks so much to Tim Luckett, Phillip Newton, Anna Green, Nikki Brown, Michelle DiGiacomo, Caleb Ferguson and Debra Jackson at UTS for your thoughts, guidance, encouragement and friendship.

Thankyou to Shoalhaven District Memorial Hospital and St Vincent's Hospital Sydney for allowing me to conduct research at these sites and thankyou so very much to all the participants in the studies, we learn so much from your experience and are privileged to gain such important insights. A particular thankyou to Nick Spiliopoulos from St George's Hospital and Shoalhaven District Memorial Hospital, you are such a generous, supportive and lovely person.

A special thanks to my friends Doranne and Ginger. You have generously welcomed me into your lives, your team and advocated for me within your professional world. We have such a connection, and I look forward to many more ATS, fondue, and Banana escapades. As Ginger would say: 'Phenomenal!'

Thankyou to my beautiful parents, Prof Peter Disler and Extraordinaire Sally Disler, for all your support, for being so proud of me and for reading my thesis! Thankyou Dad for your astute perspective, your moral compass and showing me something special about respectfully and collegially interacting with patients and those around you, your approach to care has had a true impact on me as a person and nurse. Thankyou Mum, for your friendship and love, your true intellectual inquiry. You have always had such an interest in me and my thoughts and what I am doing. Thankyou so much for both sharing my experience and for supporting me through. You both approach life with such thought and generosity; I do aspire to being even a little as good as you guys.

And last, but most certainly not least, Robert Crawford – my truly amazing husband. Thankyou for showing me a path to academia and inspiring me through your own ambition and achievements. Thankyou for encouraging me to start this process – I didn't quite believe you when you first said I could do a PhD and yet here I am – you are wise indeed! Thankyou for letting me talk at you and helping me find my way through. Thankyou for your love and humour, and for helping me to laugh, to cry and to live life to the full. I am truly myself with you and blessed everyday to have such a friend and partner.

PREFACE

This dissertation for the degree of Doctor of Philosophy in Nursing is presented as a series of discrete studies that seek to understand the experience of individuals living with chronic obstructive pulmonary disease (COPD) and how we can work towards solutions that optimise care delivery and health care utilisation in this patient group. A substantial part of this dissertation has already been published in peer review journals or submitted as manuscripts and the thesis as a whole complies with the ‘Procedures for Presentation and submission of Theses for Higher Degrees – University of Technology, Sydney; Polices and Directives of the University’. All published manuscripts are direct result of the research work undertaken for this dissertation with the majority of the authorship attributed to myself as a doctoral student.

This dissertation is organised in four sections: Section 1: Introduction and conceptual frameworks; Section 2: Understanding the barriers and facilitators to care delivery; and Section 3: Looking to innovative future approaches to COPD care and Section 4: Overall thesis discussion.

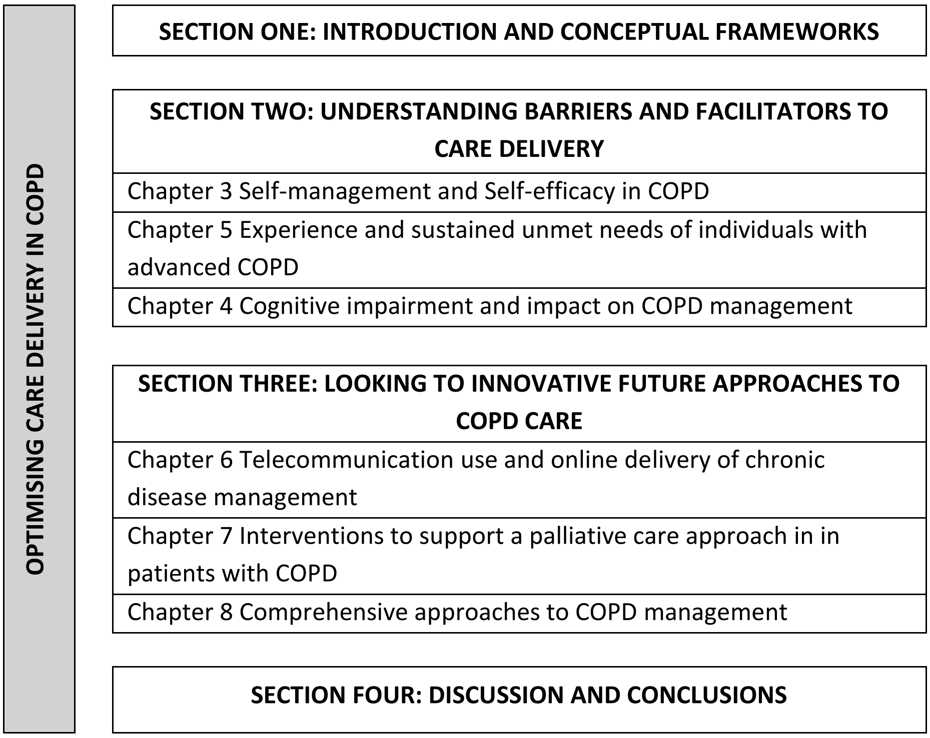

Figure i: Thesis structure

The introductory and discussion chapters are presented in a traditional format with Chapter 1: Introduction providing a broad background to the piece of work, including the prevalence and burden of COPD, the epidemiology and key features of this condition, and the management of COPD. The introduction will also outline the significance of this dissertation and the overall research problem and aim of the research. Chapter 2: Conceptual Frameworks introduces the several conceptual frameworks that have informed the development and theoretical design of the studies included in this thesis; including: the chronic care model; self-management; self-efficacy; and comprehensive approaches to chronic disease management. While a theoretical discussion and conclusion are integrated as part of each chapter, Chapter 9: Doctoral Discussion will provide a general overall discussion that summarises the collective findings and provides for implications for future policy, practice and research

The series of discrete yet interrelated studies are presented in Section Two: Understanding Barriers and Facilitators to Care Delivery and Section Three: Looking to Innovative Future Approaches to COPD Care as chapters with an introductory extended abstract followed by the published article or submitted manuscript. In Section Two, Chapter 3 presents a key integrative literature review that place the dissertation within the context of the previous knowledge, Chapter 4 provides a further metasynthesis of qualitative data from the last two decades to understand the sustained unmet needs of patients with end-stage COPD and Chapter 5 presents a focus group study exploring individuals' perspectives about cognitive impairment and how these changes might impact their ability to manage their condition.

In Section Three, Chapter 6 explores the innovative technological approaches to healthcare delivery and improved health service utilisation through a prevalence survey study and a focus group study; Chapter 7 presents an integrative review that describes the evidence for interventions that support a palliative care approach in the transition to chronic progressive COPD; and Chapter 8 presents a Cochrane Overview that explores the evidence for and elements of comprehensive approaches to complex and multifaceted disease management.

TABLE OF CONTENTS

LIST OF PEER REFEREED ARTICLES SUBMITTED FOR PUBLICATION DURING DOCTORAL TENURE

PEER REVIEWED ARTICLES PUBLISHED AS PART OF DOCTORATE

1. **Disler RT,** Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Patterns of technology use in patients attending a cardiopulmonary outpatient clinic: a self-report survey. *interactive Journal of Medical Research*. 2015; 4:1.
2. **Disler RT,** Green A, Luckett T, Newton PJ, Inglis SC, Currow DC, Davidson PM. Experience of advanced chronic obstructive pulmonary disease: Metasynthesis of qualitative research. Journal of Pain and Symptom Management *Journal of Pain and Symptom Management,* 2014; 46: 6: 1182-1199.
3. **Disler RT,** Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. *Cochrane Database of Systematic Reviews* PROTOCOL 2013 Issue 2. Art. No.: CD010384. DOI: 10.1002/14651858.CD010384
4. **Disler RT,** Gallagher RD, Davidson PM. Factors influencing self-management in chronic obstructive pulmonary disease: An integrative review *International Journal of Nursing Practice;* 2012; 49: 230-242. INDEN-IJNS publication award 2012
5. **Disler RT,** Green A, Luckett T, Newton PJ, Inglis SC, Currow DC, Davidson PM. Unmet Needs in Chronic Obstructive Pulmonary Disease: A Metasynthesis Protocol *International Journal of Research in Nursing* 2012; 3: 15-20.
6. **Disler RT,** Currow DC, Philips JL, Smith T, Johnson MJ, Davidson PM. Interventions to support a palliative care approach in patients with chronic obstructive pulmonary disease: An integrative review *International Journal of Nursing Studies* 2012; 49: 1443-1458.
7. **Disler RT,** Inglis S, Currow DC, Davidson PM. Palliative and supportive care in COPD: research priorities to decrease suffering. *Journal of Pulmonary and Respiratory Medicine* 2012; 1:1-3.

PEER REVIEWED ARTICLES CURRENTLY UNDER REVIEW

8. **Disler RT,** Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. *Cochrane Database of Systematic Review*.
9. **Disler RT,** Spiliopoulos N, Collins M, Inglis SC, Currow DC, Davidson PM. Patients' attitudes to cognitive impairment and testing in chronic obstructive pulmonary disease: focus group study. *COPD: Journal of Chronic Obstructive Pulmonary Disease.*
10. **Disler RT,** Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Patients perspectives of online health information and chronic disease management in individuals' chronic obstructive pulmonary disease: focus group study. *COPD: Journal of Chronic Obstructive Pulmonary Disease.*

AWARDS RECEIVED DURING DOCTORAL TENURE

2015 Lung Foundation Australia and A Menarini Australia Chronic Obstructive Pulmonary Disease (COPD) Travel Grant ($5000)

- This award provides support for individuals presenting at the Thoracic Society of Australia and New Zealand conference, to travel and present at the American Thoracic Society or European Respiratory Society conference in that same year.
- The research presented in the conference papers and posters is presented in Chapters are presented in Chapter 5, 6 and 8 of the thesis. One of the three papers has been published as a full peer reviewed article and the remaining two papers have been submitted and are under review.

2015 American Thoracic Society, Denver US, Abstract Award (Nursing Assembly) ($500).

- This funding was presented for the abstract: Disler RT, Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Technology Use in Patients Attending a Cardiopulmonary Clinic.
- The research presented in this conference poster is presented in Chapter 6 of this thesis and has been published in the Interactive Journal of Medical Research.

2014 Lung Foundation Australia/Cochrane Airways Group Scholarship presented at the Thoracic Society of Australia and New Zealand conference ($2500)

- This award provides recognition and support for individuals undertaking a Cochrane review or overview in the area of respiratory disease.
- The Cochrane Overview funded was: Disler RT, Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. *Cochrane Database of Systematic Reviews* 2013, Issue 2. Art. No.: CD010384. DOI: 10.1002/14651858.CD010384.
- This paper is presented in Chapter 8 of the thesis, has been submitted for publication and is currently under editorial review.

2014 Nursing International Trainee scholarship for the abstract accepted and presented at the American Thoracic Society Conference in San Diego ($1500).

- This conference presentation contributed to collaborative work undertaken with colleagues in the United States of America into those patients most likely to respond to dyspnoea self-management programs.

2014 American Thoracic Society Conference in San Diego, Abstract Award ($500)

- This funding was awarded by the Nursing Assembly for the collaborative work undertaken with colleagues in the United States of America into those patients most likely to respond to dyspnoea self-management programs. This funding was declined as this could not be taken in conjunction with the 2014 Nursing International Trainee Scholarship.

2013 Invited international speaker at the 2014 American Thoracic Society conference in Philadelphia ($2000)

- This conference presentation contributed to the Chapter 7 Interventions to support a palliative approach in patients with COPD.

2012 Inaugural International Journal of Nursing Studies/ International Network in Doctoral Education Publication Award (€500)

- This award is in recognition of the best doctoral paper accepted and published by the *International Journal of Nursing Studies* in 2012.
- The paper awarded was: Disler, R.T., Gallagher, R.D. & Davidson, P.M. 2012, 'Factors influencing self-management in chronic obstructive pulmonary disease: An integrative review', *International Journal of Nursing Studies*, vol. 49, pp. 230-242.
- This paper is presented in Chapter 3 of the thesis and has been cited 25 times over the past three years.

CONFERENCE ABSTRACTS

2015 **Disler RT,** Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Technology Use in Patients Attending a Cardiopulmonary Clinic A101. Effective communication strategies for improvement of patient care, American Thoracic Society Conference, Denver, USA 2015: A2212, 10.1164/ajrccm-conference.2015.191.1_MeetingAbstracts.A2212

2015 **Disler RT,** Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Use of technology in cardiopulmonary patients. TSANZ Gold Coast, May 2015. *Respirology*. 2015; 20: 111.

2015 **Disler RT,** Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Perspectives of Online Health Information and Support in Chronic Disease Respiratory Disease: Focus Group Study. A34. Influence of behavioral and psychosocial factors in health outcomes, American Thoracic Society Conference, Denver 2015: A1386, 10.1164/ajrccm-conference.2015.191.1_MeetingAbstracts.A1386

2015 **Disler RT,** Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Attitudes to online delivery of health information and chronic disease management in chronic obstructive pulmonary disease: Focus group study. TSANZ, Gold Coast, May 2015. *Respirology*. 2015; 20: 111.

2015 **Disler RT,** Inglis SC, Davidson PM. Cochrane Overview: Comprehensive Approaches to Chronic Obstructive Pulmonary Disease Management. A23. Not a second time: solutions to COPD readmissions and care management, American Thoracic Society Conference, Denver 2015: A1113, 10.1164/ajrccm-conference.2015.191.1_MeetingAbstracts.A1113

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2015 **Disler RT,** Spiliopoulos N, Collins M, Inglis SC, Currow DC, Davidson PM. Individuals attitudes to cognitive impairment and impact in chronic obstructive pulmonary disease: Focus group study. TSANZ, Gold Coast, May 2015. *Respirology*. 2015; 20: 111.

2014 **Disler RT,** Donesky D, Nguyen H, Carrieri-Kohlman V. Dyspnea Self-Management Programs: Who Benefits? American Thoracic Society Conference, 16-21 May 2014, San Diego, USA.

2013 **Disler RT.** Nursing Year in Review: Palliative Interventions in COPD: Current Approaches to Care. International Invited Speaker, American Thoracic Society Conference, 17-22 May 2013, Philadelphia, USA.

LIST OF TABLES

CHAPTER 1 INTRODUCTION

CHAPTER 3 INTEGRATED REVIEW SELF-MANAGEMENT AND SELF-EFFICACY FOR COPD (IJNS)

CHAPTER 4 METASYNTHESIS OF QUALITATIVE DATA EXPERIENCES OF PATIENTS WITH END STAGE COPD

CHAPTER 5 COGNITIVE IMPAIRMENT IN COPD

CHAPTER 6 TELECOMMUNICATION USE AND ONLINE DELIVERY OF CHRONIC DISEASE MANAGEMENT IN COPD

CHAPTER 7 INTEGRATIVE REVIEW INTERVENTIONS TO SUPPORT A PALLIATIVE CARE APPROACH IN PATIENTS WITH COPD (IJNS)

CHAPTER 8 COMPREHENSIVE APPROACHES TO COPD MANAGEMENT

LIST OF FIGURES

CHAPTER 1 INTRODUCTION

CHAPTER 2 CONCEPTUAL FRAMEWORKS

CHAPTER 3 INTEGRATED REVIEW SELF-MANAGEMENT AND SELF-EFFICACY FOR COPD (IJNS)

CHAPTER 5 METASYNTHESIS OF QUALITATIVE DATA

CHAPTER 6 TELECOMMUNICATION USE AND ONLINE DELIVERY OF CHRONIC DISEASE MANAGEMENT IN COPD

CHAPTER 7 INTEGRATIVE REVIEW INTERVENTIONS TO SUPPORT A PALLIATIVE CARE APPROACH IN PATIENTS WITH COPD (IJNS)

CHAPTER 8 COMPREHENSIVE APPROACHES TO COPD MANAGEMENT

DOCTORAL DISCUSSION

DOCTORAL ABSTRACT

BACKGROUND

Chronic obstructive pulmonary disease (COPD) is a substantial health problem both within Australia and internationally, and is noted by the World Health Organization *Global Burden of Disease: Update* to be one of the most common, burdensome and widespread chronic conditions internationally. It is estimated that 210 million people worldwide have COPD with 80 million in the chronic progressive phase of the disease. Moreover, it affects 10% of all people over 40. Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and economically sustainable approaches to support patients with chronic illnesses, such as COPD. Despite treatment optimisation, individuals with chronic progressive COPD continue to experience high symptom burden and have limited access to supportive services. Additionally, current care approaches to care delivery are episodic and expensive and reach only a small proportion of the population.

COPD remains a substantial problem with marked symptom burden and recognised barriers to care, yet solutions are less evident. An emerging body of data underscores the importance of collaborative and multifaceted approaches, and these approaches are currently a focus of clinicians and policy makers in hospital avoidance. Nurses play a prominent role in these approaches through planning and coordinating the complex care for individuals with COPD. Understanding the challenges to care delivery will inform health professionals and policy makers in the optimal care delivery approaches that provide sustained positive impact for individuals with COPD.

OBJECTIVES

This thesis presents a series of discrete yet interrelated studies that have sought to understand how best to optimise care delivery in COPD. Specifically, the thesis sought to:

- understand the underlying factors that influence and challenge individuals' experience of living with COPD and their ability to manage their condition and engage with health care services;

- conceptualise how can we better address unmet needs and facilitate the transition from chronic to the end stage disease; and
- conceptualise innovative, multifaceted and tailored approaches that optimise care delivery and healthcare utilisation while meeting the needs of the individual.

METHODS

This dissertation is presented as a series of discrete, interrelated studies. Several methodological approaches have been used in the development and theoretical design of the individual studies and have assisted in study design and interpretation of findings. The theoretical underpinning and methodological processes are discussed in each individual study chapter, and include: integrative review; metasynthesis of qualitative data; qualitative focus groups; quantitative self-report survey; and systematic overview of published evidence within the *Cochrane Database of Systematic Reviews*. The dissertation is organised in four sections: Section 1: Introduction and conceptual frameworks; Section 2: Understanding the barriers and facilitators to care delivery; and Section 3: Looking to innovative future approaches to COPD care and Section 4: Overall thesis discussion.

FINDINGS

Despite advances in management and optimisation of treatments, individuals living with COPD experience well-established and ongoing needs, which have not markedly improved over the past two decades. While the physical challenges associated with COPD are well recognised, existential determinants, such as social isolation, are additionally seen to have a high impact on the individuals and their ability to manage their condition. However, they are rarely acknowledged or addressed in planning care delivery. The measure of success and effectiveness of interventions remains strongly based on health related quality of life, health utilisation and mortality data. Consequently, these outcomes continue to inform and drive policy and practice development. In optimising care delivery and healthcare utilisation, it is important to also consider the impact of provider influence, socioeconomic status, cognition, and health literacy.

Support for collaborative self-management has been recognised as a vital component for increasing continuity and quality of chronic illness care in the future. Regular access to this

expert advice around symptom management, problem solving and coping techniques are necessary for patients to make self-management decisions with increased confidence. Nurses play a prominent role in facilitating and accessing such support through planning and coordinating the complex care for individuals with COPD. Understanding the challenges to care delivery will inform health professionals and policy makers in the optimal care delivery approaches that provide sustained positive impact for individuals with COPD.

The transition from chronic to chronic progressive COPD is particularly difficult for individuals living with COPD. Challenges in prognostication and the limited recommendations provided for end-stage care in international COPD guidelines are likely contributors to the lack of palliative and supportive care delivery in individuals with COPD. Improving providers' confidence in initiating end-of-life discussions, through training in approaches to end-of-life conversations and available services, would assist in the utilisation of advanced care planning and system interventions. In addition, collaboration between primary, secondary and, tertiary care should be strengthened to improve delivery of care across different parts of the health system and encourage the integration of active management with planning for the final stages of life.

Comprehensive and multivariate systems approaches are necessary to address the complex needs experienced by individuals with COPD. Evidence for these interventions is challenged due to intrinsic heterogeneity in their components and delivery. Clear articulation and consensus on essential intervention components are required for high quality care delivery; using a pre-specified and standardised taxonomy may inform health providers and consumers in design and development of future interventions for COPD management.

Finally, current care approaches are episodic, expensive, and reach only a small proportion of the population. The long-term tasks of self-management and overall burden of disease provide a compelling argument for accessible and convenient avenues for patients to obtain ongoing treatment and peer support. Communication tools are already a pervasive component of healthcare delivery and will increasingly influence future healthcare delivery in COPD and other chronic conditions. The new generation of empowered health consumers expect healthcare systems that accommodate their changing needs and preferences. Innovation in delivery approaches, such as those seen in asynchronous online health delivery platforms, may be an important adjunct to traditional forms of healthcare and address some of the limitations of traditional care delivery. Further research is required into the socioeconomic and physical benefits of such approaches particularly in those who have limited access to face to face health support.

CONCLUSIONS

There is clear documentation of the marked burden and barriers to COPD care, yet solutions are less evident. This thesis has sought to understand how we can optimise care delivery in COPD. Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and economically sustainable approaches to support patients with chronic illnesses, such as COPD. Future COPD care must be delivered through multifaceted and comprehensive approaches that tailor care to the socio-psychological needs, and associated health literacy of the individual. Collaborative care between individuals and health providers, and strengthening of relationships between primary, secondary and tertiary care, are essential to assisting individuals in accessing resources and moving between different parts of the health system. The long-term tasks of self-management and overall burden of disease provide a compelling argument for accessible and convenient avenues to obtain ongoing treatment and peer support, such as those seen in asynchronous online health delivery platforms. It is hoped that in understanding the factors that influence individuals engagement with care delivery that the work in this thesis will inform new and innovative delivery approaches that help address the varied needs of individuals with COPD and that engage patients with health professionals and peers in supportive and collaborative relationships.

SECTION ONE: INTRODUCTION AND CONCEPTUAL FRAMEWORKS

OPTIMISING MANAGEMENT AND CARE DELIVERY IN PEOPLE LIVING WITH COPD

CHAPTER 1: INTRODUCTION

Issues of healthcare access, increasing health costs and the need for improved health outcomes, drive the search for more effective and economically sustainable approaches to support patients with chronic illnesses, such as chronic obstructive pulmonary disease (COPD). Despite treatment optimisation, individuals with chronic progressive COPD continue to experience high symptom burden and have limited access to supportive services [1-5]. Additionally, current care approaches to care delivery are episodic and expensive and reach only a small proportion of the population [6-9]. COPD is a substantial problem with clear documentation of the marked symptom burden and barriers to care, yet solutions are less evident. This thesis has sought to understand how we can optimise care delivery in COPD.

The thesis chapters are presented in four sections (Figure 1) that describe: the background to COPD care delivery; the underlying factors that challenge patient's ability to engage in self-management and care activities; and to conceptualise how innovative and multifaceted approaches to disease management can best utilise available sources of support. This introductory chapter, and Chapter 2: Conceptual Frameworks, will provide important background to the key concepts and frameworks that informed the series of studies as part of this overall thesis.

OPTIMISING CARE DELIVERY IN COPD

SECTION ONE: INTRODUCTION AND CONCEPTUAL FRAMEWORKS

SECTION TWO: UNDERSTANDING BARRIERS AND FACILTATORS TO CARE DELIVERY

Chapter 3 Self-management and Self-efficacy in COPD
Chapter 5 Experience and sustained unmet needs of individuals with advanced COPD
Chapter 4 Cognitive impairment and impact on COPD management

SECTION THREE: LOOKING TO INNOVATIVE FUTURE APPROACHES TO COPD CARE

Chapter 6 Telecommunication use and online delivery of chronic disease management
Chapter 7 Interventions to support a palliative care approach in in patients with COPD
Chapter 8 Comprehensive approaches to COPD management

SECTION FOUR: DISCUSSION AND CONCLUSIONS

Figure 1.1 Thesis structure

The second section of the thesis seeks to understand the varied barriers and facilitators to care delivery through three chapters: an integrative review on self-management in COPD (Chapter 3), a metasynthesis of qualitative data to understand the sustained unmet needs of patients with end-stage COPD over the past two decades (Chapter 4), and a study describing individuals' perspectives about cognitive impairment and how these changes might impact their ability to manage their condition (Chapter 5). Section three looks to the future of COPD care delivery and explores: innovative technological approaches to in healthcare delivery and improved health service utilisation (Chapter 6); interventions that support a palliative care approach in the transition to chronic progressive COPD (Chapter 7); and comprehensive approaches to complex and multifaceted disease management (chapter 8). While a theoretical discussion and conclusion are integrated as part of each chapter, Chapter 9 will provide a general overall discussion that summarises the collective findings in the interrelated studies presented in the thesis and provides for implications for future policy, practice and research (Chapter 9).

BACKGROUND TO COPD

Prevalence

A substantial health problem both within Australia and internationally, COPD is noted by the World Health Organization *Global Burden of Disease: Update* to be one of the most common, burdensome and widespread chronic conditions internationally [10,11]. It is estimated that 210 million people and 10% of all people over 40 have the disease worldwide, with 80 million in the chronic progressive phase of the disease [10,11]. The main cause of COPD is smoking, with a smaller proportion of cases the result of occupational and environmental exposures to noxious substances [10]. Previously exhibiting a higher prevalence in men, COPD currently has an equal prevalence in men and women. This increase in women is attributed to the increase of smoking among women in high-income countries and the growing exposure to biomass fuels for heating and cooking in middle and low-income countries [10]. As populations age in the developed world and smoking rates and the use of bio-fuels rise in emergent economies, such as China and India, the global burden of COPD is predicted to increase by 30% by 2030 making it to be the third most common cause of death worldwide [10].

In the Australian context the *National Health Survey* for 2007-2008 found the combined prevalence of self-reported emphysema and bronchitis was estimated as 5.3% of the overall population aged 55 years and older (310,700 people), and this rose to 6.7% in people aged between 70-84. Prevalence did not differ between males (5.7%) and females (4.8%) [12,13]. Prevalence was reported as even higher by the *Economic impact of COPD and cost effective solutions* report in 2008, with a significant estimation of 18.6% COPD in the population over 40 years of age, with 10.2% prevalence in patients with stage II-IV disease [14]. The accurate prevalence in COPD is difficult to assess on self-report surveys and is thought to be underestimated due to the late onset of symptoms and issues of comorbidity [15,16].

Mortality and morbidity

Globally, COPD is documented as the 3rd most common cause of death, accounting for 5.6% of all deaths [17]. COPD also accounts for 61,627 years of life lost (YLL), and ranked 9th, accounts for 3.1% of global loss. COPD is also documented as ranked 6th for disability adjusted life years (DALYs), accounting for 92,377 years or 3.4% of all DALYs globally [10,17]. While COPD is currently ranked 6th most common leading cause of DALYs it is projected that COPD will rise to 5th ranked worldwide by 2030 [17]. Most alarmingly, COPD is the 4th ranked cause of years lost due to disability (YLD) globally [17], a strong argument for improvements in current approaches to care to better address the impact of this progressive disease.

A similar picture is observed in Australia, in which COPD is noted as the 5th leading cause of death with 5,878 people recorded as dying from COPD as a primary cause in 2011 [18]. The *Chronic Respiratory Diseases in Australia Report* also noted that in addition to being a primary underlying cause of death, COPD was also reported as an associated cause of death in 7,489 of cases in men and 4,615 cases in women [19]. *Australia Health 2008* [19] additionally noted that COPD was noted as having contributed to a large number of deaths but was infrequently reported as the underlying cause of death, once again suggesting that the impact of COPD is underestimated. Much like COPD prevalence, mortality in males has diminished since its peak in the 1970s, at which time male death rate was 7 times that of female. This ratio has narrowed with reduced male smoking rates and increases in female smoking reported in the 2011 Australian data, however rates in males remain twice that of females [18]. In the Australian context COPD accounted for 7% of total DALYs, with 13,010 years of life lost (YLL) and 2.4 years of life lost per death per 100,000 people [20,21]. The *2003*

Survey of Disability, Ageing and Carers found that 34.1% of those who reported bronchitis or emphysema (COPD by itself was not captured) experienced a level of disability related to their disease [20,21]. In addition, 36.1% of these individuals experienced severe or profound disability, defined as: 'sometimes or always needing personal assistance or supervision with one or more core activities'; core activities being: self-care; mobility; and communication [20,21]. While COPD contributes to significant loss due to death and disability, the day to day impact on patients' physical, social and psychological functioning is largely unnoticed, as is the impact and burden on their families and caregivers.

Marked financial and social impact from COPD is felt both in Australian health system utilisation and loss of personal financial productivity [19]. Respiratory disease is reported to cost the Australian health system $3,321million annually placing it as the 6th most costly conditions [19]. COPD specifically accounted for $929 million in 2008-2009, with 57.5% of this spent on admitted health use [22]. Costs related to COPD are predicted to increase by 35% by 2032 [19]. The *Economic impact of COPD and cost effective solutions* also reported a financial burden to Australian society of $6.8 billion in relation to reduced productivity through absenteeism, presenteeism, premature death, and search and hiring costs [14]. People aged 15-64 with COPD were seen to have an employment participation rate of 58.6% compared to 74.3% in the general population, which clearly impacts individuals' ability for financial contribution [14,19]. In addition, those who are employed were reported to have 7.4 days per person per year higher absenteeism due to their condition [14]. A further $2.4 million was reported to be spent in search and hiring to replace employees due to COPD. Loss in productivity is also reported to equate to $1.4 billion as a result of premature death due to COPD [14,19].

COPD accounts for a high proportion of hospital separations (episodes of acute admission) in Australia. In 2005-2006 COPD was the primary cause of admission in 53,726 separations with an average length of stay of 7.1 days. This was compared with an average length of stay of 4.3 days in patients with all respiratory diseases and was found to be the 6th highest total patient days in public hospitals (1,089,579) [19]. Again the low reporting and lack of recognition of COPD as a secondary diagnosis my leave this as an underestimation. What is known is that only 30% of men and 24% of woman with a diagnosis of severe COPD survive five years [23], 50% of people with COPD die within two years of their first acute admission, and 50% within one year if they require non-invasive ventilation for management of acute respiratory failure [24-26].

The marked impact on physical and social functioning is acknowledged to disrupt social functioning and roles in a community and domestic setting, and consequently will impact on their needs and interaction with their families and caregivers. Solutions that optimise condition management and care delivery will facilitate patients in managing the impact of their condition and consequently the impact on health care utilisation and health services.

CHARACTERISTICS OF COPD

Definition, diagnosis and disease severity

The Global Initiative for Chronic Obstructive Lung Disease [27] defines COPD as:

> 'a preventable and treatable disease, characterised by persistent airflow limitation that is usually progressive and associated with enhanced chronic inflammatory responses in the airways and the lung to noxious particles and gases' [27].

The combination of inflammation and obstruction of small airways and the destruction of parenchymal tissue, ultimately leads to permanent structural alteration and consequent reduction in alveolar ventilation in addition to prolonged presence of cough and increased sputum production [27].

Diagnosis of COPD is confirmed through spirometry in combination with clinical presentation of characteristic symptoms: dyspnoea, cough and sputum production [27]. Airway limitation is assessed through the ratio between forced expiratory volume in one second (FEV1) and forced vital capacity (FVC) [27]. In obstructive lung diseases such as COPD and asthma, a reduced ratio between FEV1 and FVC is observed, with an FEV1 of less than 70% of the FVC indicative of airway obstruction [27]. Disease severity is calculated on predicted FEV1 for height, age, gender and race. Stage I (mild, FEV1 less than 80% predicted) is characterised by chronic cough and sputum production, with individuals potentially unaware of diagnosis. Stage II (moderate, FEV1 50%-80% predicted) and typically presents with additional shortness of breath on exertion and involvement with medical services for exacerbations. Stage III (severe, FEV1 between 30% -50% predicted) is characterised by further worsening airway limitation in addition to greater shortness of breath, fatigue, exercise intolerance and frequent exacerbations. Quality of life is almost always impacted in this severity of COPD. Stage IV (very severe, under 30% predicted) is similar to Stage III however is also in the presence of respiratory failure (arterial partial pressure of oxygen less than 8.0KPA with or without a raised arterial partial pressure of CO2 greater than 6.7KPa) and is associated with severe symptoms as well as frequent life threatening exacerbations and systemic effects [27].

Predicting prognosis in chronic progressive COPD is difficult due to the fluctuating and episodic decline of the disease [4,28-30]. This is a well-noted, key barrier facing patients with end-stage COPD when accessing palliative care services [1,2,4,28,30]. However, these challenges are not a valid argument for avoiding providing effective care at the end of life. There is emerging data of indicators that may predict which patients with COPD are within the final two years of life, including: COPD related hospital admissions; functional limitation; severe reduction in lung function; use of long term oxygen therapy; depression; low nutritional state; and the presence of co-morbidities [2,30-32]. Additionally, a clinician's assessment that they themselves would not be surprised if their patient was unlikely to survive two years is also seen as an indicator [30,31]. Two composite indices, the BODE index (Body-Mass Index, Airflow Obstruction, Dyspnoea, and Exercise Capacity Index) and DOSE index (MRC dyspnoea scale, airflow obstruction, smoking status and exacerbation frequency), are also used to predict mortality [33,34]. While useful in prediction, it is not clear that these indices assist in the definition of the end-stage period of COPD; furthermore, the BODE relies on the a walking test that may be outside the reach of many end-stage patients, and the DOSE still requires further assessment of predictive validity [33,34]. As noted above, in spite of prognostication at the individual level, population data paints a bleak prognosis for COPD with only 30% of men and 24% of woman with a diagnosis of severe COPD surviving five years [23], with half of the individuals with COPD dying within two years of their first acute admission, and 50% of patients dying within one year if they require non-invasive ventilation for management of acute respiratory failure [24-26]. While acknowledging the uncertainty and unpredictable nature of COPD, for the purposes of this thesis 'end-stage COPD' will be taken to include individuals within the last two years of life as determined by these predictive characteristics [30,31] (Table 1.1).

Table 1.1 Characteristics of final two years of COPD

Characteristics of final two years of chronic obstructive pulmonary disease [30,31]
• Hospital admission for severe exacerbation of chronic obstructive pulmonary disease – only 50% survive two years. • Being housebound due to chronic obstructive pulmonary disease • Having an FEV1 of 30% or less • On long term oxygen therapy • Depression, poor quality of life • Loss of weight and cachexia • and co-morbidities, especially Heart Failure • Health professionals asking themselves the question 'would I be surprised if my patient were to die in the next two years? '

Key features

Characterised by fluctuations and progression, individuals with COPD experience a variety of symptoms, most commonly dyspnoea, chronic cough and increased sputum production [27,35]. Dyspnoea is the most characteristic and is the underlying cause of much of the disease burden and other symptoms that impact on patients' lives. Dyspnoea was described by J. H. Comroe [36] as: 'the subjective sensation of difficult, uncomfortable breathing and includes both the perception of laboured breathing and the reaction to unpleasant stimuli'. Carrieri-Kohlman and Stulbag [37] extended this highlighting that dyspnoea is a multifaceted symptom experienced and interpreted by the person themselves. The sensation is thought to be variable and patients experience it in a variety of forms such as shallow, rapid or tight breathing, for example. Dyspnoea is thought to result from physiological, psychological, social and environmental factors, with a strong emphasis on the affective component of the experience [27]. The consequences of this symptom are seen not only in the restricted physical functioning but also in the consequent avoidance of normal activities which leads to a far reaching psychological and social impact for the patients and their families [27]. Dyspnoea is persistent and progressive and is the main cause of disability and anxiety and therefore the key reason that patients seek medical advice [27].

Chronic cough is a variable symptom which may be 'discounted as an expected consequence of smoking and/or environmental exposures' [27]. Cough is progressive, however, it may not be present in some patients nor associated with increased sputum production [27]. The increased sputum production is thought to result from the increased presence of key inflammatory and hyperplasia of mucosal glands [27].

Significant extra-pulmonary effects contribute to COPD severity in individual patients, with aging and smoking contributing to a variety of associated conditions [27]. Reduced ventilation in addition to the loss of alveolar pulmonary bed leads to impaired gas exchange with resultant low arterial O2 and possible retention of CO_2 [27]. Raised intrapulmonary pressure, hypoxic vasoconstriction and loss of pulmonary capillary bed are also seen to result in pulmonary hypertension and eventual cor pulmonale [27]. The inflammatory component of COPD, indicated by raised C-reactive protein levels, in addition to the pulmonary hypertension, is also thought to increase the incidence of cardiovascular disease in these patients [27]. Moreover, the unusually high energy expenditure associated with active expiration and high unmet oxygen demand result in loss of skeletal muscle mass and consequent muscle wasting and fatigue; these elements adding to already impaired exercise intolerance.

Comorbidity is increasingly recognised as a contributing factor in disease burden. In addition to respiratory changes, patients with COPD experience a variety of systemic vascular and inflammatory effects that have an accumulative impact on body systems, for example associated changes in cognitive functioning [38-41]. Other commonly associated conditions include 'cardiovascular disease, skeletal dysfunction, metabolic syndrome, osteoporosis, depression and lung cancer' [27,41]. In chronic progressive disease individuals additionally experience a range of symptoms including, fatigue, pain, insomnia, weight loss, constipation and incontinence [1,27,42-44] Although discrete disease management strategies are an integral element of evidence based care, it is increasingly apparent that there are some symptom management issues that are germane across chronic conditions.[45] The prevalence and impact of comorbidity requires greater consideration of the complex and accumulated effects of multiple-condition disease management [41]. Chronic disease management support should be targeted through multiple modes of delivery with a broad based symptom focus [46].

Psycho-social burden of disease

The majority of care for COPD is undertaken by the individuals and their families in the community. The unpredictable trajectory of COPD and the characteristic progression, punctuated by episodes of acute illness and functional decline has a marked impact on individuals and their families' quality of life, social functioning, and psychological state [2,35,44,47-58]. The need to support patients physically, financially and psychologically often falls to family members and caregivers, with marked impact on roles and relationships and caregiver health and functioning. Although the rhetoric of patient-centred care is evident in multiple policy documents, there are many examples of where the health care system has failed to meet the needs of individuals with COPD and their families [1,2,4,42,44,57,59,60].

THERAPEUTIC MANAGEMENT OF COPD

The complexity and variety of symptoms experienced, requires varied pharmaceutical and non-pharmaceutical interventions within a comprehensive and coordinated approach to disease management [27] [61]. The key features of this coordinated approach are smoking cessation, inhaled agents and multifaceted interventions such as pulmonary rehabilitation that combine education with exercise and psychological support [27] [61]. Management in the chronic progressive phase, characterised by high symptom burden and increased health care utilisation, additionally require an approach that allows for active treatment to continue in combination with planning for the final stages and end of life [62,63].

Smoking cessation

Smoking cessation has 'the greatest capacity to influence the natural history of COPD' [27]. Viewed as a chronic condition in itself, nicotine addiction requires complex interventions providing dose-response nicotine replacement therapy in combination with psychological support approaches such as counselling and group base support. These combined interventions have been associated with quit rates of between 20-30% [64]. International and national strategies to reduce smoking rates will continue to impact on the incidence of COPD and other smoking related conditions [64,65].

Pharmaceutical management

Pharmaceutical treatments can improve disease impact through symptom control, reduced frequency and intensity of exacerbations and consequent improvement in overall health status [27]. Bronchodilators, corticosteroids and phosphodiesterase-4 inhibitors are the key pharmaceutical agents used to treat bronchoconstriction, inflammation or associated symptoms as the disease progresses. Inhaled bronchodilator medications provide baseline treatment and are essential to COPD management. Aimed to increase FEV_1, Beta2-agonists and anticholinergic bronchodilators improve expiratory flow, lung emptying and dynamic hyperinflation through widening of airways [27]. Bronchodilators improve exercise performance and the sensation of breathlessness [27]. Methylxanthine bronchodilators such as theophylline can be used in in tablet form but do have marked toxicity side effects and so must be monitored closely [27].

Low dose inhaled corticosteroids are added to treatment for moderate and severe disease to control the inflammatory element of COPD and are found to improve symptoms, lung function and quality of life, and reduce exacerbation frequency [27]. While improvements in health status are noted, long term mortality and FEV_1 are not modified by regular inhaled corticosteroids [27]. Combination therapy does have accumulative positive impacted on lung function, health status and exacerbation frequency, but does increase the risk of pneumonia. The addition of tiotropium to long acting beta2 agonists and inhaled corticosteroids has been shown to further improve quality of life and lung function, however further definitive studies are required [27]. Long-term treatment with oral corticosteroids are used in patients with moderate and severe disease, however associated myopathy, muscle weakness and fluid related respiratory failure, suggest that long term treatment with oral corticosteroids should be avoided. Similarly, while prophylactic antibiotics have been trialled, there is limited evidence to suggest that long term antibiotics are of benefit outside acute exacerbations particularly on balance with associated side effects [27].

Phosphodiesterase-4 inhibitors are often commenced in patients with a history of exacerbations associated with chronic bronchitis and severe to very severe COPD. These are used in combination with long acting bronchodilators to reduce inflammation, and while they have no direct bronchodilator effect, Phosphodiesterase-4 inhibitors have been shown to improve FEV1 when in combination with salmeterol or tiotropium [27]. Pneumococcal and influenza vaccines are additionally recommended to reduce the risk of serious illness in patients over the age of 65 or with significant comorbidity, and Pneumococcal vaccine is additionally effective in reducing the incidence of community-acquired pneumonia in patients with severe or very severe COPD who are under the age of 65 years [27]. Long-term oxygen therapy is a key management strategy for patients with reduced resting PaO_2 and has been shown to increase survival in these patients if delivered for more than 15 hours per day. Ambulatory oxygen is not supported in patients who do not already have reduced resting PaO_2 [27].

Pharmaceutical treatments tend to be cumulative in a step wise approach as the disease progresses. In addition to the above, mucolytic agents, immunoregulators, vasodilators, and narcotics are used to target symptoms and exacerbations [27].

Non-pharmaceutical Management

The cornerstone of non-pharmaceutical treatment is pulmonary rehabilitation (PR). The American Thoracic Society and the European Respiratory Society define PR as:

> *an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities. Integrated into the individualized treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimize functional status,* increase participation, and reduce health care costs through stabilizing or reversing systemic manifestations of the disease [16,66-68]

Pulmonary rehabilitation is a comprehensive intervention that includes education, exercise training and psychological support within a multidisciplinary framework. [27]. The key components target exercise capacity, disease and nutritional education, and psychological coaching [27,34,68,69]. There is strong evidence that pulmonary rehabilitation improves quality of life, reduces symptom burden, optimizes functional status, and lessens overall disease burden for individuals with COPD [27,66-68]. While programmes traditionally range from 6-12 weeks there is a reduction in positive impact as time passes after program completion.

Continuing exercise training at home has been shown to maintain health status above pre-rehabilitation [27]. There is marked heterogeneity in the components and sequencing of pulmonary rehabilitation programs, and pulmonary rehabilitation is further limited by the short duration, in the context of a progressive disease, the expense to deliver the interventions and that they only reaches a small proportion of the overall COPD population [6,7,9,70]. Innovative approaches are required to develop sustainable approaches that meet the ongoing needs of the larger COPD population.

Management in chronic progressive and end stage disease

There is increasing recognition that supportive care should be used in the management of life limiting conditions during the acute, chronic or terminal phases. As a life limiting and terminal condition, COPD results in a high symptom burden in their final stages of life, yet individuals have limited access to palliative and end-of-life care [1-4,27,44,57,71].

Palliative care is highly appropriate for end-stage COPD as it addresses '*the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering*' [72]. Terminal is considered to be a 'life-threatening illness for which a cure is not possible'[73]. Consensus over the term 'end-of-life' is far from universal for patients who have a prolonged and unpredictable terminal phase such as COPD [3]. Regardless of the debate around the nomenclature of 'end-stage', 'end-of-life' and 'palliative care', supportive palliative services have predominantly focused on the management of patients with malignancy. Individuals with end-stage COPD have limited access to palliative care despite experiencing similar, yet more prolonged duration of worse symptoms and a higher functional limitation [2,3,47,53,74-78]. Claessens et al. (2000) found that 56% of patients with COPD experienced debilitating breathlessness, compared with only 32% in advanced lung cancer. Physical limitation was also seen to be more severe and occur much earlier in disease progression than that seen in cancer which resulted in increased functional limitation and consequent social isolation [1,53,78]. Gore et al. (2000) note that 82% of COPD patients were housebound in their last 6 months, compared to only 32% of patients with malignancy. Identifying how best to provide a palliative approach to people with end-stage COPD within the context of active treatment is an important priority given the increasing prevalence of this disease globally.

A ‘mixed management model’ such as that seen in palliative care provides a flexible system that allows active management to be combined with planning for the final stages of life and encourages collaboration across health services and specialities (Figure 2) [71,79-81]. Health reform and further research are required to ensure the provision of supportive palliative care which is responsive to the needs of patients, provider and health systems [71]. This is an abundant area for future research given the growing burden of chronic conditions globally.

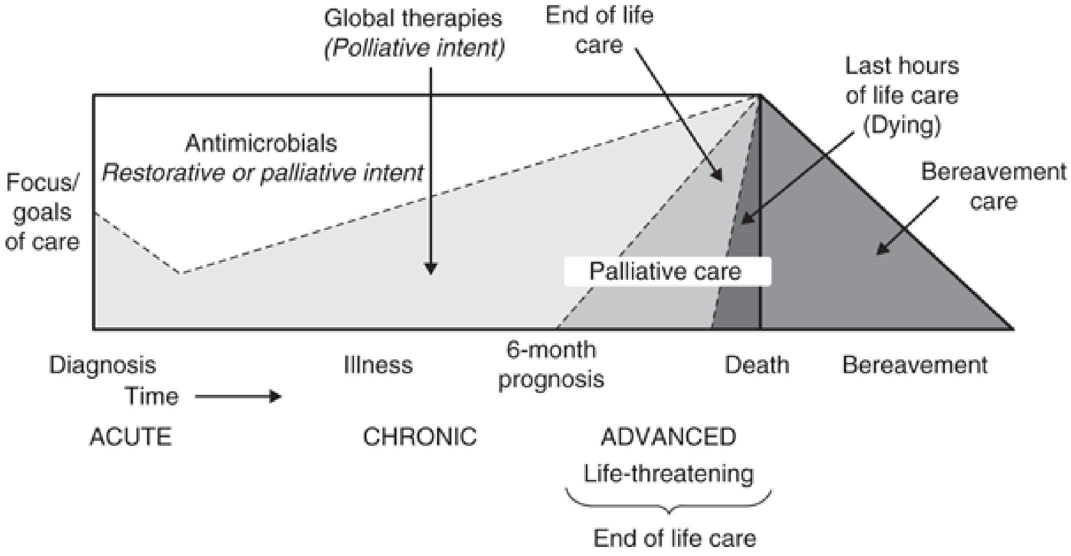

Figure 1.2 Mixed model approach to care in respiratory disease. Ahmedzai, SA, Baldwin, DR and Currow, DC. Supportive Care in Respiratory Disease, 2012, Oxford Scholarship [62]

SIGNIFICANCE OF THE RESEARCH PROBLEM

Despite treatment optimisation, individuals with advanced COPD continue to experience high symptom burden and unmet needs that they must manage on a daily basis [1-5]. Individuals and their families increasingly manage the everyday care requirements of managing chronic illness [82]. Self-management requires that individuals take an active role in their care [83], particularly in undertaking naturalistic decision making within their environment by interacting with knowledge, experience, skill, and values to interpret and implement self-care [83,84]. A focus on acute care and challenges in predicting the end-stage of disease create a milieu that is commonly reactive and *ad hoc* rather than an approach which is responsive to individuals’ ongoing needs [1-5].

Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and economically sustainable approaches to support patients with chronic illnesses, such as COPD. Developing greater insight into the experience of COPD, including the unmet needs and barriers faced by individuals with advanced COPD, has unique potential for informing the coordination and responsiveness of services for this burdensome condition [85-87]. The new generation of empowered health consumers expect health care systems that accommodate their changing needs and preferences [88-92]. It is hoped that new and innovative approaches will bridge the current physical and geographical barriers and additionally provide care that enables engagement between patients with health professionals and peers in supportive and collaborative relationships.

AIMS OF THE DISSERTATION

COPD is a substantial problem with clear documentation of the marked symptom burden and barriers to COPD care, yet solutions are less evident. This thesis presents a series of discrete yet interrelated studies that have sought to understand how best to optimise care delivery in COPD.

Specifically, the thesis has sought to answer the following research questions:

1. What are the underlying factors that challenge and influence patients' experience of COPD and their ability to manage their condition and engage with health care services?
2. How can we better address unmet needs and facilitate the transition from chronic to the end stage disease?
3. What innovative, multifaceted and tailored approaches are necessary to optimise care delivery and healthcare utilisation while meeting the needs of the individual?

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CHAPTER 2: CONCEPTUAL FRAMEWORKS

Several conceptual frameworks have informed the development and theoretical design of the individual studies included in this thesis and have assisted in study design and interpretation of findings. The theoretical underpinning and methodological processes are discussed in detail in each individual study chapter. The following chapter will provide an overview of these key frameworks by way of introduction and as context to the presented doctoral work, including: the chronic care model [1-3]; self-management [4-7]; self-efficacy [8-10]; and comprehensive approaches to chronic disease management [11]. The over-arching conceptual element of this study has been the focus on person-centred care and the need to support individuals across the illness trajectory from diagnosis to death. Whilst self-management, and some instances behaviour change, is the key focus in early stages of disease trajectory, in the later stages of the disease care focusses on a supportive care strategy. Nevertheless, across the care trajectory person-centred care is a central tenet that incorporates the following factors:

- Assessing the needs of individuals and working with them to recognise their strengths and adapt their lifestyle to enable self-care and independence.
- Affording individuals dignity and respect.
- Providing coordinated care providing evidence based treatment options.
- Fostering personalised care.

As a consequence, several conceptual frameworks have informed the development and theoretical design of the individual studies included in this thesis and have assisted in study design and interpretation of findings. These aspects are most clearly elucidated in the Chronic Care Model [1-3].

THE CHRONIC CARE MODEL

The Chronic Care Model is a framework that focuses on system reengineering to improve the care and coordination of chronic illness [1-3]. The Chronic Care Model incorporates the following six pillars: community focus where health care services interface with the community; health systems that support management of chronic conditions; self-management support incorporating a comprehensive behavioural strategy which empowers and prepares people to manage their health and health care; delivery system redesign, where roles and expectations are clarified; decision support with ongoing development of strategies to manage decision making; and clinical information systems, allowing the tracking of patients [1-3]. Implementation of the Chronic Care Model has been associated with improved health outcomes including increasing individuals' control of their symptoms, slowing disease progression, and improving health related quality of life [4,7,12-16].

The Chronic Care Model identifies the needs of the patients and their families as the focus of care and the need for coordination of care, evidence-based practice and cross-sector collaboration to achieve optimal outcomes [1-3]. A range of approaches are commonly used in the management of COPD, including pulmonary rehabilitation, clinics, home visits and telemonitoring [17]. In many of these models nurses play a prominent role in planning and coordinating care. An emerging body of data underscores the importance of this collaborative and multifaceted approach and is currently a focus of clinicians and policy makers in hospital avoidance. The Chronic Care Model, or elements of this, have informed the conceptual development throughout all chapters in this thesis.

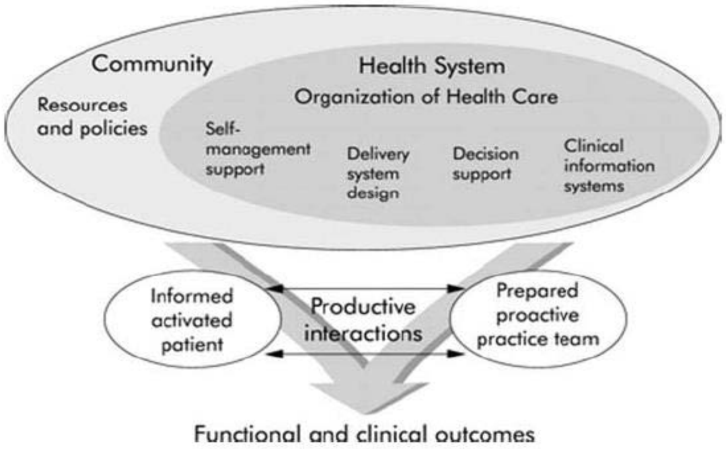


Figure 4.3 The Chronic Care Model.

Figure 2.1 The Chronic Care Model. Effective Clinical Practice, 1:2-4, Wagner: Chronic disease management: what will it take to improve care chronic illness. [18]

SELF-MANAGEMENT

Self-management is a core component of the Chronic Care Model, is a pivotal element of COPD management and care [14,19-21], and has been a key conceptual framework throughout all chapters in this thesis. Self-management represents a theoretical approach to care which is underpinned by the active participation of individuals [4], particularly in undertaking naturalistic decision making within their environment by interacting with knowledge, experience, skill, and values to interpret and implement self-care [4-7]. In chronic disease, these skills and behaviours are used to maintain physical and emotional functioning and reduce the impact of a patient's condition on their daily lives [12,16,22-24]. Specifically individuals are required to: 1) engage in activities that promote health and prevent adverse sequalae; 2) interact with health care providers and adhere to recommended treatment protocols; 3) monitor physical and emotional status and make appropriate management decisions on the basis of the results of monitoring symptoms; and 4) manage the effects of their illness on emotions, self-esteem, relationships with others and their ability to function in important roles [7,13,14].

There is lack of consensus around the term self-management. Some authors ascribe the term of self-management specifically to the day to day clinical tasks patients undertake [25-27], while others focus on patients' adherence to disease interventions [28,29]. These definitions cover important aspects of self-management but fail to encompass the complex psychological, social, existential and physical determinants that influence the lives of patients with COPD, nor recognise patients as active participants in the management of their condition [6,7,12,16,22-24].

In this thesis, self-management is viewed as an umbrella term which encompasses the elements of self-care and disease management [25-27]. Self-care refers to the specific tasks that people carry out on a day to day basis in order to manage their condition [25-27]. Conversely, disease management focuses on the utilisation of interventions which are known to improve a patient's condition or slow the progression of the disease [28,29]. Self-management additionally implies those behaviours and skills used by individuals to maintain emotional, social and physical functioning in the context of their lives with chronic illness [6,7,12,16,22-24].

Three established models of self-management are commonly used internationally: The Stanford model; The Flinders Models of Self-management; and The National Health Service (UK) Expert Patient Programme.

The Stanford Model

The Stanford Chronic Disease Self-Management Programme was developed by the Stanford Patient Education Research Centre at Stanford University in the 1990s [4,23,30,31]. Initially aimed at Arthritis Self-management it has now been translated into a range of conditions, including Chronic Disease Self-Management. The programme aims at enabling people to gain self-confidence in their own ability to control their symptoms and then way in which their symptoms integrate with their lives [4,23,30,31]. The main structure of the programme is a 6 week, peer led, group based course which is restricted to 10-15 participants and is run by a health professional and a peer leader in conjunction. Goal setting and problem solving are the main foci. Like pulmonary rehabilitation one of the benefits of this programme is the socialisation and support through peer sharing with others who have similar conditions. One of the noted limitations is the structured content of the sessions that lacks flexibility for individuals [4,23,30,31].

Flinders model of self-management

The ‘Flinders Model’ was developed at Flinders University in South Australia as part of the Flinders Human Behaviour and Health Research Unit (FHBHRU) through SA HealthPlus coordinated care trial [32,33]. This model focuses on a one-to-one programme which develops a partnership between the clinician and the person and aims to allow the person to be the decision maker and the clinician to act as facilitator [32,33]. The programme begins with self-assessment and then further assessment over the following six principles: knowledge of condition; ability to follow a treatment plan agreed to between the person and clinician; able to actively shared decision making with the clinician; ability to monitor and manage changes in condition; ability to manage the impact of the condition on the physical, social and emotional aspects of life; and that participants will adopt a life style that promotes health [32,33]. Standardised tools are used to assess the patient within these areas and then these assessments in discussion with the patient are used to create an individualised care plan [32-34]. The Flinders Model presents a person-centred focus with clear identification of the person's goals rather than based on the clinical problem. While the Flinders Model is individually based, the main limitations of this model are that this programme is time intensive and the use of a number of assessment tools can be confronting for some patients [32,33].

The NHS Expert Patient Programme

The Expert Patient Programme (EPP) was developed by the Department of Health in the UK in 2002 and was based on the principles of an activated engaged patient from the Chronic Care Model [1-3,35-38]. The EPP aimed to establish a programme of education that was self-managed or user-led. The overall aims were to encourage confidence, knowledge and skills to manage chronic disease within the context of their everyday lives; and ultimately to gain control and independence and thus quality of life [35-39]. The courses focused on 8 areas: medical self-management skills (pharmaceutical titration for example); beliefs; coping actions; confidence; motivation; perceived control; control of anxiety and depression; and mindfulness and acceptance [35-39]. It is believed that all these factors are necessary to allow for a psychological shift and long-term change in behaviour and attitudes. Experiential learning and cognitive behaviour therapy were seen to underpin the programmes as well as addressing issues of social isolation and stigma associated with disease [35-38]. Like the Stanford model the use of group learning and lay persons or peers in the sessions was seen as essential in these aspects in particular. The main objectives for EPP were to enable people to: develop communication skills; manage daily emotions and activities of daily living; build confidence to interact with the healthcare system; access healthcare resources; plan for the future; understand exercise and healthy eating; and manage fatigue, sleep, pain, anger and depression [35-39]. Self-management is complex and challenging and has a marked impact on the lives of individuals and their families. In order to promote these models widely there needs to be an understanding of conceptual elements.

Self-management in COPD

Self-management is a central aspect of life for COPD patients and is discussed broadly in the literature [12,16,22,23]. The majority of care for COPD is undertaken by the individuals and their family in the community. COPD has an unpredictable and progressive trajectory and has a marked impact on patients' physical and social functioning and quality of life [40-42]. Stigma associated with COPD can further influence health seeking behaviours [43,44]. Engagement with self-management allows patients to control their symptoms, slow disease progression, and improve health related quality of life [17].

Individuals with COPD, specifically need to engage in a range of activities to manage their condition. Importantly individuals must: (1) obtain knowledge about their condition to engage in active and informed decision making about self-management and treatment issues [6,7,45]; (2) have an accurate view of their condition and prognosis; (3) integrate healthy lifestyle choices such as appropriate nutrition, regular physical exercise, annual immunisation and smoking cessation to slow disease progression and minimise disease impact [17]; (4) undertake specific health related behaviours to ensure adequate control of symptoms, such as adherence to treatment regimens and engagement with and attendance at health services [17]; (5) recognise fluctuations in condition, and have the confidence to problem solve these fluctuations and escalate treatment to avoid potentially life threatening deterioration [6,7,45]; (6) balance the burden of functional limitations in COPD through energy conservation techniques such as pacing of physical and social activities and a move towards a more sedentary lifestyle [6,40,41,46,47]. While authors prescribe a number of necessary skills to self-manage COPD, patients clearly identify that the influence of dyspnoea and the desire to balance COPD in the context of their lives were the two key elements which influenced their self-management [47,48].

SELF-EFFICACY

According to Scherer and Schimmel [49] self-efficacy is defined as 'an individual's perception that he or she will be capable of performing as given behaviour in order to produce a certain outcome [8-10]. Self-efficacy theory postulates that two types of expectancies influence behaviour: outcome and efficacy. Outcome expectancy is the conviction that one can successfully execute the behaviour required to produce the outcome. According to Bandura [8-10], the strength of individual's convictions about their ability to produce a specific outcome determines whether they will attempt to deal with a difficult situation. Thus, self-efficacy judgements play a part in determining which activities or situation a person will perform or avoid. Expectations about personal self-efficacy are based on four sources of information: performance accomplishment, vicarious experience, verbal persuasion and emotional and physical arousal' [8-10].

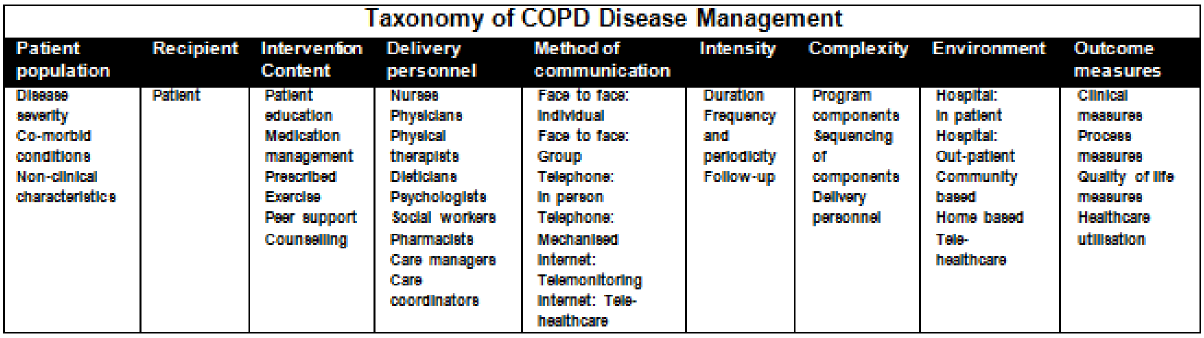
The complexity and frequency of problem solving increases with the progression of COPD. Patients must possess confidence in their self-management and decision making in order to implement actions in response to these changes. Self-efficacy for self-management, or a patient's confidence in their own ability to self-manage in future situations, is of particular importance to patients' management of their COPD. Most prominently self-efficacy influences: the individual's belief in their ability to actively perform tasks associated with self-management; and their belief that self-management will have a positive impact [7,16,25,47,50,51]. An individual's level of confidence is essential to enable them to attempt and develop the skills necessary for self-management, particularly as COPD self-management becomes progressively burdensome and complex [25,47,52]. Self-efficacy for self-management provides patients with the confidence to carry out necessary self-management activities as well as sustaining motivation for self-management despite unrelenting symptoms. Self-efficacy is a key concept within COPD self-management, and as such has informed the conceptual development throughout this thesis. Self-efficacy has been a key concept in Chapter 3 (Self-management and self-efficacy for COPD) and Chapter 4 (Experience and sustained unmet needs of individuals with advanced COPD) in particular.

COMPREHENSIVE APPROACHES TO CHRONIC DISEASE MANAGEMENT

Despite optimisation of pharmacological treatments such as inhaled medications, a large proportion of individuals with COPD continue to have inadequately managed symptoms and unmet psychosocial needs [5,53,54]. Chronic disease, such as COPD require a comprehensive approach to disease management **[11]**, potentially incorporating a range of diverse non-pharmacological, non-device and non-surgical intervention strategies. Comprehensive approaches to disease management that engage 'multiple therapies into a patient-centred plan of care' [11] delivered as a single coherent intervention by the interdisciplinary team [11,55,56]. Examples of comprehensive approaches to COPD management are: self-management programs, pulmonary rehabilitation, action plans and management guidelines, nurse led outreach programs and telemonitoring **[11,14,53,54,57-61]**.

Many of these discrete interventions are complex in both design and delivery and require distillation of essential elements: e.g. the type, frequency and level of intervention intensity as well as description of the workforce type and scope. Understanding the most efficacious organisation, timing and sequencing of these interventions within a disease management approach, as well as resource requirements for these approaches are of high interest internationally and will inform policy, health care decisions and future research [5,11,54,62].

Krumholz and colleagues' Taxonomy of Disease Management has been used to standardise reporting and also facilitate implementation of disease management programs in chronic disease and has been adapted for use in this thesis in relation to COPD. Specifically, the taxonomy of disease management articulates the following components: intervention content; personnel delivery; method of communication; intensity and complexity of intervention; the setting and environment; and outcome measures used for that intervention [62]. Using a pre-specified and standardised taxonomy may assist in providing information to health providers and consumers in design of effective and appropriate interventions for COPD management [11,62]. Comprehensive approaches to chronic disease management are necessary to optimise care delivery and healthcare utilisation. The need for multifaceted approaches informed the conceptual development of all the studies throughout the thesis and in particular in Chapter 6 (Telecommunication use and online delivery), Chapter 7 (Interventions to support a palliative care approach), and Chapter 8 (Comprehensive approaches to COPD).



Taxonomy of COPD Disease Management

Patient population	Recipient	Intervention Content	Delivery personnel	Method of communication	Intensity	Complexity	Environment	Outcome measures
Disease severity Co-morbid conditions Non-clinical characteristics	Patient	Patient education Medication management Prescribed Exercise Peer support Counselling	Nurses Physicians Physical therapists Dieticians Psychologists Social workers Pharmacists Care managers Care coordinators	Face to face: Individual Face to face: Group Telephone: In person Telephone: Mechanised Internet: Telemonitoring Internet: Tele-healthcare	Duration Frequency and periodicity Follow-up	Program components Sequencing of components Delivery personnel	Hospital: In patient Hospital: Out-patient Community based Home based Tele-healthcare	Clinical measures Process measures Quality of life measures Healthcare utilisation

Figure 2.2: Taxonomy of COPD Disease Management (Adapted from the American Heart Association) [62]

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SECTION TWO: UNDERSTANDING BARRIERS AND FACILTATORS TO CARE DELIVERY

CHAPTER 3: INTEGRATED REVIEW: SELF-MANAGEMENT AND SELF-EFFICACY FOR COPD

EXTENDED ABSTRACT

Chapter Three presents an integrative review that has explored the complex influences on self-management and self-efficacy for chronic obstructive pulmonary disease (COPD), as documented in both empirical and theoretical literature[1]. This chapter has been published in the *International Journal of Nursing Studies* and was awarded the Inaugural *International Journal of Nursing Studies* and International Network of Doctoral Education Publication Award 2012 for best doctoral paper accepted for publication by the *International Journal of Nursing Studies* in that year.

Disler RT, Gallagher RD, Davidson, PM. Factors influencing self-management in chronic obstructive pulmonary disease: An integrative review, *International Journal of Nursing Practice* 2012; 49:230-242. (IJNS/INDEN Award 2012)

BACKGROUND

A common, chronic and burdensome condition, patients and their families increasingly manage a range of self-management strategies on a day to day basis. Self-management is a core component of the Chronic Care Model and is additionally a pivotal element of COPD management and care [2-5]. Self-management represents a theoretical approach to care which is underpinned by the active participation of individuals **[6]**, particularly in undertaking naturalistic decision making within their environment by interacting with knowledge, experience, skill, and values to interpret and implement self-care [6-9]. In chronic disease, these skills and behaviours are used to maintain physical and emotional functioning and reduce the impact of a patient's condition on their daily lives [10-14]. The capacity to engage in self-management is dependent on a range of internal (e.g. personal) and external (e.g. health service) factors. Appreciating this complex interplay is critical developing interventions tailored to the needs of the individual's, and to support interaction with health and social systems [7,15-19].

OBJECTIVES

This paper sought to define self-management, identify the determinants which influence the individual's ability to cope and adjust to living with COPD in the community, and identify implications for clinical practice and research.

DESIGN

Integrative review.

DATA SOURCES

Medline, Embase, PubMed, CINAHL, Google Scholar.

REVIEW METHODS

Integrative review using prospective research questions. Papers were included in the review if they were published in peer reviewed journals and written in English between 2000 and 2010. Articles were accepted for inclusion if they discussed the determinants that influenced self-management COPD in the community. Confirmation of results and discussion themes was validated by specialists in COPD and complex care.

FINDINGS

Self-management is a complex construct and influenced by a range of factors [6,8,9,11,12,14,20]. Understanding the diverse factors contributing to self-management is important in developing tailored and targeted interventions and supporting individuals to self-care [17,21,22]. Functional limitation and the need to balance disease management with everyday life are the two key elements that patients face in managing their condition [8,15,17,23,24]. Provider characteristics, socioeconomic status and health literacy are sparsely discussed yet are known to influence COPD self-management [17,18,20,25-29]. The conceptual model developed through this integrative review (presented in Figure 1 in the published article, pg. 235) identifies the key elements which influence patients' ability to self-manage their COPD [7]. This model reflects the diverse physical, social, cultural, psychological and existential issues experienced by patients and will allow for future self-management interventions to be tailored to the complex and interrelated needs of this patient group [8,9,11,12,14,20].

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

Studies have been undertaken to explore discrete foci around self-management but few have attempted to link those things that influence self-management in COPD as an overreaching and coherent model. With concepts heavily intertwined it is clear that further exploration is required into the way in which patients cope with the major emotional, physical and social demands of COPD self-management [30]. There is furthermore a clear need for collaborative care between individuals and health providers in order to facilitate patients' confidence in managing their condition [31,32]. In addition, collaboration between primary, secondary and tertiary care should be strengthened so that individuals are assisted in accessing supportive resources and moving smoothly between different parts of the health system [30,31,33,34]. Self-management must continue to be a national and international focus to strengthen services which assist patients in managing their COPD in the community.

CONCLUSIONS

COPD is a progressive and debilitating condition requiring complex self-management behaviours. A diverse range of physical, social, cultural, psychological and existential issues influence the individuals' capacity to self-manage. Appreciating this complex interplay is critical for supporting individuals and their families. COPD self-management must be a key focus internationally as the disease incidence increases. Collaborative care is required between patients and health providers in order facilitate patients in confident management of their condition.

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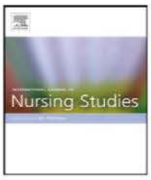
This paper was awarded the Inaugural International Journal of Nursing Studies/International Network of Doctoral Education Award in 2012 for best doctoral paper accepted and published in the International Journal of Nursing Studies in 2012.

International Journal of Nursing Studies 49 (2012) 230–242

Contents lists available at SciVerse ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns



Review

Factors influencing self-management in chronic obstructive pulmonary disease: An integrative review☆

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ARTICLE INFO

Article history:
Received 8 May 2011
Received in revised form 21 October 2011
Accepted 7 November 2011

Keywords:
Chronic obstructive pulmonary disease
Self-management
Self-care
Theoretical framework

ABSTRACT

Background: Chronic obstructive pulmonary disease is a common, chronic and burdensome condition requiring the individual to engage in a range of self-management strategies. The capacity to engage in self-management is dependent on a range of internal (e.g. personal) and external (e.g. health service) factors.
Objectives: This paper seeks to define self-management, identify the determinants which influence the individual's ability to cope and adjust to living with chronic obstructive pulmonary disease in the community, and identify implications for clinical practice and research.
Design: Integrative review.
Data sources: Medline, Embase, PubMed, CINAHL, Google Scholar.
Review methods: Integrative review using prospective research questions. Papers were included in the review if they were published in peer reviewed journals and written in English between 2000 and 2010. Articles were accepted for inclusion if they discussed the determinants that influenced self-management of chronic obstructive pulmonary disease in the community. Confirmation of results and discussion themes was validated by specialists in chronic obstructive pulmonary disease and complex care.
Findings: Self-management is less well characterised in chronic obstructive pulmonary disease compared with other chronic conditions. Functional limitation and the need to balance disease management with everyday life are the two key elements that patients face in managing their condition. Provider characteristics, socioeconomic status and health literacy are sparsely discussed yet are known to influence chronic obstructive pulmonary disease self-management.
Conclusions: Chronic obstructive pulmonary disease self-management must be a key focus internationally as the disease incidence increases. Collaborative care is required between patients and health providers in order facilitate patients in confident management of their condition.

What is already known about the topic?

- Chronic obstructive pulmonary disease is a common, chronic and burdensome condition.
- Self-management is recognised as a critical element of chronic disease management.
- There is little consensus as to a working definition of self-management specific to COPD.

☆ This paper was shortlisted for the International Network for Doctoral Research in Nursing (INDEN) Award, sponsored by the International Journal of Nursing Studies. The award is open to current doctoral students and those who have graduated from a doctoral programme within the past 12 months.

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doi:10.1016/j.ijnurstu.2011.11.005

What this paper adds

- Self-management is challenging and individuals' capability to self-manage is influenced by key physical, psychological and social, existential and provider determinants.
- Provider influence, socioeconomic status and health literacy are poorly explored in relation to self-management in chronic obstructive pulmonary disease.
- Understanding the discrete components of self-management can assist in developing and targeting interventions.

Background

Chronic obstructive pulmonary disease (COPD) is one of the most common and burdensome chronic conditions globally. COPD affects 80 million people worldwide and is the fourth most prevalent cause of death. COPD also accounts for 3.5% of total years lost due to disability (YLD). As populations age in the developed world and smoking rates and the use of bio-fuels rise in emergent economies, such as China, the burden of COPD internationally is set to increase by 30% over the next 20 years (WHO, 2004). It is therefore not surprising that COPD is projected to be the 5th most common cause of disability adjusted life years (DAYLs) worldwide by 2030 (WHO, 2004).

Self-management has been identified as a pivotal element in COPD management (Australian Institute of Health and Welfare (AIHW), 2008; Barlow et al., 2002; Pauwels, 2000). Self-management refers to the skills and behaviours that a person requires to maintain functioning in the context of their lives (Lorig et al., 1993; Redman, 2007). In chronic disease, these skills and behaviours are used to maintain physical and emotional functioning and reduce the impact of a patient's condition on their daily lives (Clark et al., 2009; Kralik et al., 2004; Koch et al., 2004; Lorig et al., 1993).

There is lack of consensus around the term self-management. Self-management is viewed, in this review, as an umbrella term which encompasses the elements of self-care and disease management (Bourbeau, 2008; Chang et al., 2008; Kara Kasikci and Alberto, 2007). Self-care refers to the specific tasks that people carry out on a day to day basis in order to manage their condition (Bourbeau, 2008; Chang et al., 2008; Kara Kasikci and Alberto, 2007). Conversely, disease management focuses on the utilisation of interventions which are known to improve a patient's condition or slow the progression of the disease (Niesink et al., 2007; Taylor et al., 2005). Self-management additionally implies those behaviours and skills used by individuals to maintain emotional, social and physical functioning in the context of their lives with chronic illness (Bodenheimer et al., 2002; Bourbeau, 2008; Kralik et al., 2004; Koch et al., 2004; Lorig et al., 1993; Lemmens et al., 2008; Redman, 2007). Self-management represents a theoretical approach to care which is underpinned by the active participation of individuals in the management of their condition and their integral role in decisions about their own treatment (Bodenheimer et al., 2002; Lemmens et al., 2008). This focus on the individual is closely aligned with Western cultural models of care and may not be appropriate in communities that take a collective healthcare approach (Chen et al., 2008). Nevertheless, this does not minimise the importance of addressing self-management which is seen to improve health outcomes for those who engage in such activities (Clark et al., 2009; Kralik et al., 2004; Koch et al., 2004; Lorig et al., 1993; Lorig and Holman, 2003).

1.1. *Self-management in COPD*

The majority of care for COPD is undertaken by the individuals and their family in the community. COPD has an unpredictable and progressive trajectory and has a marked impact on patients' physical and social functioning and quality of life (Barnett, 2005; Ek and Ternestedt, 2008; Simpson and Rocker, 2008). Stigma associated with COPD can further influence health seeking behaviours (Halding et al., 2010). Engagement with self-management allows patients to control their symptoms, slow disease progression, and improve health related quality of life (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2010). In order to promote these models widely there needs to be an understanding of conceptual elements.

Individuals with COPD need to engage in a range of activities to manage their condition. Importantly individuals must: (1) obtain knowledge about their condition to engage in active and informed decision making about self-management and treatment issues (Bodenheimer et al., 2002; Jassem et al., 2010; Lemmens et al., 2008); (2) have an accurate view of their condition and prognosis; (3) integrate healthy lifestyle choices such as appropriate nutrition, regular physical exercise, annual immunisation and smoking cessation to slow disease progression and minimise disease impact (GOLD, 2010); (4) undertake specific health related behaviours to ensure adequate control of symptoms, such as adherence to treatment regimes and engagement with and attendance at health services (GOLD, 2010); (5) recognise fluctuations in condition, and have the confidence to problem solve these fluctuations and escalate treatment to avoid potentially life threatening deterioration (Bodenheimer et al., 2002; Jassem et al., 2010; Lemmens et al., 2008); (6) balance the burden of functional limitations in COPD through energy conservation techniques such as pacing of physical and social activities and a move towards a more sedentary lifestyle (Cicutto et al., 2004; Barnett, 2005; Bourbeau, 2004; Ek and Ternestedt, 2008; Lemmens et al., 2008).

Self-management in COPD is complex and challenging and has a marked impact on the lives of individuals and their families. This review sought to explore the factors which influence self-management in COPD in order to target and tailor self-management interventions.

2. Methods

2.1. *Aims*

This integrative review sought to facilitate a comprehensive review of the influences on self-management in COPD and to develop a conceptual model to illustrate this.

2.2. Design

Using the method of an integrative review this paper sought to explore the influences on self-management in COPD. An integrative approach allows for a broad review of both empirical and theoretical literature in order to comprehensively understand complex concepts, theories or healthcare problems (Whittemore and Knafl, 2005). This approach is particularly useful in undertaking a more structured approach to a review of literature, while identifying the conceptual themes which contribute to the field of work.

2.3. Search strategy

The electronic databases CINAHL, Medline, Embase, PsychInfo were searched using Medical Subject Headings (MeSH) key words including: '*chronic obstructive pulmonary disease*', '*chronic obstructive airways disease*', '*self-management*', '*self-care*' from 2000 to December 2010. Terms were searched individually as key words and also mapped to index terms. The reference lists of published materials were searched for additional literature. Journals held locally were hand searched for relevant articles. The World Wide Web was searched using the Google Scholar and Google search engine for related electronic documents as shown in Table 1.

2.4. Study selection

Papers were included in the review if they were published in peer reviewed journals and written in English. Articles accepted for inclusion referred to the influences on self-management in COPD. Original research papers, systematic type reviews of research, and discussion papers were included in this review. The inclusion of papers for review was validated by a panel of specialists in COPD and complex disease management.

2.5. Synthesis

The included papers were explored for discussion and research around elements influencing self-management. The papers found through the review were assessed for those determinants that influence self-management (Fig. 1). Physical, psychological, social, existential and provider factors are known to influence self-management (Clark et al., 2009; Simpson and Rocker, 2008). Validity of the emergent themes was checked with specialists in COPD and chronic and complex disease management. The synthesised data is presented as an adapted model (see Fig. 1) that identifies those elements which influence patients' self-management of COPD.

3. Results

3.1. Selected papers

The process of paper selection and exclusion is demonstrated in Fig. 2. Through literature searching 29,070 papers were identified as related to COPD and 46,353 related to self-management. 550 of those papers related to COPD and self-management. 430 papers met the inclusion criteria of being written in the English language and published between the years 2000 and 2010. 162 of these papers were retrieved for detailed examination after review of abstracts and removal of duplications. Of these papers 32 met the inclusion criteria. In addition to these papers 12 were added through hand searching and searching through article references. A total of 44 were included in the final review. Of these papers 23 were original research, of which 13 were qualitative, 10 were descriptive, experimental or quasi experimental. A further 6 were systematic type reviews, and 15 were discussion papers. In addition, 20 were from the USA and Canada, 10 were from the United Kingdom, 6 were from Australia and New Zealand, 3 were from Scandinavia, 2 were from the Netherlands and a further 4 from Italy, Poland, Turkey and Taiwan. It is clear that the majority of papers originate from countries in the Western world and this may create an individualistic view of self-management (Chen et al., 2008).

3.2. Elements which influence patients' ability to self-manage COPD

Self-management is particularly challenging in COPD due to the unique and debilitating elements which affect patients with this condition (Barnett, 2005; Ek and Ternestedt, 2008). Through this review a conceptual model has been developed which illustrates those personal elements that influence self-management in COPD as well as the impact of the health system on patients' ability to self-manage their COPD (Fig. 1).

Personal influences

Physical, social, psychological and spiritual elements are key personal influences which affect a COPD patient's ability to integrate the complexities of self-management into their daily living (Cicutto et al., 2004; Gysels and Higginson, 2009a; Simpson and Rocker, 2008).

3.2.1. Physical influences

COPD is a physically debilitating condition which has a marked impact on patients' lives as well as their ability to self-manage their condition (Cicutto et al., 2004; Simpson and Rocker, 2008). The key physical elements that influence self-management in COPD are dyspnoea, functional impairment, and application of physical coping techniques (Cicutto et al., 2004; Gysels and Higginson, 2009a; Simpson and Rocker, 2008).

3.2.1.1. Dyspnoea. Dyspnoea is the core and most debilitating symptom experienced by COPD patients. Dyspnoea is difficult for patients to manage as fluctuations can result from several stimuli including: physical exertion, ambient temperature, health status and emotional state (Gullick and Stainton, 2008; Gysels and Higginson, 2009a; Pasqua et al., 2009; Simpson and Rocker, 2008). Patients often struggle to adapt to the fluctuations in their dyspnoea and furthermore struggle to distinguish between daily

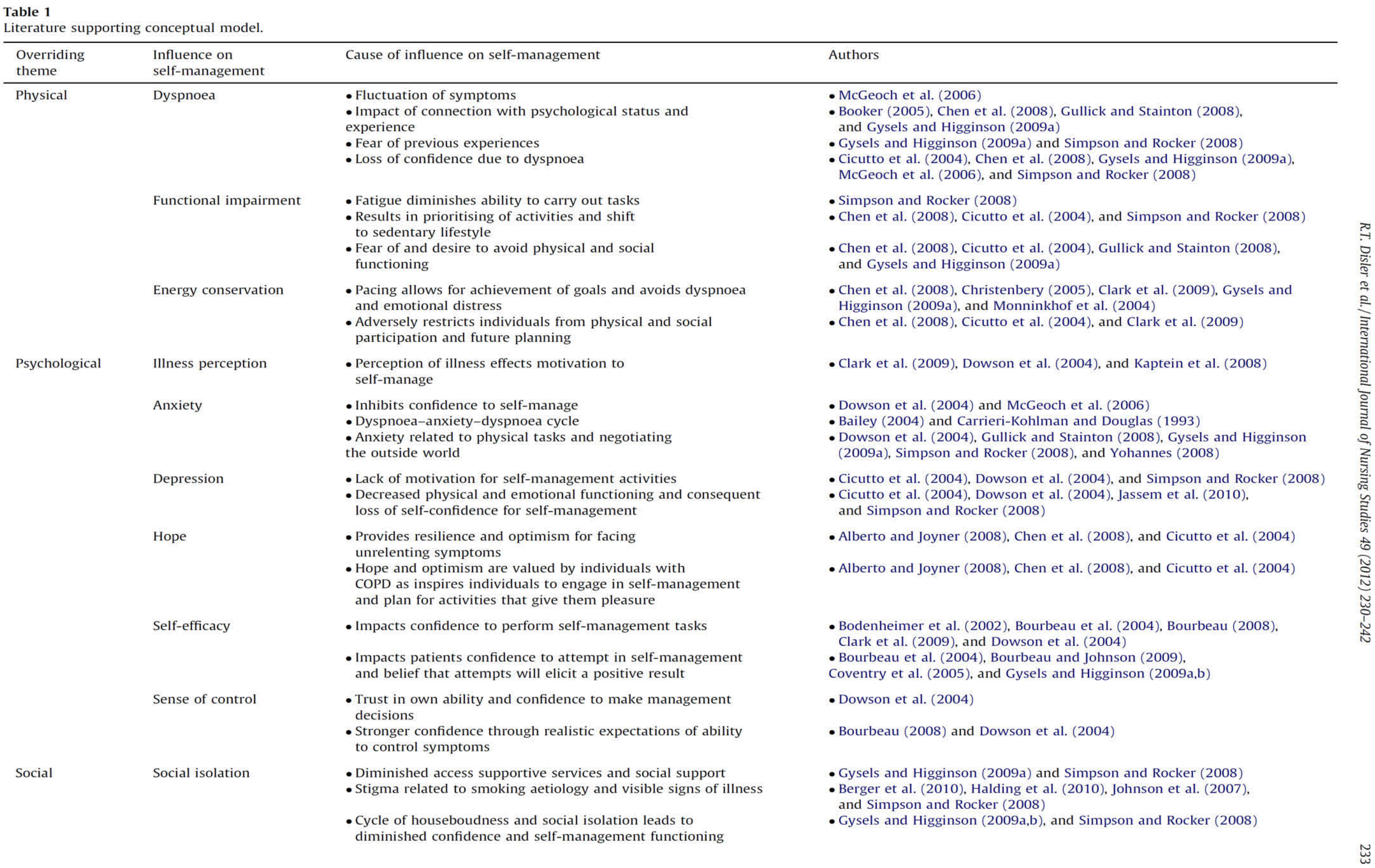

Table 1
Literature supporting conceptual model.

Overriding theme	Influence on self-management	Cause of influence on self-management	Authors
Physical	Dyspnoea	• Fluctuation of symptoms • Impact of connection with psychological status and experience • Fear of previous experiences • Loss of confidence due to dyspnoea	• McGeoch et al. (2006) • Booker (2005), Chen et al. (2008), Gullick and Stainton (2008), and Gysels and Higginson (2009a) • Gysels and Higginson (2009a) and Simpson and Rocker (2008) • Cicutto et al. (2004), Chen et al. (2008), Gysels and Higginson (2009a), McGeoch et al. (2006), and Simpson and Rocker (2008)
	Functional impairment	• Fatigue diminishes ability to carry out tasks • Results in prioritising of activities and shift to sedentary lifestyle • Fear of and desire to avoid physical and social functioning	• Simpson and Rocker (2008) • Chen et al. (2008), Cicutto et al. (2004), and Simpson and Rocker (2008) • Chen et al. (2008), Cicutto et al. (2004), Gullick and Stainton (2008), and Gysels and Higginson (2009a)
	Energy conservation	• Pacing allows for achievement of goals and avoids dyspnoea and emotional distress • Adversely restricts individuals from physical and social participation and future planning	• Chen et al. (2008), Christenbery (2005), Clark et al. (2009), Gysels and Higginson (2009a), and Monninkhof et al. (2004) • Chen et al. (2008), Cicutto et al. (2004), and Clark et al. (2009)
Psychological	Illness perception	• Perception of illness effects motivation to self-manage	• Clark et al. (2009), Dowson et al. (2004), and Kaptein et al. (2008)
	Anxiety	• Inhibits confidence to self-manage • Dyspnoea–anxiety–dyspnoea cycle • Anxiety related to physical tasks and negotiating the outside world	• Dowson et al. (2004) and McGeoch et al. (2006) • Bailey (2004) and Carrieri-Kohlman and Douglas (1993) • Dowson et al. (2004), Gullick and Stainton (2008), Gysels and Higginson (2009a), Simpson and Rocker (2008), and Yohannes (2008)
	Depression	• Lack of motivation for self-management activities • Decreased physical and emotional functioning and consequent loss of self-confidence for self-management	• Cicutto et al. (2004), Dowson et al. (2004), and Simpson and Rocker (2008) • Cicutto et al. (2004), Dowson et al. (2004), Jassem et al. (2010), and Simpson and Rocker (2008)
	Hope	• Provides resilience and optimism for facing unrelenting symptoms • Hope and optimism are valued by individuals with COPD as inspires individuals to engage in self-management and plan for activities that give them pleasure	• Alberto and Joyner (2008), Chen et al. (2008), and Cicutto et al. (2004) • Alberto and Joyner (2008), Chen et al. (2008), and Cicutto et al. (2004)
	Self-efficacy	• Impacts confidence to perform self-management tasks • Impacts patients confidence to attempt in self-management and belief that attempts will elicit a positive result	• Bodenheimer et al. (2002), Bourbeau et al. (2004), Bourbeau (2008), Clark et al. (2009), and Dowson et al. (2004) • Bourbeau et al. (2004), Bourbeau and Johnson (2009), Coventry et al. (2005), and Gysels and Higginson (2009a,b)
	Sense of control	• Trust in own ability and confidence to make management decisions • Stronger confidence through realistic expectations of ability to control symptoms	• Dowson et al. (2004) • Bourbeau (2008) and Dowson et al. (2004)
Social	Social isolation	• Diminished access supportive services and social support • Stigma related to smoking aetiology and visible signs of illness • Cycle of houseboudness and social isolation leads to diminished confidence and self-management functioning	• Gysels and Higginson (2009a) and Simpson and Rocker (2008) • Berger et al. (2010), Halding et al. (2010), Johnson et al. (2007), and Simpson and Rocker (2008) • Gysels and Higginson (2009a,b), and Simpson and Rocker (2008)

Table 1 (*Continued*)

Overriding theme	Influence on self-management	Cause of influence on self-management	Authors
	Loss of social role	• Restriction of physical and social engagement diminishes feelings of self-worth and confidence to self-manage	• Gysels and Higginson (2009b)
		• Domestic dependence further diminishes confidence	• Gullick and Stainton (2008), Gysels and Higginson (2009b), and Yohannes (2008)
		• Frustration, irritation and consequent disruption to social relationships further adds to loss of identity	• Gysels and Higginson (2009b), Jassem et al. (2010), and Simpson and Rocker (2008)
		• Erosion of social role, decreased self-confidence and self-worth consequently reduce patients' ability to independently manage their COPD	• Gysels and Higginson (2009b)
	Social support	• Peer support through joint learning and validation of life experience	• Alberto and Joyner (2008), Arnold et al. (2006), Cicutto et al. (2004), Halding et al. (2010), Monninkhof et al. (2004), and Simpson and Rocker (2008)
		• Social integration with peers adding to self-worth and motivation through increased pleasure and lightheartedness	• Alberto and Joyner (2008) and Halding et al. (2010)
		• Family and friends buffer demands of self-management and assist with coordination of services	• Bourbeau (2004, 2008), Halding et al. (2010), and Jassem et al. (2010)
		• Family also provide a strong motivator to continue to strive for best life possible	• Cicutto et al. (2004), Ek and Ternestedt (2008), Halding et al. (2010), and Kanervisto et al. (2007)
	Socioeconomic status	• Economic hardship reduces access to resources and requires patient to prioritise some management techniques while forgoing others	• Jeon et al. (2009)
	Health literacy	• Results in limited understanding of rationale for self-management techniques	• Jeon et al. (2009), Lareau and Yawn (2010), and Roberts et al. (2008)
		• Reduced access supportive services geared to maintaining stable COPD management	• Emtner et al. (2009), Gadoury et al. (2005), Jeon et al. (2009), and Roberts et al. (2008)
Existential		• Loss of meaning of life decreases motivation	• Ek and Ternestedt (2008), Cicutto et al. (2004), and Sheridan et al. (2011)
		• Gaining meaning from connectedness with others and everyday life	• Ek and Ternestedt (2008), Cicutto et al. (2004), Kanervisto et al. (2007), and Sheridan et al. (2011)
		• Religiosity provides resilience despite physical and emotional decline	• Seamark et al. (2004) and Sheridan et al. (2011)
Health system	Access to resources	• Access to resources and transport increases adherence and access to supportive services	• Gysels and Higginson (2009a)
		• Resultant increased confidence in decision making	• Gysels and Higginson (2009a) and Monninkhof et al. (2004)
	Relationships with health care professionals	• Healthcare professional guidance improves confidence in decision making	• Barnett (2009), Bourbeau and van der Palen (2009), Cicutto et al. (2004), Cranston et al. (2008), Deprez et al. (2009), Gysels and Higginson (2009a), Monninkhof et al. (2004), and Simpson and Rocker (2008)
		• Psychological support improves confidence and engagement in self-management	• Arnold et al. (2006), Bourbeau (2004, 2008), Bourbeau and van der Palen (2009), Cicutto et al. (2004), Gysels and Higginson (2009a), Halding et al. (2010), and Seamark et al. (2004)

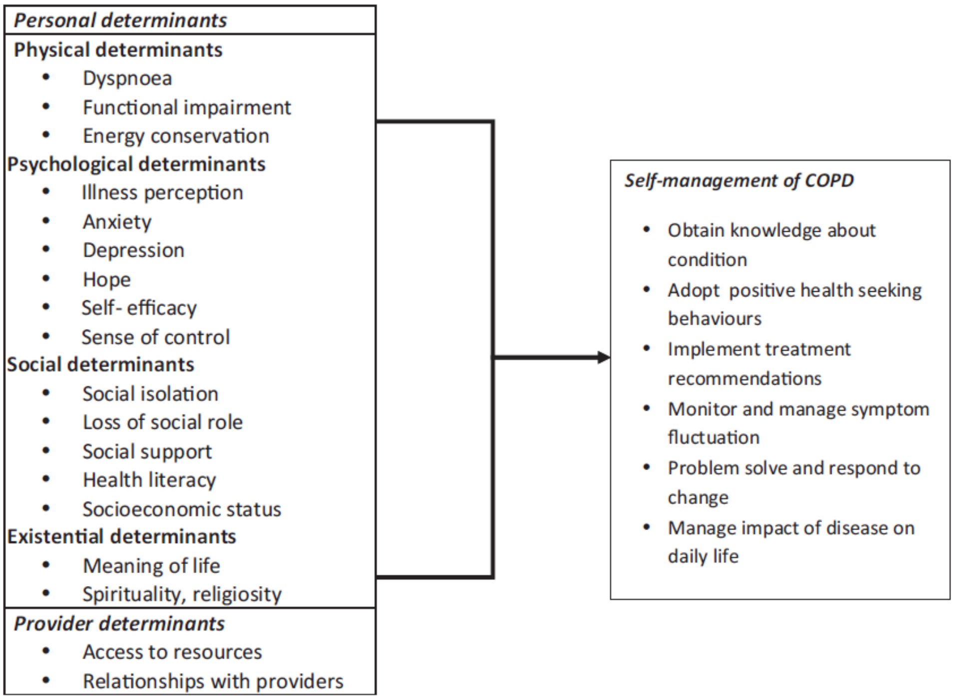

Fig. 1. Model of conceptual elements of self-management in COPD developed through integrative review.

fluctuations and deterioration of their condition (McGeoch et al., 2006).

Self-management of dyspnoea is furthermore impeded by the close interplay between the patients' psychological and emotional condition and the physical experience of dyspnoea (Booker, 2005; Chen et al., 2008; Gullick and Stainton, 2008; Gysels and Higginson, 2009a). Previous negative experiences of dyspnoea, associated with exacer-

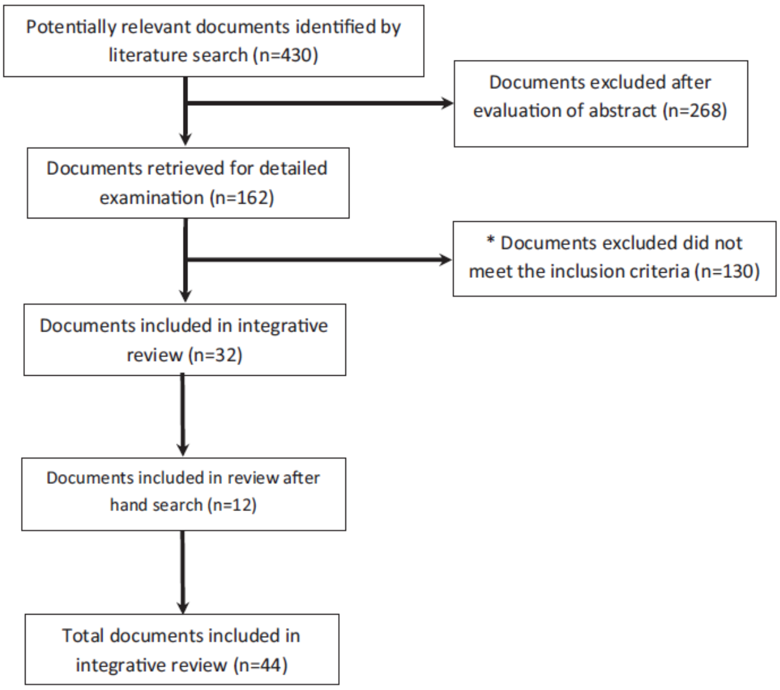

Fig. 2. Flow chart of studies from search to inclusion.

bations, severe breathlessness and hospitalisation, cultivate fear and apprehension of future dyspnoea episodes (Gysels and Higginson, 2009a; Simpson and Rocker, 2008). Patients consequently develop a heightened awareness of their symptoms and a loss of confidence in their own ability to independently recognise and manage changes in dyspnoea as they occur (Cicutto et al., 2004; Chen et al., 2008; Gysels and Higginson, 2009a; McGeoch et al., 2006; Simpson and Rocker, 2008).

3.2.1.2. Functional impairment. Physical fatigue and fear of physical activity are the key elements which lead to decreased physical functioning and ultimately diminish patients' ability to manage their COPD on a day to day basis. COPD patients experience fatigue as a consequence of increased respiratory and metabolic demands, disruption to sleep and rest, and anxiety and the emotional strain associated with living with a progressive and debilitating illness (Simpson and Rocker, 2008). A lack of energy and stamina inhibits patients from carrying out the physical tasks required for self-management, such as carrying out personal care, accessing health services and support networks such as pulmonary rehabilitation and peer support groups. Patients compensate for fatigue through a range of behavioural strategies including conserving energy through prioritising essential physical activities and replacing those unessential physical activities, like social interaction, with passive activities such as staying at home (Cicutto et al., 2004; Simpson and Rocker, 2008). While a shift to a more sedentary lifestyle does make life more manageable, a lack of physical activity ultimately leads to a spiral of physical deconditioning and further fatigue and social isolation (Chen et al., 2008; Cicutto et al., 2004; Gullick and Stainton, 2008; Simpson and Rocker, 2008).

In addition to fatigue, individuals' ability to self-manage is influenced by their negative experience of exertional dyspnoea when undertaking simple physical activities. As a consequence patients develop a fear of and a strong desire to avoid physical tasks which might cause breathlessness, including exercise, personal care activities and accessing community and medical services. As a consequence patients lose confidence in their ability to carry out activities of which they may be capable, resulting in further reduction of physical functioning and social integration and ultimately reduced ability to independently manage their own COPD in the community (Chen et al., 2008; Cicutto et al., 2004; Gysels and Higginson, 2009a).

3.2.1.3. Energy conservation techniques. One element that does positively impact patients' ability to physically self-manage their COPD is through pacing of physical activity. Completing physical activity at one's own speed enables patients to conserve energy and achieve physical goals while avoiding exertional dyspnoea and the emotional distress that comes with breathlessness (Chen et al., 2008; Christenbery, 2005; Clark et al., 2009; Gysels and Higginson, 2009a; Monninkhof et al., 2004). Unfortunately, pacing slows patients in their tasks and therefore restricts how much patients can achieve within a time frame. Patients consequently prioritise those activities which are essential to their health and let those unessential activities, such as those that give patients pleasure, slip to the way side (Chen et al., 2008; Cicutto et al., 2004; Gullick and Stainton, 2008). While pacing does restrict patients in tasks they may have been able to achieve previously, ultimately patients gain confidence in their ability to complete physical tasks without dyspnoea in the future, thereby improving self-management of COPD and potentially quality of life (Clark et al., 2009).

3.2.2. Psychological influences

Illness perception, anxiety, depression, hope and optimism, self-efficacy, and sense of control are all key psychological influences on COPD self-management (Cicutto et al., 2004; Simpson and Rocker, 2008). Actual and perceived stigma also influences psychological factors (Halding et al., 2010).

3.2.2.1. Illness perception. The way in which patients view their illness has a marked impact on their self-management (Dowson et al., 2004). Those who approach their COPD with a negative outlook, or believe little can be done for their condition, will struggle to find the motivation to engage in self-management on an ongoing basis and will furthermore lack the confidence in their ability to affect positive outcomes from self-management tasks (Clark et al., 2009; Dowson et al., 2004; Kaptein et al., 2008). Conversely, those who believe that they can elicit a positive effect on COPD will experience greater motivation for self-management and greater confidence in their own ability to integrate self-management into their lives (Clark et al., 2009; Dowson et al., 2004; Kaptein et al., 2008).

3.2.2.2. Anxiety. Anxiety is common in COPD and has a marked impact on the capacity of individuals to self-manage their condition. While anxiety can motivate patients to act to control their symptoms, the unrelenting and progressive physical deterioration associated with COPD can cause anxiety which directly inhibits patients' confidence for self-management (Dowson et al., 2004; McGeoch et al., 2006). Anxiety in COPD is closely associated with the fear of being breathless during self-management activities and the anxiety–dyspnoea cycle is a common phenomenon (Bailey, 2004; Carrieri-Kohlman and Douglas, 1993). In particular dyspnoea is associated with physical tasks such as personal care and domestic tasks, deterioration in symptoms and negotiating the outside world and social environment (Dowson et al., 2004; Gysels and Higginson, 2009a; Simpson and Rocker, 2008; Yohannes, 2008). A desire to avoid breathlessness leads patients to prioritise simple tasks carried out in the home and to take a 'one day at a time' approach which makes life tasks more manageable but inhibits both future planning of complex self-management and leisure activities (Gullick and Stainton, 2008; Simpson and Rocker, 2008). Fear and anxiety around dyspnoea, social engagement and self-management ultimately leads to a spiral of anxiety and psychological dysfunction and a dependent and limited lifestyle (Bailey, 2004; Cicutto et al., 2004; Jassem et al., 2010; Simpson and Rocker, 2008).

3.2.2.3. Depression. Clinical depression is two to four times more prevalent in COPD than in the general population (Cicutto et al., 2004; Dowson et al., 2004; Simpson and Rocker, 2008). Individuals suffering from depression can experience feelings of inertia and find it difficult to motivate themselves to engage in self-management activities (Cicutto et al., 2004; Dowson et al., 2004; Simpson and Rocker, 2008). Consequently, individuals with COPD and associated depression struggle more than ever to maintain motivation for activities such as self-management, leading to a progressive cycle of increasing functional impairment and social and emotional dysfunction (Cicutto et al., 2004; Dowson et al., 2004; Jassem et al., 2010; Simpson and Rocker, 2008). Importantly, depression impacts adversely on health related quality of life (Nguyen and Carrieri-Kohlman, 2005; Simpson and Rocker, 2008).

Anxiety and depression are key complex psychological influences on COPD self-management and whose emotional and physical impact must be managed. Importantly, hope and optimism, self-efficacy, and a sense of control play key roles in sustaining patients' psychological health despite these negative challenges (Alberto and Joyner, 2008; Bourbeau et al., 2004; Cicutto et al., 2004).

3.2.2.4. Hope and optimism. Hope and optimism are essential psychological influences on patients' self-management of COPD (Alberto and Joyner, 2008; Chen et al., 2008; Cicutto et al., 2004). The ability for the patient to stay optimistic not only assists in controlling the negative influences such as anxiety and depression but also provides patients with resilience which is particularly important in the face of unrelenting symptoms (Alberto and Joyner, 2008; Chen et al., 2008; Cicutto et al., 2004). Patients valued hope and optimism as it helped them to see the merit in undertaking interventions such as self-management (Alberto and Joyner, 2008; Chen et al., 2008; Cicutto et al., 2004). Patients voiced that an important part of maintaining hope was in fact accepting their diagnosis which allowed them to have more realistic expectations of themselves and self-management (Alberto and Joyner, 2008; Chen et al., 2008; Cicutto et al., 2004). Patients furthermore noted that light heartedness through leisure, relaxation and positive thinking were key in sustaining hope and optimism. These activities both gave patients pleasure and also inspired patients to integrate self-management into their lives with the purpose of being able to participate in those things which gave them pleasure (Chen et al., 2008; Cicutto et al., 2004).

3.2.2.5. Self-efficacy. The complexity and frequency of problem solving increases with the progression of COPD. Patients must possess confidence in their self-management and decision making in order to implement actions in response to these changes. Self-efficacy for self-management, or a patient's confidence in their own ability to self-manage in future situations, is of particular importance to patients' management of their COPD. Most prominently self-efficacy influences: the individual's belief in their ability to actively perform tasks associated with self-management; and their belief that self-management will have a positive impact (Bodenheimer et al., 2002; Bourbeau et al., 2004; Bourbeau, 2008; Clark et al., 2009; Dowson et al., 2004; Warwick et al., 2010). An individual's level of confidence is essential to enable them to attempt and develop the skills necessary for self-management, particularly as COPD self-management becomes progressively burdensome and complex (Bourbeau et al., 2004; Bourbeau and Johnson, 2009; Coventry et al., 2005; Gysels and Higginson, 2009a,b). Self-efficacy for self-management provides patients with the confidence to carry out necessary self-management activities as well as sustaining motivation for self-management despite unrelenting symptoms.

3.2.2.6. Sense of control. In addition to the self-confidence required to self-manage, patients' sense of control over their illness also has a strong impact on their ability to self-manage. Patients with a high sense of control over their illness are more likely to trust their ability to make self-management choices and therefore have a greater resilience for managing COPD despite episodic and progressive deteriorations (Dowson et al., 2004). Patients are also more likely to have realistic expectations of their ability to manage their condition and therefore have stronger confidence in their ability to manage their condition independently (Bourbeau, 2008; Dowson et al., 2004). Like self-efficacy, sense of control over illness has a marked impact on patients' ability to sustainably self-manage and must be utilised to encourage confident management of COPD in the community.

The psychological determinants of illness perception, anxiety, depression, self-efficacy, and sense of control and illness perception, have a marked impact on patients' ability to self-manage their COPD. Through managing these psychological elements, patients are enabled to both manage their COPD despite unremitting symptoms, as well as empowered to maximise their involvement and enjoyment in those things that give them pleasure (Bourbeau et al., 2004; Chen et al., 2008; Cicutto et al., 2004; Gysels and Higginson, 2009a; Simpson and Rocker, 2008; Stellefson et al., 2010).

3.2.3. Social influences

Social determinants, such as social isolation, loss of social role and social support, influence patients' management of their COPD in the community (Gysels and Higginson, 2009a; Simpson and Rocker, 2008). Culture and ethnicity also influence health seeking behaviours (Roberts et al., 2008). Health literacy and socioeconomic status are key influences on health outcomes (AIHW, 2008; Mannino and Buist, 2007).

3.2.3.1. Social isolation. Social isolation, due to functional impairment and social stigma, negatively impacts patients' self-management of COPD. Functional impairment resulting from de-conditioning and exertional dyspnoea creates a powerful deterrent to perceived laborious tasks such as leaving the home. Patients' ability to interact socially is thereby diminished as is their ability to access supportive services such as pulmonary rehabilitation and health centres (Gysels and Higginson, 2009a; Simpson and Rocker, 2008). Stigmatization and self-blame related to a smoking aetiology are also seen as key causes of social isolation (Halding et al., 2010). Patients consequently feel their condition is punishment for past behaviour and don't believe they are worthy of treatments which might improve coping with their condition, such as those used in self-management (Halding et al., 2010; Simpson and Rocker, 2008). Patients furthermore fear judgement and feelings of social inadequacy due to visible signs of ill health, such as coughing phlegm, which in addition to self-blame leads patients to avoid the outside world and engage in those activities aimed at improving what is perceived as a self-inflicted condition (Berger et al., 2010; Halding et al., 2010; Gysels and Higginson, 2009a,b; Johnson et al., 2007). The emotional and social impact of functional impairment and stigmatization severely reduces patients' integration in society and creates a cycle of social isolation and houseboundedness which directly reduces patients' ability to self-manage (Gysels and Higginson, 2009a,b; Simpson and Rocker, 2008).

3.2.3.2. Loss of social role. Loss of social identity as a result of reduced financial, domestic and social contribution leads to feelings of dependence and a loss of self-belief required for patients to self-manage (Gysels and Higginson, 2009b; Gullick and Stainton, 2008). Loss of physical ability, stamina and social stigmatization often restricts patients from maintaining full time work and financially contributing to the home. Particularly in male patients, this can be seen as a loss of social status or role reversal within the family and society and leads to reduced self-worth and self-confidence, both essential emotional elements required for self-management (Gysels and Higginson, 2009b). Domestic dependence due to physical restriction has a marked impact on patients' physical self-management but also impacts patients' feelings of social self-worth and guilt over the burden placed on family members (Gysels and Higginson, 2009b; Yohannes, 2008). The frustration and irritation expressed by patients over these restrictions further disrupted social relationships leading to further social isolation and loss of sense of identity (Gysels and Higginson, 2009b; Gullick and Stainton, 2008; Jassem et al., 2010; Simpson and Rocker, 2008). Loss of financial, domestic and social contribution and consequent feelings of burden can lead to the erosion of social role decreased self-confidence and self-worth and consequently a marked reduction in patient ability to independently manage their COPD (Gullick and Stainton, 2008; Gysels and Higginson, 2009b).

3.2.3.3. Social support. While social isolation and loss of social role clearly diminish patients' confidence in their ability to self-manage, patients also gain great emotional support to self-manage from peers, friends and family (Alberto and Joyner, 2008; Bourbeau, 2008; Halding et al., 2010; Monninkhof et al., 2004). Peer support allows patients to model important coping skills and self-management techniques which increase their confidence and motivation to engage in self-management activities (Alberto and Joyner, 2008; Arnold et al., 2006; Cicutto et al., 2004; Halding et al., 2010). In addition, integration within the COPD population provides patients with socialisation and validation of their life experience and provides patients with self-worth and confidence to manage their condition (Alberto and Joyner, 2008; Halding et al., 2010; Monninkhof et al., 2004; Simpson and Rocker, 2008). Peer socialisation also provides an environment for light-heartedness which is potentially absent from other areas of patients lives, these pleasurable interactions motivating patients to live life to the best of their ability and engage in activities that may assist them in managing their condition (Alberto and Joyner, 2008; Halding et al., 2010).

Primary carers, whether family or friends, also hold an important role by providing a buffing effect against the physical and emotional demands of self-management (Bourbeau, 2008; Halding et al., 2010). Management of COPD is often shared between the patients and their carers with carers providing assistance with daily self-management tasks such as personal care as well as coordination and interaction with supportive services, such as health appointments, which the patient may find overwhelming (Cicutto et al., 2004; Halding et al., 2010; Jassem et al., 2010). Family and friends also provide emotional support and can be in themselves a strong motivator for patients to continue to live and engage with the complex requirements of self-management (Cicutto et al., 2004; Ek and Ternestedt, 2008; Halding et al., 2010; Kanervisto et al., 2007).

Social isolation, loss of social role and social support are clear influences on patients' ability to self-manage their condition. In addition, socioeconomic status and health literacy are two key social systems influences which have a marked impact on patients' ability to self-manage their COPD.

3.2.3.4. Socioeconomic status. Low socioeconomic status is a predisposing factor for COPD and influences health status and access to health services (AIHW, 2008; Mannino and Buist, 2007). However, few authors directly discuss the impact of socioeconomic status on patients' ability to manage their own condition. Jeon et al. (2009) does discuss the impact of economic hardship and the requirement to balance care with basic living expenses. Key elements in this can be seen to influence patients' ability to self-manage, in particular: the affordability of and prioritising decisions around disease treatments; the access to transport and services; and the ability for patients to maintain a healthy lifestyle. Jeon et al. (2009) noted that economic hardship forced patients to prioritise some medications or self-management activities over others. In conjunction with physical debilitation, economic hardship furthermore restricted patients' ability to transport themselves within the community, expenses such as taxis and portable oxygen seen as an inaccessible luxury (Jeon et al., 2009). Social isolation restricts patients' access to those activities and services specifically geared at supporting patients to self-manage chronic illness in the community. Finally, economic hardship was further seen to diminish patients' ability to maintain a healthy lifestyle. Essential treatments are prioritised over incidental costs such as gym memberships and healthier yet more expensive nutritional options (Jeon et al., 2009). Patients also reduce expenditure on leisure activities such as social interaction, home improvements and vacation time which have a marked impact on quality of life and patients' psychological health (Jeon et al., 2009).

Financial pressures require patients to minimise economic pressures through balancing the demands of managing chronic illness with physical and social activities necessary for living normal life. Compromising treatments seen as non-essential and activities which give patients pleasure leads to decreased physical, social and emotional functioning and ultimately a reduction in patients' ability to manage their condition in the community.

3.2.3.5. Health literacy. Health literacy, or individuals' capacity to access, comprehend, and make appropriate decisions about health care information, is an issue in the general population (Roberts et al., 2008; United States Department of Health and Human Services, 2000). In COPD, low health literacy is a variable related to poor overall health, late presentation in the disease trajectory, low adherence to treatment regimes and increased hospital admissions (Roberts et al., 2008). Roberts et al. (2008) note that few authors have explored this influence of health literacy on COPD management. However, it is clear that low health literacy does influence patients' understanding of the rationale for self-management treatments and patients' ability to access supports in the community. COPD predominantly occurs in an elderly population who have a high incidence of impairment to memory, abstract reasoning and coordination, for some compounded by hypoxaemia (Roberts et al., 2008). Consequently information comprehension and recall is diminished leading to reduced compliance with complex self-management regimes and increased dependence and use of the health system (Jeon et al., 2009; Lareau and Yawn, 2010; Roberts et al., 2008).

Low health literacy and economic hardship isolates patients from the very supports that assist them in negotiating the complexities of the health system (Jeon et al., 2009). In assisting patients to access supportive services they are more able to maintain a stable condition and therefore quality of life (Emtner et al., 2009; Gadoury et al., 2005; Roberts et al., 2008).

3.2.4. Existential influences

The progressive life limiting characteristics of COPD challenges individuals to explore existential issues such as meaning of life and religiosity. Meaning of life is questioned as COPD burden increases and as individuals progressively forgo activities that give them pleasure (Cicutto et al., 2004; Ek and Ternestedt, 2008). Loss of connection with their own lives diminishes patients' motivation for managing their condition (Ek and Ternestedt, 2008; Sheridan et al., 2011). Cicutto et al. (2004), Ek and Ternestedt (2008) and Sheridan et al. (2011) have noted that connectedness with others, especially with children, provided a sense of belonging and life confirmation. Connectedness with peers also affirmed individuals' experience of COPD and gave patients the strength to engage in activities to control their condition (Ek and Ternestedt, 2008; Kanervisto et al., 2007). Ek and Ternestedt (2008) also identified that involvement in an ordinary life and previously joyful activities provided patients with happiness and the motivation to control their symptoms (Ek and Ternestedt, 2008). Religiosity was also found to influence individuals' motivation to manage their condition (Seamark et al., 2004; Sheridan et al., 2011). Seamark et al. (2004) and Simpson and Rocker's (2008) noted that while physical decline and isolation forced some individuals to question their faith, largely, individuals experienced a deepening of faith and spirituality which provided them with resilience to manage their COPD (Seamark et al., 2004; Sheridan et al., 2011). Clearly, appreciating the individual's existential orientation is important in supporting the individual in self-management.

3.2.5. Health system influences

While physical, psychological, social and existential determinants have a marked impact on self-management, access to resources such as transport to healthcare service centres and medications, as well as patients relationships with health care providers are key health system influences that impact on patients' ability to self-manage their COPD (Bourbeau and van der Palen, 2009; Cicutto et al., 2004; Gysels and Higginson, 2009a; Halding et al., 2010).

3.2.5.1. Access to resources. Access to health resources such as medications and transport to health service centres has a direct impact on patients' ability to manage their condition (Gysels and Higginson, 2009a). Low socioeconomic status directly impacts patients' access and adherence to medications, as mentioned previously, access to pharmacies as well medical prescriptions influences medication taking while autonomy in medication decisions increases patients' confidence in self-management (Gysels and Higginson, 2009a; Monninkhof et al., 2004). Limited access to transport, whether caused by financial hardship or functional impairment, decreases individuals' access to health centres and access to community health services such pulmonary rehabilitation, essential for self-management of COPD (Gysels and Higginson, 2009a). The inability to access transport diminishes patients' engagement in social and leisure activities which has a marked impact on psychological health and therefore patients' confidence and motivation to self-manage their condition in the community (Gysels and Higginson, 2009a).

3.2.5.2. Relationships with healthcare professionals. Access to and relationships with health providers provides patients with: symptom management techniques, including management of exacerbations; guidance in self-management decision making; emotional support; and social inclusion (Arnold et al., 2006; Bourbeau, 2004, 2008; Bourbeau and van der Palen, 2009; Cicutto et al., 2004; Gysels and Higginson, 2009a; Halding et al., 2010; Seamark et al., 2004). Regular access to this expert guidance around symptom management, problem solving and coping techniques allowed patients to make self-management decisions with increased confidence (Barnett, 2009; Bourbeau and van der Palen, 2009; Cicutto et al., 2004; Cranston et al., 2008; Deprez et al., 2009; Gysels and Higginson, 2009a; Monninkhof et al., 2004; Simpson and Rocker, 2008). Patients felt that healthcare professionals additionally served as a companion who genuinely cared for their patients (Bourbeau, 2008; Cicutto et al., 2004). This psychological support further improved patients' confidence in engaging in self-management activities, with patients experiencing positive healthcare professional relationships found to be more likely to be successful in self-management interventions such as pulmonary rehabilitation (Arnold et al., 2006; Bourbeau, 2004, 2008; Bourbeau and van der Palen, 2009; Cicutto et al., 2004; Gysels and Higginson, 2009a; Halding et al., 2010; Seamark et al., 2004). Finally, patients' ability to cope with and balance self-management with their daily lives is enabled through nurturing relationships with health professionals that foster patients' self-efficacy for their own management (Bourbeau, 2004; Cicutto et al., 2004; Bourbeau and Johnson, 2009).

4. Discussion

As outlined self-management is a complex construct and influenced by a range of factors. Understanding the diverse factors contributing to self-management is important in developing tailored and targeted interventions and supporting individuals to self-care. It is also important to consider the individuals interaction with health and social systems and the influence of socio-economic factors on health status and self-management. The conceptual model developed through this integrative review (Fig. 1) identifies the key elements which influence patients' ability to self-manage their COPD. This model reflects the diverse physical, social, cultural, psychological and existential issues experienced by patients and will allow for future self-management interventions to be tailored to the complex and interrelated needs of this patient group. Testing this model in prospective trials is warranted.

4.1. *Self-management in COPD: the need for a clear definition.*

Self-management is a central aspect of life for COPD patients and is discussed broadly in the literature (Clark et al., 2009; Kralik et al., 2004; Koch et al., 2004; Lorig et al., 1993; Lorig and Holman, 2003). Some authors ascribe the term of self-management specifically to the day to day clinical tasks patients undertake (Bourbeau, 2008; Chang et al., 2008; Kara Kasikci and Alberto, 2007), while others focus on patients' adherence to disease interventions (Niesink et al., 2007; Taylor et al., 2005). These definitions cover important aspects of self-management but fail to encompass the complex psychological, social, existential and physical determinants that influence COPD patients' lives, nor recognise patients as active participants in the management of their condition (Bodenheimer et al., 2002; Bourbeau, 2008; Clark et al., 2009; Kralik et al., 2004; Koch et al., 2004; Lorig et al., 1993; Lemmens et al., 2008; Redman, 2007). While authors prescribe a number of necessary skills to self-manage, patients clearly identify that the influence of dyspnoea and the desire to balance COPD in the context of their lives were the two key elements which influenced their self-management (Bourbeau, 2008).

4.2. *Balancing life with disease management*

One of the key and overriding themes that emerged from this review was the need for individuals with COPD to balance disease specific recommendations with everyday life (Barnett, 2005; Cicutto et al., 2004). Self-management in COPD is commonly viewed as disruptive and burdensome, particularly as self-management increases in complexity as the disease progresses. Patients often conserve energy in a sedentary lifestyle in order to cope with the physical and emotional demands of self-management (Simpson and Rocker, 2008). Given the high burden and fatigue that COPD patients experience, it is difficult for patients to balance self-management tasks with those lifestyle activities which give them pleasure (Barnett, 2005; Chen et al., 2008; Cicutto et al., 2004; Ek and Ternestedt, 2008; Gysels and Higginson, 2009a; Stellefson et al., 2010). Cicutto et al. (2004) noted that the underlying desire expressed by COPD patients is their need to survive COPD in the context of living and maintain a quality of life despite self-management. The aim is then to integrate self-management into everyday living so it is viewed less as a burden but rather as a facilitator to a full and active life (Bourbeau et al., 2004; Chen et al., 2008; Cicutto et al., 2004; Gysels and Higginson, 2009a; Stellefson et al., 2010).

4.3. *Access to resources*

The availability of resources is clearly a key influence on patients' ability to self-manage their condition in the community, there is scant literature that explores this area directly. Gysels and Higginson (2009a) in their qualitative study noted the influence of access to medications and transport and how these impacted on patients' ability to control their symptoms and maintain social integration. Jeon et al. (2009) addressed economic hardship noting that a lack of funds required patients to prioritise those essential disease treatments while compromising on others, but few other authors addressed these issues in relation to self-management. Jeon et al. (2009), Roberts et al. (2008) and Lareau and Yawn (2010) all discuss the impact of health literacy on patients' ability to access resources and supports available in the community, but these again are restricted to a recent and small group of authors. Research is required to thoroughly explore the impact of access to resources in order to provide adequate financial and infrastructural support for these patients.

4.4. *Limitations of the review*

This review sought to explore the influences on self-management in COPD through including a diverse range of literature and study designs. The review did not provide a systematic meta-analysis of the evidence, in spite of this limitation the review has provided a comprehensive understanding of the complex concepts associated with self-management in COPD.

4.5. Implications for policy, practice and research

Studies have been undertaken to explore discrete foci around self-management but few have attempted to link those things that influence self-management in COPD as an overreaching and coherent model. With concepts heavily intertwined it is clear that further exploration is required into the way in which patients cope with the major emotional, physical and social demands of COPD self-management (Bourbeau, 2004).

There is furthermore a clear need for collaborative care between individuals and health providers in order to facilitate patients' confidence in managing their condition (Bourbeau and van der Palen, 2009; Cranston et al., 2008). In addition, collaboration between primary, secondary and tertiary care should be strengthened so that individuals are assisted in accessing supportive resources and moving smoothly between different parts of the health system (Bourbeau, 2004; Bourbeau and van der Palen, 2009; Deprez et al., 2009; Jassem et al., 2010). Self-management must continue to be a national and international focus to strengthen services which assist patients in managing their COPD in the community.

5. Conclusion

COPD is a progressive and debilitating condition requiring complex self-management behaviours. A diverse range of physical, social, cultural, psychological and existential issues influence the individuals' capacity to self-manage. Appreciating this complex interplay is critical for supporting individuals and their families in living with COPD.

Contributions

RD, RG, PMD contributed towards study design; data collection and analysis; and manuscript preparation.

Conflict of interest. None.

Funding. None.

Ethical approval. Not applicable.

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CHAPTER 4: METASYNTHESIS OF QUALITATIVE RESEARCH: EXPERIENCE AND SUSTAINED UNMET NEEDS OF INDIVIDUALS WITH ADVANCED COPD

EXTENDED ABSTRACT

Chapter Five presents a metasynthesis of qualitative research that has aimed to understand the collective experience and ongoing needs of individuals with advanced COPD. [1-8] This chapter consists of two papers that have been submitted for publication, the first, the metasynthesis paper itself published in the *Journal of Pain and Symptom Management*, the second, the metasynthesis protocol, has been published as an important process in the rigour of the prospective, systematic metasynthesis method, and has been published in the *International Journal of Research in Nursing.*

Disler RT, Green A, Luckett T, Newton PJ, Inglis SC, Currow DC, Davidson PM. Experience of advanced chronic obstructive pulmonary disease: Metasynthesis of qualitative research. Journal of Pain and Symptom Management *Journal of Pain and Symptom Management,* 2014; 46: 6: 1182-1199.

Disler RT, Green A, Luckett T, Newton PJ, Inglis SC, Currow DC, Davidson PM. Unmet Needs in Chronic Obstructive Pulmonary Disease: A Metasynthesis Protocol *International Journal of Research in Nursing* 2012; 3: 15-20.

BACKGROUND

Despite best available treatments, individuals with advanced COPD continue to experience symptom burden and have high rates of health care utilisation [1,3,5,6,9-11]. Within the context of population aging and the increasing burden of chronic illness, there is an emphasis on person-centred care and shared decision making [9,12-14]. Individuals and their families increasingly accept responsibility for everyday care requirements further adding to the burden of this illness, particularly in the advanced stages [15]. Understanding the ongoing needs of individuals with COPD is of central importance in the development of health services and systems that are flexible and responsive to the individual [15,16]. This requires an understanding of not only the available therapies but also the likely experience of individuals; qualitative research elucidates the experience of individuals within the scientific discourse [17-20]. In spite of the clear benefit of this individual perspective, small sample sizes and inherent absence of generalizability, limit the capacity to incorporate this information in policy, practice and research [19-21]. Metasyntheses provide a unique perspective from qualitative data that is accessible to a wider audience and has the potential to increase the leverage of qualitative data to inform health policy and practice [19-21].

OBJECTIVES

This paper sought to increase understanding of the collective experience and ongoing needs of individuals living with COPD.

DESIGN

Metasynthesis of qualitative data

DATA SOURCES

Searches were undertaken in Medline, PsychINFO, AMED, CINAHL, and Sociological Abstracts electronic databases and through hand searching of article reference lists with the supervision of a health informatics expert.

METASYNTHESIS METHODS

Metasyntheses are increasingly used to gain understandings of complex research questions through synthesising data from individual qualitative studies [19-22]. The synthesis of qualitative data from several individual studies provides a useful perspective of and enriches 'the understanding of complex and multifaceted health experiences and healthcare practices' [19,20]. Consistency of reporting and transparency of methods were achieved through the evidence based and systematic principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [23].

The metasynthesis search was guided by search terms, derivatives and related Medical Subject Headings (MeSH) of *'COPD', 'qualitative research'* and *'advanced disease'*. The search strategy was checked against the evidence-based search strategies published by

CareSearch palliative care knowledge network [24] and the McMaster University Health Information Research Unit Terms for filtering for qualitative research [25]. Studies were included if they: were published in English between January 1 1990 and December 31 2012; reported the perspectives of individuals with advanced COPD [6,26-28]; collected data through interviews, focus groups, or open-ended survey questions; and contained primary qualitative data (i.e. direct quotations).

Thematic synthesis of qualitative data was completed by two or more authors, including independent line-by-line coding, random checking, organisation of descriptive themes and confirmation of themes through discussion of an expert panel in COPD, and palliative or chronic care (RTD, AG, TL, PJN, DC, PMD) [19,20,29]. Line-by-line free codes were kept as close to the text as possible and managed within EPPI-Reviewer 4 software [30]. Transparency of the method, the use of independent investigators and panel discussion were used to promote the validity of findings, and rigour and trustworthiness of the metasynthesis process [16,19].

FINDINGS

Literature searching revealed 138,083 articles on COPD, 955,979 publications on advanced disease; 688,181 on qualitative research. On combining the three searches 520 papers were retrieved of which 417 met the inclusion criteria. A total of 66 studies were included after abstract review and a further 34 excluded after detailed review: 22 having no qualitative data; 6 case studies format; 4 included other diagnoses from which COPD responses could not be deciphered; and 2 did not describe the experience of COPD. Twenty-two studies were included for synthesis.

Coding of the 22 studies elicited 422 individual free codes. These codes were condensed into seven descriptive themes; better understanding of condition; breathlessness; fatigue; frailty; anxiety; social isolation; and loss of hope and maintaining meaning. These seven themes were condensed further into three analytical themes that described the experience of COPD and the needs continually raised as ineffectively addressed for individuals with advanced COPD: individuals' needs to have better understanding their condition; the ongoing and sustained symptom burden; and the psychological impact of the condition.

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

Despite advances in management and optimisation of treatments, individuals with COPD continue to experience high symptom burden, ongoing needs and limited access to supportive services [3,5,6,9,31]. The synthesised data from this metasynthesis demonstrates that there are well established and ongoing needs which have not markedly improved over the past two decades [5,6,32]. Further small exploratory qualitative studies are unlikely to add to the key themes outlined in this metasynthesis, however, hearing the experiences from a larger number of individuals may still add colour and nuance to our understanding of living with COPD.

The measure of success and effectiveness of interventions remains strongly based on health related quality of life, health utilisation and mortality data. Consequently these outcomes continue to inform and drive policy and practice development [21]. COPD is a complex and multivariate condition which requires interventions and health services that address the constructs of social and existential connectedness, meaningfulness in life and self-worth [21]. There is potential to capitalize on our understanding of the ongoing needs of individuals with COPD in developing consumer driven interventions and reframing health services to address those underlying needs which impact engagement with this population [19,20,33]. Additionally, there is a lack of understanding of these issues amongst health professionals [34-36]. Training and development of guidelines to support capacity building and decision-making in this area is necessary. Only through actively addressing the ongoing need for patients' understanding of their condition, the sustained symptom burden and the psychosocial impact of the disease that we can begin to deliver services that are responsive to the needs of these individuals [17,37-41].

CONCLUSIONS

Despite prescription of the best available treatments, individuals with advanced COPD continue to experience symptom burden and have high rates of health care utilisation. Combining discrete qualitative studies has provided a useful perspective of the experience of living with COPD over the past two decades. Future research and resources should focus on solutions and the development of consumer driven interventions that optimise care delivery to meet the ongoing needs of patients and their families.

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Review Article

Experience of Advanced Chronic Obstructive Pulmonary Disease: Metasynthesis of Qualitative Research

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Abstract

Context. Chronic obstructive pulmonary disease (COPD) is a life-limiting illness. Despite best available treatments, individuals continue to experience symptom burden and have high health care utilization.

Objectives. To increase understanding of the experience and ongoing needs of individuals living with COPD.

Methods. Medline, PsycINFO, CINAHL, and Sociological Abstracts were searched for articles published between January 1990 and June 2013. Metasynthesis of qualitative data followed the principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses. Metasyntheses are increasingly used to gain understandings of complex research questions through synthesizing data from individual qualitative studies. Descriptive and analytical themes were developed through thematic synthesis and expert panel discussion of extracted primary quotes, not the primary data themselves.

Results. Twenty-two studies were included. Four hundred twenty-two free codes were condensed into seven descriptive themes: better understanding of condition, breathlessness, fatigue, frailty, anxiety, social isolation, and loss of hope and maintaining meaning. These seven themes were condensed further into three analytical themes that described the experience and ongoing needs of individuals with COPD: the need for better understanding of condition, sustained symptom burden, and the unrelenting psychological impact of living with COPD.

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Accepted for publication: April 2, 2014.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2014.03.009

Conclusion. Combining discrete qualitative studies provided a useful perspective of the experience of living with COPD over the past two decades. Further studies into the ongoing needs of individuals with COPD are unlikely to add to this well-established picture. Future research should focus on solutions through the development of interventions that address patients' ongoing needs. J Pain Symptom Manage 2014;48:1182–1199.

Key Words

Chronic obstructive pulmonary disease, advanced disease, ongoing needs, experience, qualitative, metasynthesis

Introduction

Chronic obstructive pulmonary disease (COPD) is a chronic life-limiting illness affecting more than 80 million people worldwide.[1–3] Despite best available treatments, individuals with advanced COPD continue to experience symptom burden and have high rates of health care utilization.[4–10] The fluctuating and episodic decline is characteristic of the COPD trajectory and makes it difficult to determine when death is likely.[5,11–13] Life-limiting illness is defined as an illness where death will likely be a consequence of the specified illness and likely shorten an individual's life.[14,15] The term "life-limiting illness" is inclusive of nonmalignant terminal diseases such as COPD.[16] Although not synonymous with advanced COPD, "severe COPD" or "Stage 3" COPD is defined by the Global Initiative for Chronic Obstructive Lung Disease as "characterized by further worsening of airflow limitation ($FEV_1/FVC < 0.7$; $30\% < FEV_1 < 50\%$ predicted, where FEV_1 is defined as the "forced expiratory volume in one second" and FVC is defined as "forced vital capacity")."[17] Advanced COPD also is characterized as "greater shortness of breath, reduced exercise capacity, fatigue and repeated exacerbations that almost always have an impact on patients' quality of life."[17(p. 4)] Independent predictors of death from COPD include hospitalization, functional limitation, severe reduction in lung function, use of long-term oxygen therapy, depression, low nutritional state, and the presence of comorbidities.[7,13,18,19] Additionally, a clinician's assessment that an individual is unlikely to survive two years also is seen as a useful prognostic tool.[13,19]

Within the context of population aging and the increasing burden of chronic illness, there is an emphasis on person-centered care and shared decision making.[6,20–22] Individuals and their families increasingly accept responsibility for everyday care requirements, further adding to the burden of this illness, particularly in the advanced stages.[23] Understanding the ongoing needs of individuals with COPD is of central importance in the development of health services and systems that are flexible and responsive to the individual.[23,24] This requires an understanding of not only the available therapies but also the likely experience of individuals; qualitative research elucidates the experience of individuals within the scientific discourse.[25–28] A recent Canadian report commissioned by the Health System Strategy Division of the Ministry of Health and Long-Term Care has highlighted the complexity of patients' experience of COPD from diagnosis to end of life and the impact on individuals, their caregivers, health professionals, and the health system.[29] In spite of the clear benefit of this individual perspective, small sample sizes and inherent absence of generalizability limit the capacity to incorporate this information in policy, practice, and research.[27–29]

Metasyntheses are increasingly used to gain understandings of complex research questions through synthesizing data from individual qualitative studies.[27–30] The synthesis of qualitative data from several individual studies provides a useful perspective of and enriches "the understanding of complex and multifaceted health experiences and health care practices."[27,28] Although previous discrete qualitative studies discuss symptom burden and experience,[12,18,31,32] there has been no formal integrated synthesis of the lived experience of COPD. Metasynthesis is used as the methodological approach in this article and has followed the evidence-based and systematic principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).[33]

This article aims to describe and increase the understanding of the experience and ongoing needs of individuals living with COPD and has unique potential for informing the coordination and responsiveness of services to the needs of individuals with COPD and their families.[4,5,7,10,34–37]

Methods

Research Design

A systematic metasynthesis of published, qualitative data was used as the methodological approach in this article and was completed after PRISMA[33] principles. PRISMA acts as an evidence-based and systematic approach to data searching and review and acts to achieve consistent reporting and transparency of methods. The methodological process has been previously published in detail as a peer-reviewed protocol. The methodological process is summarized briefly below for the purposes of this article.[24]

Data Search and Extraction

Searches were undertaken in Medline, PsychINFO, AMED, CINAHL, and Sociological Abstracts electronic databases and through hand searching of article reference lists, with the supervision of a health informatics expert. The search was guided by search terms, derivatives, and related Medical Subject Headings of *COPD*, *qualitative research*, and *advanced disease*. The search strategy was checked against the evidence-based search strategies published by CareSearch palliative care knowledge network[38] and the McMaster University Health Information Research Unit Terms for filtering for qualitative research[39] (Table 1).

Studies were included if they were published in English between January 1, 1990 and June 30, 2013; reported the perspectives of individuals with advanced COPD;[7,13,18,19] collected data through interviews, focus groups, or open-ended survey questions; and contained primary qualitative data (i.e., direct quotations). Study samples not limited to COPD individuals were included provided COPD-specific data were identifiable. Mixed method studies also were included if the qualitative component met the earlier mentioned criteria. Studies were evaluated for adherence clarity of aims, justification of approach, procedural rigor, representativeness of the sample, interpretation of the data, reflexivity and evaluative rigor, and transferability of findings.[28,40]

Table 1

Search Strategy (Medline Example)

1	COPD.mp. or exp Pulmonary Disease, Chronic Obstructive/	29,161
2	Exp airway obstruction/or airway obstruction.mp.	25,415
3	COAD.mp.	185
4	CALD.mp	151
5	Exp Lung Diseases, Obstructive/	94,256
6	1 or 2 or 3 or 4 or 5	140,822
7	Advance care planning.mp. or exp Advance Care Planning/	1398
8	Exp Attitude to Death/or attitude to death.mp.	12,879
9	Bereave[a].mp. or exp Bereavement/	11,404
10	Death/or death.mp.	546,114
11	Dying.mp.	23,829
12	End of life.mp.	10,359
13	Hospice[a].mp. or exp Hospices/	10,640
14	Exp Palliative Care/or palliat[a].mp.	61,504
15	Exp Terminal Care/or terminal[a].mp.	405,344
16	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	984,375
17	Exp Interview/or interview[a].mp.	226,893
18	Experience.mp.	405,966
19	Exp Qualitative Research/or qualitative.mp.	145,668
20	17 or 18 or 19	721,040
21	6 and 16 and 21	520
22	Limit to 1990—current	465
23	Limit to English language	417

exp = explode terms; COPD = chronic obstructive pulmonary disease; COAD = chronic obstructive airways disease; CALD = chronic airway limitation disease.

[a] Wild card.

Synthesis of Results

Thematic synthesis of qualitative data was completed in three stages by two or more authors as follows:[27,41] line-by-line free coding of primary data (Stage 1), on perspectives of individuals with advanced COPD, was kept as close to the text as possible and considered the setting as context (R. T. D. and P. M. D.), entered by one author (R. T. D.) into EPPI-Reviewer 4 software[42] for qualitative coding,[27] and entries checked through random selection by a second investigator (A.G.).[27] Free codes were organized into descriptive themes (Stage 2) (R. T. D. and P. M. D.) and confirmed through discussion of an expert panel in COPD and palliative or chronic care (R. T. D., A. G., T. L., P. J. N., D. C., and P. M. D.).[27,28] Lastly, central analytical themes were developed through expert panel discussion (Stage 3) to provide a broader understanding and meaning to the data within the context of patient experience of COPD (R. T. D., A. G., T. L., P. J. N., D. C., P. M. D.).[27,28] Random selection of data extracts and checking of the trustworthiness of the data was carried out by a third independent investigator (A. G.), and disagreements were resolved through discussion.[27,28] Transparency of the method, the use of independent investigators, and panel discussion were used to promote the validity of findings and rigor and trustworthiness of the metasynthesis process (Fig. 1).[24,27]

Results

Selected Studies

Literature searching revealed 138,083 articles on COPD, 955,979 publications on advanced disease, and 688,181 on qualitative research. On combining the three searches, 520 articles were retrieved, of which 417 met the inclusion criteria (Table 1). A total of 66 studies were included after abstract review and a further 34 excluded after detailed review: 22 having no qualitative data, six case studies format, four included other diagnoses from which COPD responses could not be deciphered, and two did not describe the experience of COPD (Fig. 2). Twenty-two studies were included for synthesis (Table 2).

Quality of Included Studies

Most studies presented clear aims, outlined the qualitative approach used, and described data collection techniques.[40] Studies did not consistently justify the qualitative research design.[40] Sampling techniques were assessed as having limited capacity to support generalizability to other contexts; however, this is to be expected in small cohort qualitative research and was discussed as a limitation in most studies. Discussion of reflexivity of the researcher also was limited as was the linking of discussion to existing or new theoretical frameworks. The importance of the research and implications for policy and practice were consistently discussed.[40]

Metasynthesis of Qualitative Data

Coding of the 22 studies elicited 422 individual free codes. These codes were condensed into seven descriptive themes: better understanding of condition, breathlessness, fatigue,

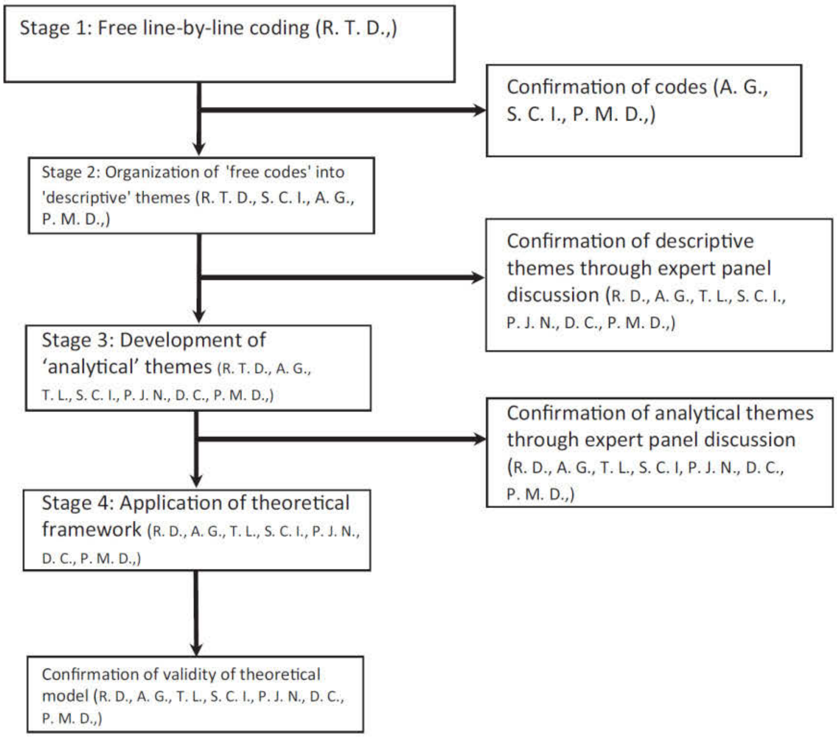

Fig. 1. Flowchart of data synthesis.

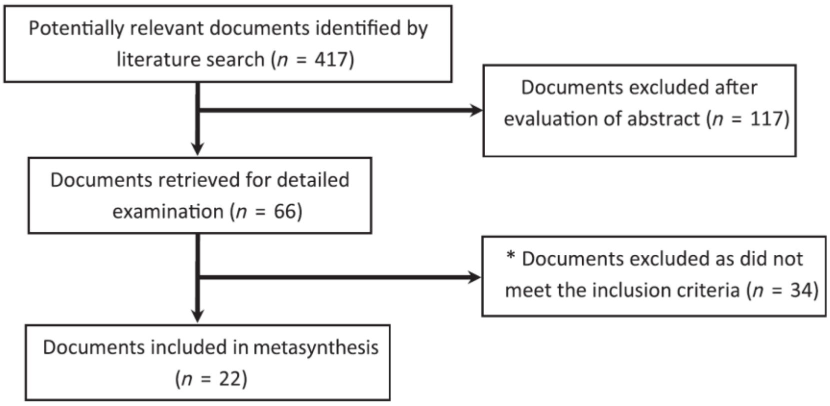

Fig. 2. PRISMA flowchart of studies from search to inclusion. * Papers were excluded if they did not contain at least one example of raw data, that is, a direct quotation ($n = 22$); they were of case-study format without analysis of the data ($n = 6$); the data included responses from individuals who had other diagnoses from which COPD responses could not be deciphered ($n = 4$); or they did not relate to patients with end-stage COPD, their family or carers, or the health professionals who interacted with them ($n = 2$).

frailty, anxiety, social isolation, and loss of hope and maintaining meaning. These seven themes were condensed further into three analytical themes that described the experience of COPD and the needs continually raised as ineffectively addressed for individuals with advanced COPD: individuals' needs to have better understanding of their condition, the ongoing and sustained symptom burden, and the psychological impact of the condition (Fig. 3 and Table 3).

The Need for Better Understanding of Condition. The insidious onset and progression of COPD are recognized as a key barrier to individuals' understanding of their condition.[4,21–23] Individuals commented, across studies, on the slow emergence of symptoms leading to their interpretation as a normal part of life: "It just goes so slowly. We don't really notice but other people do… For us it's just normal."[43(p. 847)] The normal process of aging added to this difficulty: "Life's getting shorter, and I know it's getting shorter, not because of COPD, but because I'm getting to 78, you know I'm getting a bit older now."[12(p. 694)]

Lack of discussion around lung health with health professionals was identified as a further barrier to understanding: "I visit the respiratory physician once a year, and when I'm really ill I go and see my GP. But that can be about something completely different."[43(p. 848)] The gravitas of the condition, even when raised by physicians, was not well understood: "The doctor said to me it will cut 10 years off of your life. Ten years didn't mean a thing to me at that age and I thought well 10 years I'd be too old to enjoy life by then. But if I'd been told that you're not going to be able to walk around your own home, and not play with your grandchildren… that would have made me give up smoking immediately."[44(p. 562)] Individuals regretted not having knowledge early in their condition that may have altered their behavior: "At the beginning we weren't told that it was a general decline. We were just told this is what you've got, get on with it. Yes, in the beginning I would have liked a little bit more information. At least it prepares you for the general decline in health."[44(p. 562)] Individuals commonly described watershed events in which they realized the permanence and seriousness of their disease: "In the pulmonary rehab, all of us found out for the first time that we were not going to cure or reverse emphysema. I know how I reacted, and I heard some people gasping… My doctor had not said anything like that to me."[45(p. 358)] In some cases, the life-limiting nature of COPD was not understood until involvement of palliative services: "I know when the nurse first said, 'I'm referring you to [a day centre run by the local hospice]' I thought oh God! This isn't terminal! Not me!"[18(p. 5)] The fact that this respondent was unaware of the life-limiting nature of the condition suggests a serious inadequacy in education over the years preceding this referral.

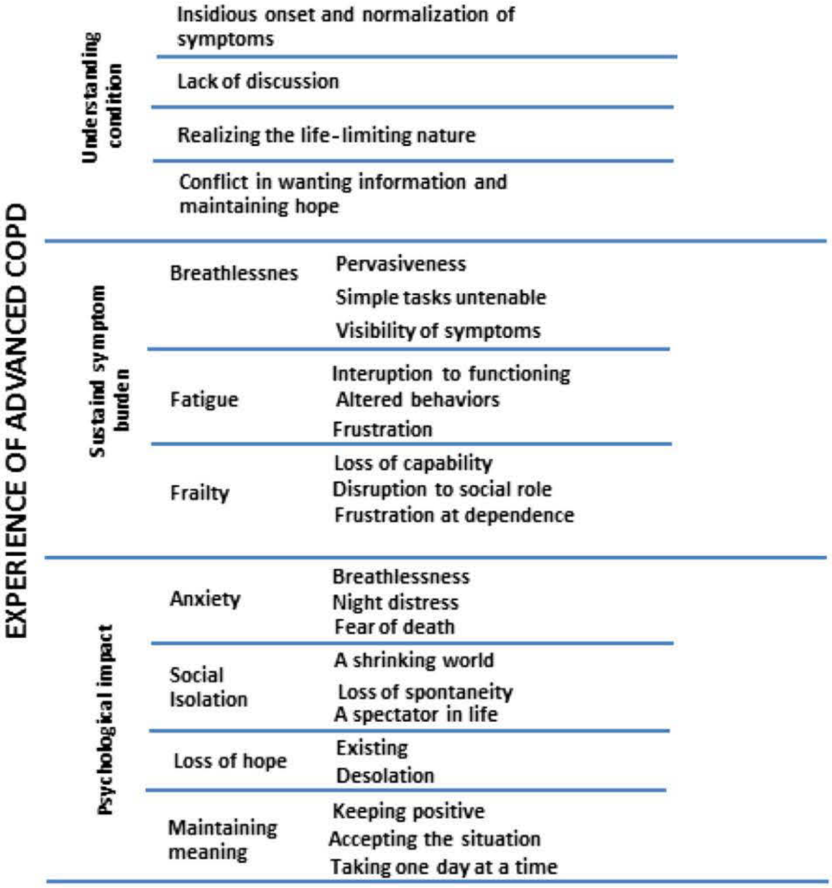

Fig. 3. Relationships between themes.

Individuals described a conflict between wanting information and fear that knowing would diminish their hope and focus on living:[46] "Let's say that I had a hundred sacs, then I would like to know if there are 50 today [stops for breath]. That's why I was curious, but at the same time afraid of knowing what was left."[47(p. 186)] Those wanting information expressed this as having a right to know their future: "Me, I want to know. I have a right to know whether or not I'm going to die.... If I have one year to go, I want to be told so I can make the most of the time I have left to live.... I have a right to. It's my life. I'm the one who's going to die."[48(p. 455)] Conversely, others did not want to engage with such topics: "There's certain information that I don't want. The doctors, the nurses, especially Dr [name], he'd have an idea how long I'm going to last, but I don't want to know, not bothered."[12(p. 694)]

Understanding COPD as a life-limiting condition is paramount to engage individuals in ongoing disease management and assisting individuals to interpret the emergence of symptoms as something more than just a normal part of life. Inadequacies in delivery of disease information by health professionals and understanding of the condition by patients were evident across studies.

Sustained Symptom Burden. Despite optimization of medical treatments, individuals with COPD continue to experience a variety of symptoms, with breathlessness, fatigue, and resulting loss of physical capability consistently reflected in the synthesized studies.[17]

Breathlessness. Breathlessness is recognized as the most common and debilitating symptom in COPD.[30,41–53] This unrelenting symptom was referred throughout the data as pervasive to every aspect of individuals' lives:[25,43,44,46–56] "I did say to him, 'you know this man that has run the London marathon in a deep sea

Table 2
Characteristics of Included Studies

	Setting	Participants	Qualitative Approach
Bailey and Tilley[25]; Bailey[61]	Acute general hospital in Canada	10 Individuals with COPD, with family and carer units. Patients had at least two acute hospitalizations for AECOPD. No other demographic information given.	Interviews with narrative analysis through storytelling theory
Curtis[5]	Outpatient settings in the U.S.	24 Individuals with severe COPD as part of mixed diagnoses study of 55 patients with family, physician, and nurse participants. Unable to decipher COPD demographic information.	Longitudinal interviews with narrative analysis through storytelling theory
Ek and Ternestedt[52]	Community and hospital setting in Sweden	Eight individuals with COPD in the palliative phase of disease and on LTOT, three male and five female, aged 48–79 years.	Interviews analyzed through phenomenological methodology
Ek et al.[47]	Community setting in Sweden	Four individuals with COPD in the palliative phase of disease and on LTOT, one male and three female, aged 66–75 years.	Repeated interviews analyzed through structural analysis for comprehensive understanding.
Elofsson and Ohlen[53]	Community setting in Sweden	Six individuals diagnosed with COPD, four male and three female, aged 78–88 years.	Interviews analyzed through narrative phenomenological/hermeneutic method
Fried and Bradley[31]	Community setting in U.S.	Nine individuals with COPD, thought to be in the last year of life, as part of a mixed diagnosis study of 23 veterans. Unable to decipher COPD demographic information.	Semi-structured interviews analyzed through thematic analysis
Gardiner et al.[12]	Community setting in U.K.	21 Individuals with moderate-to-severe COPD, 13 male and eight female, with a mean age of 70.3 (7.5 SD).	Semi-structured interviews and focus groups analyzed through constant comparative method
Gullick and Stainton[49]	Community setting in Australia	15 Individuals with severe COPD choosing palliative surgery and their family members, nine male and six female, aged 55–77 years.	In-depth interviews analyzed through hermeneutic approach. Two interviews six months apart.
Gysels and Higginson[44]	Outpatient/inpatient/community setting in Spain	18 Individuals with moderate-to-severe COPD taken from hospital and community settings, seven male and 11 female. Hospital group median age 69 years, range 23, community group median age 70 years, range 26.	In-depth interviews analyzed through grounded theory
Habraken et al.[43]	Community setting in the Netherlands	11 Individuals with severe COPD on LTOT, eight male and three female, aged 61–83 years.	Semi-structured interviews analyzed through thematic analysis
Halding et al.[57]	PR setting in Norway	18 Individuals with COPD, 13 male and five female, aged 52–81 years	Longitudinal interviews analyzed through content analysis
Hall et al.[48]	Community setting in Canada	Six individuals with severe COPD or LTOT and diagnosed with COPD, four male and two female, mean age 69 years.	Semi-structured interviews analyzed through thematic analysis
Hasson et al.[46]	Community setting in Ireland	13 Individuals with severe COPD or LTOT and diagnosed with COPD, 10 male, 3 female, median age 65 years.	Semi-structured interviews analyzed through thematic analysis
Jones et al.[54]	Community setting in U.K.	16 Individuals with COPD, thought to be in the last year of life, eight male and eight female, mean age 74.1 years, range 62–83.	Semi-structured interviews analyzed through thematic analysis
Pang et al.[62]	Acute and PR setting in Hong Kong	17 Individuals with severe COPD. No other demographic information given.	Semi-structured interviews analyzed through thematic analysis

(*Continued*)

Table 2
Continued

	Setting	Participants	Qualitative Approach
Pinnock et al.[18]	Community setting in U.K.	21 Individuals with COPD, thought to be in the last year of life, mean age 71 years, SD 8, range 50–83. No other demographic information given.	Longitudinal interviews analyzed through iterative and emergent theme development
Reinke et al.[51]	Community setting in U.S.	55 Individuals with COPD, thought to be in the last year of life, in a mixed diagnosis study with caregivers, physicians, and nurses. Unable to decipher COPD demographic information.	In-depth interviews analyzed through grounded theory
Robinson[50]	Community setting in U.K.	10 Individuals with severe COPD and on LTOT, six male and 10 female, aged 51–74 years.	Unstructured interviews analyzed through mapping the content around patient story and experience
Seamark et al.[56]	Community setting in U.K.	10 Individuals with severe COPD, nine male and one female, mean age 75 years, range 57–85.	Semi-structured interviews analyzed through interpretative phenomenological analysis
Shackell et al.[32]	Community setting in U.K.	10 Individuals with moderate-to-severe COPD, six male and four female, mean age 65.8 years, range 51–78.	Semi-structured interviews analyzed iteratively with concepts mapping and emergent themes development
Skilbeck et al.[36]	Community setting in U.K.	63 Individuals with COPD in the palliative phase of disease, 33 male and 30 female, mean age 71 years, range 55–80.	In-depth interviews using critical incident technique and analyzed using content analysis
Wilson et al.[55]	Community setting in Canada	12 Individuals with COPD, thought to be in the last year of life. No other demographic information given.	Semi-structured interviews analyzed through ethnography

COPD = chronic obstructive pulmonary disease; LTOT = long-term oxygen therapy; AECOPD = acute exacerbation of COPD; PR = pulmonary rehabilitation.

diver’s suit.’ I said, ‘I’m like [that] breathing, so it takes a long time.’”[56(p. 621)] Individuals noted the impact of breathlessness on previously simple everyday activities: “Sometimes I can’t walk from here into the back kitchen, I’m that short of breath, I get breathless even going to the toilet.”[36(p. 251)] Breathlessness was present in all aspects of life and caused individuals to be ever conscious of their bodies and their condition. In one study, the investigators noted that an individual was “distressed by the visibility of her breathing to others, who would frequently stop to offer help. What she really wanted was to be inconspicuous in her breathing—for it to be automatic and invisible.”[49(p. 608)] A further participant similarly voiced that “Everything I did was noticeable. From totally personal things, like intercourse… out of the question! Going for a walk to the shop, you had to stop and consider.”[49(p. 608)]

Fatigue. Fatigue is increasingly considered to be a key symptom in COPD and is described as unrelenting tiredness and exhaustion.[58] Individuals in the included studies noted that fatigue interrupted their previous function and capacity:[57] “I’m not that far away from the lavatory, going for maybe ten meters… in the middle of the night to go and have a wee, oh, totally exhausted, as though I had run a marathon!”[49(p. 610)] These new challenges led individuals to alter their behaviors and ultimately fatigue, like breathlessness, became a barrier to access the outside world: “I would like to be able to go to the shopping mall, but that takes so much energy, so much energy, that it would have to be really necessary. Otherwise, I don’t go there.”[43(p. 846)] The frustration and sense of disruption to life are demonstrated in the following quote in which the individual also notes the difficulty in communicating the impact of fatigue to others:

> It’s hard to explain. Sometimes, I am working in the garden without any problems. After a while, I come into the house and boom, it’s over. Suddenly I’m exhausted, I can’t do anything. That’s hard to explain.

Table 3

Themes Identified in the Synthesis of 22 Studies on the Lived Experience of COPD and Illustrative Quotes

Understanding the nature of COPD	
Insidious onset	"We're not really ill. It may sound funny, but a COPD patient is not ill. He is breathless. Whenever I get an infection, a bacterium, then I'm ill. But like now, I'm not ill because I can eat properly, I can still laugh, I still have fun in my life" (Habraken et al.,[43](p. 847) #299).
Normalization of symptoms	"Well, compared to other people… everyone has got something at my age! I feel lucky to have what I have" (Habraken et al.,[43](p. 847) #299) "Life's getting shorter, and I know it's getting shorter, not because of COPD, but because I'm getting to 78, you know I'm getting a bit older now."[12](p. 694) "It just goes so slowly. We don't really notice but other people do…. For us it's just normal'[43](p. 847); "I think I probably experienced breathing problems for about [thinks], it's difficult to say, because it comes on slowly."[44](p. 561)
Lack of discussion with health professionals	"I visit the respiratory physician once a year, and when I'm really ill I go and see my GP. But that can be about something completely different. We don't discuss my emphysema then. It's registered somewhere, emphysema, but we don't talk about it."[43](p. 848) "I've been to the doctors and they've told me I've got COPD. 'What is it?' The doctor hasn't even explained what those four letters mean and the worst thing about it, is it starts off with C, and first thing you think: 'Oh, have I got cancer?' But this is the thing that is wrong, it's [COPD] not a well-known disease, yet it's one of the greatest killers."[44](p. 562) "At the beginning we weren't told that it was a general decline. We were just told this is what you've got, get on with it. Yes, in the beginning I [.] would have liked a little bit more information. At least it prepares you for [.] the general decline in health."[44](p. 562) "The doctor said to me it will cut 10 years off of your life. Ten years didn't mean a thing to me at that age and I thought well 10 years I'd be too old to enjoy life by then. But if I'd been told that you're not going to be able to walk around your own home, and not play with your grandchildren, you see, I've always spent time with my grandchildren, that would have made me give up smoking immediately."[44](p. 562)
Realizing the life-limiting nature of COPD	"I started that winter [with] chest infections every month practically. [.] Then one day I am going to mass which is just up here, and I was walking, and I got in the middle of the road and suddenly I couldn't breathe. I managed to get to the other side because it was quite busy and I just stopped and got myself back to normal again and carried on up to the church…. couple of days later the same thing happened and then suddenly, it seemed every time I was sitting down and stood up and moved, I was getting out of breath."[44](p. 561) "In the pulmonary rehab, all of us found out for the first time that we were not going to cure or reverse emphysema. I know how I reacted, and I heard some people gasping. That was the first time we all knew that we could not reverse this disease… My doctor had not said anything like that to me."[45](p. 358) "I know when the nurse first said, 'I'm referring you to [a day centre run by the local hospice]' I thought oh God! This isn't terminal! Not me!"[18](p. 5)
Conflict in wanting information and wanting to maintain hope	"Let's say that I had a hundred sacs, then I would like to know if there are 50 today [stops for breath]. That's why I was curious, but at the same time afraid of knowing what was left."[47](p. 486) "Me, I want to know. I have a right to know whether or not I'm going to die. I know that you're not fortune-tellers, or gods.' Interviewer: 'You'd want to be told that now the end is near?' Respondent: 'Yes. If I have one year to go, I want to be told so I can make the most of the time I have left to live. One year, 6 months, 3 months, 2 months, 1 month. I want to know. I have a right to. It's my life. I'm the one who's going to die."[48](p. 455) "I'm a person who's quite open, and if I went to the doctors and he said 'well I'm sorry Mrs [name] it could be bad news, do you want to know it?' I'd say 'yes I do want to know it', because I do want to know, what's the point in hiding things? And then you know where you stand don't you?"[12](p. 694) "There's certain information that I don't want. The doctors, the nurses, especially Dr [name], he'd have an idea how long I'm going to last, but I don't want to know, not bothered."[12](p. 694)
Symptom burden	
Breathlessness	
Pervasiveness	"I did say to him, 'you know this man that has run the London marathon in a deep sea diver's suit.' I said, 'I'm like the breathing, so it takes a long time."[56](p. 621) "We used to go walking a lot. We just can't do it anymore because after about 100 meters I get out of breath. So, we don't do it anymore. There's no joy in that anymore."[43](p. 846)

(*Continued*)

Table 3
Continued

Simple tasks now untenable	“Sometimes I can’t walk from here into the back kitchen, I’m that short of breath, I get breathless even going to the toilet.”[36](p. 251) “I used to be able wash my hair and I have to stop now and it takes ages. I get out of breath even just rubbing my head.”[46](p. 529) “It takes me so long to just get dressed, because you’re stopping and starting, you have to keep sitting down and setting back the breathing, so it takes a long time. To get out by 10, I’m up at half past five. So it takes me all that time”[44](p. 562)
Visibility of symptoms	“distressed by the visibility of her breathing to others, who would frequently stop to offer help. What she really wanted was to be inconspicuous in her breathing - for it to be automatic and invisible”[49](p. 608) (researcher quote) “Everything I did was noticeable. From totally personal things, like intercourse… out of the question! Going for a walk to the shop, you had to stop and consider.” [49](p. 608)
Fatigue	
Interruption to life	I’m not that far away from the lavatory, going for maybe ten meters… in the middle of the night to go and have a wee, oh, totally exhausted, as though I had run a marathon![49](p. 610)
Altered behaviors	“I used to run out and put washing on the line and be back in vacuuming, and be doing all the odd jobs around, and now I’m refined to just doing a couple of things a day.[49](p. 608) “I would like to be able to go to the shopping mall, but that takes so much energy, so much energy, that it would have to be really necessary. Otherwise, I don’t go there.”[43](p. 846)
Frustration	“It’s hard to explain. Sometimes, I am working in the garden without any problems. After a while, I come into the house and boom, it’s over. Suddenly I’m exhausted, I can’t do anything. That’s hard to explain. She [my wife] sometimes doesn’t understand. But I don’t even understand! Because one moment, I’m working and the next, I can’t do anything anymore. It’s hard to explain because you can’t see any difference, I still look the same.”[43](p. 847)
Frailty	
Loss of capability	“A compete loss of personal liberty and now I can’t walk, I can’t do anything.”[56](p. 621) “If I go to town shopping, by the time I come home I want to lie in the lounge. If I do a wash, I want to lie in the lounge.”[49](p. 608)
Disruption to social role	“It stopped everything in its tracks (had to stop work), yeah change of lifestyle completely from a doer to a non-doer. And the simplest tasks now are a big effort.”[56](p. 621) “I used to do a lot of things like that (help around the house), when she (wife) used to go to work. I used to cook the meals, you see, do everything, and I was quite good. I kept everything reasonably clean. I used to use the Hoover and that, but I could do the odd job outside, but I can’t do a damn thing now. It hits you and when it hits you it do hit you, believe me that’s the hard task of it.”[56](p. 621)
Frustration at dependence	“She has to help me up the stairs… She has got to shower me. Help me get dressed. Basically, the stupid things that I should be able to do myself.”[49](p. 609) “I’ve gotten to the point where I can hardly function in my home anymore. Taking a shower is a burden. Cleaning the house is a burden. Washing dishes is a burden.”[48](p. 453) “I even have a job to undress myself, or dress myself. I have to struggle to undress and dress for everything.”[56](p. 621) “I did have help from the home care service… but it was hard many times. They were supposed to come in the morning… they came at nine o’clock or at half past nine/ that was very late.”[53](p. 615) “I hate housework now. I’ve got to get somebody, it’s driving me crazy, I swear to God I’ve never had such a messy house, because I can’t vacuum. I have a hard time washing the floor.”[55](p. 352) “I felt no, not a new one [staff]. I hung up the phone and then I thought [stops for breath] I will not do it. I called back and lied and said that they didn’t have to come because my daughter had just called and she would give me a shower. It felt, no, I just won’t do it.”[47](p. 1485) “When a new carer comes they don’t know anything, you know, if I take a shower and they give me a washcloth [stops for breath], I don’t have the strength to wash myself and then I have to tell them that I can’t do that, I have to save my energy.”[47](p. 1485)
Psychological impact	
Anxiety	
Breathlessness and anxiety	“I think it’s very claustrophobic, if I do get these coughing bouts, which I do get and really terribly out of breath as a result, then it’s very frightening.”[56](p. 621) “You’re fighting for your life and it’s scary, the more you try to calm yourself down and regulate your breathing to get the deep breaths in, it’s like trying to choke yourself at the same time—I wouldn’t wish it on anyone.”[46](p. 529) “… and you feel as if you’re going to die and you take everything off. You open all the windows up because you think if you can open all the windows and the doors, and take your clothes off, you’re gonna be able to breathe better but it doesn’t mean a thing. But it is the most frightening thing that I have ever experienced.”[44](p. 562)

(*Continued*)

Table 3
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Night-time distress	‘But sometimes during the night it gets frightening. I will say that… well, er, you feel something coming on, er, you sense your breathing’s not too good or it’s getting worse and panic sets in a bit and makes it that little bit more worse.”[32(p. 3)] ‘I think a lot of it as well is ‘am I gonna see the next morning?’ Well with my complaint, you know, you get an illness and you don’t know whether you’re gonna see the next morning.”[32(p. 4)] “Yeah, just the breathlessness frightens me. When I’m on my own, if I’m on my own I’m afraid that something might happen to me, you know, and I’m on my own, there’s nobody here, that’s what I’m afraid about.”[32(p. 4)]
Fear of death and being alone	‘I’m not afraid of anything, except for suffocation. I’ve experienced the beginning of suffocation twice, and I really don’t want that to be my ending!”[43(p. 846)] “My current concern is… well, dying. I’m not afraid of dying, I’m afraid of the way I will die, I don’t want to die in agony like I am if I’ve got one of them attacks… that’s about it really. I know I won’t get better, I can only get worse really.”[12(p. 695)] “I want my children around me, otherwise I couldn’t make it, I think.”[47(p. 1486)] “I worry in the middle of the night if I can’t get my breath I shall be on my own and die.”[54(p. 312)]
Social isolation	
Life in a shrinking world	“I can’t remember the last time I went out.”[56(p. 621)] “If I’m honest, I have to say that I live in that chair for 99% of the time.”[43(p. 847)] “There’s a lot you can’t do… a great deal, and much you have to give up… for example, do I have the strength to go out now? No, I don’t have the strength to go out, and then I really wish I could and that makes me sad. So there’s a lot you have to give up, a great deal.”[52(p. 474)] “I used to dance and travel; then I was diagnosed with COPD and oxygen therapy, everything stops—it’s like you are on a leash, tied to a regimen. I feel sad I can’t do the things I would like to do with my kids… go to the horse races. I haven’t done anything I like to do.”[51(p. 606)] “We used to go walking a lot. We just can’t do it anymore because after about 100 metres I get out of breath. So, we don’t do it anymore. There’s no joy in that anymore.”[43(p. 847)] “We had a lot of ideas, but you know, ill health messed it all up. That’s life for you.”[56(p. 621)] “When we first married we couldn’t afford to do the things we wanted to do, now we can and I’ve got this damn thing.”[56(p. 621)]
Loss of spontaneity	“You had to stop and consider… so that instead of saying, ‘Oh, I’ll walk up to the corner and get a taxi or a bus’, you’ve got to plan everything.”[49(p. 610)] “I should get out and enjoy myself when the weather is nice… but you know that you have to think about these hours that you use up… I have to save them to get out on another day… one hour goes by so quickly.”[52(p. 472)] “Well I can’t just think to myself, ‘well I’ll put me coat on and I’ll walk to the village’, I can’t do that. I’m in here, and I’ve got to rely on someone to come and take me out. It’s affected my family life. Yes, because I used to be able to go and visit the kids; I can’t you see.”[36(p. 251)] “I haven’t seen many people this past month. I was afraid of getting an infection”.[47(p. 1484)] “Last winter, I didn’t go out at all.”[43(p. 846)]
A spectator in life	“I was a very ardent DIY merchant, and having to sit here it’s frustrating; I’m not a spectator, I like to be doing, it’s something I have got to get used to, I have to accept it, I don’t like it. I get depressed.”[36(p. 252)] “if you lose the social aspect, when everyone else comes home from work, I have nothing new to share. I have nothing to talk about—I don’t get to hear about how a coworker’s washing machine breaks down or about children who keep them awake all night.”[52(p. 474)] “I watch them go out and potter…. and then I feel bad, worthless. I sit here and feel that I can’t accomplish anything.”[52(p. 472)] “The only problem is loneliness… but I can only blame myself… I could go out, but I usually just sit here.”[52(p. 472)] “I have no opportunity to meet with old friends. That’s a disadvantage.” (Elofsson and Ohlen,[53(p. 614)] #107)
Lack of discussion of social and existential issues	“Some of it is the medical aspect… (taking medicine, etc.), but that’s the smallest part… the big problem is the social aspect… but no one takes that into account… the healthcare staff never ask about this… but it’s the social aspect that’s important.”[52(p. 475)]

(*Continued*)

Table 3
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Loss of hope and maintaining meaning	
Existing	“At times like this I feel… I only want to cry… and then I think… no, God, ugh!!… this is no fun and I don’t want to live any more… I have nothing to look forward to … I’ve had these thoughts many times…. So essentially my day consists of nothing more than resting and reading a little; no, this isn’t living, it’s just existing… I just am.”[52](p. 475) “I haven’t got any future.”[55](p. 351) “First you don’t want to recognize that you’re repressing everything unpleasant… like sweeping it under the rug… but sometimes it all comes out anyway. Times like this are awful… you know how they talk about those black holes that people fall into and are supposed to climb out of again… that’s a pretty good comparison.”[52](p. 475)
Loss of hope and desolation	“I don’t believe in just living for the sake of living… If it gets down to a certain point.”[49](p. 611) “If you were a dog, the RSPCA would have you up for keeping me alive.”[50](p. 41) “I feel that I am a burden to others, why not return to the heavenly god earlier? I feel that I am a burden to my family and to society. I do not want to waste public resources.”[62](p. 138)
Keeping positive and accepting the situation	“I’m not going to be cured and there’s no point worrying over it… It’s getting to accept it is the biggest problem. If you lie back everything will get on top of you. I try to keep myself in good humor.”[46](p. 529) “I am at peace with myself because I did nothing purposely in harming others and I did not owe anybody anything that I did not return in my life. I have raised my family, and I have fulfilled my life responsibilities. I have no more worries. I am already so old. I have enough years of life.”[62](p. 138) “[I] always reckon, if you worry about it, the worry will kill you before the other does… that’s just my idea. I’ll start to get upset about things, and I’ll pick up my fishing gear and go fishing.”[49](p. 610)
Taking one day at a time	“I guess I just take a day at a time… If I got more time than they say, that’s fine, if not, then nothing I can do about it.”[5](p. 615) “I think every person wishes to live forever. As a matter of fact no one can do this. I learn how to live one day at one time because I do not know whether I can live two days later.”[62](p. 141)
Connectedness with family	“Walking was so difficult and we were supposed to bring our swimming gear and bottles (referring to oxygen tanks), so I got a wheelchair and the children pushed me and then parked me somewhere… I sat there and drank coffee and read… and occasionally they came over to touch base… it was great… but they could hardly reach the handles to steer and people didn’t get out of the way… so I had to call out beep beep (laughter)… it probably looked pretty funny… but we had an outing anyhow, and that was the main thing.”[52](p. 475)
Reminiscing in past joys	“I have so much to give—I’m great with teenagers, I’m a good grandmother, I’m a good wife, that’s what I believe… you understand… no one asks about that.”[52](p. 475) “It was evident that hunting and being in the countryside gave his life meaning. He felt sad that he was no longer able to take part in activities in the same way. Now, he participated only through his memories and by sharing hunting stories with his friends.”[47](p. 1486)

> She [my wife] sometimes doesn’t understand. But I don’t even understand! Because one moment, I’m working and the next, I can’t do anything anymore. It’s hard to explain because you can’t see any difference, I still look the same.[43](p. 847)

Impact on Functioning. Respondents distress at their loss of physical capability, and increased dependence was evident across studies:[59,60] “I’ve gotten to the point where I can hardly function in my home anymore. Taking a shower is a burden. Cleaning the house is a burden. Washing dishes is a burden.”[48](p. 453) This increased frailty also undermined individuals’ feelings of self-worth and disrupted individuals’ social identity: “It stopped everything in its tracks (had to stop work), yeah change of lifestyle completely from a doer to a non-doer. And the simplest tasks now are a big effort.”[57](p. 621) Inability to contribute to social activities and domestic duties additionally disrupted social relationships: “I used to do a lot of things like that (help around the house), when she (wife) used to go to work… I kept everything reasonably clean. I used to use the Hoover and that, but I could do the odd job outside, but I can’t do a damn thing now.”[57](p. 621)

Individuals across the data stated that they avoided leaving the home because of the effort required and the need to rely on others: "Well I can't just think to myself, 'well I'll put me coat on and I'll walk to the village', I can't do that. I'm in here, and I've got to rely on someone to come and take me out."[36(p. 251)] Individuals also described embarrassment and frustration at their dependence on others for self-care: "She has to help me up the stairs… She has got to shower me. Help me get dressed. Basically, the stupid things that I should be able to do myself."[49(p. 609)]

Despite optimization of pharmacological treatments and interventions that directly target breathlessness and fatigue (such as pulmonary rehabilitation), individuals continue to experience high symptom burden and restriction in life activities.[36,44,49]

Unrelenting Psychological Impact of Living with COPD. The psychological impact of COPD was consistently raised in relation to anxiety, social isolation, loss of hope, and the need to maintain meaning in life.[32,44,46,52,56,61]

Anxiety. The relationship between anxiety and breathlessness, or the dyspnea-anxiety-dyspnea cycle,[61] has been well documented and was evident across the data: "You're fighting for your life and it's scary, the more you try to calm yourself down and regulate your breathing to get the deep breaths in, it's like trying to choke yourself at the same time—I wouldn't wish it on anyone."[46(p. 529)] Nighttime distress and panic also were commonly described: "But sometimes during the night it gets frightening. I will say that… well, er, you feel something coming on, er, you sense your breathing's not too good or it's getting worse and panic sets in a bit and makes it that little bit more worse."[32(p. 3)] Fear and anxiety at night were commonly translated into fear of not seeing the next day: "I think a lot of it as well is 'am I gonna see the next morning?' Well with my complaint, you know, you get an illness and you don't know whether you're gonna see the next morning."[32(p. 4)]

The fear of death in itself was frequently discussed and in particular fear of an unpleasant death of suffocation, pain or discomfort: "I'm not afraid of anything, except for suffocation. I've experienced the beginning of suffocation twice, and I really don't want that to be my ending!"[43(p. 846)] The importance and need to have family present was closely tied to anxiety about being alone at death: "I want my children around me, otherwise I couldn't make it, I think"[47(p. 1486)]; "I worry in the middle of the night if I can't get my breath I shall be on my own and die."[54(p. 312)]

Social Isolation. The physical and psychological impact of COPD led individuals to live in an ever-shrinking and isolated world:[43,52] "There's a lot you can't do… a great deal, and much you have to give up… for example, do I have the strength to go out now? No, I don't have the strength to go out, and then I really wish I could and that makes me sad."[52(p. 474)] Restrictions on previously pleasurable activities were a constant theme throughout the data: "I used to dance and travel; then I was diagnosed with COPD and oxygen therapy, everything stops—it's like you are on a leash, tied to a regimen. I feel sad I can't do the things I would like to do with my kids."[51(p. 606)] Loss of spontaneity because of a need to plan outings further diminished individuals' social integration: "You had to stop and consider… so that instead of saying, 'Oh, I'll walk up to the corner and get a taxi or a bus', you've got to plan everything."[49(p. 610)] Individuals also referred to the need to conserve energy as a barrier to leave the home: "I should get out and enjoy myself when the weather is nice… but you know that you have to think about these hours that you use up… I have to save them to get out on another day… one hour goes by so quickly."[52(p. 472)]

Lost capability led to further disconnection and feelings of being a spectator: "I was a very ardent DIY merchant, and having to sit here it's frustrating; I'm not a spectator, I like to be doing, it's something I have got to get used to, I have to accept it… I get depressed."[36(p. 252)] Existential and social isolation was further intensified by individuals' apparent mundane lives, leaving little to add to social conversation: "If you lose the social aspect, when everyone else comes home from work, I have nothing new to share. I have nothing to talk about—I don't get to hear about how a coworker's washing machine breaks down or about children who keep them awake all night."[52](p. 474) Individuals noted that although social and existential issues were of high importance, these were rarely addressed by health professionals: "Some of it is the medical aspect… (taking medicine, etc.), but that's the smallest part… the big problem is the social aspect… but no one takes that into account."[52](p. 475)

Loss of Hope and Maintaining Meaning. The psychological impact of COPD was commonly described as a loss of hope and meaning: "At times like this I feel… I only want to cry… and then I think… no, God, ugh!!… this is no fun and I don't want to live any more… no, this isn't living, it's just existing."[52](p. 475) On reflecting back over life, individuals often lamented lost dreams: "When we first married we couldn't afford to do the things we wanted to do, now we can and I've got this damn thing."[56](p. 621) Individuals spoke gravely of a life of loss and isolation: "You know how they talk about those black holes that people fall into and are supposed to climb out of again… that's a pretty good comparison,"[52](p. 475) whereas others viewed themselves as a burden on society: "I feel that I am a burden to others, why not return to the heavenly god earlier? I feel that I am a burden to my family and to society. I do not want to waste public resources."[62](p. 138) Some individuals were so desolate as to make comments such as: "If you were a dog, the RSPCA would have you up for keeping me alive."[50](p. 41)

Despite the difficulties faced, a need to remain positive and accept the situation was reflected by many people: "I'm not going to be cured and there's no point worrying over it… If you lie back everything will get on top of you. I try to keep myself in good humor."[46](p. 529) The notion of "taking one day at a time" also was widely raised: "I guess I just take a day at a time… If I got more time than they say, that's fine, if not, then nothing I can do about it."[5](p. 615) Taking refuge in joyful activities also was noted as a strategy to alleviate negative feelings: "[I] always reckon, if you worry about it, the worry will kill you before the other does… I'll start to get upset about things, and I'll pick up my fishing gear and go fishing."[49](p. 610) Some individuals took solace in what they had achieved in life: "I am at peace with myself because I did nothing purposely in harming others and I did not owe anybody anything that I did not return in my life. I have raised my family, and I have fulfilled my life responsibilities. I have no more worries. I am already so old. I have enough years of life."[62](p. 138)

Maintaining meaning in life was closely tied to a connectedness with family and society. The happiness from engaging in everyday activities is illustrated in the following quote:

> Walking was so difficult and we were supposed to bring our swimming gear and bottles (referring to oxygen tanks), so I got a wheelchair and the children pushed me and then parked me somewhere… I sat there and drank coffee and read… and occasionally they came over to touch base… it was great… but they could hardly reach the handles to steer and people didn't get out of the way… so I had to call out beep beep (laughter)… it probably looked pretty funny… but we had an outing anyhow, and that was the main thing.[52](p. 475)

Social and existential connectedness is central to maintain hope and meaning in COPD. These aspects of chronic disease are frequently overlooked in disease management and must be considered in the development of future consumer-driven care and interventions.

Discussion

This metasynthesis described the lived experience of COPD and the ongoing unmet needs: needing a better understanding of the condition, breathlessness, fatigue, frailty, anxiety, social isolation, and loss of hope and maintaining meaning. Three analytical themes were drawn from these data: the need to have better understanding of their condition, the ongoing and sustained symptom burden, and the psychological impact of the condition. The synthesis of these discrete qualitative studies has provided a collective voice and an important insight into the broader experiential perspective of living with COPD.[25–28]

The Ongoing Needs of Individuals With COPD

The overarching themes drawn from the data have highlighted the ongoing psychosocial and existential needs of individuals with

COPD. Disconnection with society and disconnection of feeling of a "shrinking world" were commonly raised throughout the data.[25,43,44,46–56] Loss of hope and meaningless in life have a marked impact on individuals' experience of illness and resilience to engage with management techniques, yet they have a limited presence in management models and quantitative outcome measurement.[46,47] Preparation for end of life is equally recognized as important,[63,64] and although there is increasing research into the barriers and facilitators for initiating end-of-life discussions, again there is limited evidence of innovations to address the lack of proactive discussion.[63,64]

The multidimensionality and interconnectedness of individuals' symptoms and experiences were evident throughout the data. Such relationships have previously been documented in relation to the dyspnea-anxiety-dyspnea cycle and the relationship between breathlessness and fatigue.[17,61] Complex relationships present in the data were between lost capability, increased dependence, and social and existential isolation.[43,47,49,53,59] Internationally, there is a move to consider patient experience through symptom clusters, which recognize the complexity of chronic illness.[10,65,66] Future interventions must address the variety of symptoms and complex experiences of individuals with COPD and respond to the psychological, existential, and sociological needs of this population.[10,65,66]

A Time for Solutions

Despite advances in management and optimization of treatments, individuals with COPD continue to experience high symptom burden, ongoing needs, and limited access to supportive services.[4–7,67] The synthesized data from this metasynthesis demonstrate that there are well-established and ongoing needs that have not markedly improved over the past two decades.[4,7,68] Further small exploratory qualitative studies are unlikely to add to the key themes outlined in this metasynthesis; however, hearing the experiences from a larger number of individuals may still add color and nuance to our understanding of living with COPD.

The measure of success and effectiveness of interventions remain strongly based on health-related quality of life, health utilization, and mortality data. Consequently, these outcomes continue to inform and drive policy and practice development.[29] COPD is a complex and multivariate condition that requires interventions and health services that address the constructs of social and existential connectedness and meaningfulness in life and self-worth.[29] There is a potential to capitalize on our understanding of the ongoing needs of individuals with COPD in developing consumer-driven interventions and reframing health services to address those underlying needs that affect engagement with this population.[27,28,69] Additionally, there is a lack of understanding of these issues among health professionals.[70–72] Training and development of guidelines to support capacity building and decision making in this area are necessary. Only through actively addressing the ongoing need for patients' understanding of their condition, the sustained symptom burden and the psychological impact of the disease can begin to deliver services that are responsive to the needs of these individuals.[25,43,47,49,52,53]

Limitations of This Review

Synthesizing qualitative data from individual studies remains contentious.[27–29] However, rigor has been supported through the systematic and transparent presentation of the metasynthesis method.[24] Rigor was furthermore increased through the use of independent investigators and expert panel discussion in developing descriptive and analytical themes. This metasynthesis provides insight and understanding of the collective ongoing needs of individuals with advanced COPD and has unique potential for informing the coordination and responsiveness of services for this burdensome condition.

Conclusion

Despite prescription of the best available treatments, individuals with advanced COPD continue to experience symptom burden and have high rates of health care utilization. Combining discrete qualitative studies has provided a useful perspective of the experience of living with COPD over the past two decades. Further studies into the ongoing needs of individuals with COPD are unlikely to add to this well-established picture. Future research and resources should focus on solutions through the development of consumer-driven interventions that address patients' ongoing needs.

Disclosures and Acknowledgments

No funding was received for this study and the authors declare no conflicts of interest.

The authors thank the health informatics experts for their assistance in developing the search strategy.

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Disler RT, Green A, Luckett T, Newton PJ, Inglis SC, Currow DC, Davidson PM. Unmet Needs in Chronic Obstructive Pulmonary Disease: A Metasynthesis Protocol *International Journal of Research in Nursing* 2012; 3: 15-20.

International Journal of Research in Nursing 3 (1): 15-20, 2012
ISSN 1949-0194

Unmet Needs in Chronic Obstructive Pulmonary Disease: A Metasynthesis Protocol

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Abstract: Problem statement: Chronic obstructive pulmonary disease is a chronic progressive illness. Despite the high burden experienced by individuals in the advanced stages of illness, individuals with advanced COPD continue to have unmet needs and limited access to palliative care. This Metasynthesis seeks to describe: the barriers and facilitators care access and provision; the unmet needs of individuals with advanced COPD, their families and carers; and the experiences of health professionals. Data sources: Medline, PsychINFO, AMED, CINAHL and Sociological Abstracts were searched for articles published between 1990 and December 31st 2011. Medical Subject Headings (MeSH) and key words will be used to guide the search. The strategy will be reviewed by the CareSearch palliative knowledge network and a health informatics expert. **Approach:** Metasyntheses are increasingly used to gain new insights and understandings of complex research questions through the amalgamation of data from individual qualitative studies. The principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and thematic synthesis will be used to achieve consistent reporting and transparency of methods. **Results:** Inclusion of studies, quality assessment and allocation of free codes into EPPI-Reviewer 4 software will be carried out by two independent investigators. Auditing of random cases will be undertaken and disagreements resolved through group discussion of an expert panel. Descriptive and analytical themes will be developed through thematic synthesis and expert panel discussion. **Conclusion:** Qualitative data provide useful information in understanding the individual's unique experience. Combining discrete qualitative studies provides an important opportunity to provide a voice to patients, their families and professional careers in managing advanced COPD.

Key words: Medical Subject Headings (MeSH), Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), Chronic Obstructive Pulmonary Disease (COPD)

INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) is a life-limiting illness affecting 80 million people worldwide, is the fourth most prevalent cause of death globally and accounts for 3.5% of total years lost due to disability (World Health Organization, 2004). Despite the high symptom burden, individuals with advanced COPD continue to experience unmet needs and have limited access to palliative care at the end-of-life (Elkington *et al*., 2005; Gore *et al*., 2000; Luddington *et al*., 2001; Curtis, 2008; Gysels and Higginson, 2008). A focus on acute care and challenges in predicting the end-stage of disease creates a milieu that is commonly reactive and ad hoc rather than an approach which is responsive to individuals' ongoing needs (Elkington *et al*., 2005; Gore *et al*., 2000; Luddington *et al*., 2001; Curtis, 2008; Gysels and Higginson, 2008).

The fluctuating and episodic decline is characteristic of the COPD trajectory and makes it difficult to determine when death is likely (Creagh-Brown and Shee, 2008; Curtis, 2008; Gardiner *et al*., 2009; Hansen-Flaschen, 2004). 'Life-limiting' illness is

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defined as an illness where death will likely be a consequence of the specified illness and likely shorten an individual's life (Clayton *et al*., 2007). The term 'life limiting' illness is inclusive of non-malignant terminal diseases such as COPD (Steinhauser *et al*., 2011). While not synonymous with advanced COPD, 'Severe COPD' or 'Stage 3' COPD is defined by the Global Initiative for Chronic Obstructive Lung Disease (GOLD) as 'characterized by further worsening of airflow limitation (FEV1/FVC <0.7; 30% <FEV1 < 50% predicted)' along with 'greater shortness of breath, reduced exercise capacity, fatigue and repeated exacerbations that almost always have an impact on patients' quality of life' (Global Initiative for Chronic Obstructive Lung Disease, 2010), p4). Independent predictors of death from COPD include: hospitalization; functional limitation; severe reduction in lung function; use of long term oxygen therapy; depression; low nutritional state; and the presence of co-morbidities (Gore *et al*., 2000; Hansen-Flaschen, 2004; Pinnock *et al*., 2011; Murray *et al*., 2006). Additionally a clinician's assessment that an individual is unlikely to survive two years is also seen as a useful prognostic tool (Hansen-Flaschen, 2004; Murray *et al*., 2006).

Metasyntheses have increasingly been used to gather qualitative data from different studies in order to gain an understanding of complex research questions (Thomas and Harden, 2008; Walsh and Downe, 2005). The integration of a number of individual qualitative studies is argued to provide an interpretation that 'will not be found in any one research report but, rather, are inferences derived from taking all of the reports in a sample as a whole' (Sandelowski *et al*., 1997). Through the amalgamation and syntheses of these data new insights and meanings may be generated which may not have been evident in individual qualitative studies (Sandelowski *et al*., 1997; Thomas and Harden, 2008; Walsh and Downe, 2005).

In the context of health care, metasyntheses are used to 'enrich understanding of complex and multifaceted health experiences and health care practices' (Walsh and Downe, 2005). The outcomes of metasyntheses are not merely summative of individual qualitative studies but also cast a lens on a broader experiential perspective (Walsh and Downe, 2005).

This technique also responds to a desire to make qualitative data and the unique perspective it presents, accessible to wider audiences who may not have the capacity to interpret large bodies of qualitative evidence (Thomas and Harden, 2008). Metasyntheses consequently have the potential to increase the leverage of qualitative data to inform policy and practice (Thomas and Harden, 2008).

The conduct of metasyntheses has not been without contention (Thomas and Harden, 2008; Walsh and Downe, 2005). Separating qualitative data from the timing and participant characteristics of each study opens authors to accusations of 'de-contextualising findings and wrongly assuming that there are commensurable' (Thomas and Harden, 2008). However the summarizing and synthesis of primary data (i.e., Direct quotations) and themes identified by article authors does allow metasyntheses to summarize the individuals' experience within the context of the study (Thomas and Harden, 2008; Walsh and Downe, 2005).

This metasynthesis will allow the authors to explore the complexities of individuals' experience of advanced COPD (Thomas and Harden, 2008; Walsh and Downe, 2005). Developing greater insight into the experience of COPD-including the unmet needs and barriers faced by individuals with advanced COPD, their families and the healthcare professionals who care for them-has unique potential for informing the coordination and responsiveness of services for this burdensome condition.

In exploring individuals' experiences of illness, we take this to be a constructed and experiential phenomenon concerned with how individuals come to understand and live with their illness and its management (Conrad and Barker, 2010). We anticipate that this will include not only perceptions of how disease and management have impacted daily life (e.g., through symptom burden) but also cultural and societal meaning for the individual as well as the way in which society interacts with individuals with illness (Conrad and Barker, 2010). Exploration of unmet needs will be based on those experiences in which individuals require assistance but for which inadequate management is in place. In the context of chronic illness, individuals' needs may include physical, psychological, cultural, existential, sexual and financial (Desai *et al*., 2001; Elkington *et al*., 2005; Gore *et al*., 2000).

The objectives of this review are to describe:

- The barriers and facilitators to care access and provision for individuals with advanced COPD, their families and carers and health professionals
- The unmet needs of individuals with advanced COPD and their families and
- The experiences of healthcare professionals caring for individuals with advanced COPD

Approach:

Methods: The principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses

(PRISMA) approach have been used to achieve consistent reporting and transparency of the methods used in this metasynthesis (Moher *et al*., 2009).

Eligibility criteria:
Studies will be included if:

- Reported in English
- Published in a peer reviewed journal between 1990 and December 2011
- The publication reports the perspectives of individuals with advanced COPD and/or their family/carers and/or health professionals involved in COPD management
- The publication contains qualitative data; that is, presentation and or synthesis of primary data (i.e., direct quotations) and themes identified by article authors. To ensure a minimum quality standard, we will require reports to include at least one excerpt of raw data; and
- Data collection included interviews, focus groups, or open-ended survey questions

Studies with samples that include but are not limited to COPD individuals, family/carers and health professionals will be included provided COPD-specific data can be extracted. Qualitative data from mixed methods studies will also be included if the above criteria are met.

Population: For the context of this metasynthesis, individuals with advanced COPD are defined as those with an advanced life-limiting illness and predictors associated with adverse outcomes (Gore *et al*., 2000; Hansen-Flaschen, 2004; Pinnock *et al*., 2011; Murray *et al*., 2006). Family and carers (both informal and formal) will be taken to be any significant person involved in the care and management of individuals with advanced COPD (Seamark *et al*., 2004; Spence *et al*., 2008; Gysels and Higginson, 2009). Healthcare professionals will to include healthcare professionals who discuss their experiences of management of advanced COPD, including nurses, physicians and allied health professionals (Blackler *et al*., 2004; Goodridge *et al*., 2008).

Information sources: The following electronic databases-Medline, PsychINFO, AMED, CINAHL and Sociological Abstracts-will be searched for articles published between 1990 and February 29th 2012. These dates were decided to reflect contemporaneous approaches to COPD management, particularly approaches to chronic disease management. Included article reference lists will be hand searched for additional studies.

Table 1: Search strategy (medline example)

1	exp Pulmonary Disease, Chronic Obstructive/	17330
2	COPD*.mp.	19799
3	exp Airway Obstruction/	18032
4	airway obstruction.mp.	21470
5	COAD*.mp.	185
6	Exp Lung Diseases, Obstructive/	144900
7	1 or 2 or 3 or 4 or 5 or 6	49454
8	advance care planning.mp. or exp Advance Care Planning/	6307
9	exp Attitude to Death/ or attitude to death.mp.	12505
10	bereave$.mp. or exp Bereavement/	10837
11	Death/ or death.mp.	467014
12	dying.mp.	22516
13	end of life.mp.	9102
14	hospice$.mp. or exp Hospices/	9912
15	exp Palliative Care/ or palliat$.mp.	57391
16	exp Terminal Care/ or terminal$.mp.	392871
17	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	899336
18	6 and 16	3367
19	exp Interview/ or interview$.mp.	207087
20	experience.mp.	378908
21	exp Qualitative Research/ or qualitative.mp.	102207
22	18 or 19 or 20	640536
23	17 and 21	292
24	limit 23 to English language	261
25	limit 24 to "all adult (19 plus years)"	182

* COPD: chronic obstructive pulmonary disease, * COAD: chronic obstructive airways disease, $: wildcard, exp: explode terms

Search: Medical Subject Headings (MeSH) and key words will be used to guide the search including the terms outlined in Table 1 for Medline and will be adjusted as appropriate for each database. These search terms and strategies have been reviewed by the CareSearch palliative knowledge network (CareSearch, 2012). Terms of filtering for qualitative research were those recommended by the McMaster University Health Information Research Unit (McMaster University, 2011). The overall search strategy will be reviewed by a health informatics expert (Fig. 1).

Study selection: Inclusion of studies will be independently assessed by two researchers specialized in COPD, palliative and chronic care (RTD, PMD). These entries will be checked by a third independent investigator (AG) through random selection and checking. Disagreements will be resolved by consensus (Fig. 2).

Data management: Data from the selected papers will be entered into EPPI-Reviewer 4 software by one investigator (RTD) to allow for assessment against inclusion criteria and coding by multiple investigators (Thomas and Harden, 2008). These entries will be checked by a second investigator (AG) through random selection and checking. Any disagreements over quality assessment will be resolved through group discussion (Walsh and Downe, 2005).

Descriptive details of the selected studies will be recorded with country of origin, sample characteristics (participant type, setting and demographics), study characteristics (method, conceptual approach) and results (themes identified by the authors). Where possible description of the stage of illness trajectory will be collected, as well data on family and career relationship to the individual and the characteristics of the assistance they provide. Provider data will be collected on discipline and role in patient care.

Quality assessment: The quality of studies will be independently evaluated with by two investigators (RTD, AG) with the checklist developed by Kitto *et al.* (2008). This checklist evaluates studies in terms of clarity of aims/research question, justification of the approach used, procedural rigor, representativeness of the sample, interpretation of the data, reflexivity and evaluative rigor and transferability of findings (Kitto *et al.*, 2008; Walsh and Downe, 2005).

Synthesis of results (Fig. 2): This metasynthesis will use a thematic synthesis of qualitative research as developed by (Thomas and Harden, 2008; Barnett-Page and Thomas, 2009). It is anticipated that the systematic approach to combining qualitative data in this metasynthesis will generate new insights and meanings which may not have been evident in the discrete studies (Sandelowski *et al.*, 1997; Thomas and Harden, 2008; Walsh and Downe, 2005).

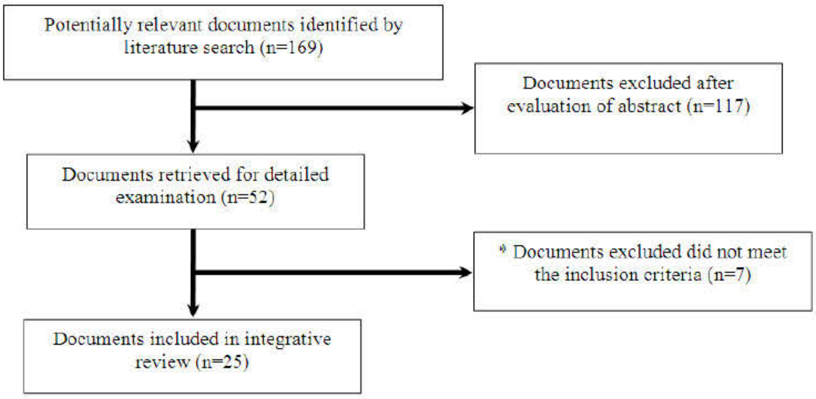

Fig. 1: Flow chart of studies from search for inclusion (Medline example)

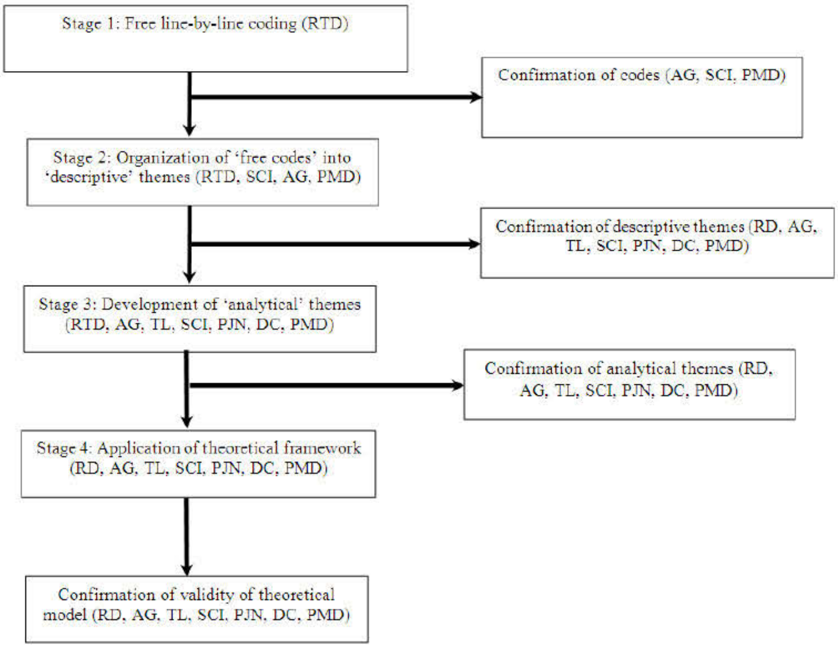

Fig. 2: Flow chart of data synthesis

Stage 1: Free line-by-line coding: Line-by-line free coding will be carried out by two independent investigators (RTD, AG). Free codes will be kept as close to the primary data as possible (Thomas and Harden, 2008). Coding will be carried out on the presentation and/or synthesis of primary data (interpreted within the context of the setting) of the perspectives of individuals with advanced COPD, or their family and careers, or health professionals (Thomas and Harden, 2008). The trustworthiness of the data will be ensured through random selection and checking (PMD, SCI). Disagreements will be resolved by consensus of four reviewers (RTD, PMD, AG, TL).

Stage 2: organization of 'free codes' into related areas to construct 'descriptive' themes: The free codes will be organized into descriptive themes by three investigators initially (RTD, AG, PMD) and then confirmed through discussion of an expert panel in COPD, palliative and chronic care (RTD, AG, TL, SCI, PJN, DC, PMD) (Walsh and Downe, 2005; Thomas and Harden, 2008). In the first instance, codes will be grouped into a topic area and super- and sub-ordinate relationships. Disagreements in descriptive themes will be resolved through group discussion (Walsh and Downe, 2005; Thomas and Harden, 2008).

Stage 3: Development of 'analytical' themes: An expert panel in COPD, palliative and chronic care will be used to develop central themes and analytical inferences not overtly evident in the initial codes (RTD, AG, TL, SCI, PJN, DC, PMD) (Thomas and Harden, 2008; Walsh and Downe, 2005). The development of analytical themes will allow for a broader understanding and interconnectedness between themes within the data (Walsh and Downe, 2005; Thomas and Harden, 2008). A theoretical framework will be sought to assist in the organization of analytical themes organizing the relationships between those issues found to be central to individual with advanced COPD, their family and carers and health professionals (Lovell, 2012).

Rigor: The use of qualitative primary data is an inductive, reflective and critical process in theme development and understanding of complex issues (Walsh and Downe, 2005). Rigor is supported in qualitative research through reflexivity and systematic approaches to data analysis, interpretation and synthesis (Barnett-Page and Thomas, 2009). The transparent presentation of the method of undertaking metasynthesis, as well as the use of independent investigators and panel discussion to promote the validity of findings increases the rigor of this metasythnesis (Thomas and Harden, 2008).

CONCLUSION

Qualitative data provide useful information in understanding the individual's unique experience. Combining discrete qualitative studies provides an important opportunity to provide a voice to patients, their families and professional careers in managing advanced COPD.

ACKNOWLEDGEMENT

No financial support was provided and no conflicts of interest exist within this research.

Authors' contributions: Conception and design RTD, SCI, PMD; acquisition of data RTD; analysis and interpretation of data RTD, AG, TL, SCI, PJN, DC, PMD; drafting the manuscript RTD, AG, TL, SCI, PJN, DC, PMD. All authors have given final approval of the version to be submitted.

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CHAPTER 5: PATIENTS' ATTITUDES TO COGNITIVE IMPAIRMENT AND TESTING IN CHRONIC OBSTRUCTIVE PULMONARY DISEASE: FOCUS GROUP STUDY

EXTENDED ABSTRACT

Chapter Four presents a focus group study that has sought to understand individuals' attitudes to cognitive impairment and cognitive testing in COPD. This chapter has been submitted for publication in *COPD: Journal of Chronic Obstructive Pulmonary Disease*, and is currently under review.

Disler RT, Spiliopoulos N, Collins M, Inglis SC, Currow DC, Davidson PM. Patients' attitudes to cognitive impairment and testing in chronic obstructive pulmonary disease: focus group study. *COPD: Journal of Chronic Obstructive Pulmonary Disease.* Under review.

BACKGROUND

The impact of cognitive impairment on individuals' self-management of chronic illness is increasingly recognised in such conditions as chronic heart failure, diabetes and COPD [1-3]. Cognitive impairment occurs in up to 77% in patients with chronic obstructive pulmonary disease (COPD) and hypoxaemia [4]. In addition to respiratory changes, patients with COPD experience a variety of systemic vascular and inflammatory, and aging and comorbidity effects that have an accumulative as well as direct effect on cognitive functioning [3,5,6]. Self-management of COPD is challenging and complex and requires individuals and their families to take actively engage in naturalistic decision making within their environment by interacting with knowledge, experience, skill, and values to interpret and implement self-care [7-10]. Cognitive impairment is recognised to inhibit decision making as a cognitive process [1], yet to date the impact of cognitive impairment on self-management in COPD has received limited attention [5] and is infrequently considered in delivery and planning of care [3].

This study has described individuals' attitudes of cognitive impairment and the barriers to cognitive testing. Optimisation of disease management, including decision making in the context of complex medication regimens, is essential in symptom control and slowing of disease progression [11-13]. Understanding the influence of cognition on self-management will assist nurses and other health professionals in recognising and addressing cognitive impairment as an underlying influence on individuals' understanding and adherence to healthcare regimens[3].

OBJECTIVES

This study sought to explore the individuals' attitudes to cognitive impairment and testing in COPD

METHODS

Patients participating in weekly exercise maintenance classes were recruited to participate in the focus groups to discuss whether changes in cognition due to COPD had been raised by health professionals; what techniques they currently used to assist in remembering self-management tasks associated with chronic disease management; whether cognitive changes were of concern in the context of their condition management; and what techniques, if any, they were using to maintain cognitive function. Guiding questions were developed in consultation with experts in the field of chronic illness and in cognitive functioning.

Focus groups were carried out after usual pulmonary rehabilitation maintenance exercise sessions. Conversations were recorded, transcribed verbatim and thematic analysis used to explore core themes. Sessions were facilitated by an investigator experience in facilitating group discussions and with a clinical background in chronic disease management. Discussions in a group setting promote interaction and exploration of the collective experience of complex health issues [14-17]. Observing others encourages reflection supportive social integration and sharing of personal experience that may be limited outside this setting [18-21]. Cognitive function is a delicate topic, however, group discussion is a key component of the pulmonary rehabilitation approach and created a familiar setting for this cohort [18-21]. Interaction between individuals with similar experiences was used to enable freer discussion of this potentially confronting topic [22,23].

Participant demographic and clinical data were collected from the patients and patient's files prior to the focus group sessions. Dyspnoea severity was collected from the most recent dyspnoea score documented in patients' files using the Medical Research Council Scale (MRC) [24,25]. Disease severity in COPD was collected from patients files based on most recent spirometry measurements including forced expiratory volume in one second (FEV1% predicted), slow and forced vital capacity (FVC), and FEV1/FVC ratio or classified according to Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines [26,27]. Comorbidities were measured using the Charlson comorbidity index; a weighted index composed of 19 conditions, with higher scores representing poorer prognoses [28].

FINDINGS

Five focus groups were carried out between November 2013 and May 2014, with a duration of 35 to 65 minutes. Data analysis of focus group transcripts elicited five key themes; the limited awareness of the connection between COPD and cognition; little reservation over cognitive testing; changes in memory seen as normal part of life; strategies used to remember activities of self-management; and actively seeking activities to maintain cognitive function.

Participants in this study noted that changes in cognition related to disease process had not been raised over the years of their condition, nor had they been approached for cognitive screening. Similar to previous research, changes in memory were commonly viewed as part of normal life and aging, and made light of by participants [29]; with issues around cognition viewed as likely to be considered of low priority for their treating clinicians in the context of other disease related issues [29]. Much like the study by Lingler, expectations and understandings of cognitive changes were built on personal experiences with Alzheimer's Disease and Dementia [29], in this group of patients, these experiences had led them to seek activities and interventions that would assist them in maintaining cognitive functioning in later years, such as eating a Mediterranean diet, exercising and engaging in word games.

Optimisation of disease management, including medication adherence, is acknowledged as key in improving symptom control and slowing disease progression [11-13], however little research has explored the impact of cognitive changes on naturalistic discussion making in the context of complex medication regimens [11-13]. Self-management strategies that address impaired cognition, such as reminders, family involvement, visual aids and minimising complexity of medication administration through dose administration units, may help patients to better manage the numerous and varied tasks associated with ongoing COPD management [13,30,31].

Previous research has found that physicians are reluctant to raise issues around cognition due to the potentially confronting nature and this has been echoed in the small number studies that explored patients' and caregivers' experience of receiving diagnoses [23,29,32]. However, this was not the viewpoint of participants in this study who on the contrary were eager for further information, and in reality already using tools to remember self-management activities and actively seeking activities to maintain or improve cognitive functioning [3,5]. It may be that this group are a select population, acknowledge to be highly engaged in their own care, however, as noted by Borson et al, the majority of evidence around reluctance to discuss cognition is based on physician practice rather than patient response, or indeed interest, when offered screening or discussion [33]. Health provider reluctance to engage patients in discussions around cognitive impairment, in the context of high prevalence of cognitive impairment in COPD, misses an important opportunity to target cognitive testing and interventions that may improve patients' and caregivers' ability to cope with and manage COPD [3,29,33,34].

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

As the burden of COPD increases, appreciating the role of cognition in patient assessment, treatment and self-management will be of increasing importance to future nursing and healthcare [3]. Further research is required to understand the impact of cognitive dysfunction on daily living and to explore those solutions most effective in chronic illness [3].

Self-management strategies that address impaired cognition, such as reminders, family support, visual aids and minimising complexity of use of medication administration through dose administration units, may help patients to better manage the numerous and varied tasks associated with ongoing COPD management [13,30,31]. Future research into interventions that address decline in cognitive function we have the potential to improve patients' ability to cope and adjust to living with COPD [3,34].

Verification and validation of tools that accurately measure mild cognitive impairment [34] along with the implementation of evidence based guidelines for use in primary health care [35], are required to encourage targeted screening and early intervention in patient groups known to have a high incidence of mild cognitive impairment, such as patients with COPD [3,5,34].

CONCLUSIONS

Changes in cognition are increasingly recognised as a barrier to optimal self-management in chronic disease. Participants in this study had few reservations over cognitive testing and in reality were eager for information and actively using strategies to facilitate self-management activities and maintain or improve cognitive functioning. Optimisation of disease management, including decision making in the context of complex medication regimens, is essential in symptom control and slowing of disease progression [11-13]. Understanding the influence of cognition on self-management will assist health professionals in recognising and addressing cognitive impairment as an underlying influence on individuals' understanding and adherence to treatment recommendations. Cognitive change must additionally be recognised as a key issue to be addressed when designing interventions that seek to optimise health care delivery and utilisation in patients with chronic disease [3,36].

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Disler RT, Spiliopoulos N, Collins M, Inglis SC, Currow DC, Davidson PM. Patients' attitudes to cognitive impairment and testing in chronic obstructive pulmonary disease: focus group study. *COPD: Journal of Chronic Obstructive Pulmonary Disease.* Under Review.

Patient's attitudes to cognitive impairment and testing in chronic obstructive pulmonary disease: focus group study

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) ranks fourth as a cause of death worldwide and is projected to become the third cause of death by 2030 [1,2]. The economic costs of COPD are approximately US$40 billion annually worldwide and this burden is only expected to increase as the populations age [1]. Social costs include significant disability as reflected in daily symptoms, poor physical functioning, social isolation, and caregiver burden [1]. In addition to respiratory changes, patients with COPD experience a variety of systemic vascular and inflammatory, and aging and comorbidity effects that have an accumulative as well as direct effect on cognitive functioning [3-5]. Cognitive impairment occurs in up to 77% in patients with COPD and hypoxaemia [6].

The impact of cognitive impairment on individuals' self-management of chronic illness is increasingly recognised in such conditions as chronic heart failure, diabetes and COPD [4,7,8]. Self-management of COPD is challenging and complex and requires individuals and their families to take an active role in their care [9,10], particularly in undertaking naturalistic decision making within their environment by interacting with knowledge, experience, skill, and values to interpret and implement self-care [9,11-13]. Cognitive impairment inhibits decision making as a cognitive process [7], yet to date the impact of cognitive impairment on self-management in COPD has received limited attention [3] and is infrequently considered in delivery and planning of care [4]. As Borson et al and other authors have noted, the key barriers to cognitive screening has been physician's views that cognitive testing is confronting and potentially disconcerting to patients [14-16], with concerns over labelling and perceived patient fear over diagnoses with limited treatment options [14-16]. However, these viewpoints are mainly based on physician practice rather than evidence of patient response when offered screening as part of routine care [14-16]. Health provider reluctance misses an important opportunity to target cognitive testing and interventions that may improve patients' ability to cope and adjust to living with their disease [4,16,17].

Previous investigation of cognitive function in COPD has focused on broad screening of cognitive impairment using tools not necessarily designed to capture the subtle cognitive changes seen in chronic disease, such as the commonly used Minimental State exam developed for dementia screening [3,4,17]. A systematic review published in August 2012 combined 15 studies found that cognitive function was impaired in the individuals with COPD, compared to the control, and that there was also a significant association between severe COPD and cognition [4]. The review called for future studies to explore the impact of cognitive dysfunction on daily living and to explore those solutions which would assist in individual's self-management of their disease [4]. These sentiments were also communicated in the narrative review published in 2010 that described 17 studies. Dodd et al[3] grouped the evidence in relation to several factors which influence cognitive function, including those specific to individuals with COPD (lung function, hypoxemia, hypercapnia and exacerbations of COPD) and those which would be found in an aging health population (activity, depression, vascular disease and comorbidities, and smoking). Dodd et al[3] summarized that overall there is inconsistency and poor correlation between to hypoxemia and cognitive function. Limited information is available regarding the cognitive domains most affected (attention, perception, memory and motor function) in COPD and less still on the impact of cognitive impairment on self-management [3,4]. Future research must describe the domains of cognitive function that are most affected in COPD and have the strongest impact on patients' self-management, as well as which interventions are best suited to addressing these underlying influences.

This study has described individuals' attitudes of cognitive impairment and the barriers to cognitive testing. Optimisation of disease management, including decision making in the context of complex medication regimens, is essential in symptom control and slowing of disease progression [18-20]. Understanding the influence of cognition on self-management will furthermore assist health professionals in recognising and addressing cognitive impairment as an underlying influence on individuals' engagement with and adherence to healthcare regimens [4,21]. Cognitive change must additionally be recognised as a key issue to be addressed when designing interventions that seek to optimise health care delivery and utilisation [4,21].

METHODS

Aim

This study sought to explore the individuals' attitudes to cognitive impairment and testing in COPD

Design

Focus groups analysed through thematic analysis. Discussions in a group setting allow for exploration of the collective experience of complex health issues accessible through group interaction [22-25]. Observing others encourages reflection supportive social integration and sharing of personal experience that may be limited outside this setting [26-29]. Cognitive function is a delicate topic, however, group discussion is a key component of the pulmonary rehabilitation approach and created a familiar setting for this cohort [26-29]. Interaction between individuals with similar experiences was used to enable freer discussion of this potentially confronting topic [14,30].

Guiding questions were developed in consultation with experts in the field of chronic illness and in cognitive functioning. These question facilitated participants to consider: whether changes in cognition due to COPD had been raised by health professionals; what techniques they currently used to assist in remembering self-management tasks associated with chronic disease management; whether cognitive changes were of concern in the context of their condition management; and what techniques, if any, they were using to maintain cognitive function.

Sample and setting

Individuals with COPD were recruited through a pulmonary rehabilitation program at a regional hospital. Individuals participating in weekly exercise maintenance classes were approached by the specialist respiratory nurse or specialist physiotherapist and invited to participate in the focus groups.

Data collection

This study was undertaken through a series of focus groups until data saturation occurred. Focus groups were carried out after usual pulmonary rehabilitation maintenance exercise sessions. Conversations were recorded, transcribed verbatim and thematic analysis used to explore core themes. Sessions were facilitated by an investigator with a clinical background in chronic disease management and who has experience in facilitating group discussions. Participant demographic and clinical data were collected from the patients and patient’s files prior to the focus group sessions.

Medical Research Council scale

Dyspnoea severity was collected from the most recent dyspnoea score documented in the patients files using the Medical Research Council Scale (MRC) [31,32].

Spirometry and disease severity

Disease severity in COPD was collected from patients files based on most recent spirometry measurements including forced expiratory volume in one second (FEV1% predicted), slow and forced vital capacity (FVC), and FEV1/FVC ratio or classified according to Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines [33,34].

Comorbidity prevalence

Comorbidities were measured using the Charlson comorbidity index; a weighted index composed of 19 conditions, with higher scores representing poorer prognoses [35].

Analysis of results

Descriptive statistics were used to report patient characteristics. Thematic synthesis of qualitative data was conducted through initial free coding by two independent researchers and subsequent identification of repeated descriptive themes and organisational themes by the two researchers [36,37]. Analytical themes were developed through panel discussion to establish broader understanding and meaning in the context of participants' attitudes to cognitive impairment and receptivity of cognitive assessment [36,37]. Rigour was supported in this study through reflexivity and systematic approaches to data analysis, interpretation and synthesis, and the use of independent data checking and consultation from the expert members of the investigation team and member checking [36,38].

Ethical issues

Ethical clearances from the academic and clinical institutions were gained; approval number: HE13/285, LNR/13/WGONG/91 and HREC 2012000156. The sample consisted of adults with COPD who are limited primarily by chronic dyspnoea and fatigue. Participants were informed that participation was voluntary and would in no impact the quality of care delivered at the site or their relationship with their treating health professionals.

RESULTS

Five focus groups were carried out between November 2013 and May 2014, with a duration of 35 to 65 minutes. Of the approximately eighteen individuals who attended the bi-weekly exercise maintenance classes, fifteen participated in the focus groups; the variation in attendance a result of fluctuation in condition due to illness and individuals taking leave for vacation for example. The majority of participants had a diagnosis of COPD (12 of 15), were female (9 of the 15) and were aged between 63 to 90 with an average age of 73 years. Airway obstruction was evenly spread from Mild to Severe, with slightly higher participants tested as having mild disease. All but three individuals were ex-smokers, one participant was currently smoking and two individuals had not smoked at all. In those with a smoking history, they had an average pack years of 40. No participants used long term oxygen therapy and all but three participants lived at home with family (Table 1).

ATTITUDES TO COGNITIVE IMPAIRMENT AND COGNITIVE SCREENING

Data analysis of focus group transcripts elicited five key themes; the limited awareness of the connection between COPD and cognition; little reservation over cognitive testing; changes in memory seen as normal part of life; strategies used to remember activities of self-management; and actively seeking activities to maintain cognitive function.

Limited awareness of the cognitive impairment associated with COPD

On discussing the systemic effects of COPD cognitive functioning, most individuals were unaware of this association. The majority of participants voiced memory or cognition testing had not discussed with healthcare professionals, although one individual had experienced neurological observations whilst in intensive care. Participants were interested in the prevalence of cognitive impairment in COPD and on consideration could see how this would be the case: '*My brain ain't getting the oxygen it should have. Well, when I'm out pushing the lawn mower or walking up a hill... My brain would be starved of oxygen for sure'* FG2. Participants themselves raised the difficulty in distinguishing the cause of changes to memory: *'How do you tell the difference between what's normal memory loss? What's COPD? What's just inherited? What's genetic? So how on earth do you tell the difference?* FG2.

Individuals guessed that cognition was likely of low priority when faced with more obvious or acute respiratory issues, and this was the cause for the lack of discussion with health professionals: '*It's not something that we have talked about at all, not at all. I guess it isn't a high priority, it's low on the list. When you have a breathing problem, it's like they say, if you can't breathe nothing else matters.'* FG5 R1. Others commented on the segregation between health specialties as a reason: '*You see a specialist about your lungs but they don't talk about the other things. They don't connect the dots'* FG 3.

Reservations over cognitive testing

Little reservation was voiced over the concept of cognitive testing with all participants voicing that it would just be seen as part of the normal treatment: *'I think if it's a part of the course, it's* *a part of the course'* FG2. For others, testing was seen as an opportunity for intervention: *I'd like testing. I might find I'm pleasantly surprised'* FG2 and '*I wouldn't worry, why should I worry. The more knowledge you have the better, and maybe there is something that you can do about it'* FG5 R1. When discussing the possible implications of being labelled as cognitively impaired, participants voiced similar sentiments to the above, however one individual did raise in passing that this may have an impact on employment, but overall felt it was more beneficial if the issues could be addressed.

Changes in memory seen as normal part of life

The majority of participants did not feel that they had difficulty with their memory or cognition and any difficulties were commonly attributed to normal aging: '*I go to the pantry and think what the hell am I doing here. I want the fridge. But that's old fellow's disease, isn't it'* FG1. Remembering people's names often came up, and again this was attributed to aging or something that participants had struggled with throughout their lives*: 'No it's not an issue for me. I mean, I forget peoples' names, but I've always been a bit bad with that, it's just my age really'* (FG 5 R1). Increased activity or busyness of modern day life were also seen as causes of forgetfulness. '*My daughter is worried, and if she ever say anything to me, I say - everybody forgets things. I think it's the pressure of being busy and that sometimes*' FG1.

While memory changes were often dismissed or joked about, many individuals were already thinking deeply about the impact of changes in cognition, '*It does play on your mind, if you lose your ability to move, well you can use a walker, but if you lose your memory it's worse because you can't do anything, you become a burden on your family. Yes, I think that would scare me the most'* FG5 R1. Concerns were commonly associated with having witnessed a friend or family member go through dementia or Alzheimer's disease, with a sense of loss commonly discussed: *I just remember my mother, she got dementia … and what happened over a period of four years, she forgot today … and that stuck with me so now I do free cell to keep my memory and my mind active'* FG3 R1.

There was also a concern across groups around safety and risk associated with memory changes. Several participants talked with concern about their family members: *'I know that she's getting problems now. Like, forgetting to turn the stove off … So I go around and check everything before I go to bed at night just to make sure that we're not going to burn down at night'* FG2. There was a particular concern for those individuals living alone: '*Oh yes that would be hard as you wouldn't have someone to remind you'* FG5 R1.

Strategies used to remember activities of self-management

Remembering appointments and medications were seen as the key self-management tasks that individuals had trouble remembering. Many participants used common tools, such as diaries, to help them remember everyday aspects of care: *'I've still got it written on the fridge. My husband circles the date on the calendar and then scribbles something on there'* FG1.

Managing the complex medication regime was a key focus of discussion in each focus group. Changes in medication and continual and common frustration, whether type of medication or differences in brand name compared with generic pharmaceutical name:

> *The girl came around and said that oh the doctor had changed [the medications], thank goodness we had the conversation. They wrote the full list, four pages, they gave me what they did and the different names, that makes it hard* FG3.

The majority of participants used some kind of dose administration unit: '*And you can't remember, what is that one for, when am I supposed to take that one? That is why I got the Webster pack'* FG4 R1. Changes in brand names and generic pharmaceutical names were also seen as a challenge across the groups: *'I've been taking it for 30 years … and they changed brands which had a different name, it took me ages, I went to the internet and after a while I found what it was, it's so confusing with the different names'* FG3 Several noted that they had held off taking medications until they had received advise from the pharmacist or specialist: *'I took a packet to the pharmacist and said what am I supposed to be taking this for, I'd forgotten it was in the cupboard, and it turned out to be just another generic name for something'.* FG3 Participants did raise concerns around medication in regards to changes in cognition, and the risk of people missing or overdosing the medications: ‘*What leads from this not remembering, especially on a medication change because some of these bloody things are dangerous. You double-dose or whatever.’* FG1.

Actively seeking activities to maintain cognitive function

While memory was voiced as not being a serious issue, the majority of participants were already engaged in activities expressly to improve or maintain cognitive functioning. Many had read articles and heard articles on the radio about what they could do to maintain their cognitive functioning and were actively seeking evidence based activities.

Many individuals were already engaging in paper based and online games such as crosswords, word games and number games ‘*keep the mind active’* FG3 R1. Others engaged in exercising for cognition as part of healthy living and others followed a Mediterranean diet. Several participants talked with knowledge about the need to engage in activities that encouraged interconnected thinking such as learning a language, for one individual this was through photography:

> *it's not just straight memory, it's kind of an interconnected thing. when you're taking a paragraph, frame it, the exposure that you're - and the focus and all those sort of things tying together You've got to tie it together, but everyone's coming up with bright ideas so I don't know which of them are kosher and which aren't*. FG2 R1.

DISCUSSION

This study sought to explore the individuals’ attitudes to cognitive impairment and testing in COPD. Five themes were raised throughout the focus groups: the limited awareness of the connection between COPD and cognition; little reservation over cognitive testing; changes in memory seen as normal part of life; strategies used to remember activities of self-management; and that participants were actively engaging in activities viewed as helping to maintain cognitive functioning.

Self-management of COPD is challenging and complex and requires individuals and their families to take an active role in their care [9], particularly in undertaking naturalistic decision making within their environment by interacting with knowledge, experience, skill, and values to interpret and implement self-care [9,11-13]. Cognitive impairment further burdens patients and inhibits this cognitive process [7], yet is infrequently considered in delivery and planning of care[3,4,7,8]. Participants in this study noted that changes in cognition related to disease process had not been raised over the years of their condition, nor had they been approached for cognitive screening. Similar to previous research, changes in memory were commonly viewed as part of normal life and aging, and made light of by participants[39]; with issues around cognitive viewed as likely to be of low priority for their treating clinicians in the context of other disease related issues[39]. Much like the study by Lingler, expectations and understandings of cognitive changes were built on personal experiences with Alzheimer's Disease and Dementia[39], in this group of patients, these experiences had led them to seek activities and interventions that would assist them in maintaining cognitive functioning in later years, eating a Mediterranean diet, exercising and engaging in word games for example.

Managing the complex and dynamic medication regimens was a prominent and consistent theme throughout the study, and there was concern that individuals who did have cognitive impairment would be at high risk of inaccurate medication behaviours with dangerous consequences. Optimisation of disease management, including medication adherence, is acknowledged as key in improving symptom control and slowing disease progression [18-20], however little research has explored the impact of cognitive changes on naturalistic discussion making in the context of complex medication regimens [18-20]. Self-management strategies that address impaired cognition, such as reminders, family involvement, visual aids and minimising complexity of use of medication administration through dose administration units, may help patients to better manage the numerous and varied tasks associated with ongoing COPD management [20,40,41].

Previous research has found that physicians are reluctant to raise issues around cognition due to the potentially confronting nature and this has been echoed in the small number studies that explored patients and caregivers experience of receiving diagnoses[14,15,39]. However, this was not the viewpoint of participants in this study who on the contrary were eager for further information, and in reality already using tools to remember self-management activities and actively seeking activities to maintain or improve cognitive functioning[3,4]. It may be that this group are a select population, acknowledge to be highly engaged in their own care, however, as noted by Borson et al, the majority of evidence around reluctance to discuss cognition is based on physician practice rather than patient response, or indeed interest, when offered screening or discussion [16]. Health provider reluctance to engage patients in discussions around cognitive impairment, in the context of high prevalence of cognitive impairment in COPD, misses an important opportunity to target cognitive testing and interventions that may improve patients' and caregivers' ability to cope with and manage COPD [4,16,17,39].

Previous investigation of cognitive function in COPD has focused on broad screening of cognitive impairment [3,4,17] with little investigation into which domains of cognition are most affected in COPD and have the greatest impact on self-management [3,4]. A recent report from the International Working Group on Mild Cognitive Impairment has raised the need for improved screening and identification of modifiable risk factors as well as verification and validation of tools that accurately measure mild cognitive impairment [17]. Implementation of evidence based guidelines are also necessary to facilitate primary health care providers in screening for changes in cognition [42]. Targeted cognitive screening and interventions that address decline in cognitive function we have the potential to improve patients' and their families' ability to cope and adjust to living with COPD [4,17].

Implications for Practice

As the burden of COPD increases, appreciating the role of cognition in patient assessment, treatment and self-management will be of increasing importance to future nursing and healthcare [4]. Further research is required to understand the impact of cognitive dysfunction on daily living and to explore those solutions most effective in chronic illness. [4]

Self-management strategies that address impaired cognition, such as reminders, family support, visual aids and minimising complexity of use of medication administration through dose administration units, may help patients to better manage the numerous and varied tasks associated with ongoing COPD management [20,40,41]. Future research into interventions that address decline in cognitive function we have the potential to improve patients' ability to cope and adjust to living with COPD [4,17].

Verification and validation of tools that accurately measure mild cognitive impairment [17] along with the implementation of evidence based guidelines for use in primary health care [42], are required to encourage targeted screening and early intervention in patients group known to have a high incidence of mild cognitive impairment, such as patients with COPD [3,4,17].

Understanding the influence of cognition on self-management will assist nurses and other health professionals in recognising and addressing cognitive impairment as an underlying influence on individuals' understanding and adherence to healthcare regimens [4].

Limitations

The use of focus groups at a single site may limit generalizability and external validity. The highly engaged patient cohort and perspective of the investigator may have influenced the interpretation of the available data. However, rigour was supported in this study through reflexivity and systematic approaches to data analysis, interpretation and synthesis, and the use of independent data checking and consultation from the expert members of the investigation team and member checking [36,38].

This study does provide a voice and elicit understandings as to individuals' attitudes to cognitive impairment and cognitive testing. Future research must describe those domains of cognitive function that are most affected in COPD and have the strongest impact on patients self-management, as well as which interventions are best suited to addressing these underlying influences.

CONCLUSION

Changes in cognition are increasingly recognised as a barrier to optimal self-management in chronic disease. Participants in this study had few reservations over cognitive testing and in reality were eager for information and actively using strategies to facilitate self-management activities and maintain or improve cognitive functioning. Understanding the influence of cognition on self-management will assist health professionals in recognising and addressing cognitive impairment as an underlying influence on individuals' understanding and adherence to treatment recommendations.

Table 1 Patient demographic characteristics

Descriptive characteristics	Frequency
Gender	
Male	6
Female	9
(n=15)	
Age	
Mean	73
Range	63-90
(n=15)	
Montreal Cognitive Assessment test http://www.mocatest.org/	
Median	29
Range	22-30
(n=15)	
Pulmonary Diagnosis	12
COPD	1
Mild airways disease	1
Emphysema	1
Asthma and sleep apnoea	
(n=15)	
Airways obstruction	5
Mild	4
Moderate	3
Severe	3
Very severe	
(n=15)	
Long term oxygen therapy	15
No	
(n=15)	
Smoking status	1
Current smoker	12
Ex-smoker	(40 years)
(Average pack years)	2
Non-smoker	
(n=15)	
Body Mass Index	
Median	26
Range	19-45
(n=15)	
Comorbidity burden (Charlson comorbidity index (CCI))	
Median	5
Range	3-8
1 year survival based on CCI	89%
10 year survival based on CCI	16%
(n=15)	
Living situation	12
Lives with family/spouse	1
Lives alone with formal help	2
Lives alone without formal help	
(n=15)	

COPD: chronic obstructive pulmonary disease

CCI: Charlson comorbidity index

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SECTION THREE: LOOKING TO INNOVATIVE FUTURE APPROACHES TO COPD CARE

CHAPTER 6: TELECOMMUNICATION USE AND ONLINE DELIVERY OF CHRONIC DISEASE MANAGEMENT IN COPD

EXTENDED ABSTRACT

Chapter Six presents a prevalence and focus group study that describe the patterns of technology use and individuals attitudes to health care delivery through telecommunication interfaces. This chapter consists of two papers, the first, prevalence survey study, has been published in the Interactive Journal of Medical Research, the second, focus group study, has been submitted to the *COPD: Journal of Chronic Obstructive Pulmonary Disease* and is currently under review.

Disler RT, Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Patterns of technology use in patients attending a cardiopulmonary outpatient clinic: a self-report survey. *Interactive Journal of Medical Research*; 2015; 4: 1.

Disler RT, Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Patients perspectives of online health information and chronic disease management in individuals' chronic obstructive pulmonary disease: focus group study. *COPD: Journal of Chronic Obstructive Pulmonary Disease.* Under Review.

BACKGROUND

The increasing burden of non-communicable diseases (NCDs), such as heart and respiratory disease, is placing increasing economic and social burden on global health systems [1,2]. International guidelines and Level 1 evidence recommend that self-management people with cardiopulmonary disease, including symptom management strategies, exercise, and reinforcement of activity and medication adherence, are primarily provided through time-limited, face-to-face programs, with access limited to a small percentage of patients due to individual, provider and health system factors [3-7]. Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and economically sustainable approaches to support patients with chronic illnesses, such as COPD [8-10].

The evolution of e-health (health care delivery through internet and telehealth communications for surveillance, health promotion and symptom or disease management) and the introduction of m-health (monitoring, personal digital assistants, and other wireless devices) are altering the collaboration and interaction between consumers, health providers and institutions [11-13]. Asynchronous forms of health interaction, such as through email or discussion boards, allow individuals to receive ongoing self-management and condition support by posing questions to their provider without having to establish a formal face to face consultation (synchronous interaction) [14,15]. These converging factors will shape the development and testing of future interventions aimed at improving health outcomes and reducing costs across chronic illnesses [11-13,16-19].

Access to online health information and support is well established in the United States of American with a recent report by Pew Internet and American Life Project reporting that at least 50% of adults over the age of 65 are now online [19]. However, online health care delivery is not widespread in Australian healthcare or in majority of other regions internationally [17-23]. Although technology access is challenging, for some older adults who are the most burdened with chronic conditions, this new generation of empowered health consumers expect health care systems that accommodate their changing needs and preferences for how they receive care [16-18].

Delivery of health information through multimedia formats has the capacity to provide more accessible and convenient self-management education to a large number of individuals living and will increasingly influence future healthcare delivery in COPD and other chronic conditions [16-18,20].

OBJECTIVES

- To describe the patterns of technology use in patients attending a cardiopulmonary clinic in a large quaternary referral metropolitan hospital.

- To understand the perspectives of patients currently living with COPD towards healthcare information and delivery through an online interface.

METHODS

Patterns of technology use were collected through a prevalence survey developed in consultation with experts in the field of chronic illness and internet-based healthcare delivery. The survey was presented in four sections with eleven questions used to capture information on participant demographics (age in years, sex, socio-economic status); access and use of computers, internet and mobile telephones; and currently accessed health support sites. Socio-economic status was described using the Australian socio-economic indexes for areas (SEIFA) [24]. These indices summarise 'the relative socio-economic advantage and disadvantage of areas using data from the Census of Population and Housing' and are reported through Australian area postcode. Indices are based a number of variables including employment, private and rented occupied housing, family makeup and highest qualification, to name a few [24].

Individuals' attitudes regarding the online delivery of health care information and support were collected through a series of focus groups with patients attending a maintenance pulmonary rehabilitation program within a major metropolitan hospital. Group discussions allowed for understanding of the collective perspectives of complex issues through reflection on and validation of shared feelings and experiences [25-28]. The focus groups question routes were developed in consultation with experts in the field of chronic illness and online health care delivery. Conversations were recorded, transcribed verbatim and analysed using thematic analysis to identify key and repeated emergent themes regarding the delivery of healthcare information and management through an online interface.

FINDINGS

123 surveys were collected between March and April 2014. Technological devices were a pervasive part of everyday life with respondents engaged in regular computer (102 of 123, 83%), mobile telephone (115 of 117, 97%) and internet (104 of 121, 86%) use. Emailing (101 of 121, 83%), researching and reading of news articles (93 of 121, 77%), social media (71 of 121, 59%) and day to day activities (65 of 121, 54%) were the most common telecommunication

activities. The majority of respondents reported that access to health support programs and assistance through the internet (82 of 111, 74%) would be of use, with benefits reported as better understanding of health information (16 of 111, 23%), avoidance of difficult travel requirements and time-consuming face-to-face appointments (13, 18%), convenient and easily accessible help and information (12 of 111, 17%) and access to peer support and sharing (9 of 111, 13%). The majority of patients did not have concerns over participating in the online environment (87 of 111, 78%); the few concerns noted related to privacy and security (10 of 15), information accuracy (2 of 15) and computer literacy and access (2 of 15).

Three focus groups were undertaken during January and April 2014, with duration of 55-65 minutes. All individuals had a primary diagnosis of COPD, were over the age of 65 and none required long term oxygen. Six themes emerged through thematic analysis: (1) multimedia is a pervasive aspect of the modern landscape; (2) online remains a risky environment; (3) pulmonary rehabilitation - a central point of access; (4) there are key benefits to online delivery, primarily in the timely and accessible delivery of information; (5) access to new or forgotten knowledge; (6) there is a need for improved collaborative decision making and symptom management.

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

Technology use is a pervasive part of everyday life regardless of age or socio-economic group with individuals with chronic disease increasingly engaged in health seeking behaviours and peer interaction through online sources [16-19,29]. Online delivery of health information and support is of particular importance in patients with cardiopulmonary disease, who are most likely to have high symptom burden and healthcare utilisation needs. Current consumer-health provider interfaces need to be improved to accommodate the changing needs and preferences of an empowered generation of health consumers. Telecommunication tools may alleviate some of the difficulties with current healthcare access and provide an increasingly important adjunct to traditional forms of healthcare delivery [16-19].

Consumer's ability to distinguishing accurate, trustworthy and personally applicable information, when faced with the sheer volume of health information sites available, is a commonly reported challenge in the literature [30-32]. There is a necessity to develop and validate online sites, and an opportunity to ensure that patients and their families have guidance to accurate and credible health information sources. Central points of access to reliable information and clear path finding through online interfaces are likely to be defining factors in the success or failure of any future online system. Computer literacy training and practical access issues a consideration for future technology based health delivery interventions, and to meet the needs of a generation of already engaged and empowered health consumers [33,34]. Facilitating access to online support networks may additionally provide an important resource in future healthcare delivery [16-18,29], with increased social well-being, enhanced self-management and self-efficacy and sense of belonging and normalcy reported as benefits in the context of prolonged disease duration [16-19]. Utilising online healthcare delivery may be an important adjunct to traditional forms of healthcare [16-19]. Further research is required into the socioeconomic and physical benefits of such approaches particularly in those who have limited access to face to face health support [16-1933,34].

CONCLUSIONS

Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and sustainable approaches to support patients with chronic illnesses, such as COPD. Online access to health support programs and assistance was reported as useful and perceived as providing convenient, timely and easily accessible health support and information. Distance from the health care facility and a lack of information provision through traditional health sources were both barriers and enablers to telehealth. This is particularly important in the context of a cardiopulmonary clinic that attracts patients from a large geographical area, and in patients who are most likely to have high health care utilisation needs in the future. We are at a turning point within the evolution of healthcare delivery and have the opportunity to shape how future interventions deliver health information and promote self-management. Telecommunication interfaces will be an increasingly important adjunct to traditional forms of healthcare delivery. Future research must explore the feasibility of delivering healthcare through online platforms across larger cohorts and explore the social and economic impact of this approach on health care delivery.

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Original Paper

Patterns of Technology Use in Patients Attending a Cardiopulmonary Outpatient Clinic: A Self-Report Survey

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Abstract

Background: Self-management education for cardiopulmonary diseases is primarily provided through time-limited, face-to-face programs, with access limited to a small percentage of patients. Telecommunication tools will increasingly be an important component of future health care delivery.

Objective: The purpose of this study was to describe the patterns of technology use in patients attending a cardiopulmonary clinic in an academic medical center.

Methods: A prevalence survey was developed to collect data on participant demographics (age in years, sex, and socioeconomic status); access to computers, Internet, and mobile phones; and use of current online health support sites or programs. Surveys were offered by reception staff to all patients attending the outpatient clinic.

Results: A total of 123 surveys were collected between March and April 2014. Technological devices were a pervasive part of everyday life with respondents engaged in regular computer (102/123, 82.9%), mobile telephone (115/117, 98.3%), and Internet (104/121, 86.0%) use. Emailing (101/121, 83.4%), researching and reading news articles (93/121, 76.9%), social media (71/121, 58.7%), and day-to-day activities (65/121, 53.7%) were the most common telecommunication activities. The majority of respondents reported that access to health support programs and assistance through the Internet (82/111, 73.9%) would be of use, with benefits reported as better understanding of health information (16/111, 22.5%), avoidance of difficult travel requirements and time-consuming face-to-face appointments (13/111, 18.3%), convenient and easily accessible help and information (12/111, 16.9%), and access to peer support and sharing (9/111, 12.7%). The majority of patients did not have concerns over participating in the online environment (87/111, 78.4%); the few concerns noted related to privacy and security (10/15), information accuracy (2/15), and computer literacy and access (2/15).

Conclusions: Chronic disease burden and long-term self-management tasks provide a compelling argument for accessible and convenient avenues to obtaining ongoing treatment and peer support. Online access to health support programs and assistance was reported as useful and perceived as providing convenient, timely, and easily accessible health support and information.

Distance from the health care facility and a lack of information provision through traditional health sources were both barriers and enablers to telehealth. This is particularly important in the context of a cardiopulmonary clinic that attracts patients from a large geographical area, and in patients who are most likely to have high health care utilization needs in the future. Telecommunication interfaces will be an increasingly important adjunct to traditional forms of health care delivery.

(Interact J Med Res 2015;4(1):e5) doi:10.2196/ijmr.3955

KEYWORDS

chronic obstructive pulmonary disease; chronic disease; self-management; self-care; telemedicine, eHealth; mHealth

Introduction

The increasing burden of non-communicable diseases, such as heart and respiratory disease, is placing increasing pressure on global health systems [1,2]. The incidence and cumulative burden of these chronic progressive disorders is accentuated through population aging [1]. The prevalence of chronic heart failure (CHF) is 23 million worldwide with an overall prevalence of 2-3% of the population in the United States and Europe [2-5]. The global prevalence of chronic obstructive pulmonary disease (COPD) is estimated at 65 million and COPD is now responsible for 5% of all deaths globally [6,7]. Despite optimal pharmacological and medical treatments, individuals with COPD and CHF continue to experience high symptom burden, most commonly dyspnea and fatigue [8-12]. Both COPD and CHF are frequent causes of hospitalization and require self-management strategies [8-12]. The economic costs of COPD are approximately US$ 40 billion annually and this financial burden will only increase [8-12]. Daily symptoms, poor physical functioning, progressive social isolation, and caregiver burden contribute to this disease burden [6,7,13].

The burden of non-communicable diseases extends over time and the life course [14,15]. Self-management education for people with COPD and CHF, including symptom management strategies, exercise, and reinforcement of activity and medication adherence, are primarily provided through pulmonary and cardiac rehabilitation and heart failure specific disease management programs [16-20]. These interventions are commonly episodic, of short duration, and available only to a small percentage of individuals [16,17], with access limited by functional debilitation associated with chronic illness [21,22]. Although discrete disease management strategies are an integral element of evidence-based care, it is increasingly apparent that there are some symptom management issues that are germane across chronic conditions [23]. Self-management support should be targeted through multiple modes of delivery with a broad-based symptom focus [24]. Although chronic conditions such as COPD and CHF have received greater attention from the medical community over the past decades, the burden of disease at an individual level is less well recognized [25].

The most effective and economically sustainable approaches to support patients with chronic illnesses such as COPD and CHF, beyond acute exacerbations, require future investigation [13,18,24,26-28]. The disease burden and long-term tasks of self-management that confront patients are a compelling argument for accessible and convenient avenues to obtaining ongoing treatment and peer support [29-31]. Access to Web-based health information and support is well established in the United States with a recent report noting that over 50% of adults aged over 65 years use the Internet [28,32-35]; however, internationally, use is not so widespread [28,30-36]. In the Australian context, studies have explored Web-based health interventions, but there is limited information as to the patterns of technology use in this particular patient group [37].

Although technology access is challenging for some older adults who are the most burdened with chronic conditions, communication tools have become a critical component of health care delivery [29-31]. Rapid advances in tools that provide instant access to health information and rich resources for self-care have already created paradigm shifts in health consumer attitudes about their health and health care [28-31]. The evolution of eHealth (health care delivery through Internet and telehealth communications for surveillance, health promotion, and symptom or disease management) and the introduction of mHealth (monitoring, personal digital assistants, and other wireless devices) are markedly altering the collaboration and interaction between consumers, health providers, and institutions [38-40]. Asynchronous forms of health interaction, such as through email or discussion boards, allow individuals to receive self-management and condition support by posing questions to their provider without having to establish a formal face-to-face consultation (synchronous interaction) [36,41]. These converging factors will shape the development and testing of future interventions aimed at improving health outcomes and reducing costs across chronic illnesses. The new generation of empowered health consumers will expect that health care systems accommodate their changing needs and preferences for how they receive care, including access to evidence-based therapies [28-31].

In order to determine the future feasibility of Internet-based health care delivery, the reported prevalence study was undertaken to describe the patterns of technology use in patients attending a cardiopulmonary clinic in an academic medical center. The cardiopulmonary patients responding to this survey have provided a sample of those individuals most likely to have high health care utilization needs in the future; it is important to take this initial step in understanding whether these consumers are technology ready [42-44].

Methods

Objective

The objective of the study was to describe the prevalence and patterns of technology use in patients attending a cardiopulmonary outpatient clinic through a self-report survey.

Recruitment

Patients attending a cardiopulmonary outpatient clinic at an academic medical center were invited to participate in this anonymous survey. All patients attending the cardiopulmonary outpatient clinic were eligible to participate.

The cardiopulmonary clinic is located within an academic medical center and provides services for patients with a variety of conditions including COPD, CHF, advanced lung disease, heart transplantation, and pulmonary hypertension. This clinic is a central referral setting for surrounding regional areas; consequently, individuals travel from all areas within the state to access specialist treatment.

Instrument

A prevalence survey was developed in consultation with experts in the field of chronic illness and Internet-based health care delivery. The survey was presented in four sections with 11 questions used to capture information on participant demographics (age in years, sex, socioeconomic status); access and use of computers, Internet, and mobile telephones; and currently accessed health support sites. Socioeconomic status was described using the Australian socioeconomic indexes for areas (SEIFA) [45]. These indices summarize “the relative socioeconomic advantage and disadvantage of areas using data from the Census of Population and Housing” and are reported through Australian area postcode (area zip code). Indices are based on a number of variables including employment, private and rented occupied housing, family makeup, and highest qualification, to name a few [45]. Nominal tick boxes and free text short answer questions were used to collect responses. Respondents were able to give multiple answers to appropriate nominal and free text questions, noted by “please tick all that apply”.

The survey was piloted for 1 week in the cardiopulmonary clinic and 10 surveys were checked for completion and coherence with the questions asked prior to continuing with data collection. There was limited missing data in this initial phase, however, “Please turn over” was added to the bottom of the page for ease. No other adjustments were required. The final survey contained four sections with 11 questions and took approximately 5-10 minutes to complete (see Multimedia Appendix 1).

Data Collection

Surveys were offered by reception staff to all patients attending the outpatient clinic at appointment registration. Surveys on clipboards were also placed on tables within the waiting area for patients to complete as they wished. Participation was voluntary with hard copy surveys completed and placed anonymously in a sealed submission box within the waiting area.

Data Analysis

Descriptive statistics were used to analyze all aspects of the survey data.

Ethical Issues

Ethical approval was provided by the collaborating academic institution and clinical site; approval numbers LHR/13/SVH/5 and 2012-149A. Participation was voluntary and anonymous.

Results

Respondents

A total of 123 surveys were collected between March and April 2014. Approximately 543 patients attended appointments at the cardiopulmonary clinic during the study period, resulting in an overall response rate of 22.7%. The overwhelming majority of respondents completed the survey questions in full. This took into consideration respondents who answered “no” to regular computer or Internet who were precluded from completing particular subsequent questions; all previous responses from these respondents were included in the descriptive statistics. All 123 respondents answered questions in regards to gender, with more females (72/123, 58.5%) noted to have completed the surveys than males (51/123, 41.5%). Age was reported in 118 of 123 (95.9%) surveys with median respondent age of 56 years (range 18-77), and 52.5% (62/118) of respondents aged between 50 and 64 years. All respondents noted their area zip code and from this just under half (55/123, 44.7%) of the respondents were considered to live in middle socioeconomic areas with under one-third coming from low socioeconomic areas (32/123, 26.0%) and under one-third living in high socioeconomic areas (36/123, 29.3%) (Table 1).

Table 1. Respondent demographic characteristics.

Descriptive characteristics		n (%)
Gender (n=123)		
	Male	51 (41.5)
	Female	72 (58.5)
Age, years (n=118)		
	Median (range)	56 (18-77)
	Under 50	42 (35.6)
	50-64	62 (52.5)
	Over 65	14 (11.9)
Socioeconomic indexes for areas based on postcode (SEIFA), Australia, 2011 [a] (n=123)		
	Low income (Deciles 1 and 2)	32 (26.0)
	Middle income (Deciles 3 to 8)	55 (44.7)
	High income (Deciles 9 and 10)	36 (29.3)

[a] Australian Bureau of Statistics. Socioeconomic indexes for areas: robustness, diversity within larger areas, and the new geography standard Commonwealth of Australia 2012; ABS Catalogue no. 1351.0.55.038.

Computer Use

All 123 respondents answered questions related to computer use with the majority of respondents engaged in regular computer use (102/123, 82.9%), defined as more than four times per week. The overwhelming majority had access to a device at home (118/123, 95.9%) mainly in the form of a laptop (91/123, 77.1%); however, over half additionally had access to a desktop (60/123, 50.8%) and a tablet (60/123, 50.8%). Fewer than half the respondents had access to a computer at work for personal use (58/123, 47.2%) and in most cases this access was a desktop computer (44/58, 75.9%). There was no marked difference in computer use across age groups or gender; however, respondents who came from lower socioeconomic areas (32/123, 26.0%) noted less regular computer use (24/32, 75%) compared with other groups (47/55, 85% in middle and 31/36, 86% in high socioeconomic groups) (Table 2).

Table 2. Questions relating to access and use of technology.

Access to technology	n (%)[a]
Regular computer use (n=123)	
Yes	102 (82.9)
No	21 (17.1)
Regular computer use, “yes”, by age group, years (n=118)	
Under 50 (n=42)	33 (78.6)
50 – 65 (n=62)	53 (85.5)
65 and over (n=14)	11 (78.6)
Regular computer use, “yes”, by socioeconomic area [b] (n=123)	
Low socioeconomic area (n=32)	24 (75.0)
Middle socioeconomic area (n=55)	47 (85.5)
High socioeconomic area (n=36)	36 (86.1)
Access to a computer device at home (n=118)	
Desktop	60 (50.8)
Laptop	91 (77.1)
Tablet	60 (50.8)
Access to a computer device through work (n=58)	
Desktop	44 (75.9)
Laptop	31 (53.4)
Tablet	17 (29.3)
Regular Internet use (n=121)	
Yes	104 (86.0)
No	17 (14.0)
Regular Internet use, “yes”, by age group, years (n=116)	
Under 50 (n=41)	37 (90.2)
50 – 65 (n=62)	52 (83.9)
65 and over (n=13)	11 (84.6)
Regular Internet use, “yes”, by socioeconomic area [b] (n=121)	
Low socioeconomic area (n=32)	25 (78.1)
Middle socioeconomic area (n=54)	48 (88.9)
High socioeconomic area (n=35)	31 (88.6)
Mode of Internet access at home (n=120)	
Yes	113 (94.2)
No	7 (5.8)
If yes to home Internet access, (n=110)	
Wireless	61 (55.5)
Broadband	34 (30.9)
Cable/DSL/fiber	9 (8.2)
Dial-up	2 (1.8)
Unsure	4 (3.6)
Mode of Internet access outside the home (n=120)	
Yes	81 (67.5)

Access to technology	n (%)[a]
No	39 (32.5)
If yes to Internet access outside the home (n=93)	
At work	62 (66.7)
Via public wireless	58 (62.4)
Via smartphone	31 (33.3)
Via friend’s place	24 (25.8)
Via Internet café	10 (10.8)
Key Internet activities (n=121)	
Emailing	101 (83.4)
Browsing, researching, reading news articles	93 (76.9)
Social media	71 (58.7)
Day to day activities (shopping, banking, and browsing)	65 (53.7)
Browsing for health information	56 (46.3)
Skype or video calls	36 (29.8)
Access to a mobile phone (n=117)	
Yes	115 (98.3)
No	2 (1.7)
Key mobile phone activities (n=115)	
Phone calls	111 (96.5)
Sending texts	100 (86.9)
Internet browsing	62 (53.9)
Checking and sending emails	57 (49.5)
Other (playing games, social media, apps)	6 (5.3)

[a] Multiple responses to questions were accepted in free text questions and respondents were instructed to “tick all that apply” when responding to nominal questions. In this context, the sum of percentages will be more than 100%.

[b] Australian Bureau of Statistics. Socioeconomic indexes for areas: robustness, diversity within larger areas, and the new geography standard Commonwealth of Australia 2012; ABS Catalogue no. 1351.0.55.038

Mobile Phone Use and Activities

The majority (117/123, 95.1%) of respondents answered questions related to mobile phone use and activities, with all but two respondents reporting that they used a mobile phone (115/117, 98.3%). Phone calls (111/115, 96.5%) and sending texts (100/115, 86.9%) were the two main activities carried out using a mobile phone. Over half of the respondents additionally used their phone for Internet browsing (62/117, 53.0%) and half for checking and sending emails (57/115, 49.5%) (Table 2).

Internet Use and Activities

The majority (121/123, 98.4%) of respondents answered questions related to Internet use and activities, with the majority reporting regular Internet use (104/121, 86.0%). Internet use did not differ across age or gender; however, similar to computer use, those from lower socioeconomic areas had a reduced regular Internet use (25/32, 78%). Internet in the home setting was accessed by 94.2% (113/120) of respondents and in the main this was through wireless (61/110, 55.5%) or through broadband access (34/110, 30.9%). The majority of respondents also reported access to the Internet outside the home (81/120, 67.5%) and this was accessed either at work in line with computer access above (62/93, 67%) or through public wireless (58/93, 62%). A further third of individuals additionally had access to the Internet through smartphones (31/93, 33%) and others had access through a friend’s home (24/93, 26%) and Internet cafes (10/93, 11%) (Table 2).

The main activities undertaken through an Internet platform were reported in 121 of 123 (98.4%) of respondents with emailing (101/121, 83.4%), browsing, researching, and reading news articles (93/121, 76.9%), accessing social media (71/121, 58.7%), and day-to-day activities including online shopping, banking, and general browsing (65/121, 53.7%), as the most common. Just under half of respondents (56/121, 46.3%) used the Internet to browse health information and under a third (36/121, 29.8%) for Skype and video calling (Table 2). More female respondents noted that they used the Internet for both social media (female 50/69, 72% vs male 21/47, 45%,) and daily activities including online shopping banking and browsing (female 42/69, 61%, vs male 23/47, 49%) compared with their male counterparts. In regard to socioeconomic status, those from higher income areas showed a higher rate of email (32/34, 94% vs 43/51, 84% and 26/31, 84% in middle and lower socioeconomic groups respectively), research and reading the news (30/34, 88% vs 39/51, 76% in middle and 39/51, 77% in lower socioeconomic groups), and accessing health information through the Internet (21/34, 62% vs 23/51, 45% in middle and 12/31, 39% in lower socioeconomic groups). Those respondents from middle socioeconomic areas were more likely to access social media (37/51, 73%) compared with the other groups (17/34, 50% in higher and 17/31, 55% in lower socioeconomic groups). Respondents from lower socioeconomic areas were additionally less likely to Skype (6/31, 19% vs 12/34, 35% in higher and 18/51, 35% in lower socioeconomic groups) or engage in daily online activities, such as shopping, banking, and browsing (11/31, 35% vs 23/34, 86% in higher and 31/51, 61% in lower socioeconomic groups) (Table 2).

The Potential for Web-Based Support and Information

The majority of respondents (111/123, 90.2%) answered questions in relation to access, concerns, and use of technology-based health websites. The majority answered that they would find it useful to have access to support programs and assistance with health problems through the Internet (82/111, 73.9%). Respondents between the ages of 50 to 65 years had a slightly higher positive response to this (45/54, 83%) compared with those in the under 50 years group (25/40, 63%) and the over 65 years group (8/12, 67%). Interestingly, those from higher socioeconomic areas were less likely to respond positively to finding benefit from online support and information, with only 67% (22/33) responding "yes", compared with 75% (21/28) in lower socioeconomic areas and 78% (39/50) in middle socioeconomic areas. The majority of respondents gave reasons as to why they would access online support (71/111, 63.9%) with the main reasons being: better able to understand health information and condition management (16/71, 23%), avoid difficult travel requirements and time-consuming face-to-face appointments (13/71, 18%), and have convenient and easily accessible help and information (12/71, 17%). Nine (13%) of 71 reported "the more help the better" or words to that effect, and nine (13%) of 71 noted the benefit of peer support and sharing. It is also important to note that six (8%) of 17 respondents wrote that online information would address the difficulty they experienced in accessing information from their health providers and a further six (8%) of 71 noted that they would be able to get up-to-date advice on management and treatments (Table 3).

Table 3. Questions regarding online access, concerns, and currently used sites.

Online access, concerns and currently accessed sites		n (%)[a]
Would you find it useful to be able to access support programs using the Internet to assist you with your health problems? (n=111)		
Yes		82 (73.9)
No		29 (26.1)
Would you find access through Internet useful, "yes", by age group, years (n=106)		
Under 50 (n=40)		25 (62.5)
50 – 65 (n=54)		45 (83.3)
65 and over (n=12)		8 (66.7)
Would you find access through Internet useful, "yes", by socioeconomic area [b] (n=111)		
Low socioeconomic area (n=28)		21 (75.0)
Middle socioeconomic area (n=50)		39 (78.0)
High socioeconomic area (n=33)		22 (66.7)
Reported reasons (n=71)		
Better understanding of health information and condition management		16 (22.5)
Avoid difficult travel requirements and less time consuming		13 (18.3)
Convenient and accessible help and information		12 (16.9)
"The more help the better"		9 (12.7)
Peer support and sharing		9 (12.7)
Address difficulty in accessing disease information from health providers		6 (8.5)
Up-to-date advice on management and treatments		6 (8.5)
Are there health education or social group sites on the Internet that you have found helpful? (n=112)		
Yes		60 (53.6)
No		52 (46.4)
Health education or social group sites helpful, "yes", by age group, years (n=107)		
Under 50 (n=38)		20 (52.6)
50 – 65 (n=57)		29 (50.9)
65 and over (n=12)		7 (58.3)
Health education or social group sites helpful, "yes", by socioeconomic area [b] (n=112)		
Low socioeconomic area (n=30)		14 (46.7)
Middle socioeconomic area (n=48)		27 (56.3)
High socioeconomic area (n=34)		19 (55.9)
Reported health education or social group sites (n=52)		
Health organization or research sites		16 (31)
	Australian Heart/Lung Transplant Association	7 (43.8)
	Diabetes	3 (18.8)
	Heart Lung Transplant Network	1 (6.3)
	Arthritis Australia	1 (6.3)
	Cystic Fibrosis	1 (6.3)
	Hemochromatosis organization	1 (6.3)
	Heart and lung sites	1 (6.3)
	Heart foundation	1 (6.3)
General browsing for health information and education		13 (25.0)

Online access, concerns and currently accessed sites	n (%)[a]
Medication and treatment information and side effects	9 (17.9)
Facebook for disease-specific support groups	8 (15.4)
Donate Life	1 (1.9)
Health rebate and concession information	1 (1.9)
Online mental health programs (Sadness and Depression program)	1 (1.9)
Would you have any concerns about participating in support programs via the Internet? (n=111)	
Yes	24 (21.6)
No	87 (78.4)
Concern about participating, "yes", by age group, years (n=106)	
Under 50 (n=41)	8 (19.5)
50 – 65 (n=53)	12 (22.6)
65 and over (n=12)	3 (25.0)
Would you find access through Internet useful, "yes", by socioeconomic area [b] (n=111)	
Low socioeconomic area (n=28)	5 (17.9)
Middle socioeconomic area (n=50)	13 (26.0)
High socioeconomic area (n=33)	6 (18.2)
Reported concerns (n=15)	
Privacy and security	10 (66.7)
Accuracy of information	2 (13.3)
Computer literacy and access	2 (13.3)
Limited Australian-based sites	1 (6.7)
Misinterpretation of information	1 (6.7)
No support group for my condition	1 (6.7)

[a] Multiple responses to questions were accepted in free text questions and respondents were instructed to "tick all that apply" when responding to nominal questions. In this context, the sum of percentages will be more than 100%.

[b] Australian Bureau of Statistics. Socioeconomic indexes for areas: robustness, diversity within larger areas, and the new geography standard Commonwealth of Australia 2012; ABS Catalogue no. 1351.0.55.038.

Health Information and Education Websites Currently Accessed

The majority of respondents answered questions relating to health information and education sites currently accessed through the Internet (112/123, 91.1%). Over half of the respondents were already accessing websites that they felt were useful (60/112, 53.6%) and this was marginally higher in those aged 65 years and above (7/12, 58%) than those from middle (29/57, 51%) and low socioeconomic areas (20/38, 53%). A total of 52 (46.4%) of the 112 respondents reported commonly accessed sites, with health organizations and research sites (16/52, 31%), including Australian Heart/Lung Transplant Association, most common. One-third (16/52, 31%) of respondents stated that they did not access a particular website, but that they generally browsed the Internet for health information and education, with a further nine (17%) of 52 respondents accessing sites for medication and treatment information specifically. Eight (15%) of 52 responded that they accessed disease-specific Facebook support groups, and single individuals noted they accessed Donate Life, health rebate and concession sites, and an online mental health support program run by the academic medical center itself (1/52, 2%, respectively) (Table 3).

Concerns Over Accessing Information and Support Online

When asked if respondents had concerns over accessing and participating in online support programs, the overwhelming majority of respondents answered the question (111/123, 90.2%) and did not have concerns (87/111, 78.4% answered "no"). This did not differ across gender, age, or socioeconomic groups. Reasons for concern were given by a small number of respondents (15/111, 13.5%), with privacy and security most common (10/15). Other reasons for individual concern included accuracy of information (2/15), computer literacy and access (2/15), limited Australian-based sites (1/15), the opportunity for misinterpretation of information (1/15), and the lack of a support group for that individual's particular condition (1/15) (Table 3).

Discussion

Principal Findings

Web-based health information and support are available in the United States [28, 32-35]; however, internationally, the use is not as widespread [28,30-36]. In the Australian context, studies have explored Web-based health interventions, but there is limited information as to the patterns of technology use in cardiopulmonary patients [37]. The reported study sought to describe patterns of technology use in patients attending a cardiopulmonary clinic. The patients responding to this survey provide a sample of those individuals likely to have increasing health care utilization needs. It is important to take this initial step in understanding whether these consumers have technology capabilities and receptivity to these modalities [42-44].

Study results indicated that computer, mobile phone, and Internet use are a pervasive part of everyday life with individuals using their technological devices for a variety of reasons, including accessing and browsing health information websites. The majority of respondents additionally answered that access to support programs through a telecommunication platform would provide assistance with their health problems; this was most common in individuals aged 50-65 years. The most commonly accessed websites were disease-specific sites, organizations, and research sites, as well as sites that provided information on specific medications and treatments. In agreement with previous literature, peer support and sharing of experiences were also noted as benefits of access through an online platform, and was noted as providing support and information that they may not otherwise be able to access in their everyday life [29-31,46,47].

Patterns of technology use did differ between patients from different socioeconomic groups, as measured using advantage/disadvantage index based on area [45]. Although overall technology use was pervasive in all groups, patients who lived in higher socioeconomic areas used the Internet most regularly and those patients from middle socioeconomic areas were most likely to access social media compared with the other groups. Although still high users of technology, those from low socioeconomic areas had less access to computers and used computers and the Internet less frequently, a situation evident in international literature; technological access and literacy are a consideration for future technology-based health delivery interventions [48,49]. Interestingly, while those who lived in higher socioeconomic areas were most likely to be already accessing Web-based health information sites, when asked if they would benefit from delivery of health information and support through an online interface, those from higher socioeconomic areas were least likely to respond positively; this may reflect higher health literacy [27,50], better health access [2,45], and therefore less need for additional support, but this would need further investigation.

Respondents indicated clear issues with current health care delivery through face-to-face interaction, with several noting the long distance they had to travel to access care and the lack of information provision through traditional sources; Web-based health information delivery may go some way to alleviating the limitations of current health care provision. As similarly noted in previous literature, respondents viewed online health care delivery as providing convenient, timely, and easily accessible information, currently difficult to obtain through traditional face-to-face sources [29-31,51]. This is particularly important in the context of this cardiopulmonary clinic, which acts as a quaternary referral clinic attracting patients from a large geographical area across the state. Several studies have highlighted the relationship between patient satisfaction and Web-based health information seeking behavior [51-53]. Consumer-health provider interfaces need to be improved to provide timely and accessible health care interaction that reduces the geographical burden of current health care delivery [28-31,51-53].

While the majority of respondents stated that they did not have concerns over accessing information or support online, issues of privacy and security, the accuracy of information, and the potential for misinterpretation of information were raised by a smaller number of patients. Consumers' ability to distinguish accurate, trustworthy, and personally applicable information, when faced with the sheer volume of health information sites available, is a commonly reported challenge in the literature [42-44]. Development and validation of websites is essential; health professionals have an opportunity to ensure that patients and their families have guidance to accurate and trustworthy Web-based health information sources [42-44].

Web-based health care delivery has particular potential to provide convenient and accessible access for individuals and their families living with chronic, complex, and progressive conditions [28-31]. Providing ongoing care through technology platforms may address the issues associated with short-term episodic programs, such as pulmonary and cardiac rehabilitation, in providing ongoing education, social support, and exercise maintenance to larger patient cohorts [16,17,21,22,28]. Self-management programs that are provided through a Web-based interface may leverage computer-based and mobile technology to facilitate continued care and support [28-31]. This may be of particular value to aging "baby boomers", who have already incorporated these technologies into their daily lives [28-31]. Web-based health care delivery additionally has the potential to help those at end of life who need increasingly complex strategies to cope with dyspnea and fatigue, especially as they become homebound [28-31].

Implications for Practice

This study sought to describe patterns of technology use in patients attending a cardiopulmonary clinic. Technology use is a pervasive part of everyday life regardless of age or socioeconomic group with patients already heavily engaged in health-seeking behaviors through Web-based sources. There is a necessity to develop and validate websites, and an opportunity to ensure that patients and their families have guidance to accurate and credible health information sources. Web-based delivery of health information and support is of particular importance in patients with cardiopulmonary disease, who are most likely to have high symptom burden and health care utilization needs in the future. Current consumer-health provider interfaces need to be improved to accommodate the changing needs and preferences of an empowered generation of health consumers, and to provide timely and accessible health care interaction that addresses the geographical burden of current health care delivery. Telecommunication interfaces may alleviate some of the difficulties with current health care access and provide an increasingly important adjunct to traditional forms of health care delivery. We are at a turning point within the evolution of health care delivery and have the opportunity to shape how future interventions deliver health information and promote self-management. Future research must explore the feasibility of delivering health care through Web-based platforms across larger cohorts and explore the social and economic impact of this approach on health care delivery.

Limitations

This prevalence study was undertaken in a small cohort of patients from a single clinical site. While survey responses were completed in full in most cases, there is a possibility that patients who do not engage with technology may have self-excluded from participating. Further, large cohort, multi-site research would be required to describe overall population technology use. Additionally, this study only sought to describe the patterns of technology use and further research is required to understand the attitudes and specific barriers faced by cardiopulmonary pulmonary patients in regard to the delivery of health information and education through telecommunication interfaces. While this initial study does have its limitations, the results do provide important information regarding patients' access to technological devices, their use of Web-based information and support for their health conditions, and the perceived potential benefits of health care delivery through Web-based platforms. This is particularly important in the context of patients attending a cardiopulmonary clinic, who are most likely to have high symptom burden and associated health care utilization needs in the future.

Conclusions

Chronic disease burden and the long-term self-management tasks that challenge patients with cardiopulmonary disease are a compelling argument for accessible and convenient avenues to obtaining ongoing treatment and peer support. Technology use was already a pervasive part of everyday life for study participants, and a central platform for health care interactions including common access of health information and education. Patterns of use and access differed marginally across age and socioeconomic groups, however, accessing Web-based health information was prevalent for all groups. Clear issues were raised over long distance travel and a lack of information provision through traditional health delivery sources. Web-based access to health support programs are perceived as providing convenient, timely, and easily accessible information—particularly important in the context of a quaternary referral clinic attracting patients from a large geographical area, and in cardiopulmonary patients most likely to have high health care utilization needs in the future. Telecommunication interfaces will be an increasingly important adjunct to traditional forms of health care delivery. These will need to be assessed for the validity of content and access to target populations.

Acknowledgments

We would like to acknowledge the patients and staff at St Vincent's Hospital, Sydney, Australia for their participation and assistance in this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Internet access and use survey.

[PDF File (Adobe PDF File), 6KB - ijmr_v4i1e5_app1.pdf]

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Abbreviations

CHF: congestive heart failure
COPD: chronic obstructive pulmonary disease

Edited by G Eysenbach; submitted 20.10.14; peer-reviewed by H Du, R McNamara, A Lau; comments to author 12.11.14; revised version received 30.11.14; accepted 20.12.14; published 06.03.15

Please cite as:
Disler RT, Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM
Patterns of Technology Use in Patients Attending a Cardiopulmonary Outpatient Clinic: A Self-Report Survey
Interact J Med Res 2015;4(1):e5
URL: http://www.i-jmr.org/2015/1/e5/
doi:10.2196/ijmr.3955
PMID:25798814

Chapter Figure 1

INTERNET ACCESS AND USE SURVEY

Demographics

☐Male ☐Female

Postcode ____________

Date of birth __/__/_____

Section 1 Computer access

1. Do you use a computer regularly? (more than 4 times a week)
   ☐Yes ☐ No

2. Do you have access to the following **at home** for personal use?
   (please tick all that apply)
   ☐ Desktop computer
   ☐ Laptop
   ☐ Tablet computer (i.e. iPad or similar)

3. Do you have access to the following **at work** for personal use?
   ☐ Computer
   ☐ Laptop
   ☐ Tablet computer (i.e. iPad or similar)

Section 2 Internet access

4. Do you use the **internet** regularly? (more than 4 times a week)
   ☐Yes ☐ No

5. Do you have internet access at **home**
   ☐Yes ☐ No

   If yes, is this:
   - ☐ Broadband
   - ☐ Dial-up
   - ☐ Cable/DSL/fibre
   - ☐ Wireless
   - ☐ Unsure

6. Is there anywhere else where you **access** the internet regularly?
   (please tick all that apply)
   - ☐ Via a smartphone
   - ☐ Wireless connection in public places (i.e. cafe's etc)
   - ☐ Internet cafe
   - ☐ Public library or educational institution
   - ☐ Friend or family's place

   Other ____________________________

7. What activities do you use the internet for?
   (please tick all that apply)
   - ☐ Emailing
   - ☐ Social media (Facebook etc)
   - ☐ Skype or video calls
   - ☐ Shopping

☐ Browsing, researching, reading news articles
☐ Browsing for health information
Other ___________________________

Section 3 Mobile phone access

8. Do you own a mobile phone?
☐Yes ☐ No
If yes, what do you use you mobile phone for? (tick all that apply)
☐ Phone calls
☐ Sending SMS texts
☐ Checking /sending emails
☐ Internet browsing
Other ________________________

Section 4 Health support programs via the internet

9. Are there health education or social group sites on the internet that you have found helpful?
☐Yes ☐ No
If yes, please provide examples:____

10. Would you find it useful to be able to access support programs using the internet to assist you with your health problems?
☐Yes ☐ No
Why? ____

11. Would you have any concerns about participating in support programs via the internet?
☐Yes ☐ No
Why? ____

Thank you for taking the time to participate in this study.

Disler RT, Inglis SC, Newton PJ, Currow DC, Macdonald PS, Glanville AR, Donesky D, Carrieri-Kohlman V, Davidson PM. Patients perspectives of online health information and chronic disease management in individuals' chronic obstructive pulmonary disease: focus group study. *COPD: Journal of Chronic Obstructive Pulmonary Disease.* Under Review.

Patients' perspectives of online health information and chronic disease management in chronic obstructive pulmonary disease: focus group study

ABSTRACT

Background: Chronic obstructive pulmonary disease (COPD) is a chronic and complex condition requiring self-care strategies. International guidelines and Level 1 evidence recommend that self-management education is primarily provided through pulmonary rehabilitation programs. However, these are commonly of short duration and of limited access. Delivery of health information through multimedia formats has the capacity to increase access to self-management education in both synchronous and asynchronous modes.

Objective: To understand the perspectives of patients currently living with COPD regarding healthcare information and delivery through an online interface.

Methods: Participants were recruited from a maintenance pulmonary rehabilitation program within a large metropolitan hospital. Conversations were recorded, transcribed verbatim and analysed using thematic analysis to identify key and repeated emergent themes regarding the delivery of healthcare information and management within an online setting.

Results: Focus groups were undertaken between January 2014 and April 2014. Five themes emerged through thematic analysis: (1) multimedia is a pervasive aspect of the modern landscape with patients interacting with peers and health professionals through a range of media; (2) privacy, safety and accurate interpretation of online information are of concern, illustrating a need for validation of online sites and resources; (3) moderated or direct health provider interfaces may provide timely and accessible healthcare interaction sought by individuals isolated geographically or through debilitation; and peer-sharing may provide a sense of belonging in the context of prolonged disease duration; (4) access to new or

forgotten information was also a key benefit to online delivery; (5) there is a need for improved collaborative decision-making and symptom management.

Conclusions: Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and sustainable approaches to chronic disease management. Participants in the focus groups were already interacting with peers and health professionals using a range of media. Privacy, safety and accurate interpretation of online information were concerns; validation of online sites along with moderated or direct health provider interfaces may provide the timely and accessible healthcare interaction sought by individuals who are isolated by debilitation or geographical barriers. Online peer interaction provides additional sharing of experiences and may offer a sense of belonging and normalcy in the context of prolonged disease duration. Delivery of health care through varied formats has the capacity to provide accessible and convenient self-management education as an adjunct to traditional approaches. Further research is required into the feasibility and sustainability of online approaches to support patients with chronic illnesses such as COPD.

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality and ranks fourth as a cause of death worldwide and is projected to become the third cause of death by 2030 [1,2]. The economic and social burden is both substantial and increasing with costs of COPD estimated at $40 billion globally [3]. Social costs include significant disability as reflected in daily symptoms, poor physical functioning, social isolation, and caregiver burden [4]. Population aging further accentuates the cumulative burden of these chronic progressive disorders [5]. Although COPD has recently received greater attention from the medical community, the social, psychological and financial burden of disease is less well recognised [6].

Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and sustainable approaches to support patients with chronic illnesses, such as COPD [1,2,4]. Collaboration and interaction between consumers and health providers have already been altered by the introduction of mHealth (personal digital assistants, monitoring, and other wireless devices) and e-health (delivery of healthcare through telehealth communications for surveillance, support of management and health promotion) [7-9]. Asynchronous forms of health interaction, such as through email or discussion boards, have the capacity for patients to pose questions of their provider without having to wait for a formal consultation, and thereby access self- management and condition support that meets their ongoing needs [10,11].

Telecommunication tools, such as video conferencing, are already a pervasive component of healthcare delivery and will increasingly influence future healthcare delivery in COPD and other chronic conditions [12-15]. Support for collaborative self-management has been recognized as a vital component for increasing continuity and quality of chronic illness care [16,17]. Patients and their families manage their symptoms on a day-to-day basis and need to be engaged when negotiating their ongoing plan of care [18]. Self-management education for individuals with COPD, including symptom management strategies, exercise, and reinforcement of activity and medication adherence, are commonly provided through pulmonary rehabilitation programs, of short duration and are only available to a small percentage of patients mostly after an acute exacerbation [19,20]. Decreased mobility further inhibits chronically ill patients from accessing these programs [21,22]. Self-management and overall burden of chronic disease provide a compelling argument for accessible and convenient avenues to obtain ongoing treatment and peer support.

In the 2010 systematic review of home telehealthcare for COPD, Polisena [23] compared telemonitoring or telephone support with usual care in nine studies and found a reduction in hospitalisation rates and emergency department visits in those receiving home telehealth, with similar or better quality of life and patient satisfaction between the two groups [23]. In the 2011 Cochrane review, McLean et al [24] reviewed ten trials that included telehealthcare as part of an integrated complex interventions. A clinically significant increase in quality of life and a significant reduction in emergency department presentations were observed. Mortality was not found to be different between the intervention and control groups [24]. Additionally, several studies have identified that older individuals and those with chronic disease increasingly use social media to provide important peer support and a sense of belonging and normalcy [13-15,25-28]. Online support groups have additionally been reported to improve social well-being, enhance self-management and self-efficacy in a range of chronic illnesses [12-14].

The new generation of empowered health consumers expect health care systems that accommodate their changing needs and preferences for how they receive care [12-14]. A recent report by Pew Internet and American Life Project showed that at least 50% of adults over the age of 65 are now online [29]. While online health interaction is well established in the United States of America [29], it is not used as extensively internationally [13-15,26-28]. Access to online programs are especially limited in older adults who are most burdened with chronic conditions due to limited expertise and resources and attitudes to health care professionals [13-15,26-28] Delivery of healthcare through online or technological devices offers a potential adjunct to traditional forms of face-to-face healthcare and could bridge the geographical and physical barriers often experienced by those living with chronic diseases [13-15,26-28]

This study aimed to describe the perspectives of patients currently living with COPD regarding the delivery of healthcare information through an online interface. Patients attending maintenance pulmonary rehabilitation are considered highly engaged in their chronic disease management and are ideally placed to comment on the future delivery of health care information.

METHODS

Study design

Focus groups were used to capture data on the perspectives of patients currently living with COPD regarding the delivery of healthcare information through an online interface. Groups discussions allow for understanding of collective perspectives of complex issues accessible through group interaction [30-32] Group discussion is familiar to this cohort as group interaction is a key component of the regular pulmonary rehabilitation sessions and encourages supportive social integration and sharing of personal experience that may be limited outside this setting [33-36] Group discussions allowed for understanding of the collective perspectives of complex issues [30-32]. Observing others encouraged participants to discuss and reflect on issues within the group as well as assisting in validation of shared feelings and experiences [30-32]

The focus groups question routes were developed in consultation with experts in the field of chronic illness and online health care delivery (Appendix A). Discussion was guided by the following four question themes: current access and pathways to health information and disease management; current use of computer and internet devices in everyday life and in healthcare; the risks and benefits associated with online health care information and care delivery; and what the ideal future would look like in terms of health care delivery from the patient perspective.

Sample, setting and participants

Participants were recruited from patients attending a maintenance pulmonary rehabilitation program within an academic medical centre. The pulmonary rehabilitation sessions run twice a week for one hour and are open on an ongoing basis to all patients with chronic respiratory disease who have completed the initial eight week pulmonary rehabilitation program.

Inclusion criteria

- A confirmed diagnosis of COPD which was clinically stable (including medications) for at least one month;

- Currently attending maintenance exercise classes;
- Ability to speak English and sign consent;

Exclusion Criteria

- It was not necessary to exclude any individuals attending the exercise sessions.

Data collection

This study was undertaken through a series of focus groups until data saturation occurred, that is no new information emerged. Conversations were recorded, transcribed verbatim and analysed using thematic analysis. Sessions were facilitated by an investigator with a clinical background in chronic disease management, an interested in innovative approaches to health care delivery, and who has been trained in facilitating group discussions. Individuals were encouraged to consider their access to computer and online devices and the benefits and issues that might be associated with accessing health information and management through an online interface. As part of the focus group, several online sites were demonstrated and discussed to illustrate the variety of online material available for understanding of collective perspectives of complex issues accessible through group interaction [30,31,37,38] COPD care. Participants were then facilitated in a discussion as to the benefits and issues of these approaches and whether they might access these types of approach in the management of their condition.

The focus groups were intended to capture data on the attitudes of individuals currently living with COPD regarding the delivery of healthcare information through an online interface. Group discussions allowed for understanding of the collective perspectives of complex issues [30,31,37,38] Observing others encouraged participants to discuss and reflect on issues within the group as well as assisting in validation of shared feelings and experiences [30,31,37,38] The focus groups question routes were developed in consultation with experts in the field of chronic illness and online health care delivery (Appendix A). Discussion was guided by the following seven question themes: current access and pathways to health information and disease management; current use of computer and internet devices in everyday life and in healthcare; the risks and benefits associated with online health care information and care delivery; and what the ideal future would look like in terms of health care delivery from the patient perspective.

Synthesis of results

Thematic analysis was used to identify themes from repeated patterns of meaning and identify connections between these different themes [39] The method of Krueger's (1994) framework guided the analysis, particularly the categories of context, internal consistency, frequency and extensiveness of responses; and big ideas [40] Thematic analysis was used to consider both overt and latent data at three levels: articulated; attributional; and emergent [41] Methods of maintaining the rigor and trustworthiness of qualitative data were applied with two independent investigators coding raw data for themes and confirmation of themes undertaken through discussion with an expert panel in chronic disease management and delivery of health care information and management in the online context. Credibility, transferability, dependability and confirmability were assured by an ongoing, reflexive and iterative process including positioning and the use of journals, consultation and member checking [42]

Ethical approval

Ethical clearance was approved by the academic institution and hospital ethics committees (Approval number: LHR/13/SVH/5 and 2012-149A). The sample consisted of patients with COPD who are limited primarily by chronic dyspnoea and fatigue. Focus groups were run before or after participants usual maintenance exercise class at participants' convenience and were run in an education room within the same department to reduce the need for travel. Participants were informed that participation was voluntary and would not impact the quality of care delivered at the site or their relationship with their treating health professionals.

RESULTS

Focus groups were undertaken between January 2014 and May 2014. Ten of the thirteen participants who regularly attended the maintenance program participated in the focus groups. Of the three who did not participate in the study, two stated that they did not want to participate and the third was unwell during the recruitment and data collection period.

Three focus groups were undertaken with duration of 55-65 minutes. All participants had a primary diagnosis of COPD, were over the age of 65 and none required long term oxygen. Two of the participants who did participate in the focus group were initially reluctant to be involved as they felt they had little technological skill or access to computers, but were more than happy to participate on realising that this was a discussion which would welcome their opinion in this context.

PERSPECTIVES OF ONLINE BASED INFORMATION

Thematic analysis resulted in the following core themes: online is a risky environment; multimedia is a common aspect of the modern landscape; pulmonary rehabilitation remains a central point of access; benefits of online support; access to new or forgotten knowledge; collaborative decision making and symptom management; peer support; and care delivery across geographical and physical barriers.

Online is a risky environment

All participants raised concern over the risks associated with the online environment. There was strong fear over security of personal details and access to personal information, however the stronger concern was the reliability of internet based material. *'You get all mish mash of stuff in Google. You know, I mean, it's brilliant, Google is brilliant, but you could get into, you could get anywhere … a mish mash of things that aren't helpful'* FG2. This was reiterated across the groups with: '*Because they'll give you stuff that's not relevant to you' (R1) 'Exactly, I don't want the wrong information'*.'R2

There was concern that access to too much information would lead to anxiety and obsessing over possible diagnoses from the internet. While participants agreed that they would not use the internet in this way, they knew of others who relied on the internet and were concerned that the information others received was not accurate *'I mean, this is insane, because she looks everything up on computer. You can't do that, because if you say "I've got a tummy ache", it could be anything. You could be dying of cancer, you could have air, you* *could have tight pants, who knows?*' FG3. Others balanced this with that view that educating yourself to the best of your ability is central to living with chronic disease, but that the issue was accessing a credible source of information.

Multimedia; a common aspect of the modern landscape

One key concern for participants was that individuals with COPD may not have access to computers due to general age of the population, and that some individuals would feel further isolated in having to access an unfamiliar platform. '*I think it's difficult, for the simple reason the majority of people that have COPD are older, obviously because smoking, it takes more years to get this disease, and even though there are a lot of oldies out there on computers, there are also I think more not*.'(FG2) However this was generally balanced with comments regarding friends and others who used the computers constantly.

In talking further, the majority of participants had access to computers and used the internet and email in varying degrees. Several participants used smart telephones and a number had tablet devises for frequent internet and email browsing. The majority of participants used the devices for email, and others for social networking, teleconferencing with friends and grandchildren and for internet browsing. Several participants additionally had a strong grasp of technological vocabulary including '*backing up your ipad data to a cloud to avoid losing data in iTunes*' and suggestions that to maintain desktop computer memory '*you have to defrag(ment) regularly*'. There were several participants who used more traditional mobile telephones and others who stated that they did not have access to online material. In most cases there was multimedia access within the home setting, but some lacked the confidence in their own technological ability. One participant noted that they relied on their children to guide them and another noted that they only used the computer for email.

Pulmonary rehabilitation remains a central point of access

Individuals who participated in the focus groups regularly attended twice weekly exercise maintenance classes, consequently the face-to-face interaction and environment is understandably an important part of their health engagement. The initial seven week pulmonary rehabilitation course was commonly noted as a turning point in their disease management that 'changed their lives', prior to which participants voiced that they lacked understanding and control of their condition. Pulmonary rehabilitation provided them access to information about their condition management that they had not received through other avenues: *'I have a GP, but in depth [disease information]., it was more the classes here [The PR staff]. set me up for medication and things'* (FG2). Two other participants noted that prior to starting pulmonary rehabilitation they were markedly debilitated, spending little time outside the house and felt they had little prospect of improved quality of life (FG1, FG2).

Participants noted that the information booklet received during their initial pulmonary rehabilitation program was useful and one participant stated they would not access online materials as this resource was all they would need (FG2). Conversely, others noted that the booklet might be misplaced or that individuals might not have access to pulmonary rehabilitation and therefore this resource. The currency of printed information may also be questionable given patients, in some cases, had completed the initial program seven or eight years previously. Participants additionally stated that they felt referral into pulmonary rehabilitation was too late, only once they were markedly impaired, and also somewhat by chance (FG1, FG2, FG3): '*It was only offered to me after I got pneumonia, otherwise I wouldn't have known, it's only when something bad went wrong*.' (FG1) The short term course (6-8 weeks) was additionally felt to address only the immediate acute situation and not the ongoing condition management that may last five to fifteen years: *'It's very much ongoing, because I had a good run in the beginning, and then I started getting infections, so then you go down and down…'* (FG2).

Resoundingly, participants noted that face-to-face element was essential as motivation to exercise: '*When you have to go to an exercise class you do it, when you're left to your own, you're weak, sometimes you just say "I just don't really, I think I'll put that off till then".(*FG2) However, participants raised that only few individuals continued with maintenance classes and consequently access to regular advice around ongoing issues was limited. Pulmonary rehabilitation has a marked impact on individual quality of life [43] but remains a costly intervention that reaches a small proportion of the affected population [19,20] It is important to consider alternate ways of delivering supportive healthcare to address the increasing need for individuals living with chronic disease.

Benefits of online support

Traditional face-to-face contact remained the main source of support for this patient group, however, it was evident that they also accessed their health professionals through a variety of media, including telephone, fax and email: '*I e-mail [my specialist]., and she's very good, she answers back. …*' (R1) and '*Yeah, I had a couple of questions, because I needed to go on the prednisone, and the last time I was in hospital I doubled the dose. So I needed to ask her should I go back on the lower dose, when I needed to take it at home. It was easier to ask by e-mail.*' (FG1) The level of interaction was reliant on the approach of the health professionals with some participants noting that they only saw their specialist every six months.

Across the groups participants stated that they often missed the opportunity to ask questions about ongoing issues during face-to-face visits due to focus on their immediate exacerbation, lack of consultation time, and the effort required to see the doctor if they had no other pressing issue. Several participants noted that they consequently delayed changing or starting newly prescribed medications from their GP or the hospital while awaiting their next specialist appointment. Participants noted that online resources may facilitate these non-urgent questions while they await face-to-face contact:

I mean, look, I haven't even taken that [expectorant]. yet because I want to ask what's his name [specialist physician].. It said something about antibiotics and I was on antibiotics, but now I'm off antibiotics, but I would have gone on [to the internet]. to find out something like that, yeah. *(FG2)*

Looking up medications online was noted as safer than looking up general health information and participants across the groups commented that they were already doing this.

The key benefits of an online support network were: easy access to unfamiliar or forgotten knowledge; provision of information early in disease progression; access to advice when making decisions; delivery of care to those isolated from face-to-face services; and peer support from those who know what you are going through:

Access to new or forgotten knowledge

Access to information and support through a disease specific portal was viewed positively with participants noting that access to up to date information would be useful as a reminder of their prior learning. On showing an online video demonstrating the common *'purse lipped breathing'* technique, several participants had forgotten that this was a useful management strategy for breathlessness. Others commented that they had known about this but they remembered it from the early days of their initial pulmonary rehabilitation program many years ago (FG1).

Participants were equally interested in such topics as *'what causes shortness of breath'*, *'how does arm strength reduce shortness of breath'* and *'depression and COPD'*, and commonly commented that '*I had forgotten that*', '*didn't know that*' or '*must read that'*. The focus group discussion itself appeared useful with participants commenting that talking together helped them remember and learn from each other. Access to a COPD specific resource was seen as something that might be '*a nice little safety net*' and, particularly for non-urgent questions, such a resource would be '*comfort to me, [as I could]. go and look it up', R2: 'I would have accessed [the online network]. to ask that question*'.

Participants voiced that while education is important at any phase, the types of resources demonstrated would be particularly beneficial to those new to COPD or early in disease progression, with participants commonly voicing that that they didn't know how or who to ask for advice when they first became unwell: *'Well, in earlier days I wouldn't speak to anyone about it, not even, well, there was no one that really understood what I was going through'.* Access to a space where individuals would be able to learn and hear others' experiences was seen as invaluable *'I walked in here, like a scared child, like a bunny rabbit, and I thought "God, what's this about?", and all of a sudden the confidence comes back, and you're away … But in the very beginning, yeah, millions of questions, but you're not sure how to ask them.'* (FG2) Asking advice of others was an important aspect of learning how to manage disease and how to cope with challenges during disease progression.

Collaborative decision making and symptom management

Participants voiced that management of COPD is a collaborative interaction between the individual and the health professional. A key barrier to supported decision making was at night when advice from those familiar with COPD is limited: *'Well, I would, but the trouble is if there's a specialist , very often when you don't feel well it's night time. It could be one o'clock in the morning'.* (FG3) The generalist nurse help line service was not seen as useful across the focus groups as past experience indicated that they would be instructed to call an ambulance because of breathing difficulty. Ultimately individuals had to make a decision about their own action; access to a specialist, whether online or over the telephone, was voiced as something wanted, yet absent, in these situations.

Participants were open to a system in which they could enter detailed symptom and management information and receive advice from a specialist nurse through this interface. The ability for individuals to see their own symptom and medication trends was also something of positive interest, and the ability to communicate directly with a specialist clinician was of high importance. Participants voiced that this type of program might be something they could access prior to calling emergency services to remind them of the strategies they have in place:

while you're in the middle of like a bad breathing episode, and you've either got the choice of ringing 000 or sort of getting into a panic and thinking, that program, that could calm you down a bit, because when you look at it, you can see you've got the means at your disposal, and the choice of doing certain things to help your breathing that they can remind you of, about. (FG2)

Several participants noted that completing information every day would not be useful, and would be considered laborious, but that they certainly would access this when they were feeling unwell so that they could record their condition and seek support.

Access to peer support

Peer network sites were of strong interest throughout the groups with participants discussing the benefit of being able to access others who were living with a similar condition. There was also a feeling that individuals with the disease brought a different kind of knowledge from that of a health professional, knowledge born from being the person who actually experiences the condition:

> *We'll actually be talking to people that understand what we've got and why we're asking, it's not just a general thing, it's specific to people with COPD. R1*
> *Well, it's just like, a doctor can do all the study in the world, but how does he actually know how that person actually feels when you have it? So if you know someone that's been through it or is going through it, or has a chronic condition, this is ideal. R4 (FG1)*

Other participants did question the legitimacy of information given by a patient rather than a health professional, and while this is valid, others commented that within this moderated environment, listening and sharing with someone who has the same condition did lead to learning and understanding.

> *Yeah, but what he's saying, I mean, he's not trained, he's just a patient, isn't he? R3*
> *Well, he's self-trained, he's telling you his experience. R2*
> *You can relate to something that he's saying, though, it may not be exactly the same, but you could probably relate. R1*
> *Yeah, when you say that, it makes sense to me too, like that. Ours is a bit different, but I still learn when I learn off your experience. R3 (FG2)*

It was noted by the interviewer that the demonstrated site was developed in collaboration with health professionals; this type of moderated site was seen as more trustworthy and accurate. Overall there was interest in peer sharing and that it would provide additional support particularly in the context of clarifying queries and gaining tips and tricks on how to manage disease on a day to day basis.

Care delivery across geographical and physical barriers

One of the key areas of perceived benefit was for those with limited access to face-to-face services due to geographical or physical restriction, common in remote locations in Australia. Participants recognised that people living regionally would not have the same opportunity for engagement that they themselves experienced and that an online or alternate source of interaction would be of particular benefit in this context:

People in regional areas have very little access to anything. Some of them may be better computer literate, but then you don't know that they've got a good computer, because you don't know what their availability is out there. They could be sick, but they really need to speak to somebody. FG3.

Regardless of location, individuals with COPD are commonly socially isolated or housebound due to physical debility; focus group participants themselves noted that while they attended twice weekly exercise they equally avoided functions even close to their house due to physical effort. Participants additionally noted that there were people currently unable to attend the exercise classes due to ill health who were *'just sitting at home'* FG2 and that an online interaction would be beneficial when individuals were restricted in this way: *'if you're at home and you're housebound and can't get out, yeah, you need somebody to talk to'* FG1. Even for the highly engaged patients in this focus group, many noted that an online social group would be something that they would access, and in reality there were a number who were already emailing peers in the group in addition to the twice weekly face-to-face sessions.

DISCUSSION

This study sought to understand the perspectives of patients living with COPD regarding the delivery of healthcare information through an online interface. Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and sustainable approaches to support patients with chronic illnesses, such as COPD [1,2,4] Population aging further accentuates the cumulative burden of these chronic progressive disorders [5] Participants in this focus group study were already interacting with peers and health professionals using a range of media, but did have concerns over privacy and safety in the online environment and in regards to patients' ability to accurately interpret the volume of available online information. Computer literacy and the age of individuals with COPD were also seen as limiting factors to the applicability of an online approach, however recent international reports suggest that older people are now commonly online [29]

Multimedia resources demonstrated during the focus groups were noted as a source of accessible, reliable information that would help individuals to ask questions otherwise missed during face-to-face consultations. This had particular application early in disease progression when individuals were overwhelmed with questions, but unsure whom or how to ask. The benefits of online interaction were voiced as access to timely and up to date information, and the ability to ask questions and receive responses when making care decisions; support for this collaborative approach a vital component of chronic illness self-management [16,17] Similar to previous studies, participants noted that they often missed the opportunity to ask questions about ongoing issues during health consultations due to focus on immediate acute episode and lack of consultation time [44-46] Asynchronous online interaction was seen as providing space for these questions not necessarily relevant to the immediate medical situation, but equally as important to individuals' decision making and quality of life [44-46]

The contribution of peer networking and sharing was also highly valued by participants, this similar to previous studies that highlight social media and online support groups as an important source of sharing experiences, belonging and normalcy [12-14,25] The increased social well-being, enhanced self-management and self-efficacy and sense of belonging and normalcy offer important benefits in the context of prolonged disease duration [12-14,29] Facilitating access to online support networks may provide an important resource in future healthcare delivery [12-14,25]

Telecommunication tools, such as video conferencing, will increasingly influence future healthcare delivery in COPD and other chronic conditions [12-15], particularly in the context of time-limited, face-to-face self-management programs [19,20] with access further restricted due to geographical barriers and mobility issues in chronically ill patients [21,22] The new generation of empowered health consumers expect health care systems that accommodate their changing needs and preferences for how they receive care [12-14]

Implications for practice

Individuals with chronic disease are increasingly accessing health information and peer interaction through the online environment [12-14,25,29] Healthcare professionals have an opportunity to validate sources of health information and direct patients and families to trusted and accurate health sites. Moderated sites or direct health provider interfaces may provide the timely and accessible healthcare interaction sought by individuals who are isolated by debilitation or geographical barriers. Central points of access to reliable information and clear path finding through online interfaces are likely to be defining factors in the success or failure of any future online system. Computer literacy training and practical access issues must also be considered in developing future online heath care delivery programs [47,48] Utilising online healthcare delivery may be an important adjunct to traditional forms of healthcare [12-14,29] Further research is required into the socioeconomic and physical benefits of such approaches particularly in those who have limited access to face-to-face health support.

Limitations

This study was undertaken at a single clinical site and with a group of engaged patients already attending regular face-to-face exercise classes. The single context, particular patient group and view point of the investigator likely influenced the emergent themes from the data. However, rigor and trustworthiness were supported through engaging two independent investigators to code the raw data for themes, and the use of expert panel discussion to confirm themes. Credibility, transferability, dependability and confirmability were furthermore supported through ongoing, reflexive and iterative processes including positioning and the use of journals, consultation and member checking [42] While the study findings do provide valuable insights into patients' perspectives of online based interaction, future research must explore the perspectives of a broad variety of individuals living with COPD to understand the feasibility and sustainability of online approaches in chronic disease.

CONCLUSION

Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and sustainable approaches to chronic disease management. Participants in the focus groups were already interacting with peers and health professionals using a range of media. Privacy, safety and accurate interpretation of online information were concerns; validation of online sites along with moderated or direct health provider interfaces may provide the timely and accessible healthcare interaction sought by individuals who are isolated by debilitation or geographical barriers. Online peer interaction provides additional sharing of experiences and may offer a sense of belonging and normalcy in the context of prolonged disease duration. Delivery of health care through varied formats has the capacity to provide accessible and convenient self-management education as an adjunct to traditional approaches. Further research is required into the feasibility and sustainability of online approaches to support patients with chronic illnesses such as COPD.

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CHAPTER 7: INTEGRATIVE REVIEW: INTERVENTIONS TO SUPPORT A PALLIATIVE CARE APPROACH IN PATIENTS WITH COPD

EXTENDED ABSTRACT

Chapter Seven presents two published articles. The first is an integrative review, published in the *International Journal of Nursing Studies*, that has explored and presented a narrative summary of both empirical and theoretical literature on those interventions that support a palliative care approach in managing the complexity of advanced progressive COPD, as documented in [1]. The second piece presents a short discussion that describes the future research priorities for end stage COPD care and was published through *the Journal of Pulmonary and Respiratory Medicine in Open Access Scientific Reports.*

Disler RT, Currow DC, Philips JL, Smith T, Johnson MJ, Davidson PM. Interventions to support a palliative care approach in patients with chronic obstructive pulmonary disease: An integrative review *International Journal of Nursing Studies* 2012; 49: 1443-1458.

Disler RT, Inglis S, Currow DC, Davidson PM. Palliative and supportive care in COPD: research priorities to decrease suffering. *Journal of Pulmonary and Respiratory Medicine* 2012; 1:1-3.

BACKGROUND

End-stage chronic obstructive pulmonary disease (COPD) is a debilitating, life-limiting condition that requires a systems approach [2-9]. Despite the high symptom burden individuals with COPD have limited access to palliative and end-of-life care [4-8,10]. This is likely due to the fluctuating and episodic decline of COPD that creates challenges in prognostication [4,11-13].

International policy documents indicate the need for individuals to have access to supportive and palliative services regardless of underlying diagnosis, and in particular for those who have non-malignant terminal conditions [14-17]. The complexity and severity of symptoms highlights the need for a systems based approach that allows active management to be combined with planning for the final stages of life [14,16-21], yet currently few interventions embrace this holistic, multidisciplinary and inclusive perspective [14,15,17,22].

Identifying how best to provide a palliative approach to people with end-stage COPD within the context of active treatment is an important priority given the increasing prevalence of this disease globally.

OBJECTIVE

- To describe those interventions that support a palliative care approach in patients with end-stage COPD.
- To provide comment on the future research priorities in the provision of palliative care for patients with end-stage COPD

DESIGN

Integrative review and discussion piece

METHOD

The integrative review was undertaken using prospective research questions [1]. Papers were included if they were published in peer reviewed journals and written in the English language between 1995 and 30 April 2011 and described interventions addressing the needs of individuals with end-stage COPD or discussing strategies supporting a palliative care approach. Inclusion was validated by a panel of specialists in COPD, palliative and chronic care (RD, DC, JP, MJ, PMD, TS). Original research papers, systematic reviews, opinion pieces and reviews were considered to identify interventions. The domains of quality palliative care developed by Steinhauser and colleagues were used as the conceptual framework to synthesise information according to patient, provider and system domains, providing high utility for developing health service models. [23] The results from the search for interventions are presented in relation to the previously acknowledged unmet needs for patients with COPD, being; (1) symptom management (2) psychological and social issues and (3) communication around end-stage COPD [7,10,20,24-26].

Key research priorities for palliative and supportive care were identified through the issues raised in the following data sources:

- international policy and strategy documents [16,17,27];
- evidence for palliative care interventions for COPD [28-30];

- discussion documents and opinions pieces regarding the need for improvements to COPD care [17,25]; and
- two previous reviews undertaken by the research team [31,32].

FINDINGS

The complex needs experienced by patients with end-stage COPD, and the subsequent variety of associated interventions, demonstrate the need for a systems approach to care such as that seen in palliative services [18,19,33]. The fluctuating and episodic decline of COPD is seen as a key barrier to providing palliative care services, to which access remains limited in this patient group [4,6,11,13].

Provider communication is central to the access and provision of interventions which address the needs of this patient group [34-37]. Providers do acknowledge that the majority of patients with end-stage COPD are unaware of the terminal nature of their condition [37,38] and the need for timely advance care planning [6,37,38]. However, the difficulty in estimating the terminal phase of COPD and lack of communication around end-of-life planning has been a well-documented barrier to engaging individuals with interventions such as supportive palliative care [25,34,39,40]. Building the capacity of patients and providers to engage in advance care planning is required for this to occur [16,25,39,41].

Social isolation, difficulty in prognostication and focus on treating acute symptoms has meant that health care for individuals with end-stage COPD has been driven by acute care models rather than a collaborative approached shared across acute life sustaining and palliative care services [25,42-45]. Implementation of clinical pathways that incorporate aspects of evidence based pharmacological and non-pharmacological strategies, and self-management support may be of use in both community and acute healthcare settings [14,16,17,27,46].

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

A ‘mixed management model’ such as that seen in palliative care would provide a flexible system that allows active management to be combined with planning for the final stages of life and encourages collaboration across health services and specialities [18,19,33]. Communication around end-of-life should be commenced early to ensure that individuals are able to articulate their wishes and goals in approaching the final stages of life [25,35,44].

Prospective and systematic development of innovative, interdisciplinary interventions may allow for evidence based pathways that address the physical, psychological and social issues associated with end-stage COPD [16,27,46].

A collaborative palliative care approach would assist patients in utilising supports and interventions that enable patients to balance the demands of their disease while maximising involvement and enjoyment in pursuits that give them pleasure [3,4,20,43,47,48]. Health reform that builds the capacity for patients and providers to engage in advance care planning is required for more effective and timely end-of-life care planning [25,39,41]. Improving providers' confidence in initiating end-of-life discussions, through training in approaches to end-of-life conversations and the services available to end-stage COPD patients, would assist providers in implementing advanced care planning and system interventions that support patients through the palliative phase [25,39,41,49].

CONCLUSION

COPD is a complex and burdensome condition particularly in the final phases of the disease. Although literature concerning discrete elements of management is present, there are limited data discussing the comprehensive and collaborative approaches necessary to address the complex and multivariate needs of end-stage COPD patients. Considering the symptom burden experienced in end-stage COPD, health reform is required to address the complex personal, provider and system elements in achieving collaborative and high-quality palliative care.

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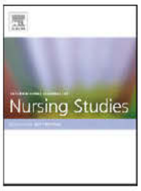
Disler RT, Currow DC, Philips JL, Smith T, Johnson MJ, Davidson PM. Interventions to support a palliative care approach in patients with chronic obstructive pulmonary disease: An integrative review *International Journal of Nursing Studies* 2012; 49: 1443-1458.

International Journal of Nursing Studies 49 (2012) 1443–1458

Contents lists available at SciVerse ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns



Review

Interventions to support a palliative care approach in patients with chronic obstructive pulmonary disease: An integrative review

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ARTICLE INFO

Article history:
Received 27 July 2011
Received in revised form 2 February 2012
Accepted 5 February 2012

Keywords:
Chronic obstructive pulmonary disease
Palliative care
Advanced care
Interventions

ABSTRACT

Background: End-stage chronic obstructive pulmonary disease (COPD) is a debilitating, life-limiting condition. A palliative approach is appropriate for individuals with end-stage COPD, yet currently few interventions embrace this holistic, multidisciplinary and inclusive perspective.

Objective: To describe interventions to support a palliative care approach in patients with end-stage COPD.

Design: Integrative review.

Data sources and review method: Peer reviewed articles meeting the search criteria were accessed from Medline, PsychINFO, CINAHL and Google Scholar databases as well as Caresearch online resource. The domains of quality palliative care developed by Steinhauser were used as the conceptual framework to synthesise information.

Results: This review has shown that a range of palliative interventions are used to address the needs of individuals with end-stage COPD. Although evidence exists for discrete elements of palliative management in this patient group, there is limited evidence for health service coordination and models that integrate the multiple domains of palliative care with active management.

Conclusion: Further investigation is required to address the complex personal, provider and system elements associated with managing end-stage COPD. A comprehensive and collaborative approach is required to address the complex and varied needs of individuals with end-stage COPD and their families.

What is already known about the topic?

- COPD is a life-limiting and burdensome disease
- Patients with COPD experience a variety of symptoms which impacts on their quality of life
- Access to palliative care is limited in this patient group

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[1] ImPACCT: Improving Palliative Care through Clinical Trials. NSW Palliative Care Clinical Trials.

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doi:10.1016/j.ijnurstu.2012.02.004

What this paper adds

- A range of palliative interventions are used to address the diverse needs of patients and their families with end-stage COPD. A comprehensive and collaborative approach is required to address the complex and varied needs of individuals with end-stage COPD and their families.
- Further investigation is required to address the complex personal, provider and system elements associated with managing end-stage COPD.

1. Background

Chronic obstructive pulmonary disease (COPD) is one of the most common and burdensome chronic conditions internationally (World Health Organisation (WHO, 2004)). Affecting 80 million people globally, COPD is the fourth most prevalent cause of death and accounts for 3.5% of total years lost due to disability (WHO, 2004). As populations age in the developed world and smoking rates and the use of bio-fuels rise in emergent economies, such as China and India, the global burden of COPD is set to increase by 30% by 2030 (WHO, 2004). This life limiting and terminal condition results in a high symptom burden in their final stages of life (Blinderman et al., 2009; Cicutto et al., 2004; Curtis, 2008; Edmonds et al., 2001; Elkington et al., 2005; Gore et al., 2000; Skilbeck et al., 1998; Walke et al., 2004). Although breathlessness is one of the most debilitating and burdensome symptoms of end-stage COPD, individuals also experience a range of additional symptoms including, fatigue, pain, insomnia, weight loss, constipation and incontinence (Blinderman et al., 2009; Currow et al., 2010; Edmonds et al., 2001; Elkington et al., 2005; Skilbeck et al., 1998).

Limited recommendations are provided for the care of 'end-stage' COPD by the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines (GOLD, 2010). This is likely due to challenges in prognostication (Creagh-Brown and Shee, 2008; Curtis, 2008; Gardiner et al., 2009; Hansen-Flaschen, 2004). Severe COPD is defined by the GOLD guidelines as Stage 3 in disease progression and is 'characterised by further worsening of airflow limitation (FEV1/FVC <0.7; $30\% < \text{FEV1} < 50\%$ predicted)' along 'greater shortness of breath, reduced exercise capacity, fatigue and repeated exacerbations that almost always have an impact on patients' quality of life' (GOLD, 2010, p. 4). Stage 3 COPD is not synonymous with 'end-stage' disease and a range of other factors such as functional decline and comorbidity burden contribute to an adverse prognosis (Creagh-Brown and Shee, 2008; Curtis, 2008; Gardiner et al., 2009; Hansen-Flaschen, 2004).

Predicting prognosis in the end-stage of COPD is difficult due to the fluctuating and episodic decline of the disease (Creagh-Brown and Shee, 2008; Curtis, 2008; Gardiner et al., 2009; Hansen-Flaschen, 2004). This is a well-noted, key barrier for patients with end-stage COPD when accessing palliative care services (Creagh-Brown and Shee, 2008; Curtis, 2008; Elkington et al., 2005; Gore et al., 2000; Hansen-Flaschen, 2004). However, these challenges are not a valid argument for avoiding providing effective care at the end of life. There is emerging data of indicators that may suggest patients with COPD are within the final two years of life, including: COPD related hospital admissions; functional limitation; severe reduction in lung function; use of long term oxygen therapy; depression; low nutritional state; and the presence of co-morbidities (Gore et al., 2000; Hansen-Flaschen, 2004; Murray et al., 2006; Pinnock et al., 2011). Additionally, a clinician's assessment that they themselves would not be surprised if their patient was unlikely to survive two years is also seen as an indicator (see Table 1) (Hansen-Flaschen, 2004; Murray et al., 2006). Two composite indices, the BODE index (Body The Body-Mass Index, Airflow Obstruction, Dyspnoea, and Exercise Capacity Index) and DOSE index (MRC dyspnoea scale, airflow obstruction, smoking status and exacerbation frequency), are also used to predict mortality (Celli et al., 2004; Jones et al., 2009). While useful in prediction, it is not clear that these indices assist in the definition of end-stage period of COPD and furthermore, the BODE relies on the a walking test that may be outside the reach of many end-stage patients, and the DOSE still requires further assessment of predictive validity (Celli et al., 2004; Jones et al., 2009). In spite of prognostication at the individual level, population data paints a bleak prognosis for COPD with only 30% of men and 24% of woman with a diagnosis of severe COPD surviving five years (Soriano et al., 2000). Half of the individuals with COPD die within two years of their first acute admission, with 50% of patients dying within one year if they require non-invasive ventilation for management of acute respiratory failure (Chu et al., 2004; Connors et al., 1996; Scala and Naldi, 2008). While acknowledging the uncertainty and unpredictable nature of COPD, for the purposes of this paper 'end-stage COPD' will be taken to include individuals within the last two years of life as determined by these predictive characteristics (Hansen-Flaschen, 2004; Murray et al., 2006) (Table 1).

Table 1
Characteristics of final two years of chronic obstructive pulmonary disease.

Hospital admission for severe exacerbation of chronic obstructive pulmonary disease—only 50% survive two years
Being housebound due to chronic obstructive pulmonary disease
Having an FEV1 of 30% or less
On long term oxygen therapy
Depression, poor quality of life
Loss of weight and cachexia
and co-morbidities, especially Heart Failure
Health professionals asking themselves the question 'would I be surprised if my patient were to die in the next two years? (Murray et al., 2006; Hansen-Flaschen, 2004)

1.1. Need to address unmet needs for palliative care

Despite the high symptom burden of end-stage COPD individuals have limited access to palliative and end-of-life care (Curtis, 2008; Edmonds et al., 2001; Elkington et al., 2005; Gore et al., 2000; Luddington et al., 2001; Skilbeck et al., 1998). Terminal is considered to be a 'life-threatening illness for which a cure is not possible' (Jennings et al., 2011). Palliative care is highly appropriate for end-stage COPD as it addresses '*the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering*' (World Health Organisation, 2002). While a palliative approach can be used in the management of life limiting conditions during the acute, chronic or terminal phases, the term 'end-of-life care' is commonly taken to refer to care provided in the final phase of life (Curtis, 2008).

Consensus over the term 'end-of-life' is far from universal for patients who have a prolonged and unpredictable terminal phase such as COPD (Luddington et al., 2001). Regardless of the nomenclature around 'end-stage', 'end-of-life' and 'palliative care', supportive palliative services have predominantly focused on the management of patients with malignancy. Individuals with end-stage COPD have limited access to palliative care despite experiencing similar, yet more prolonged duration of worse symptoms and a higher functional limitation (Addington-Hall, 2001; Ambrosino and Simonds, 2007; Bausewein et al., 2010; Claessens et al., 2000; Disler and Jones, 2010; Goodridge, 2006; Gore et al., 2000; Luddington et al., 2001; McKinley et al., 2004). Claessens et al. (2000) found that 56% of people with COPD experienced debilitating breathlessness, compared with only 32% in advanced lung cancer. Physical limitation was also seen to be more severe and occur much earlier in disease progression than that seen in cancer which resulted in increased functional limitation and consequent social isolation (Elkington et al., 2005; Goodridge, 2006; McKinley et al., 2004). Gore et al. (2000) notes that 82% of COPD patients were housebound in their last 6 months, compared to only 32% of patients with malignancy. Identifying how best to provide a palliative approach to people with end-stage COPD within the context of active treatment is an important priority given the increasing prevalence of this disease globally.

2. Method

2.1. *Objective*

To review the interventions used to support a palliative approach in patients with COPD.

2.2. *Design and literature search method*

This review took an integrative approach using prospective research questions (Whittemore and Knafl, 2005). Papers were sought that explored interventions which addressed the needs of patients with end-stage COPD or discussed interventions which supported a palliative care approach for these patients. The electronic databases MEDLINE, PSYCHINFO, CINAHL and Google Scholar were searched using Medical Subject Headings (MeSH) and key words (Fig. 1). The following search terms with appropriate derivatives were used: '*chronic obstructive pulmonary disease*', '*chronic obstructive airways disease*', '*COPD*' *OR* '*COAD*' *OR* '*respiratory disease*' *OR* '*lung disease*' and '*palliative care*' *OR* '*terminal care*' *OR* *terminally ill*' *OR* '*end-of-life care*' *OR* '*end-of-life*' *OR* '*advanced care*' *OR* '*advanced disease OR hospice*' *OR* '*death*'. The World Wide Web was searched using Google Scholar and Google search engine for related electronic documents. Journals held locally were hand searched for relevant articles. The search terms and strategy were checked through the CareSearch

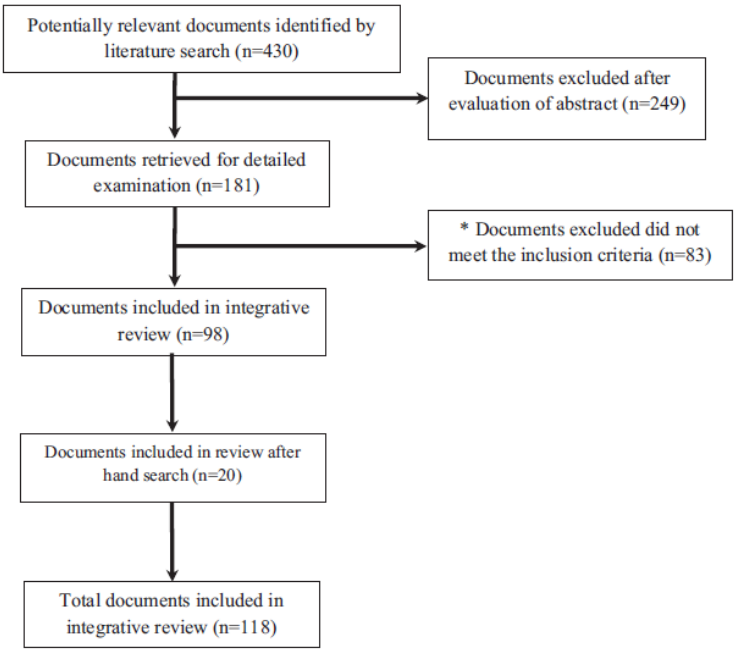

Fig. 1. Flow chart of studies from search to inclusion.

Table 2
Factors that determine quality end-of-life care (Steinhauser, 2005).

Symptom management
Support of function and autonomy
Advance care planning
Use of resources
Patient and family satisfaction
Patient–provider communication
Quality of life
Patient and family education
Family burden
Survival time
Provider continuity and skill
Bereavement support

palliative knowledge network (http://www.caresearch.com.au/) and with the local health librarian. Due to the variability of the illness trajectory a range of issues were considered in accordance with recommendations of best practice guidelines and the Steinhauser framework (GOLD, 2010; Steinhauser, 2005). The review is based on Steinhauser's (2005) broad and inclusive framework for quality end-of-life care (Table 2). Steinhauser's (2005) framework categorises issues according to patient, provider and system domains, providing high utility for developing health service models. The results from the search for interventions are presented in relation to the previously acknowledged unmet needs for patients with COPD, being; (1) symptom management (2) psychological and social issues and (3) communication around end-stage COPD (Goodridge, 2006; Gore et al., 2000; Gysels and Higginson, 2008; Luddington et al., 2001; Spathis and Booth, 2008; WHO, 2004).

2.3. Study selection

Papers were included if they were published in peer reviewed journals and written in the English language between 1995 and 30 April 2011. This time window was identified to ensure contemporaneous practice patterns were included. Inclusion was validated by a panel of specialists in chronic obstructive pulmonary disease, palliative and chronic care (RD, DC, JP, MJ, PMD, TS). Papers were included if they described interventions addressing the needs of individuals with end-stage COPD or discussing strategies supporting a palliative care approach. Original research papers, systematic reviews, opinion pieces and reviews were considered to identify interventions. Case studies were excluded from this review.

3. Results

3.1. Selected papers

The process of paper selection and exclusion is demonstrated in Fig. 1. Through literature searching 112,616 papers were identified as related to COPD and 56,235 related to palliative care. A total of 870 of those papers related to COPD and palliative care; 487 papers met the inclusion criteria. Following the review of abstracts and removal of duplications 181 of these papers were retrieved for detailed examination. Of these papers 98 met the inclusion criteria. In addition to these papers 20 were added through hand searching of article references. A total 118 were included in the final review. Of these papers: 97 were original research (25 randomised controlled trials (RCTs), 53 descriptive, experimental or quasi experimental designs and 19 qualitative studies). The remaining 21 were systematic reviews, summaries and literature reviews.

3.2. Interventions that support palliative care in COPD

Previous unmet needs for patients with COPD have focused on (1) symptom management, (2) psychological and social issues and (3) communication around end-stage COPD (Goodridge, 2006; Gore et al., 2000; Gysels and Higginson, 2008; Luddington et al., 2001; Spathis and Booth, 2008; WHO, 2004) (Table 3).

3.2.1. Symptom management

3.2.1.1. Pharmacological interventions for dyspnoea. Palliative oxygen refers to oxygen used for symptomatic and functional relief in end-stage disease rather than as a treatment to increase life expectancy (Uronis et al., 2011). While studies have demonstrated unequivocally the utility of oxygen in hypoxemic COPD patients, the use and efficacy of oxygen in palliation is less well evidenced (Cranston et al., 2005). A recent double blind RCT investigated the use of palliative oxygen in 235 patients with life-limiting illness and refractory dyspnoea without hypoxemia, of which 152 (64%) of participants had COPD as a primary cause of dyspnoea (Abernethy et al., 2010). Palliative oxygen did not significantly improve dyspnoea when compared with room air (Abernethy et al., 2010). The exclusion of patients with a recent oxygen prescription and a PaO_2 *of less than 7.3 pKa should be noted as this may have reduced the efficacy of the intervention in a COPD population. Uronis et al. (2006) in their systematic review of palliative management of refractory dyspnoea in COPD, equally found that studies with respect to the utility of oxygen in relieving dyspnoea were inconsistent in their results, small in sample size and had a variety of foci. Uronis et al. (2006) noted three studies that explored the use of oxygen at rest for the relief of dyspnoea in COPD patients and found inconclusive results (Liss and Grant, 1988; O'Donnell et al., 2001; Swinburn et al., 1991). Additionally a recent Cochrane review by Uronis et al. (2011) found there was evidence that oxygen was effective in reducing dyspnoea when again used in people who were mildly and non-hypoxaemic (Booth et al., 2004; Ries et al., 1995). This review noted the significant heterogeneity between the included studies and consequently recommended that palliative oxygen should be continued to be prescribed on an individual basis until further powered studies are undertaken (Uronis et al., 2011). Further investigation is required to explore the utility of palliative oxygen in end-stage COPD patients.*

Opioids are prescribed in the management of the sensation of breathlessness in COPD (Barnett, 2008). The Jennings et al.'s (2011) reprinted version of their 2002 Cochrane systematic review of the same title, reviewed the evidence for opioid use in dyspnoea and included nine studies of parenteral opioids and a further nine studies of

Table 3
Summary of approaches to support palliative care approach to end-stage chronic obstructive pulmonary disease.

Symptom	Management	Supporting evidence
Dyspnoea	Palliative oxygen	
	Oxygen unconvincing in treating breathlessness in end-stage chronic obstructive pulmonary disease	Abernethy et al. (2010), Booth et al. (2004), Uronis et al. (2011)
	Opioids	
	Parentarel opioids significant statistical impact on dyspnoea but questionable clinical impact	Jennings et al. (2011)
	Nebulised opioids not statistically or clinically effective	Jennings et al. (2011)
	Incremental dose of sustain release opioids found to be safe and effective in responsive patients	Currow et al. (2011)
	Benzodiazepines	Simon et al. (2010)
	Benzodiazepines no significant impact on dyspnoea, studies methodologically limited	
	Non-invasive ventilation	
	NIV has been shown to improve hypercapnia and dyspnoea when used in combination with LTOT	Clini et al. (2002)
	NIV evidence focused on avoidance for intubation in end-stage chronic obstructive pulmonary disease	Cuomo et al. (2004)
	Distraction and relaxation techniques	
	Relaxation techniques found to have questionable reliable evidence	Bausewein et al. (2008)
	Distraction techniques taught in early phase of disease found to have limited impact	Bausewein et al. (2008)
	Music as distractive auditory stimuli has also been trialled in chronic obstructive pulmonary disease with some success	Bausewein et al. (2008)
	Breathing training	
	Breathing techniques found to improve dyspnoea and recovery from dyspnoea	Hochstetter et al. (2005), Wu et al. (2006)
	Fans and air movement found to decrease sensation of dyspnoea in some studies.	Bausewein et al. (2008), Bausewein et al. (2010), Galbraith et al. (2010)
	Neuromuscular electrical stimulation was found to improve dyspnoea however this was in small studies with high heterogeneity.	Bausewein et al. (2008), Neder et al. (2002), Vivodtzev et al. (2006), Bourjeily-Habr et al. (2002), Sillen et al. (2009)
	Acupuncture and complementary therapies	
	Support for intervention, however heterogeneous methodology questions statistical reliability	Bausewein et al. (2008)
Fatigue and functional limitation	Exercise	
	Pulmonary rehabilitation key in managing dyspnoea and fatigue	Ambrosino et al. (2009), Davidson and Currow (2010), Spathis and Booth (2008)
	Exercise difficult for end-stage patients	Clini and Ambrosino (2008), Dahlin (2006), Ek and Ternestedt (2008)
	Energy conservation techniques	
	Little statistical evidence into the use of energy conservation. Evidence present in qualitative research	
Psychological and social management		
Anxiety and depression	Antidepressants, selective serotonin reuptake inhibitors	
	Inconclusive or no significant impact on activity and quality of life	Eiser et al. (2005), Yohannes et al. (2001)
	Anxiolytics	
	Limited evidence and conflicting results for use of anxiolytics in end-stage chronic obstructive pulmonary disease. Intervention may have merit on an individual basis	Uronis et al. (2011)
	Pulmonary rehabilitation	
	Conflicting results of pulmonary rehabilitation impact on anxiety and depression. Some studies showing positive and sustained results, while others no significant impact.	Yohannes (2008)

Table 3 (*Continued*)

Symptom	Management	Supporting evidence
	Cognitive behavioural therapy	
	Cognitive behavioural therapy in combination with pulmonary rehabilitation found to have significant impact	Kunik et al. (2008), Hynninen et al. (2010), Hill et al. (2008), Yohannes (2008)
	Small unblinded quasi experimental showed no improvement	Renfoe et al. (1998), Gift et al. (1992)
	Progressive muscle relaxation	
	Progressive muscle relaxation is found to be successful in reducing anxiety in end-stage chronic obstructive pulmonary disease however evidence is limited	
Social isolation	Peer support	
	Peer support through pulmonary rehabilitation improves depression, anxiety and quality of life	Kanervisto et al. (2007)
	Peer support provides socialisation, life validation and shared pleasure in life	Alberto and Joyner (2008), Cicutto et al. (2004), Halding et al. (2010)
	Family support	
	Family provides emotional support and assistance with self care activities	Kara Kasikci and Alberto (2007), Bourbeau (2008), Cicutto et al. (2004), Halding et al. (2010),
	Family are key motivator for patients to continue living	Jassem et al. (2010), Xiaolian et al. (2002)
Existential issues	Connectedness with others provides a sense of worth and pleasure issues	Cicutto et al. (2004), Ek and Ternestedt (2008), Milne et al. (2009), Sheridan et al. (2011), Simpson and Rocker (2008)
	Religiosity and spirituality provide resilience and integration into a supportive community	
Communication		
Relationships with healthcare professionals	Positive relationships with healthcare professionals increase patient understanding of chronic obstructive pulmonary disease and feelings of control over disease	Milne et al. (2009)
	Negative results isolate patients from services and result in unmet patient needs	Curtis et al. (2004), Milne et al. (2009)
	Relationships with healthcare professionals with specialist knowledge provide emotional support and a source of reliable information	Halding et al. (2010), Bourbeau (2008), Cicutto et al. (2004)
Advance care planning	Advance care planning improves patient engagement in decision making, sense of control in preparation for end-of-life	Goodridge (2006), Heffner (2011), Spathis and Booth (2008)
	Advance care planning improves family preparation for final stages of disease	Teno (2005)
	Engaging patients in decision making lowers stress and anxiety	Detering et al. (2010)
Access to palliative care	Access to specialist palliative care limited	Knauft et al. (2005), Gore et al. (2000)
	Access to generalist care is lacking which leaves patients isolated and with clear unmet end-of-life needs	Gysels and Higginson (2008), Disler and Jones (2010), Knauft et al. (2005)

nebulised opioids (Jennings et al., 2011). Parenteral opioids were found to have a highly statistically significant impact on dyspnoea, but relatively minor clinical effect. This was thought to potentially result from small sample groups, lack of titration and length of dosing intervals (Jennings et al., 2011). These earlier results are strengthened by a further adequately powered study by Abernethy et al. (2003) of 48 participants of which 88% had COPD. Abernethy et al. (2003) similarly found that the use of sustained release parenteral morphine had a significant impact on dyspnoea as well as sleep in patients with refractory dyspnoea. The efficacy of nebulised morphine, when compared with nebulised saline for reducing breathlessness, was questioned by Jennings et al. (2011) as the evidence relied heavily on case studies and descriptive studies (Masood and Thomas, 1996; Noseda et al., 1997; Zeppetella, 1997). Furthermore, subsequent studies have demonstrated that nebulised saline, as used in these studies, should not be considered to be placebo, as breathlessness and mucous clearance both improved significantly following administration (Khan and O'Driscoll, 2004). Further investigation into the use of nebulised opioids is needed.

Currow et al. (2011) recently responded to an ongoing call for investigation of the safety of opioids when used in patients who have COPD with a recent pharmocovigliance study (Abernethy et al., 2010; Jennings et al., 2011; Spathis and Booth, 2008). Currow et al. (2011) investigated the use opioids in 83 patients with chronic dyspnoea (45 (54%) patients with a primary cause of dyspnoea being COPD) and found that it was safe and effective in participants who responded to this intervention. Currow et al. (2011) found that a significant number of patients derived benefit from sustained-release morphine and that this was maintained in 33% of patients over three months. Breathlessness was found to be significantly reduced, and no episodes of respiratory depression or hospitalisation were recorded. Patients did experience increased constipation as a result of the intervention, despite the use of laxatives (Currow et al., 2011).

Benzodiazepines have been identified as key pharmaceutical agents used in end-stage COPD dyspnoea management. Simon et al.'s (2010) Cochrane systematic review explored the relief of breathlessness in advanced malignant and non-malignant diseases and found six studies, undertaken in the 1980s which investigated the use of benzodiazepines in COPD. These studies were found to have small sample groups, a moderate level of heterogeneity and found that benzodiazepines had no significant benefit on dyspnoea when compared with placebo. Large scale research is required to establish the efficacy and safety of using benzodiazepines in managing breathlessness in COPD.

3.2.1.2. Non-pharmacological interventions for dyspnoea. - Non-invasive ventilation, distraction and relaxation techniques and breathing training techniques, hand-held fans, and neuromuscular electrical stimulation have all been used in the management of dyspnoea.

Non-invasive ventilation (NIV) is used for respiratory failure as well as breathlessness in COPD (Clini and Ambrosino, 2008; Smith et al., 2011). The use of NIV in palliative care is controversial particularly when viewed as potentially prolonging the experience of death and inhibiting communication in the final stages of life (Curtis, 2008; Sinuff et al., 2008). Unfortunately the majority of studies investigating NIV in end-stage COPD focus on avoidance of intubation and attitudes to continuing treatment rather than symptom relief (Benhamou et al., 1992; Chu et al., 2004; Curtis et al., 2007; Levy et al., 2004; Lightowler et al., 2003; Plant et al., 2000; Sinuff et al., 2008). Clini et al.'s (2002) RCT of 90 COPD patients found that NIV improved dyspnoea when used as a domiciliary treatment in combination with long term oxygen in patients with severe stable COPD patients (Clini et al., 2002). In addition Cuomo et al. (2004) also found in their explorative study that NIV reduced dyspnoea in 23 patients with concurrent end-stage lung cancer and acute respiratory failure. However, Smith et al.'s (2011) recent systematic review suggests that there is not enough evidence to confidently conclude that NIV is effective in relieving dyspnoea in acute exacerbations of COPD. While there is some evidence around the use of NIV for dyspnoea, it is clear that further research is required particularly in the utility of NIV in palliation of end-stage COPD.

Relaxation and distraction techniques have also been used to manage breathlessness related to anxiety in COPD (Bailey, 2004; Brenes, 2003; Renfroe, 1988). Bausewein et al.'s (2008) systematic review found that studies investigating these techniques were limited by small sample size and high heterogeneity. Studies investigating *distraction techniques* have shown positive results in controlling breathing in stable asthmatics of varying ages. These small scale studies have focused on relaxation breathing techniques such as rosary prayer, yoga mantra and buteyko (Bernardi et al., 2001; Bowler et al., 1998; Cooper et al., 2003). The lack of power and heterogeneity of patient populations questions the application of distractive techniques in patients with end-stage COPD. *Guided imagery* as a relaxation technique was found to have no significant impact in 26 COPD patients in a study by Louie (2004). However, the use of a single session may have compromised the efficacy of this intervention (Louie, 2004). *Music* as distractive auditory stimuli also had variable influence in COPD (Bauldoff et al., 2005; Brooks et al., 2003; Pfister et al., 1998). Brooks et al. (2003) found no improvement in dyspnoea in their comparative study of 30 patients with severe COPD. Pfister et al. (1998) similarly found music in conjunction with walking during pulmonary rehabilitation had no significant effect in their comparative study of 19 patients. Bauldoff et al. (2005) did find a positive impact on dyspnoea in their comparative study also with 30 participants. The evidence for the use of relaxation techniques in end-stage COPD appears to be varied and limited due to the small sample sizes and heterogeneity of the studies. Further research is required to establish the reliability and application of these techniques for managing dyspnoea.

Breathing training, focusing on diaphragmatic breathing and purse-lipped breathing, has been found to improve dyspnoea in Hochstetter et al.'s (2005) comparative study of 30 patients with cardiopulmonary disease and Wu et al.'s (2006) RCT of 31 COPD patients. Breathing training was also found to improve the recovery from dyspnoea after exercise in Garrod et al.'s (2005) randomised cross over trial of 48 patients with COPD. Again the limited evidence and heterogeneity of these studies calls for adequately powered and consistent studies into the use of these techniques.

The use of *hand-held fans* and air movement has had success on dyspnoea in COPD and are noted to be a simple and practical home intervention in a recent cross over trial of 50 patients with advanced disease (Galbraith et al., 2010). Bausewein et al.'s (2010) longitudinal RCT of 70 patients comparing hand-held fans with wrist bands, again noted that patients were able to use the hand-held fan, but found the effectiveness of the intervention could not be proved due to the high drop off and lack of viable control. Any benefits seen in the remaining, small cohort could not reliably be attributed to relief in breathlessness

(Bausewein et al., 2010). Bausewein et al.'s (2010) study did little to add to Bausewein et al.'s (2008) Cochrane review, which found that both breathing training and air movement research was based on small and methodologically heterogeneous studies and therefore could confirm little as to the efficacy of these interventions. This underscores the importance of adequately powered studies to identify efficacious and acceptable interventions to address breathlessness.

Neuromuscular electrical stimulation (NMES) is the use of electrical stimulation to increase and maintain muscular strength. Bausewein et al.'s (2008) Cochrane review identified three studies which investigated the use of NMES in COPD. Neder et al.'s (2002) home based cross over study of 16 severely disabled COPD patients found that short term use of NMES on lower limb muscles did improve breathlessness during activities of daily living in addition to muscle strength and endurance and exercise tolerance (Neder et al., 2002). Vivodtzev et al.'s (2006) RCT of 17 patients similarly found positive results in dyspnoea and muscle strength when electrical stimulation with rehabilitation was compared with a standard rehabilitation program. Bourjeily-Habr et al.'s (2002) RCT of 18 COPD patients receiving transcutaneous electrical muscle stimulation also showed improvements in muscle strength and exercise capacity and breathlessness. While participant groups were small, Bausewein et al.'s (2008) found that quality of the studies and strength of evidence was high but was unable to perform a meta-analysis due to lack of published data. Sillen et al.'s (2009) review of current literature for NMES, for patients with COPD and chronic heart failure, also noted the effectiveness of this intervention in a number of domains including dyspnoea but again noted the heterogeneity of evidence which precluded a meta-analysis. Further investigation and analysis is required to explore the use of NMES in palliation of breathlessness for end-stage COPD specifically.

Acupuncture and complementary therapies have traditionally been used in non-Western countries for the management of dyspnoea but are increasingly used in conjunction with Western approaches internationally. Bausewein et al.'s (2008) Cochrane systematic review found that while there is support for acupuncture in particular, variations in study designs, course and combination of treatments and difficulty in providing a true control indicates a lack of evidence overall (Jobst et al., 1986; Lewith et al., 2004; Maa et al., 1997; Wu et al., 2004).

3.2.1.3. Fatigue and functional limitation. Fatigue is a debilitating and prevalent symptom in COPD that causes functional limitation as well as diminished social and psychological coping (Theander et al., 2008). The key interventions for managing fatigue and functional limitation are *exercise* and *energy saving techniques* (Davidson and Currow, 2010). *Exercise*, in particular through pulmonary rehabilitation, has been extensively used for the management of breathlessness, functional decline and consequently control of fatigue (Ambrosino and Simonds, 2007; Davidson and Currow, 2010; Lacasse et al., 2006; Spathis and Booth, 2008). The positive impact of pulmonary rehabilitation on breathlessness and fatigue has been shown in a variety of patient groups, most broadly in a multicentre study of 1047 COPD patients with varying degrees of respiratory failure (Carone et al., 2007). Cote and Celli (2005) also found positive results in their comparative study of 201 COPD patients. It should be noted that Cote and Celli (2005) study was not randomised and allocated those who refused PR or dropped out of pulmonary rehab to the non-intervention group which may have given bias to the positive results seen in the intervention participants. Unfortunately, physical reconditioning is often difficult and burdensome for patients in end-stage disease, which may inhibit the implementation of this intervention (Spathis and Booth, 2008). *Energy conservation* through the pacing of activities can be integrated into everyday life for end-stage COPD patients. Little statistical evidence describes the effect of energy conservation on fatigue. The positive impact of energy conservation is discussed by patients in qualitative research who note that while functionally limiting, energy conservation techniques allow patients to manage the impact of fatigue (Barnett, 2005; Bourbeau, 2004; Cicutto et al., 2004; Ek and Ternestedt, 2008).

3.2.1.4. Physical impact of COPD. Breathlessness and functional limitation are the key physical symptoms experienced by individuals with end-stage COPD. Individuals also experience other signs and symptoms such as *cough and excessive sputum production, cachexia and malnutrition, constipation, and insomnia*. These symptoms are managed through a variety of pharmaceutical and non-pharmaceutical interventions commonly used in other patient groups as well as those with COPD (Dahlin, 2006). Cough and excessive phlegm production cause dyspnoea, fatigue and irritation and are most commonly treated through coughing clearance techniques in combination with anticholinergics to specifically control secretions, as is commonly seen in terminal care (Dahlin, 2006). Opioids in conjunction with inhaled medications are also used to manage ongoing cough (Dahlin, 2006; Morice et al., 2007). Cachexia and malnutrition are highly prevalent in end-stage COPD and relate to chronic systemic inflammation, low nutritional intake as a result of dyspnoea and energy imbalance resulting from high metabolic requirements and increased respiratory workload (Clini and Ambrosino, 2008; Wagner, 2008). While little has been shown to address the chronic inflammatory process causing cachexia (Wagner, 2008), supportive treatments to address malnutrition are recommended such as encouraging small and frequent meals to avoid dyspnoea, in conjunction with nutritional supplements and close monitoring of nutritional status (Dahlin, 2006). Constipation is equally common and results from functional limitation, decreased oral intake and the use of some medications (Dahlin, 2006). Management relies heavily on pharmaceutical interventions along with encouraging appropriate fluid, nutrition and mobility management (Dahlin, 2006). Finally insomnia and sleep disturbance are common symptoms associated with cough, excessive phlegm, dyspnoea and anxiety and depression in COPD (Sharafkhaneh et al., 2009). Interventions rely on cognitive behavioural therapy and pharmaceuticals, such as sedatives and hypnotics.

Authors note that caution should be paid when using these pharmaceuticals in patients with hypercapnia in particular (George and Bayliff, 2003; Sharafkhaneh et al., 2009).

3.2.2. Psychological and social issues

3.2.2.1. Anxiety and depression. Anxiety and depression are two interconnected and highly prevalent conditions which lead to increased symptom burden, poor health outcomes and feelings of hopelessness if untreated in patients with COPD (Bailey, 2004; Yohannes, 2008). Anxiety and dyspnoea in particular have a reciprocal and perpetual relationship described as the dyspnoea–anxiety–dyspnoea cycle (Bailey, 2004). Pharmaceutical and non-pharmaceutical approaches have been employed to address anxiety and depression with varying results (Yohannes, 2008).

Evidence for the use of *antidepressant agents* in managing depression and anxiety in end-stage COPD is inconclusive (Borson et al., 1992; Yohannes et al., 2001). Yohannes et al.'s (2001) pilot study of seven patients with COPD receiving *selective serotonin reuptake inhibitors* (*SSRIs*) found that four patients responded to SSRI therapy indicated by change in major depression scores. No data was given for secondary outcomes of activities of daily living and disease specific quality of life. The lack of power and number of withdrawals due to side effects may have contributed to these findings. Eiser et al.'s (2005) unblended study of 38 patients with COPD and depression, found no significant difference in depression, exercise tolerance and quality of life over a six week trial of SSRIs. On unblinding and extending the trial to three months, Eiser et al. (2005) did find that positive results in all three outcomes. Eiser et al. (2005) noted the need for further reliable research. Positive results were also found in patients prescribed tricyclic antidepressants, but again adequately powered studies are needed (Borson et al., 1992). *Anxiolytics* are also cited for use in anxiety in end-stage COPD. Two studies by Singh et al. (1993) and Argyropoulou et al. (1993) discuss Buspirone as an anti-anxiety agent in COPD. Singh et al. (1993) compared Buspirone with a placebo in 11 COPD in relation to anxiety and exercise tolerance and found significant improvements in dyspnoea sensation and exercise toleration. Argyropoulou et al. (1993) conversely found no improvements at all in their randomised cross-over trial of 16 patients. While this suggests a lack of reliability in the intervention, there are clear issues with power and also differences in methodology, Argyropoulou et al. (1993) used a 12 min walk test compared to a 6 min walk test in Singh et al.'s (1993) study for example. Lack of consistent evidence is noted by Uronis et al. (2011), in their review, with a final suggestion that anxiolytics may have a place in end-stage COPD in individual cases, regardless further investigation is required.

Pulmonary rehabilitation is an important non-pharmacological approach to managing depression and anxiety in end-stage COPD with pulmonary rehabilitation programs all including some form of psychological therapy (Ambrosino et al., 2009; Paz-Diaz et al., 2007). The evidence in support of pulmonary rehabilitation in managing depression and anxiety is conflicted (Yohannes, 2008). Comparative studies by Griffiths et al. (2000), Guell et al. (2006) and Withers et al. (1999) all showed strong evidence for the positive impact of pulmonary rehabilitation on depression and anxiety following outpatient pulmonary rehabilitation which was sustained over 6–12 months. Ries et al. (1995) found no significant difference in anxiety and depression when comparing education with comprehensive pulmonary rehabilitation in conjunction with a home maintenance program. The generalised benefits maintain pulmonary rehabilitation as a key intervention for the complex and multivariate symptoms faced by individuals with end-stage COPD. The role of pulmonary rehabilitation in anxiety and depression requires further investigation.

Cognitive behavioural therapy is used to address depression and anxiety in COPD with the focus on breaking the anxiety–dyspnoea–anxiety cycle and assisting patients to cope with the psychological burden of disease (Hill et al., 2008). Small comparative studies by de Godoy and de Godoy (2003) and Emery et al. (1998) found that the addition of cognitive behavioural therapy to pulmonary rehabilitation had a significant impact on depression and anxiety. Kunik et al.'s (2008) large comparative study of 238 participants also showed the positive impact of cognitive behavioural therapy when compared to education as an intervention for depression and anxiety. These positive results were further strengthened in a recent RCT by Hynninen et al. (2010) who compared 31 patients receiving standard care with those provided with additional cognitive behavioural therapy. Hynninen et al. (2010) found significant improvements in anxiety and depression in trial participants compared with control, maintained to 8 months follow up. A small, low intensity, unblinded study of 10 participants by Eiser et al. (1997) conversely did not show improvements in anxiety and depression following intervention. Considering the recent, larger studies the lack of impact seen in Eiser et al. (1997) is likely due to the methodological limitations rather than the efficacy of the technique. *Progressive muscle relaxation* (PMR) has also been successful in reducing anxiety in end-stage COPD in comparative studies by Renfroe (1988) and Gift et al. (1992). Like many interventions in end-stage COPD, these studies had methodologically limitations indicating the need for further research to explore use of PMR for anxiety in end-stage COPD.

3.2.2.2. Social isolation. Social isolation resulting from functional limitation and exertional dyspnoea has a marked impact on psychological and social wellbeing (Gysels and Higginson, 2008; Simpson and Rocker, 2008). Socialisation through *peer support*, particularly through pulmonary rehabilitation, is shown to improve depression, anxiety and quality of life (Kanervisto et al., 2007). Peer support groups run by individuals with COPD, such as Better Breathers in the United States of America and Breathe Easy in the United Kingdom, are similarly noted in qualitative research to provide validation of life experience and a shared understanding as part of a community (Alberto and Joyner, 2008; Cicutto et al., 2004; Halding et al., 2010; Nicolson and Anderson, 2003). Peer interaction was also felt to provide a light-heartedness and pleasure in life, often found to be lacking in the other areas of life for end-stage COPD patients (Alberto and Joyner, 2008; Cicutto et al., 2004; Halding et al., 2010; Nicolson and

Anderson, 2003). Alberto and Joyner (2008) highlight the need for statistical data to support the current body of qualitative research. ***Family support*** has equally been found to provide patients with essential emotional support as well improving patients' engagement with self care in descriptive studies by Kara Kasikci and Alberto (2007) and Xiaolian et al. (2002). Qualitative studies have identified that family members provide a buffering effect against the physical and emotional demands of end-stage COPD by coordinating care and in assisting patients in their self management tasks on a day to day basis (Bourbeau, 2008; Cicutto et al., 2004; Halding et al., 2010; Jassem et al., 2010; Milne et al., 2009). Family and friends are furthermore cited as key motivators for patients to continue to live in face of the burden experienced in end-stage COPD (Cicutto et al., 2004; Ek and Ternestedt, 2008; Kanervisto et al., 2007). There is strong evidence from qualitative data of the importance of peer support and family support in the end-stage of COPD. Systems approaches which recognise the importance of these elements, such as a palliative care approach should be implemented in this high needs patient group.

3.2.2.3. Existential issues and concerns. Existential issues around the meaning of life, fear of death and religiosity are a common focus as COPD burden increases and individuals progressively forgo activities that give them pleasure (Cicutto et al., 2004; Ek and Ternestedt, 2008; Nicolson and Anderson, 2003). Increasing functional limitation and dyspnoea, in particular, further add uncertainty, anxiety and vulnerability (Guthrie et al., 2001; Nicolson and Anderson, 2003). In qualitative research by Cicutto et al. (2004), Ek and Ternestedt (2008) and Sheridan et al. (2011), ***connectedness with others***, especially with children, was found to provide a sense of belonging and life confirmation. Individuals with end-stage COPD gained happiness and a sense of worth through engaging in 'ordinary' activities and those things that had previously given them pleasure (Ek and Ternestedt, 2008). ***Religiosity*** was also found in qualitative studies to provide individuals with resilience to continue living with their disease as well as provide integration into a community for those who participated in formal spiritual activities (Milne et al., 2009; Seamark et al., 2004; Sheridan et al., 2011; Simpson and Rocker, 2008).

3.2.3. Communication around end-of-life care

Individuals with end-stage COPD have consistently raised the need for greater communication and the information around disease trajectory, prognosis and what to expect when nearing the final stages of life (Curtis, 2008; Edmonds et al., 2001; Heffner, 2011; Jones et al., 2004; Pang et al., 2005; Seamark et al., 2004). Qualitative research has found that ***relationships with healthcare professionals*** are essential for building open discourse and communication with end-stage COPD patients (Halding et al., 2010; Milne et al., 2009). In Milne et al.'s (2009) qualitative study individuals voiced that positive doctor patient relationships increased understanding around COPD and thereby feelings of security as patients progressed through their illness. Negative relationships conversely left individuals feelings isolated and their needs and wishes dismissed (Milne et al., 2009). Curtis et al. (2004) also noted that patients interpreted avoidance of end-of-life discussions by healthcare professionals as a lack of understanding of patients needs in the final phases of life. Relationships in the pulmonary rehabilitation setting were also seen as essential, with Halding et al. (2010) noting that respiratory nurses in particular provided emotional support as well as being a consistent and familiar source of information. Bourbeau (2008) and Curtis et al. (2004) also noted the importance of specialised healthcare professionals who performed the role as a companion who genuinely cared for their patients as much as providing knowledge and guidance. Relationships with health care providers not only influence the engagement of patients with their care but more importantly can facilitate the provision of a palliative approach in later stages of the disease (Halding et al., 2010; Milne et al., 2009).

Timely ***advance care planning*** is essential to engage patients in decision making and facilitate the implementation of supportive end-of-life services (Exley et al., 2005; Goodridge, 2006; Heffner, 2011; Patel et al., 2012; Spathis and Booth, 2008). Early advance care planning is imperative in end-stage COPD due to the acute fluctuations in disease trajectory and the speed at which patients can deteriorate into the terminal phase (Curtis, 2008). Curtis et al. (2004), Heffner (2011) and Guthrie et al. (2001)'s qualitative studies found that patients valued advance care planning which provided them with a sense of control in preparation for the final stages of life. Dean (2008) and Heffner (2011) note that good advance care planning should extend beyond treatment choice and ceiling of treatment to include planning for goals and values in life, such as aiming for important events. In a further survey study by Teno (2005), families noted that advance care planning abated fears around communication and better prepared family members for the individual's death. This was further evidenced in a RCT by Detering et al. (2010) who compared 309 elderly patients (31.4% of which had a primary respiratory diagnosis) who received usual care with facilitated advance care planning. Patients in the intervention group were more likely to have their wishes known and followed at end of life and for families to have lower levels of distress following the patient's death (Detering et al., 2010). Satisfaction with care was seen to be higher for both families and patients in the intervention group as a result of facilitated advance care planning (Detering et al., 2010).

Blackler et al. (2004) reported that some patients and healthcare professionals actively avoid discussions around death, even if they felt these issues should be discussed. Gott et al. (2009) and Knauft et al.'s (2005) qualitative research noted that providers' unwillingness came from their reluctance to destroy patients' hopes through discussions around death. Knauft et al. (2005) furthermore noted that often patients themselves avoided such discussions to maintain a focus on living. Lack of communication led to delayed implementation of a palliative approach to end-stage COPD and decreased the opportunities for patients to feel prepared and supported to die at home (Murray et al., 2006).

Access to palliative services is limited for individuals living with end-stage COPD in the community (Ambrosino et al., 2009; Claessens et al., 2000; Coventry et al., 2005; Gore et al., 2000; Simonds, 2003). Despite individuals with COPD experiencing a more prolonged duration of worse symptoms and higher functional limitation than patients with terminal malignancy access to *specialist palliative* care for this patient group is severely limited (Addington-Hall, 2001; Claessens et al., 2000; Goodridge, 2006; Gore et al., 2000; Knauft et al., 2005; McKinley et al., 2004). Gore et al.'s (2000) study found that no COPD patients had access to specialist palliative care compared with 30% in malignant patients.

Knauft et al. (2005) and Disler and Jones (2010) also noted that individuals with end-stage COPD lacked *access to generalist community nursing*. A number of studies have noted that when community nurses have been in contact with COPD patients that their interaction was strictly task-based (provision of medication or dressings for example) and unrelated to the end-stage needs of COPD patients (Disler and Jones, 2010; Elkington et al., 2005; Exley et al., 2005; Luddington et al., 2001; Skilbeck et al., 1998). Gysels and Higginson (2008) furthermore illustrated the lack of contact between community nurses and end-stage COPD patients in their qualitative research, outlining a conversation between an individual with moderate-severe COPD and ongoing debilitating symptoms and breathlessness and a community nurse. While the individual saw the community nurse four times in three years for non-COPD related interventions, their neighbour, who had malignant disease, received frequent support visits and daily visits from community nurses in the final stages of life. Enquiring why the former was not seen in the same way, they were told that they 'looked well'. A recent study by Disler and Jones (2010) extended on this noting that while end-stage COPD symptoms are common to people with malignancy, the lack of clarity around the role of the community nurse in the provision of end-stage care for COPD reduces individuals' access to these key community services. This lack of community support from specialist and generalist providers, in addition to the frequent hospitalisations resulting from COPD exacerbation, contributes to the high likelihood that individuals with COPD die in the acute hospital setting rather than being given the opportunity of dying in the community as offered to other terminal patient groups (Edmonds et al., 2001; Goodridge, 2006; Lunney et al., 2003; McKinley et al., 2004).

4. Discussion

Three key themes arose from this review. Firstly, patients have a variety of needs which would be appropriate for a palliative care approach. Secondly, provider communication is central to the access and provision of interventions which address the needs of this patient group. Lastly, there is a need to address patient, provider and systems issues in achieving health care reform. The implications of these issues are discussed below.

4.1. Needs of individuals with end-stage COPD

COPD is a progressive, life limiting condition associated with a high symptom burden (Blinderman et al., 2009; Cicutto et al., 2004; Curtis, 2008; Gore et al., 2000). Breathlessness is the most prominent and debilitating symptom experienced in end-stage COPD and attracts a range of interventions of varying efficacy including the use of opioids, benzodiazepines, palliative oxygen, non-invasive ventilation and a variety of distraction, breathing and complementary therapy techniques (Abernethy et al., 2010; Bausewein et al., 2008; Cuomo et al., 2004; Jennings et al., 2011). Patients experience further additional symptoms that also require effective management, the most prominent being fatigue and functional limitation, psychological and social barriers and limitations and communication issues in the form of the need for advance care planning, access to palliative care and stronger relationships with healthcare professionals (Edmonds et al., 2001; Elkington et al., 2005; Skilbeck et al., 1998). The evidence for the interventions designed to address these symptoms and issues is varied as is the efficacy of these treatments in end-stage COPD (Ambrosino and Simonds, 2007; Cicutto et al., 2004; Dahlin, 2006; Heffner, 2011; Yohannes, 2008).

Inadequate symptom control and progressive functional limitation leads to a spiral of physical deconditioning, further fatigue and social isolation and adoption of a dependent and sedentary lifestyle (Cicutto et al., 2004; Simpson and Rocker, 2008). Individuals' loss of control over their lives leads to a high prevalence of social and psychological dysfunction (Gysels and Higginson, 2008; Simpson and Rocker, 2008; Yohannes, 2008). Gysels and Higginson (2008) and Simpson and Rocker (2008) argue that supportive approaches such as those seen in pulmonary rehabilitation and palliative care should be integrated into care to assist patients in continuing to manage their condition despite unremitting symptoms (Gysels and Higginson, 2008; Simpson and Rocker, 2008). A collaborative palliative care approach would assist patients in utilising supports and interventions that enable patients to balance the demands of their disease while maximising involvement and enjoyment in pursuits that give them pleasure (Bourbeau, 2008; Cicutto et al., 2004; Coventry et al., 2005; Curtis, 2008; Gysels and Higginson, 2008; Simpson and Rocker, 2008).

Evidence from adequately powered RCTs is needed to address the physical, psychological and system needs of patients, such as self-management and supportive palliative care approaches. Equally health care reform is needed to support a systems approach to managing patient with end-stage COPD and to support healthcare providers in implementing and developing comprehensive and effective treatments.

4.2. Provider communication

A key overriding principle throughout the review was the role of provider communication in ensuring patient access to services and interventions in the management of end-stage COPD (Gott et al., 2009; Halding et al., 2010;

Lunney et al., 2003; Milne et al., 2009). Interventions such as advance care planning are shown to improve engagement with palliative care services and therefore quality of life and decision-making in individuals with end-stage COPD (Gott et al., 2009; Halding et al., 2010; Lunney et al., 2003; Milne et al., 2009). However, the difficulty in estimating the terminal phase of COPD and lack of communication around end-of-life planning has been a well-documented barrier to engaging individuals with interventions such as supportive palliative care (Janssen et al., 2008; Lunney et al., 2003; Pinnock et al., 2011; Spathis and Booth, 2008). The progressive deterioration of COPD, punctuated with a series of potentially fatal deteriorations, decreases providers' confidence in the appropriate timing of conversations and consequently the referral of patients to palliative care (Coventry et al., 2005; Curtis, 2008; Lehman, 2004; Lunney et al., 2003; Spathis and Booth, 2008; Spence et al., 2009). Evidence indicates that providers acknowledge that most patients are unaware of the terminal nature of COPD and the need for timely advance care planning, however few initiate such discussions (Blackler et al., 2004; Elkington et al., 2005; Gott et al., 2009).

Health reform that builds the capacity for patients and providers to engage in advance care planning is required for more effective and timely end-of-life care planning (Janssen et al., 2008; Spathis and Booth, 2008; Spence et al., 2009). Improving providers' confidence in initiating end-of-life discussions, through training in approaches to end-of-life conversations and the services available to end-stage COPD patients, would assist providers in implementing advanced care planning and system interventions that support patients through the palliative phase (Janssen et al., 2008; Patel et al., 2012; Spathis and Booth, 2008; Spence et al., 2009).

4.3. Systems approaches to end-stage COPD

The complex needs experienced by patients with end-stage COPD, and the subsequent variety of associated interventions, demonstrate the need for a systems approach to care such as that seen in palliative services. Despite, access to supportive community services is limited (Ambrosino and Simonds, 2007; Claessens et al., 2000; Coventry et al., 2005; Gore et al., 2000; Simonds, 2003). The fluctuating COPD trajectory can make the application of a palliative model difficult (Gott et al., 2009; Simonds, 2003). The cyclical and unpredictable nature of COPD may not be compatible with the stereotypical malignant trajectory around which palliative care was developed, that is, a prolonged stable period followed by a short final rapid functional decline (Goodridge, 2006; Gott et al., 2009; Simonds, 2003). Although increasingly cancer is recognised as a chronic condition (Phillips and Currow, 2010).

Social isolation, difficulty in prognostication and focus on treating acute symptoms has meant that health care for individuals with end-stage COPD has been driven by acute care models rather than a collaborative approached shared across acute life sustaining and palliative care services (Au et al., 2006; Coventry et al., 2005; Harris, 2007; Heffner, 2011; Spathis and Booth, 2008). A central goal of palliative care, regardless of diagnosis, is aimed at supporting patients and families for the best possible quality of life (WHO, 2002). Considering the symptom burden experienced in end-stage COPD, a palliative approach is required (Spathis and Booth, 2008). A 'mixed management model' such as that seen in palliative care provides a flexible system which allows active management to be combined with planning for the final stages of life and encourages collaboration across health services and specialities (Braun et al., 2007; Dy and Lynn, 2007; Glare and Virik, 2001). Health reform and further research are required to ensure the provision of supportive palliative care which is responsive to the needs of patients with end-stage COPD and their families.

Two health reform programmes based around the mixed management model are the '*Promoting Excellence in End-of-life Care*' from the United States of America (Byock et al., 2006), and the '*End-of-life Programme*' in the United Kingdom (National Health Service, 2006). *The* '*Promoting Excellence in End-of-life Care*' program has focused on the implementation of quality palliative care to individuals with non-malignant diagnoses with a focus on case management and home-based palliation. This national strategy was found to lower symptoms and improve vitality and self-rated health particularly in individuals with COPD (Spathis and Booth, 2008). Equally the '*End-of-life Programme*' in the United Kingdom used a number of strategies to target quality end-of-life care provided by generalists in the acute as well as community setting. The program encompasses three directives, the *Liverpool Care Pathway* to prompt and guide care in the final phases of life, the *Gold Standard Framework* to empower and guide community based generalist to provide high quality communication, coordination of care, support and symptom control, and the *Preferred Place of Care* document aimed at advance care planning around patient choices and in particular preferred place of death. All three components of this programme support providers to facilitate palliative care planning and interventions (Spathis and Booth, 2008). The '*Promoting Excellence in End-of-life Care Program*' and the '*End-of-life Programme*' have progressed non-malignant palliative care within health systems and increased the provision of high-quality palliative care to a broad range of patient groups. Further research is required to identify interventions which best address the needs of individual patients groups such as those living with end-stage COPD and which enable health reform through the provision of collaborative and systems approaches to care of patients with end-stage disease (Spathis and Booth, 2008).

4.4. Limitations and strengths of the review

This review explored the use of a palliative care approach and interventions for the management of end-stage COPD. The diverse range of literature and study designs, and consequent heterogeneity, have lent this review to an integrative approach to provide an overview of available interventions. In order to develop specific clinical guidelines for palliative care in COPD, a rigorous method of a systematic review including appraisal of evidence for individual items is warranted. In spite of this, the review has provided a comprehensive understanding of the interventions used to support a palliative care approach in caring for patients with end-stage COPD and the need for a systems approach to managing this complex condition. Furthermore, it has identified that there is a need for ongoing research for interventions at the level of the individual, provider and patient.

5. Conclusion

COPD is a complex and burdensome condition particularly in the final phases of the disease. Although literature concerning discrete elements of management is present, there are limited data discussing the comprehensive and collaborative approaches necessary to address the complex and multivariate needs of end-stage COPD patients. Health reform that enables the provision of high-quality palliative care is required to address the needs of patients and providers in a range of patient groups. This is an abundant area for future research given the growing burden of chronic conditions globally.

5.1. Implications for practice

- Symptom control for individuals with end-stage COPD can likely be improved using a palliative approach.
- Advance care planning should be commenced early to ensure care is commensurate with individuals' needs.
- Training is required to support providers in commencing advance care planning discussions.
- A comprehensive and collaborative approach is required to address the complex needs of end-stage COPD patients.

Conflict of interest: None declared.

Author's contributions: All authors contributed considerably to interpretation and synthesis of information. Study design: RD, PMD; data collection and analysis: RD, DC, JP, MJ, PMD, TS; data review, interpretation and manuscript preparation: RD, DC, JP, MJ, PMD, TS.

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Disler RT, Inglis S, Currow DC, Davidson PM. Palliative and supportive care in COPD: research priorities to decrease suffering. *Journal of Pulmonary and Respiratory Medicine* 2012; 1:1-3.

Disler et al., 1:6
http://dx.doi.org/10.4172/scientificreports.301

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Review Article Open Access

Palliative and Supportive Care in Chronic Obstructive Pulmonary Disease: Research Priorities to Decrease Suffering

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Abstract

Chronic obstructive pulmonary disease (COPD) affects 80 million people worldwide, is the fourth most prevalent cause of death globally and accounts for 3.5% of total years lost due to disability. Despite the similarities with malignant disease, many individuals suffer unnecessarily and continue to have limited access to palliative and end-of-life care. Changing this will require a shift in focus and approach as well as support for clinical decision making. Lack of communication regarding care plans and prognosis and coordination across care settings has been identified as barriers to end-of-life care. Research specifically should focus on improving the use of comprehensive and collaborative approaches to end-stage COPD care such as those illustrated in the Chronic Care Model which has demonstrated improved outcomes for chronic conditions. Revision of funding models and workforce organisation, aided by clinical pathways may improve end of life care for COPD.

Keywords: Chronic obstructive pulmonary disease (COPD); Palliative care; Research priorities

Abbreviations: COPD: Chronic obstructive pulmonary disease; WHO: World Health Organisation

Introduction

Chronic obstructive pulmonary disease (COPD) affects 80 million people worldwide, is the fourth most prevalent cause of death globally and accounts for 3.5% of total years lost due to disability [1]. Despite the high symptom burden and parallels with malignant disease, individuals with end-stage COPD continue to have limited access to palliative and end-of-life care and suffer unnecessarily [2-4]. Social isolation, difficulties in prognostication and a focus on the acute crisis, create care that is reactive, burdensome to informal caregivers and ad hoc rather than a collaborative approached shared across acute life sustaining care and palliative services [3-7].

The increasing prevalence of COPD [1] challenges the provision of effective health care interventions, particularly in the context of an aging population who commonly present with multiple chronic conditions [1]. This is aggravated by the contentious and value laden dimension of end-of-life care. Key research priorities for palliative and supportive care were identified through the issues raised in the following data sources:

1. International policy and strategy documents [8-10];
2. Evidence for palliative care interventions for COPD [11-13];
3. Discussion documents and opinions pieces regarding the need for improvements to COPD care [8,14]; and
4. Two previous reviews undertaken by the research team [15,16].

Palliative care is defined as that which addresses 'the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering' [17] pp84. While a palliative approach can be used in the management of life limiting conditions during the acute, chronic or terminal phases, the term 'end-of-life care' is commonly taken to refer to care provided in the final phase of life [3,5]. Additionally, supportive care is an umbrella term which encompasses palliative care and focuses on helping the consumer, family and provider in coping with the condition 'from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease' [9]. Regardless of the nomenclature, individuals with end-stage COPD have limited access to supportive palliative services despite experiencing similar yet more severe symptoms than those with malignant disease [3,18,19]. Integrating these philosophical approaches in care provision is more challenging. Based upon the review of the management of chronic illness, The Chronic Care Model has been shown to be useful in addressing the burden of chronic disease [17]. This approach for reform, that focuses on the patient and their family at the centre of care, supported by enabling policy and care coordination, was used as a unifying framework to organise issues emerging from the review and to develop priorities for further research [17,20].

International policy documents indicate the need for individuals to have access to supportive and palliative services regardless of underlying diagnosis, and in particular for those who have non-malignant terminal conditions [8,10,17,21]. However, this rhetoric will require reengineering of work practice, health care organisation and the ways in which health professionals and consumers view palliative care [22]. Priorities for research must work to develop and evaluate

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Received November 18, 2011; **Published** September 10, 2012

Citation: Disler R, Inglis SC, Currow DC, Davidson PM (2012) Palliative and Supportive Care in Chronic Obstructive Pulmonary Disease: Research Priorities to Decrease Suffering. 1:301. doi:10.4172/scientificreports.301

effective health service models for end-stage COPD [8,23]. Specifically the key priorities for research around end-stage COPD should address developing:

- evidence for a systems approach to non-malignant palliative care, such as that seen in national programs such as The 'Promoting Excellence in End-of-life Care Program' and the 'End-of-life Programme' [21,24];
- advance care planning and training of providers in undertaking advance care planning [25-27];
- evidence based decision pathways to assist providers, consumers and their families in accessing health services [1,27,28]; and
- more effective strategies for symptom management, particularly breathlessness [2-5,25,29].

Systems Approach to Non-Malignant Palliative Care

The fluctuating and episodic decline of COPD is seen as a key barrier to providing palliative care services, to which access remains limited in this patient group [4,5,29,30]. The complexity and severity of symptoms experienced by patients with end-stage COPD highlights the need for a systems approach to palliation, such as those outlined in the 'Promoting Excellence in End-of-life Care Program' in the USA, the 'End-of-life Programme' in the United Kingdom, and in organising frameworks such as the Chronic Care Model [8,21,23,24].

Although literature concerning discrete elements of end-stage COPD management is present, such as pharmacological and non-pharmacological interventions [11-13], there are limited data which discusses the comprehensive and collaborative approaches required to address the complex and multivariate needs of patients with end-stage COPD [6,31]. These needs extend beyond the patients to caregivers [7,20]. A systems based method, integrating a palliative approach, would ideally allow for active management to be combined with planning for the final stages of life and encourage collaboration and continuity across health services [6,8,10,17,23,31-33]. Programs such as the 'Promoting Excellence in End-of-life Care Program' in the USA and the 'End-of-life Programme' in the United Kingdom have been successful in integrating palliative care for non-malignant conditions within the health system and increased the provision of high-quality palliative care to a broader range of patient groups [8,21,24]. Research is required to strengthen the evidence for a systems approach to managing end-stage COPD across a variety of settings, from primary to acute care [23].

Prioritisation of Advance Care Planning and Training of Providers

Communication around end-of-life should be commenced early to ensure that individuals are able to articulate their wishes and goals in approaching the final stages of life [14,25,34]. The fluctuations in the disease trajectory and speed at which patients can deteriorate into the terminal phase strengthens the argument for early advance care planning in patients with end-stage COPD in particular [5].

Providers do acknowledge that the majority of patients with end-stage COPD are unaware of the terminal nature of their condition [26,35]. Furthermore, providers acknowledge the need for timely advance care planning [4,26,35]. Building the capacity of patients and providers to engage in advance care planning is required for this to occur [10,14,22,28].

Providers' confidence in undertaking end-of-life discussions would improve through training in: techniques for initiating discussion; the content which patients' value; and what services are available to end-stage COPD patients [10,22]. Better understanding for patients and providers, and the use of a unifying framework such as the Chronic Care Model, would assist in the early implementation of system interventions and advance care planning that support patients through the palliative phase of their disease [10,22,23].

Development of Decision Pathways

Emerging from the review is the high symptom burden experienced by patients with end-stage COPD and the failure of current management systems to relieve suffering [2-4,23]. Clinical pathways are standardised, evidence-based multidisciplinary management plans that identify the sequence of assessment and clinical interventions within a framework [27]. They provide a mechanism for decision support and timeframes for expected outcomes for clinical conditions. Considering the complexity and variability of end-stage COPD, it is difficult for providers and consumers to react with confidence to ever changing symptoms and maintain confidence in management decisions when faced with unremitting symptoms [8,27]. Evaluating such an approach may assist in symptom management. For example clinical pathways that identify early deterioration, provide decision support and facilitate referral to appropriate providers may be of use in avoiding unnecessary episodes of respiratory failure [25,27].

Prospective and systematic development of innovative, interdisciplinary interventions may allow for evidence based pathways that address the physical, psychological and social issues associated with end-stage COPD [9,10,27]. Implementation of clinical pathways that incorporate aspects of evidence based pharmacological and non-pharmacological strategies, and self-management support may be of use in both community and acute healthcare settings [8-10,23,27].

Conclusion

To date the literature in end-stage COPD is more replete with challenges rather than solutions. Emerging from this review is the importance of adequately powered clinical trials to not only address clinical management but also health services planning and evaluation of Models of care. Models that incorporate policy makers, providers, consumers and their families in effective care provision are an important strategy to address the increasing numbers of individuals dying with COPD.

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CHAPTER 8: COMPREHENSIVE APPROACHES TO CHRONIC OBSTRUCTIVE PULMONARY DISEASE MANAGEMENT

EXTENDED ABSTRACT

Chapter Eight presents a Cochrane Overview of that summarises the evidence for comprehensive approaches to managing COPD and describes the elements of these interventions using a standardised taxonomy for disease management. This chapter consists of two papers that have been submitted for publication, the first, the overview itself that is currently under editorial review with the *Cochrane Database of Systematic Reviews,* and the second is the Cochrane Overview Protocol published a prior within the *Cochrane Database of Systematic Reviews* prior to the commencement of the overview process.

Disler RT, Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. *Cochrane Database of Systematic Review*s. Under editorial review

Disler RT, Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. *Cochrane Database of Systematic Reviews* PROTCOL 2013, Issue 2. Art. No.: CD010384. DOI: 10.1002/14651858.CD010384

BACKGROUND

Despite optimisation of treatments individuals with chronic obstructive pulmonary disease (COPD) continue to experience inadequately managed symptoms and unmet psychosocial and physical needs. Comprehensive approaches to disease management that engage ‘multiple therapies in a patient-centred plan of care’ are necessary to meet these healthcare needs [1-3]. Comprehensive approaches include pulmonary rehabilitation; self-management programs; action plans as an integrated strategy and management guideline; telehealthcare; outreach programs and integrated disease management programs [4-6].

Many of these discrete interventions are complex in both design and delivery and require distillation of essential elements: e.g. the type, frequency and level of intervention intensity as well as description of the workforce type and scope. Using a pre-specified and standardised taxonomy may assist in providing information to health providers and consumers in design of effective and appropriate interventions for COPD management [5,7]. Understanding the most efficacious organisation, timing and sequencing of these interventions within a disease management approach, as well as resource requirements for these approaches are of high interest internationally and will inform policy, health care decisions and future research [2,3,5,7].

OBJECTIVES

The purpose of this Cochrane overview was to summarise evidence for comprehensive approaches to managing COPD, identify gaps in the current evidence base, and to describe the elements of these interventions using a standardised taxonomy for disease management using a standardised taxonomy for disease management adapted from the American Heart Association [7].

DESIGN

This overview presents a narrative summary of results for the individual reviews and primary outcomes of the evidence for non-pharmacological, non-surgical and non-device intervention strategies for COPD using two comparisons: intervention versus placebo and intervention A versus intervention B (e.g. self-management versus usual care or self-management versus action plans). Achieving translation of research is critical. A standardised disease management taxonomy [7] has been adapted and used to organise a discussion of the utility of intervention intensity and duration and workforce requirements.

METHODS

The *Cochrane Database of Systematic Reviews,* Issue 1 2014, was searched to identify all relevant Cochrane reviews reporting evidence for comprehensive approaches to COPD management. The Cochrane reviews identified by the search were assessed by two independent investigators for inclusion, review objectives, participant information, primary outcome measurements and noted limitations, as well as methodological quality of included reviews and quality of evidence in included reviews.

Due to the intrinsic heterogeneity between systematic reviews and included studies, it was not anticipated that this overview would perform any quantitative data analyses. Therefore the overview is presented as a narrative summary of results for the individual reviews and primary outcomes. This descriptive approach to summarising evidence is similar to the successful approaches seen in Cochrane Overview of Pain management for women in labour [8] and Cochrane Overview of Consumer-oriented interventions for evidence-based prescribing and medicines use [9].

In addition, the elements of the multi-component programs were extracted for discussion, specifically: Intervention content; personnel delivery; method of communication; intensity and complexity of intervention; the setting and environment; and outcome measures used for that intervention [7]. The application of a standardised disease management taxonomy [7] additionally provided a narrative summary of the components of comprehensive disease management, the use of this framework is hoped to increase the utility of the review by increased understanding of intervention intensity and duration and workforce requirements [7]. This is critical in achieving research translation efforts as well as standardisation of outcome assessment and benchmarking.

FINDINGS

Seven Cochrane Reviews were included, addressing: pulmonary rehabilitation; self-management programs; action plans as an integrated strategy and management guideline; telehealthcare; outreach programs and integrated disease management programs. The overview again confirmed the strong evidence that pulmonary rehabilitation improves quality of life and lessens disease burden, however mixed evidence was reported for self-management, hospital at home, pulmonary rehabilitation exercise programs following acute exacerbation, integrated disease management, care delivered through telehealth platforms and home care delivered by outreach nursing services. Heterogeneity in study design, intervention components and outcome measures inhibits understanding of the most effective interventions for COPD.

IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

Heterogeneity across study design and reporting of results often restricted meta-analyses across the majority of studies. Articulation and consensus of operational definitions, essential intervention components and outcome measurement are required for cross study comparisons and delivery of high quality future care. A standardised taxonomy will allow for clearer guidelines as to intervention requirements and allow for replication and translation. Impact on frequency and overall healthcare utilisation must remain a key focus and endpoint in future research for comprehensive interventions. Additionally, patient and caregiver satisfaction and the impact on disease experience should be considered beyond health related quality of life (HRQoL) measures.

CONCLUSIONS

COPD is a complex and debilitating condition that requires individuals to actively engage in a variety of comprehensive and complex self-care management activities. Definitive evidence as to the most efficacious and effective interventions in COPD management remains unclear. In recognising the complexity and potential burden of these interventions, it is imperative that we have clear evidence as to those that are most efficacy and those that produce sustainable positive impact in this group of patients. Articulation and consensus of operational definitions, essential intervention components and outcome measurement are required for cross study comparisons. A standardised taxonomy will allow for clearer guidelines as to intervention requirements and allow for replication and translation.

Grant Support: 2014 Lung Foundation Australia/Australian Satellite Cochrane Airways Group scholarship: Comprehensive approaches to the management of chronic obstructive pulmonary disease $2500.

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BACKGROUND

Description of the condition

Chronic obstructive pulmonary disease (COPD) is the fourth most common cause of death internationally and accounts for 3.5% of total years lost due to disability [1]. This highly burdensome condition impacts on 80 million people and their families globally and is characterised by non-reversible airflow limitation in conjunction with progressive debilitating symptoms and systemic effects [2]. Increases in bio-fuel use and smoking particularly in developing countries is set to increase the prevalence of COPD globally by 30% by 2030 [1,3,4].

Despite optimisation of pharmacological treatments such as inhaled medications, a large proportion of individuals with COPD continue to have inadequately managed symptoms and unmet psychosocial needs [5-7]. Comprehensive approaches to disease management that engage ‘multiple therapies into a patient-centred plan of care’ [8] are necessary to meet these healthcare needs [8-10].

Description of the interventions

Key non-pharmacological interventions such as pulmonary rehabilitation and self-management programmes are central to COPD management and are highlighted in international COPD management guidelines [2,11,12]. Chronic diseases, such as COPD, require a comprehensive approach to disease management [8], potentially incorporating a range of diverse non-pharmacological, non-device and non-surgical intervention strategies. The intervention strategies discussed in this review, and defined below are: pulmonary rehabilitation; self-management programs; action plans as an integrated strategy and management guideline; telehealthcare; outreach programs; and integrated disease management programs [1,2,5,7,8,11,13-15].

1. Pulmonary rehabilitation

Pulmonary rehabilitation focuses on building exercise capacity, disease and nutritional education, and psychological coaching [2,11,16,17]. Pulmonary rehabilitation is defined as 'an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities. Integrated into the individualized treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimize functional status, increase participation, and reduce health care costs through stabilizing or reversing systemic manifestations of the disease' [2,17-19].

2. Self-management programs

Self-management programs are defined as formalised programs in which training aims to 'training aims to help patients acquire and practise the skills they need to carry out disease-specific medical regimens, to guide changes in health behaviour and to provide emotional support to enable patients to adjust their roles for optimal function and control of their disease' [7]. Patients with COPD experience high symptom burden and poor health related quality of life (HRQoL) and are required to manage their condition over extended periods [20]. Evidence suggests that self-management education programs that target skills to assist patients in coping are likely to reduce hospital admissions in patients with COPD. In addition consensus is required on the definition of self-management and the most effective combination of intervention characteristics [7,21]. There is agreement that successful self-management programs should focus on sustained behaviour change, self-efficacy for managing health and patient skills in 'solving, decision making, resource utilisation, forming a partnership between patient and healthcare provider, taking action and self-tailoring' [21,22].

3. Action plans as part of an integrated strategy and management guidelines

Action plans are defined as 'the use of guidelines which outline self-initiated interventions (such as changing medication regime or visiting the general practitioner or hospital) which are undertaken appropriately in response to alterations in the state of the patients' COPD (e.g. increase in breathlessness, increased amount or purulence of sputum) that suggest the commencement of an exacerbation' [23]. Patients who receive early intervention for exacerbations of COPD symptoms are shown to recover sooner and experience better quality of life with ongoing optimal management [24]. Action plans have been shown to be effective in early intervention in asthma management; however the evidence for their efficacy in COPD has been limited [23-25].

4. Telehealthcare

Telehealthcare is a rapidly expanding field in healthcare and chronic disease management [15,26]. Telehealthcare in COPD is described as 'using technology such as telephones, video cameras and the Internet to allow people to stay at home and communicate with a nurse or doctor when they have a period of increased breathlessness' [15]. Considering the housebound nature of advanced COPD and the frequency with which patients access acute health services as the disease progresses, telehealthcare has particular applicability in this population [15]. Telehealthcare has great potential in the resource limited future of modern healthcare and potential to address issues of limited healthcare access.

5. Outreach programs

Outreach programs are those interventions that 'comprise home visits by a respiratory nurse or similar respiratory health worker, to facilitate health care, provide education, provide social support, identify respiratory deteriorations promptly and reinforce correct technique with inhaler therapy' [27]. Delivery of care in the community targets those patients who are housebound or frequently reliant on acute services in the advanced stages of COPD. Outreach programs strive to maintain optimal management of disease and assist patients in self-management behaviours, as well as regular monitoring and early intervention in condition deterioration. A recent Cochrane Systematic review found that this type of intervention does improve HRQoL; however the current studies are heterogeneous in their approach [27].

6. Integrated disease management

Integrated disease management is described as an intervention that combines 'a group of coherent interventions designed to prevent or manage one or more chronic conditions using a community wide, systematic and structured multidisciplinary approach potentially employing multiple treatment modalities.' [28,29]. Integrated chronic disease management specifically aims to identify and assist individuals with one or more associated chronic conditions [29]. Similar to the approach in self-management, chronic disease management aims to promote self-management and 'to address the illness or conditions according to disease severity and patient needs and based on the best available evidence, maximizing clinical effectiveness and efficiency regardless of treatment setting(s) or typical reimbursement patterns' [28].

WHY IT IS IMPORTANT TO DO THIS OVERVIEW?

Chronic diseases, such as COPD, require a comprehensive and multi-dimensional approach to disease management that incorporate a range of integrated intervention strategies, for example exercise rehabilitation with self-management education [1,2,8].

Many of these discrete interventions are complex in both design and delivery and require distillation of essential elements: e.g. the type, frequency and level of intervention intensity as well as description of the workforce type and scope. Using a pre-specified and standardised taxonomy may assist in providing information to health providers and consumers in design of effective and appropriate interventions for COPD management [8,30] (Figure 1). Understanding the most efficacious organisation, timing and sequencing of these interventions within a disease management approach, as well as resource requirements for these approaches are of high interest internationally and will inform policy, health care decisions and future research [6-8,30].

This overview will summarise evidence for non-pharmacological, non-surgical, non-device intervention strategies, highlight the current gaps in knowledge, provide recommendations for how best to report outcomes for these complex interventions and inform future program improvement and design. Specifically the evidence for pulmonary rehabilitation, self-management programs, action plans as part of an integrated strategy and management guidelines, telehealthcare and outreach programs will be investigated.

OBJECTIVES

This overview aimed to a) summarise the evidence, b) identify gaps in the evidence base and c) describe elements of non-pharmacological, non-surgical and non-device interventions for the management of COPD using a standardised taxonomy for disease management adapted from the American Heart Association [30].

METHODS

Criteria for considering reviews for inclusion

Types of Reviews

Reviews published in the *Cochrane Database of Systematic Reviews* that examined non-pharmacological, non-surgical, or non-device strategies for the management of COPD were included in this overview. This overview sought to summarise the evidence published in the original Cochrane reviews and did not seek to update these individual reviews.

Types of participants

People with a clinical diagnosis of COPD according to the definitions in the original reviews.

Types of interventions

Non-pharmacological, non-surgical, non-device intervention strategies for the management of COPD within a comprehensive and multifaceted approach have been included in this overview, specifically: pulmonary rehabilitation; self-management programs; action plans as an integrated strategy and management guideline; telehealthcare; outreach programs; and integrated disease management programs. We excluded reviews of surgical treatments and treatment devices as outside of the scope of this overview, for example non-invasive ventilation, continuous positive airway pressure and lung volume reduction surgery.

Types of outcome

The following outcomes have been discussed and reported if present within the included original Cochrane Reviews.

Primary outcomes

- HRQoL (any validated measure)
- All cause hospital admissions
- All cause emergency department presentations

Secondary outcomes

- Patient reported breathlessness (any validated measure)
- Functional capacity (any validated measure)

Search methods for identification of reviews

The *Cochrane Database of Systematic Reviews* on *the Cochrane Library (*Issue 1 2014) in February 2014 was searched using the search strategy in Appendix 1. Date or language restrictions were not applied. All protocols for ongoing reviews are noted in the 'Studies awaiting assessment' discussion and will be integrated in future updates once published.

Data collection and analysis

Selection of reviews

Cochrane Reviews were assessed as 'for exclusion', 'for inclusion', or 'potentially eligible' by two independent investigators (RTD, PMD) on the basis of title and abstract. Full texts for Cochrane reviews were judged as 'eligible' or 'potentially eligible' and suitable for inclusion by two independent review authors (RTD, PMD) against the inclusion criteria. In the instance of disagreement a third reviewer adjudicated.

Data extraction and management

Two reviewers (RTD, PMD) independently extracted data from the included Cochrane reviews and a third reviewer checked all extracted data for accuracy and consistency. Extracted data was collected through a customised electronic data extraction form. The data extracted included review objectives, participant information, primary outcome measurements and limitations noted in the review. Quality of included reviews (using AMSTAR) and quality of evidence in included reviews (using GRADE and risk of bias) data were extracted for assessment of overall methodological quality.

In addition, the elements of the multi-component programs have been extracted and discussed in relation to: intervention content; personnel delivery; method of communication; intensity and complexity of intervention; the setting and environment; and outcome measures used for that intervention [30,31].

Dealing with missing data

Outcomes have been discussed and reported if present within the included original Cochrane Reviews. If any information from the reviews is unclear or missing, we will access the published reports of the individual trials.

Assessment of methodological quality of included reviews

Quality of included reviews

Two review authors (RTD, PMD) assessed the methodological quality of the included reviews independently using the 'assessment of multiple systematic reviews' (AMSTAR) measurement tool [32]. Disagreements were resolved through a third investigator. We did not exclude Cochrane reviews on the basis of methodological quality.

Quality of evidence in included reviews

Two review authors (RTD, PMD) assessed the quality of evidence presented in the included reviews using the GRADE assessment tool and through assessment of risk of bias in the included evidence. We retrospectively applied the risk of bias tool and GRADE the evidence from trials in individual systematic review where this was not done previously [33].

Summary of findings tables

Summary tables present data on; the characteristics of included reviews (Table 1); the methodological quality of included reviews (AMSTAR ratings) (Table 2); the quality of evidence in included reviews (GRADE and risk of bias) (Table 3); the summary of comparisons within reviews (Table 4); and a summary of primary outcomes reported in included reviews by intervention (pulmonary rehabilitation, self-management programs, action plans as part of an integrated approach, telehealthcare and outreach programs) (Table 5). We will additionally summarise information on the multi-component interventions used in COPD disease management, using an adapted standardised disease management taxonomy [30]. The 'elements of multi-component interventions' figure presents he following content: intervention content, personnel delivery, method of communication, intensity and complexity of intervention, the setting and environment and outcome measures [30] (Figure 1).

Data synthesis

It was not anticipated that we would be able to perform any quantitative data analyses. Therefore we presented a narrative summary of results for the individual reviews and primary outcomes. For future updates of this overview we may perform quantitative data analysis of interventions across reviews for the primary outcomes if future review data permits.

We have presented narrative descriptions of the evidence for non-pharmacological, non-surgical and non-device intervention strategies for COPD using two comparisons: intervention versus placebo and intervention A versus intervention B (e.g. self-management versus usual care or self-management versus action plans). This descriptive approach to summarising evidence is similar to the successful approaches seen in Cochrane Overview of Pain management for women in labour [34] and Cochrane Overview of Consumer-oriented interventions for evidence-based prescribing and medicines use [31].

We have additionally adapted and applied a standardised disease management taxonomy to organise discussion of the components of comprehensive disease management interventions for COPD (Figure 1). We hope that the use of such a framework has increased the utility of this review with increased understanding of intervention intensity and duration and workforce requirements [30].

RESULTS

Description of included reviews

A total of 183 potentially eligible Cochrane Reviews were identified by the Trials Search Coordinator of the Cochrane Airways group. A priori, the research question and inclusion criteria were provided in a published generic protocol [35]. Based on the published inclusion criteria 174 Cochrane reviews were excluded, 128 reviews were excluded as they addressed pharmacological interventions, non-invasive ventilation or oxygen therapy, eight reviews were excluded as they only discussed discrete interventions, ten presented data that did not relate to COPD or data from which COPD data could not be distinguished and two were excluded as they were in protocol form. Seven Cochrane reviews met the inclusion criteria for this overview. (Figure 2)

We included seven published Cochrane reviews: one review on self-management education [7]; two reviews on pulmonary rehabilitation (for COPD and following acute exacerbation of COPD) [36,37]; two on comprehensive services delivered to the home (Hospital at home for acute exacerbations of COPD and home care by outreach nurses for COPD) [36,37]; one review that reported evidence on telehealthcare for COPD [15]; and one review that reported evidence on integrated disease management for COPD [38].

All included reviews had been published at the time this overview was prepared. Four of the seven reviews have been updated in the past two years.

The titles of the seven Cochrane reviews are listed below:

- Self-management for patients with chronic obstructive pulmonary disease [7]
- Hospital at home for acute exacerbations of chronic obstructive pulmonary disease[39]

- Pulmonary rehabilitation for chronic obstructive pulmonary disease [36]
- Telehealthcare for chronic obstructive pulmonary disease [15]
- Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease [37]
- Home care by outreach nursing for chronic obstructive pulmonary disease [40]
- Integrated disease management interventions for patients with chronic obstructive pulmonary disease [38]

All reviews included patients with a primary diagnosis of COPD, additionally Puhan [37] allowed inclusion of studies with more than 90% COPD patients.

The review of self-management interventions for COPD included trials that assessed the efficacy of self-management interventions. Studies published before 1995 were excluded as the focus prior to this was on 'improving knowledge through education rather than initiating and enabling sustained behaviour change' and therefore were not comparable with current practice [7]. The reviews of the efficacy of pulmonary rehabilitation included trials that compared pulmonary rehabilitation to conventional hospital and community based pulmonary rehabilitation [36,37]. In the pulmonary rehabilitation for COPD review, trials that included exercise that was not considered aerobically demanding (such as breathing exercises or tai chi) were excluded, trials that compared pulmonary rehabilitation with another type of intervention, education for example, were excluded from meta-analyses given education are considered as a component of the pulmonary rehab intervention and would risk masking the impact of rehabilitation versus usual care [14].

The review of hospital at home for acute exacerbations of COPD included trials that compared care delivered to patients presenting to the emergency department with an exacerbation of their COPD and were randomised to either home support or hospital admission. Home support in this instance was defined as discharged from hospital within 72 hours of presentation and after initial assessment by the medical team [40]. The review of home care by outreach nursing for COPD took a broader approach of any trial that compared home visits provided by a respiratory nurse or similar respiratory health worker to patients with COPD with conventional community care. Telehealthcare for COPD compared intervention with a control group [15].

The number of trials included varied across the reviews. The review of pulmonary rehabilitation included the highest number of trials with 31 trials included with 1673 patients randomised and 1348 included in analyses [36]. The other six reviews included between 8 to 29 trials with a range of 509 to 3850 patients randomised and 389 to 2751 included in analyses. The trials were drawn from a range of international locations and all reviews including at least four different countries. Trials were drawn from the years 1977 to 2013. The review of self-management in COPD justified the exclusion of trials prior to 1985 on the basis that medicinal treatments were not comparable with current practice.

The characteristics of the included reviews are reported in the Characteristics of included Cochrane Reviews table (Table 1). It is imperative that the findings of this Cochrane Overview must be considered in light of this information.

Methodological quality of included reviews

Quality of included reviews

The AMSTAR rating scale was used to assess the methodological quality of included reviews. All Cochrane reviews followed a generic protocol with clearly specified methods and consequently all reviews received high-quality ratings. According to the *Cochrane Handbook for Systematic Reviews of Interventions*, the search for included reviews should be comprehensive; 'data should be extracted independently by at least two people; reasons for inclusion and exclusion criteria should be specified; included studies should be assessed and reported for quality; methods for data synthesis should be clearly documented; and findings reported using a systematic approach [33]. All included reviews adhered to these requirements and went through a transparent peer review process. All reviews were of a high quality. The AMSTAR ratings for each Cochrane systematic review are reported in Table 2.

Quality of evidence in included reviews

The methodological quality of individual trials included within the reviews was assessed using the Cochrane Risk of Bias tool [33] and is summarised in the quality of evidence in included Cochrane Reviews table (Table 3). The majority of reviews included trials that had a low risk of bias associated with sequence generation; however a number of trials did not report this resulting in unclear risk of selection bias unclear. Allocation concealment was considered of high risk of bias across several studies, for example when convenience and cluster sampling were used in clinical settings [14,27,37]. Similarly, there was a high risk of bias in the blinding of participants and investigators; however this is expected given the necessary awareness required in all included interventions. In addition, the telehealthcare review did include individual trials where there was a risk of attrition bias for the quality of outcome data assessment as potential for selective outcome reporting [15]. Reporting bias was considered high risk in the majority of trials included in the Self-management in COPD and Pulmonary in rehabilitation in COPD reviews, with the lack of an available protocol for the trials making assessment difficult [7,14].

The overall evidence of data in the included reviews was of high quality and represented a low risk of bias; however, this quality did vary. There is clear need for improved consistency and clarity in methodological and outcome reporting across studies to allow for future high quality comparison.

Effects of interventions

Available data to support differing interventions were set out under two major comparison groups:

- Intervention versus usual care (e.g. self-management versus usual care)
- Different forms of the same intervention (e.g. self-management versus action plans).

The outcomes used in the included reviews varied. All reviews measured HRQoL as a primary outcome [7,14,15,37,41]. The review of pulmonary rehabilitation only included functional capacity as a secondary outcome in addition to HRQoL [36], while the review of pulmonary rehabilitation post exacerbation also collected data on hospital admissions [37]. Number of hospital admissions and emergency presentations were also reported as primary outcomes in the reviews on self-management in COPD, hospital at home, home care nursing outreach and telehealthcare. Functional capacity was similarly reported as a secondary outcome in the review of self-management and home care nursing outreach [7,15,39,41]. Patient reported symptom outcomes were only reported in the self-management for patients in COPD review [7].

While all reviews were based on a priori generic protocol and all collected data from pre-specified lists of primary and secondary outcomes, individual review authors may have also collected data on other outcomes that we have not reported in this overview. We have additionally adapted and applied a standardised disease management taxonomy to organise discussion of the components of comprehensive disease management interventions for COPD (Figure 1). We hope that the use of such a framework will guide discussion and increase the utility of the review by increased understanding of intervention intensity and duration and workforce requirements [30].

COCHRANE REVIEWS (SEVEN REVIEWS)

Self-management education for patients with chronic obstructive pulmonary disease (29 studies, 3,850 participants) (Table 8.3)

This review included 29 studies randomising 3,850 participants [7]. Twenty three of the included studies (2751 participants) reported data from self-management in comparison to usual care in which usual care was provided by their general practitioner and respiratory specialist. The remaining six studies (579 participants) reported data from head to head studies in which a self-management program was compared with a different type of self-management program [42-48].

Intervention content in the 23 studies comparing usual care was varied. Study duration was up to six months in nine studies (39%), twelve studies (52%) completed 12 month follow-up, and two studies (9%) compared 24 months of follow-up. Intervention delivery was individual in 12 studies (52%), in small groups in six studies (26%) and in both group and individual in five studies (22%). Cognitive-behavioural therapy was used in four (17%) studies, motivational interviewing in six (26%), and goal setting or providing feedback was used in eleven (48%) and eighteen (78%) studies, respectively. Action plans were integrated as part of seventeen studies (74%) and exercise as a standardised program was integrated into eleven studies (48%).

Similarly there was variation in content in the six head to head studies (579 participants). Duration of intervention was up to six months in four studies (67%) and 12 months in two studies (33%). Intervention delivery was implemented individually in three studies (50%) and in small groups in the remaining three studies (50%). An action plan was integrated into two studies (33%) and a standardised exercise program into five (83%) of studies. Each of the six head to head studies had a different self-management approach including comparison between: a face-to-face self-management intervention and an internet-based self-management intervention [47]; three intervention groups experiencing

different levels of exercise combined with self-management training [43]; mobile phone intervention with exercise program delivered using a coach versus self-monitoring [48]; and a dyspnoea program and a health education [42]. The final remaining study compared two separate interventions using the one design: self-management only compared to self-management with an action plan [44], and self-management only compared with a community education plan [45].

Self-management versus no usual care

This review included 29 studies randomising 3,850 participants [7]. Twenty three of the included studies (2751 participants) reported data from self-management in comparison to usual care in which usual care was provided by their general practitioner and respiratory specialist. Intervention content varied with study duration was up to six months in nine studies (39%), twelve studies (52%) completed 12 month follow-up, and two studies (9%) compared 24 months of follow-up. Intervention delivery was by individual in 12 studies (52%), in small groups in six studies (26%) and in both group and individual in five studies (22%). Cognitive-behavioural therapy was used in four (17%) studies, motivational interviewing in six (26%), and goal setting or providing feedback was used in eleven (48%) and eighteen (78%) studies, respectively. Action plans were integrated as part of seventeen

Table 4 Summary of comparisons within reviews

Method/ studies(participants)	Usual Care	Self-manage ment	Internet based self-management	Telephone coach self-management	Hospital at home	Pulmonary rehabilitation	Telemonitoring and virtual consultation	Tele-self-management	Home outreach nursing	Specialist follow-up with education
Usual Care	0 (0)									
Self-management	23 (2751)	11 (776)	1 (38)	2 (174)						
Internet based self-management	1 (120)	1 (38)	2 (196)							
Telephone coach self-management	3 (206)	2 (124)		0 (0)						
Hospital at home	8 (870)				0 (0)					
Pulmonary rehabilitation	40 (1842)					2 (98)				
Telemonitoring and virtual consultation	3 (454)						1 (212)			
Tele-self-management	4 (326)							0 (0)		
Home outreach nursing	9 (1381)								0 (0)	
Specialist follow-up with education	2 (227)									1 (25)

studies (74%) and exercise as a standardised program was integrated into eleven studies (48%).

Disease specific HRQoL was measured using the SGRQ in fifteen studies [7], however five studies were exclude due to lack of data [49,50] or approach as controlled clinical trials [51-53]. Pooled analyses of the remaining ten studies (1413 participants) did not find a clinically significant difference between self-management and usual care (MD -3.51, 95%CI -5.37 to -1.65, $p<0.001$), although there was statistically significant difference both in total score and score from baseline. In pooled analysis of SGRQ domain score, reported in nine studies (1356 participants), a significant difference between the intervention and control group was noted in the impact domain (MD -5.71, 95% CI -9.17 to -2.25), with marked heterogeneity between studies (I^2 = 51%), but difference was seen between groups in symptom or activity domains (MD 3.09, 95% CI -5.42 to -0.77; -2.75, 95% CI -4.93 to -0.56, respectively). A clinically significant difference was found when the previously excluded CCTs were included, however high heterogeneity (I^2 from 60% to 79%) was indicated.

The CCQ was used to measure HRQoL in two studies (194 participants). Kheirabadi et al [54] (42 participants) found no difference between groups, while Chavannes et al [52] (152 participants) did report a lower score in the intervention group (0.92 ± 0.72) compared with usual care (1.74 ± 0.95). The CRQ was used in three studies (170 participants) but was unable to be pooled as a metanalysis due to lack of data [55-57]. In individual results, Rea et al [57] (117 participants) reported statistically significant difference in favour of the intervention in fatigue and mastery domains (intervention 17.7 and 21.4, control group (15.7 and 20.7, respectively), Ghanem et al [56] (39 participants) reported statistically significantly difference in all domains (dyspnoea 19.6 ± 5.2 vs 13.5 ± 4.3, fatigue 17.4 ± 5.4 vs 13.2 ± 5.1, emotion 33.5 ± 7.2 vs 29.7 ± 11.4, mastery values not reported). These positive results were not reflected in the study by Faulkner et al [55] (14 participants) with no significant differences found on any domain in the CRQ. The SF-36 was used to measure generic HRQoL in three studies (307 participants) for which pooled analyses were not possible [56-58]. No significant outcomes were noted in two of these studies [57,58], and in one study there were substantial differences at baseline measurement which restricted the authors to reporting change in intervention group only, which was significant in physical functioning, pain, vitality and role emotions [56] (39 participants). Generic HRQoL was also measured on a variety of other scales: Moullec et al [53] (27 participants) found statistically significantly higher scores in the physical domain of the short version of the questionnaire validated by the WHO (WHOQOL-BREF) (13.4 ± 1.9 vs 9.4 ± 2.2); Coultas et al [58] found statistically significant improvement in Illness Intrusiveness Rating Scale (IIRS) following nurse-assisted collaborative management; Ninot et al [59] found significant differences in the Nottingham Health Profile (NHP); and Emery et al [60] found no significant change on the Sickness Impact Profile (SIP) in the intervention group but a significant change in control.

Hospital admissions data were reported and pooled in six studies (1077 participants) with no significant difference noted between intervention and control (OR 0.77, 95% CI 0.45 to 1.30) [57-59,61-64]. Nor were there difference seen in individual studies that could not be included in metanalysis with van Wetering et al [50] (158 participants) reporting mean number of hospitalisations of (0.75 ± 1.29) in the group receiving integrated disease management compared with usual care (0.96 ± 1.35) over a 24 month period; Wakabayashi et al [65] (85 participants) reporting no difference in intervention (0.07 ± 0.3) compared with control (0.19 ± 0.8) over a 12 month period; and Chuang et al [66] (282 participants) reporting no significant difference between all-cause hospital admissions in the intervention group than in the control group (40 ± 27 vs 57 ± 27). Moullec et al [53](27 participants) reported all-cause hospital admissions for intervention (3 out of 11 participants and control (4 out of 16 participants) in their controlled clinical trial. Including this in the primary metanalysis produced comparable odds ratio of 0.78 (95% CI 0.48 to 1.28), with an I^2 of 65%.

Emergency department presentations were reported in five studies [20,57,61,64-66] (1318 participants), however data could not be pooled due to methodological differences. In individual results: Rea et al [57] (117 participants) reported five (6%) visits in the intervention group and seven (13.5%) visits in the control group after 12 months of follow-up; Bourbeau et al [20] (175 participants) reported a significant difference in favour of the group receiving integrated disease management with 2.5 compared to 3.2 visits per year over a 24 month period; Rice et al [64] (659 participants) similarly reported significantly fewer visits in the intervention compared with control (67.0 vs 91.2 per 100 person-years); this positive impact was not found in the study by Wakabayashi et al [65] (85 participants) who found no significant difference in emergency department presentations; and finally changes in the frequency of ED visits were found during follow-up. Chuang et al [66] (282 participants) did report fewer presentations in the intervention group (92 ± 42 vs 71 ± 29), however this difference was not statistically significant.

Patient reported breathlessness was reported on the MRC in six studies, with three using the MRC (286 participants) [52,55,62] and three the modified MRC (mMRC) (284 participants) [50,65,67]. Three studies [55,62,67] (175 participants) were combined in metanalysis and reported as a statistically significant improvement in the intervention group (MD -0.83, 95% CI -1.36, to -0.30), however the clinical significance is unclear. The inclusion of the controlled clinical trial by Chavannes et al [52] (152 participants) did not alter the impact of these results (-0.67, 95% CI -1.19 to -0.16). In individual study results; Wakabayashi et al reported no significant difference between groups although there was an improvement in mMRC in those receiving self-management over a 12 month follow-up; van Wetering et al [50] found a statistically significant difference between groups in change from baseline on MRC (0.21 ± 0.10); Baseline Dyspnoea Index (BDI) was used in the study by Akinci et al [51], but no significant change in dyspnoea was noted;. Similarly, the studies by Monninkhof et al [68] and Bourbeau et al [20] showed no significant between-group differences. Dyspnoea measured using the and a visual analogue scale (VAS) was observed to be lower in the intervention group in 12 month follow-up in the study by Moullec et al [53] (intervention group 1.3 ± 1.2 vs control 4.0 ± 3.0).

Functional capacity was measured in eight studies using the six minute walk test [20,51,53,56,65,67-71] (673 participants). Pooled meta-analysis was able to be completed in six studies (259 participants) but did not result in a clinically or statistically significant difference between groups (MD 33.69 m, 95%CI -9.12 to 76.50, p = 0.12) and heterogeneity was high between studies ($I^2 = 89\%$) [20,56,65,67,68,70,71]. Results from the two excluded controlled clinical trials reported statistically and clinically significant improvement in six minute walk test in favour of the intervention (Moullec et al [53] intervention 510.6 ± 80.2 vs control 436.3 ± 82.1; Akinci et al intervention 190.3 ± 65 vs control 170.6 ± 55.4). When these studies were combined in metanalysis the mean distance increased to clinical and statistical significance (MD 35.90, 95% CI 1.35 to 70.44). The Voorrips Questionnaire was used to measure activity level in two studies (65 participants) with both showing significant improvement in favour of the intervention groups [53,71]. Faulkner et al [55] measured physical activity using the seven-day physical activity recall questionnaire; however there were no statistically significant differences between intervention and usual care.

One type of self-management versus another type of self-management

Six studies (579 participants) reported data from head to head studies in which a self-management program was compared with a different type of self-management program [42-48]. HRQoL was measured using the SGRQ in one study (17 participants) with no significant difference between found no between-group differences in those receiving a mobile telephone based coach or self-directed program [48]. The CRQ was used in three studies. Nguyen et al [47] (38 participants) reported a statistically significant improvement total score and all except emotional domain in both study groups. Stulbarg et al [43] (103 participants) found that in individuals who received less intensive versus those who received most intensive exercise training in addition to dyspnoea self-management, that this who received higher intensity statistically improved better in both mastery and dyspnoea domains. In the community based exercise program in addition to self-management Effing et al [45] (142 participants) found a higher CRQ dyspnoea score compared to those receiving self-management only. They did not find a significant difference among individuals who received community based exacerbation education compared to only self-management [44] (139 participants). Effing et al [44,45] additionally measured HRQoL on the CCQ and SF-36 but found no statistically significant difference between groups (281 participants). Stulbarg et al [43] found no statistically significant differences between groups in the SF-36 mental and physical components. However, when reporting difference between groups using the SF-36, Nguyen did find statistically significant difference between groups in the physical component and physical and mental component in their two studies respectively [47,48]. Finally, Sassi-Dambron et al [42] (80 participants) used a quality of well-being scale and found no differences among their three intervention groups.

Hospital admissions were measured in three studies but none found a difference in hospital admissions between groups receiving different types of self-management interventions, which is reassuring [43-45]. Similarly, the studies by Effing [44,45] (281 participants) observed no difference in emergency department presentations between their intervention groups. Patient reported breathlessness was measured by three studies (322 studies) and on a variety of measures. The MRC was used by Effing et al [45] (142 participants) but resulted in no differences between groups (2.2 ± 1.1 vs 2.5 ± 1.2). The University of California San Diego (UCSD) Shortness of Breath Questionnaire (SOBQ) and the Transitional Dyspnoea Index (TDI) were reported by [43] with dyspnoea significantly improved on the SOBQ but not on the TDI. Sassi-Dambron et al [42] did report a significant improvement on both the SOBQ and the TDI but not on the other measures they included being American Thoracic Society Dyspnoea Scale (ATS-DS), the Oxygen Cost Diagram (OCD), a VAS scale and the Borg Scale of Perceived Dyspnoea.

Functional capacity was measured on six minute walk by four studies (238 participants) [42,43,47,48]. While there was an improvement in six minute walk distance in the internet based self-management group compared with the face to face dyspnoea program, Nguyen et al [47] (38 participants) did not find this to a statistically or clinically significant level, nor did they find a significant difference between groups on the incremental cycle ergometer test. Similarly, Stulbarg et al [43] and Sassi-Dambron et al [42] found no significant difference in six minute walk distance in their intervention groups (183 participants). Stulbarg et al also did observe an improvement on the incremental and endurance walk tests undertaken on a treadmill in those individuals who received an intensive exercise program.

Effing et al [45] (142 participants) measured functional capacity using the incremental shuttle walking test (ISWT), the endurance shuttle walk test (ESWT) and daily physical activity. There was a statistically significant improvement in favour of the group participating in an exercise program in addition to self-management in the ISWT; however ESWT difference was not significant. Effing et al [45] additionally measured daily physical activity using pedometres. The mean between-group difference over 12 months of follow-up of 877 steps per day was statistically significant in favour of the group that participated in an exercise programme in addition to a self-management programme. Nguyen et al [48] (17 participants) also measured daily physical activity using a dual-axis accelerometer and found a decrease in mean number of steps/d with the coached management compared with lesser increase with the self-monitored intervention.

Hospital at home for acute exacerbations of chronic obstructive pulmonary disease. (8 studies, 870 participants) (Table 8.4)

This review included eight studies randomising 870 participants. All studies reported data from hospital care provided at home compared with usual care[72-79]. The hospital at home programs were for patients admitted with an exacerbation of COPD and who were transferred from the hospital setting to receive care at home within 72 hours of admission. Assistance with medication and condition management was delivered by respiratory specialist nurses in all studies, and this was supplemented with home visits from general practices or medical officer as part of the hospital at home team in two studies [79,80]. Allied health interventions were integrated as part of one program [80] and nurses provided education in addition to usual condition management in one further study [77].Telephone calls were provided in addition to home based visits in all programs. Out of hours support was provided by usual community services in most instances, with additional district nursing services providing overnight support in one study [73], and a direct phone number for the medical unit in the hospital given in another study [77]. Only one study provided twenty-four hour support visits as required in a “clinical unit” model [78].

Hospital at home versus no usual care

All eight studies compared hospital at home with usual care received as part of an acute admission to hospital for the management of an exacerbation for COPD.

Three studies reported HRQoL using the St Georges Respiratory Questionnaire (432 participants) in hospital at home programs compared with usual care [73,74,77]. The differences in reporting between the studies and missing data restricted the Cochrane Systematic Review authors from undertaking a meta-analysis [39]. Absolute mean change in SGRQ was reported in two studies [73,74]. Hernandez [74] reported a significant improvement in quality of life reported as reduction in SGRQ of 6.9 in the home hospitalisation group compared with 2.4 in usual care, however standard deviations were not reported. Davies [73] reported on the 50 participants remaining in the study at three months post exacerbation and found no significant difference in SGRQs scores from admission or between groups for those who received home based care and those who received in hospital care. Those participants receiving home based care decreased scores by 0.48 (SD 16.92) compared to those who remained in usual care reporting a reduction in SGRQ of 3.13 (SD 14.02). Ojoo [77] further only reported percentage improvement in SGRQ scores. Overall the authors concluded that there was very limited evidence ‘with regard to the association between hospital at home and health-related quality of life’ [39].

All included studies reported data on hospital readmissions and were included in the meta-analyses carried out in the included Cochrane Systematic Review [39]. The rate of hospital readmissions was reported as having a small but significant reduction in those who received hospital care at home (RR 0.76, 95% CI 0.59 to 0.99, p=0.04). The effect on reduction in admission was increased (RR0.73 , 95% CI 0.58 to 0.91, p = 0.006) with the removal of one high risk study [80] that resulted in a narrower confidence interval and improved heterogeneity (34% to 16%).

Emergency department presentations were not reported in the Cochrane Systematic review and were only reported in only one of the eight included studies [74]. Emergency department presentations that did not result in an admission were reported as almost half of the readmissions reported for those who received conventional hospital based care (15 per 11 patients in home hospitalisation and 29 per 21 patients in conventional care, p=0.01). Patient reported breathlessness and functional capacity were not reported in the Cochrane Systematic Review or in the included studies that compared hospital at home program following acute exacerbation of COPD [39].

Pulmonary rehabilitation for chronic obstructive pulmonary disease. (31 studies) (Table 4)

This review included 31 studies randomising 1348 participants that measured short term outcomes at completion of program. All included studies reported data from pulmonary rehabilitation versus usual care and all, except on cross over trial [81], undertook a randomised controlled approach.

Intervention setting, duration, intensity of exercise and included components did vary across studies, however there was clear homogeneity across study results allowing for metanalysis and interpretation.

Pulmonary rehabilitation versus usual care

Thirteen trials measured HRQoL (1002 participants) using a number of measurement tools. The review authors reported on the Chronic Respiratory Disease Questionnaire (CRQ) (11 studies, 618 participants) [81-91] and the St Georges Respiratory Questionnaire (6 studies, 384 participants) [85,92-96]. HRQoL was significantly improved in the pulmonary rehabilitation group in all domains of the CRQ (Fatigue 0.92, 95% CI 0.71 to 1.13 p<0.00; emotion 0.76, 95% CI 0.52 to 1.00 p<0.001; mastery 0.97, 95% CI 0.74 to 1.20 p<0.001; dyspnoea 1.06, 95% CI 0.85 to 1.20 p<0.001). Similarly HRQoL improved in favour of intervention in the total score for SGRQ (-6.11, 95% CI -8.98 to -3.24 p<0.001) and in impact (-6.27, 95% CI -10.08 to -2.47 p<0.001) and activity domain (-4.78, 95% CI -7.83 to -1.72 p<0.05). Functional capacity was measured on the six minute walk test in sixteen trials (669 participants) [14] with an overall positive effect in favour of the intervention group (MD 48 metres 95%CI 32 to 65). While the review authors reported this as under MCID, more recent papers have reported MCID as 25 metres [97].

Hospital admissions and emergency department presentations were not reported in this systematic review nor in the included studies. Patient reported breathlessness were not reported in this systematic review either but was reported in four studies (168 participants) [88,92,98,99]. Boxall [92] (45 participants) found a significant difference statistical and clinical difference in change from baseline in patient reported breathlessness on the Borg scale in favour of the intervention group at 12 month follow-up (intervention -0.13 vs +0.22, p<0.05). Similarly, Hernandez [88] (37 participants) reported a significant improvement on MRC scale (p=0.02); on the basal dyspnoea index (BDI) globally (p<0.05) and in all components (magnitude of task p=0.05; functional impairment, p = 0.03; magnitude of effort, p = 0.01) ; and on the transitional dyspnoea index (TDI) globally (1.4) and in each dimension (0.4) in each dimension. Xie [99] (50 participants) also reported a significant improvement in dyspnoea based on the BDI (p<0.05). Guell et al [98](40 participants) only measured at baseline for purposes of correlation.

Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease (9 studies, 509 participants) (Table 4)

This review included nine studies randomising 509 participants with 389 participants included in analyses. Four studies provided an intervention that included elements that reflect the current definition of pulmonary rehab in including exercise training, education to elicit behaviour change [100-103]. The four remaining studies only provided endurance exercises [104-107]. Pulmonary rehabilitation was commenced at a range of time points post exacerbation and as part of inpatient, outpatient and in or outpatient services. Four studies compared inpatient programs with usual care that were commenced between 3 to 8 days of admission [106-108] or when deemed medically fit (day of stay not reported) [101]. Four included studies compared outpatient pulmonary rehabilitation programs that commenced between 6 to 10 days of discharge [100,103,104], however one study commenced this post discharge from hospital at home [105], and a further requiring individuals to be well for four weeks before commencement [104]. A final study explored repeat abbreviated inpatient or outpatient pulmonary rehabilitation commenced within 12 months of a previous pulmonary rehabilitation program [102].

Eight of the nine studies compared the intervention with usual care [100-107]. One further study, based on individuals recovering from an intensive care admission associated with acute respiratory failure, provided all patients with lower extremities mobilisation when unable to walk followed by endurance exercise once mobile. The intervention group proceeded to increased endurance training through cycling and stair climbing to highest tolerated intensity [108]

Pulmonary rehabilitation following exacerbations versus usual care

Eight of the nine studies of pulmonary rehabilitation compared the intervention with usual care [100-107]. Usual care was described as usual care without exercise, as an inpatient this was standard inpatient care and as an outpatient usual care was care under their general practitioner and respiratory therapist.

Six studies reported HRQoL (320 participants) [100-103,105,107]. Five of these studies used the Chronic Respiratory Questionnaire (CRQ) [100-103,107] (in 259 participants) with a pooled significant mean difference of 0.81 (95% CI 0.16 to 1.45) for the fatigue domain and 0.97 (95% CI 0.35 to 1.58) for the dyspnoea domain, both well above the required MCID of 0.5 per unit of CRQ domain. There was marked heterogeneity noted in the study results (I^2 = 82% CRQ-D, I^2 = 89% CRQ-F), and while the interventions ranged from only endurance exercise to full behavioural change and symptom management programs and implemented within days of discharge to within 12 months following a previous pulmonary rehabilitation program and varied duration from 10 days to several months, the authors judged that there were no key differences in methodological or program approaches that would have impacted this heterogeneity. The St George's Respiratory Questionnaire (SGRQ) was reported in three studies [100,103,105] (128 participants) and found that the pooled results of the SGRQ total score were significantly lower in the pulmonary rehabilitation group compared with usual care (mean difference -9.88; 95% CI -14.40 to -5.37) and reported that the sub domain scores similarly favoured the intervention. These studies were noted to have a more homogenous approach (I^2 = 59%) and this reflects the context of all studies being within outpatient setting, commenced within a week of discharge and compared with usual care without additional disease or exercise education or exercise training.

All cause hospital admissions were reported in five studies [100,101,103,105,107] (250 participants). Pooled data analysis was reported as a significant reduction in odds of readmission to hospital (OR 0.22; 95% CI 0.08 to 0.58; I^2=51%) and a NNT of 4 (95% CI 3 to 8). Emergency department presentations were reported in only one study (42 participants) [103] who reported that there was a significantly higher emergency presentation rate in the individuals receiving usual care with a mean difference of 0.14 (95% CI 0.3 to 1.5, p = 0.01).

Patient reported breathlessness was not reported in the systematic review or included in analyses however this was reported in the three of the included studies (90 participants) [105-107]. Behnke [107] reported that that Transient Dyspnoea Index scores, while significantly improved did not differ between the intervention and control in the initial 1 and 11 day results, however scores continued to improve for the exercise group at both 3 and 6 months (4.6±+0.7 and 0.4± 0.8 respectively, p< 0.001), whereas the control remained stable. Kirsten

[106], being part of the same research group similarly used the Transient Dyspnoea Index and found that these scores were larger at day 5 and 10 for those in the exercise group versus the control ($p<0.05$). Murphy [105] reported that there was a significant improvement in breathlessness at rest in both the control and intervention group assessed on the MRC dyspnoea scale but no significant changed in resting breathlessness based on BORG in either exercise or control group, however between group statistics were not reported.

All eight studies reported functional capacity (449 participants) [100,102-107] using either the six minute walk (six studies, 300 participants) [101,102,104,106-108] or a shuttle walk test (three studies, 128 participants) [100,103,105]. The pooled results from the six-minute walk distance was significantly improved in those undertaking an exercise or pulmonary rehabilitation programs with a mean different in distance of 77.70 metres (95% CI 12.21 to 143.20) representing an important clinically significant difference above MCID 25 metres. The review authors did note the large to moderate heterogeneity between the trials at a high $I^2 = 93\%$ [101,102,104,106-108]. The pooled results from the shuttle walk tests similarly favoured the intervention groups reported as a weighted mean difference of 64 metres (95% CI 41.28 to 87.43). There was less statistical heterogeneity across these three studies with an $I^2 = 8\%$ [100,103,105].

One type of pulmonary rehabilitation following exacerbations versus another type of pulmonary rehabilitation following exacerbations

One study (57 participants) compared two groups of a staged exercise program following intensive care admission for acute respiratory failure. The intervention group received a four staged progressive exercise program from stages I to IV (stage IV being highest tolerated intensity in cycling and stair climbing) and the comparison group receiving stages I and II, including mobilisation and strength training while unable to walk and endurance walking training once mobile [108].

This study did not report on HRQoL, hospital admission or emergency department presentations. Breathlessness on exertion was reported using a visual analogue scale and functional capacity was measured using a six minute walk. Both groups significantly improved in sense of breathlessness using a visual analogue scale ($p<0.001$), however the improvement in the group who received stages I – IV was significantly higher than that in the group who only received the initial exercise training stages ($p < 0.01$). Six minute walk distance was however significantly improved in the group who received the full program compared with those who received the first two phases who showed no significant improvement in six minute walk distance.

Of these, three studies provided an intervention that included elements that reflect the current definition of pulmonary rehab in including exercise training, education to elicit behaviour change [100,102,103], and four studies only provided endurance exercises [104-107].

Telehealthcare for chronic obstructive pulmonary disease. (10 studies, 1188 participants) (Table 4)

This review included 10 studies randomising 1307 participants with 1188 included in analyses. Seven of the included studies reported data from telehealthcare versus usual care and three reported data from telehealthcare versus another type of intervention. The telehealthcare interventions included in this review were self-management through telephone support [20,109,110], delivery of a self-management program through the internet [47,62,111], the use of a specialist independent network [112] and videoconferencing [113-115].

Telehealthcare intervention versus usual care

The majority of studies used a telehealth program compared with usual care which consisted of interaction with their usual health provider in the community or home setting [20,62,109-111,113]. HRQoL was reported for three studies (420 participants) with a minimally clinically significant change with a random-effects generated mean difference of -6.57 reported St Georges Respiratory Questionnaire (SGRQ) with a wide 95%confidence interval of (CI) -13.62 to 0.48 [20,62,115]. Hospital admissions were reported in three studies that compared intervention to usual care. In reporting hospitalisations, McLean et al [15] pooled data with a further study that compared videoconferencing within an integrated program with usual care plus education and home visits. Hospitalisations were significantly improved (OR 0.46, 95% CI 0.33 to 0.65, $p < 0.00001$). Emergency department presentations were significantly reduced in two studies that compared COPD self-management program delivered through a telehealth system with usual care [20,111] (OR 0.40, 95% CI 0.22, 0.71 and OR 0.47, 95% CI 0.24, 0.89 respectively). Emergency department presentations were additionally reported as significantly different when pooled with a study that compared management through a specialist independent network with usual care plus education and home visits (OR0.27, 95% CI 0.11, 0.66). The average number of visits per patient over a three month period was also reported as greater in the control group in one study that investigated nurse led telephone follow up program (OR 0.17, 95% CI 0.04 to 0.67) [110]. Patient reported breathlessness and functional capacity were not discussed as part of the Cochrane Systematic review of telehealthcare interventions compared with a control [15]. However breathlessness was not seen to significantly improve when reported as daytime breathless ness scores in a study that compared a home theophylline monitoring system with usual care [116]. Similarly, functional capacity was reported as having no significant improvement (OR 0.998, 95% CI 0.997, 0.999) in a single study that compared COPD self-management program compared with usual care [117].

Telehealthcare intervention versus another type of management program

Two studies compared an internet or telephone based self-management program with usual care plus home visits and education (370 participants) [118,119], and a single study compared an internet based dyspnoea self-management program with a face to face program (38 participants) [120]. A minimally clinically important mean difference of 0.5 ($P < 0.001$) was found in HRQL when a web-based dyspnoea management program was compared with a face to face dyspnoea management program [120]. HRQL was not reported in the other two studies. Hospital admissions were reported to significant change in a single study that compared videoconferencing within an integrated program with usual care plus education and home visits (OR 0.45, 95% CI 0.24, 0.86) [118]. This study also reported a significant difference in emergency department presentations (OR 0.47 , 95% CI 0.24, 0.89) (OR 0.27 , 95% CI 0.11, 0.66) [118]. Johnston 2000 [119] reported no significant difference between the average number of visits per patient (1.79, SD 1.48) for intervention patients and those receiving usual care plus home visits (1.53 (SD 1.43)). In the study by Nguyen [120] there was no significant difference in hospital admissions between the two interventions.

As above, patient reported breathlessness and functional capacity were not discussed as part of the Cochrane Reviews, however the study by Nguyen reported both for their internet based self-management program when compared with a face to face program (CRQ mean change 15.9 ± 5.4 vs 18.8 ± 6.2, $p<0.001$). Breathlessness with activities of daily living improved significantly over time in both intervention groups but there was not a significant difference observed between the two programs ($p=0.51$), functional capacity as measured by six minute walk was significantly higher in those who participated in the online dyspnoea management program.

Home care by outreach nursing for chronic obstructive pulmonary disease (9 studies, 1381 participants) (Table 4)

This review included 9 studies randomising 1381 participants. All included studies reported data from outreach nursing versus usual care [117,121-128].

Home care by outreach nursing versus usual care

Home outreach nursing was delivered as home-based care delivered by a respiratory nurse that focused on disease and self-management education, case management and care coordination, and disease management support in the form of exacerbation planning and symptom management. Usual care took the form of community based support from general practitioners and specialist and acute services regularly available to the participants. One study included a third study arm with the nurses delivering care receiving additional training in collaborative management [124]. The authors for the Cochrane Systematic Review judged both intervention arms of this study to be delivering nursing home visits and consequently combined and reported the results from this study as a single intervention [129].

Seven included studies reported HRQoL [117,121,122,124,125,127,128]. A statistically significant improvement in HRQoL was found in the home-based care group in the meta-analysis of four studies that used SGRQ (MD -2.60; 95% CI -4.81 to -0.39, $p = 0.02$) [117,124,125,127]. Subgroup analysis was available in three studies and showed no significant difference between intervention and control scores: activity (-1.32 , 95%CI -4.46 to 1.82) $p = 0.41$); impact (-2.63 (-5.77, 0.50), $p = 0.10$); and symptoms (-1.15 (-4.70, 2.41). HRQoL data measured using the Sickness Impact Profile (SIP) was reported in two studies [122,127]. Littlejohns [127] reported a significant improvement in physical scores (3.90 , 95% CI 1.50 to 6.30), p <0.01) in contradiction to Bergner [122] who reported no significant difference between the intervention group and the control (0.0 , 95% IC 0.00 to 0.0)). Data was not pooled in the Cochrane Systematic Review as standard deviations were only available from Littlejohn [129]. Two further studies measured HRQL using the SF-36, however analysis was not possible due to insufficient reported data [121,124]. SF-36 scores were not reported as significantly different in the intervention compared to control in Coultas' [124] study of COPD patients. A significant improvement in scores was reported in Aiken [121], however data included individuals with both COPD and congestive heart failure. The modified Dartmouth Primary Care Cooperative (COOP) was used to measure HRQoL in one study [128]. The Cochrane Systematic Review stated that there was insufficient data reported to perform a pooled analysis, however significant reduction in intervention group scores at 12 months was reported in emotional condition, difficulty doing daily tasks and general HRQoL (p=0.01, p=0.03, and p=0.03 respectively).

Hospital admissions were reported in five studies [117,123,125,126,128]. When pooled as a meta-analysis, no significant change in number of hospitalisations for the intervention group was reported (Peto OR 1.01; 95% CI 0.71 to 1.44; p = 0.17) [129]. Bourbeau [117] was identified as an outlying study and the potential cause of significant statistical heterogeneity (I^2 = 65%). On subgroup analysis, the number of hospitalisations in patients receiving home-based nursing care was reported as statistically significantly increased (OR 1.59; 95%CI 1.02 to 2.47) [129].

Emergency department presentations were reported in four studies [117,121,124,126], however the Cochrane Systematic Review stated that there was insufficient data reported to perform a pooled analysis [129]. A significant difference in the number of patients presenting to the emergency department was reported in a single study (41% difference, p=0.02) [117], with the three other studies reported no difference in average presentations per month (0.11 (SD 0.02) vs 0.10 (SD 0.31))[121], average presentations per patient (2.2 (SD 2.4) vs 2.3 (SD 3.1), p = 0.997) [126] or average change in number of presentations per patient (-0.02 , 95% CI -0.3 to 0.1) vs 0.04 (95% CI -0.1 to 0.3) [124].

Functional capacity was reported in two studies [126,127], both finding no significant difference in distance walked during a six minute walk test when comparing those who received a home-based nursing care intervention and those receiving usual care (pooled mean difference 5.05; 95% CI -15.08 to 25.18; p = 0.62). Patient reported breathlessness was not discussed as part of the Cochrane Systematic Review or reported in the included studies.

Integrated disease management for patients with chronic obstructive pulmonary disease (26 studies, 2997 participants) (Table 4)

This review included 26 studies randomising 2997 participants [130]. Twenty studies (1555 participants) compared an integrated disease management program with usual care which consisted of regular follow up from health providers. Two studies (70 participants) compared the intervention with a mono-disciplinary intervention in providing medication optimisation and [81,131] and four studies (981 participants) compared the intervention with education provided in addition to usual care [64,132-134]. Studies were undertaken in primary care settings (eight studies), secondary care settings (12 studies), tertiary care settings (one study) and for five studies the setting was both in the primary and secondary care environment. The mean number of intervention components was four and ranged from two to eight, including for example: tailored self-management; exercise training; actions plans; nutritional guidance; and smoking cessation. Three health care providers were involved in the interventions on average and this ranged from two to seven, including for example; general practitioners, respiratory nurses, health workers; and case managers.

Integrated disease management versus usual care

The review authors included all twenty six studies in their analyses of integrated disease management compared with usual care, where usual care was considered regular follow-up from the individuals' general practitioner and respiratory specialist.

Twenty three of the included studies reported health related quality of life (2344 participants) and measured this on a range of instruments. Disease specific HRQoL was measured on the SGRQ in thirteen studies (1425 participants) with short term follow-up (defined as up to 12 months). Those enrolled in the integrated disease management had a statistically significant improvement in HRQOL (MD -3.71, 95% CI -5.83 to -1.59, p< 0.001), but this did not meet minimal clinically important difference of -4 units change. High heterogeneity (I^2 = 56%, P = 0.01) was noted and likely due to the variation in study quality. Following sensitivity analyses, there remained no clinically significant difference in pooled analysis of studies with adequate allocation concealment group (MD -3.16; 95% CI -4.75 to -1.57, P < 0.001) [20,133,135-140] or adequate blinding of outcome assessment (MD -3.16; 95% CI -4.81 to -1.51, p < 0.001). [20,64,133,139-141] . A clinically significant effect (-4.22; 95% CI -6.14 to -2.30, P < 0.001) in favour of the intervention was found on excluding a cluster-randomized study with an unclear risk of recruitment bias and a high risk of bias on baseline imbalance [134]. A clinically significant effect was also found when two studies were analysed based on intention to treat (MD -4.65; 95% CI -6.69 to -2.62, P < 0.0001) [20,64].

Disease specific HRQoL was also measured using SGRQ in two studies (189 participants) with long term follow-up, defined by the review authors as 12 to 24 months [136,140] and similar to the results seen in the overall short term follow-up studies, there was no clinically or statistically significant difference (MD -0.22; 95% CI -7.43 to 6.99, P = 0.95; I^2 = 54%, P = 0.14) between those who participated in integrated disease management compared with usual care.

The review authors undertook subgroup analysis for disease specific HRQoL for the SGRQ results based on: type of control group; type of setting; study design; and main component of program. Nine studies compared integrated disease management with usual care with no other input (744 participants) and when pooled, results indicated a clinically significant difference in SGRQ in favour of those who received integrated disease management (MD -4.09, 95% CI -6.35 to -1.84, P < 0.001). Four studies included a control of usual care with mono-disciplinary treatment of education and when compared with the intervention there was no significant difference in SGRQ (MD -2.98; 95% CI -7.69 to 1.74, P = 0.022).In relation to study setting, a statistically and clinically significant difference was observed in the pooled results of the six studies (456 participants) undertaken in a primary care setting in favour of those who received integrated disease management (MD -4.68, 95% CI -8.80 to - 0.56) [132,134-137,140]. Subgroup analysis of the seven studies (969 participants) undertaken from within a secondary care setting did show a statistically significant different but did not reach minimally clinical important difference between the intervention group and usual care (-3.41, 95%CI -5.97 to -0.85) [20,64,133,138,139,141,142]. In relation to study design, subgroup analysis based on study design found no difference in SGRQ between intervention and usual care within the single cluster randomised controlled trials (121 participants) when compared with usual care (MD2.30; 95%CI - 1.62 to 6.22_[134]. Pooled meta-analysis of the remaining randomised controlled trials (1304 participants) revealed a clinically significant change in the SGRQ in favour of those receiving integrated disease management (MD -4.22, 95% CI -6.14 to -2.30, P < 0.0001). Review authors additionally carried out sub-group analysis based on dominant component of the program being either self-management or exercise training. Pooled analyses revealed no statistical or clinical significance in the four programs (942 participants) that included self-management as their major component (MD -2.76, 95%CI -5.88 to 0.36, P = 0.08)[20,64,134,137], but did find a statistically and clinically significant improvement in SGRQ in the six studies (373 participants) that placed exercise training as their major component (MD -4.74, 95% CI -7.05 to -2.43, P <0.0001) [132,135,136,138,140,141]. One further study included a tailored education program as the core component [133] and a further study focused on structured follow-up with nurses and GPs.

Disease related quality of life was also measured using the CRQ in eight trials (493 participants) [57,81,131,143-147]. Four studies (148 participants) with short term follow-up (up to 12 months) were able to have data pooled and a statistically and clinically significant difference was seen between those receiving integrated disease management compared with usual care (Of the four studies whose data could be pooled, (dyspnoea MD 1.02; 95% CI 0.67 to 1.36, P < 0.0001; fatigue MD 0.82; 95% CI 0.46 to 1.17, P < 0.0001; emotion MD 0.61; 95% CI 0.26 to 0.95, P < 0.0005; and mastery MD 0.75; 95% CI 0.38 to 1.12, P < 0.0001) [81,131,145,147]. Two studies (149 participants) reported CRQ on interventions with long term follow-up (12 to 24 months) and pooled analyses showed a statistically and clinically significant difference in favour of intervention in both CRQ emotion and mastery (emotion MD 0.53, 95%CI 0.10 to 0.95, P = 0.02; mastery MD 0.80, 95% CI 0.37 to 1.23, P < 0.01). Pooled analyses were not possible on dyspnoea domain due to heterogeneity and although there was a statistical effect in the fatigue domain, this did not reach clinical relevance (0.45 MD, 95%CI 0.05 to 0.85, P = 0.03) [140,146].

General HRQoL was measured on the SF-36 in three studies [57,142,148], however, pooled analysis was not possible due to lack of reported data, and small sample size in two studies questions their reliability. The Sickness Impact Profile was used in two studies (183 participants) with no difference between groups noted [141,149]. Similarly no significance was seen in the York Quality of Life Questionnaire used in a single study (32 participants) [143]. There was a significant improvement in general HRQoL seen on the Dartmouth Primary COOP, however this was only analysed in the intervention group of 30 participants due to lack of control data [150].

Hospital admissions were reported in four studies and reported in the review as two studies with short-term follow-up (266 participants) and two studies with long term follow-up between 12 and 24 months. No difference was observed between those receiving integrated disease management compared to usual care in the two studies (266 participants) with short term follow-up of12 months (OR 0.62; 95% CI 0.36 to 1.07, P = 0.49) [57,149]. Similarly, no difference was observed in hospital admissions in the pooled results of the two studies (283 participants) with between 12 and 24 months follow-up (OR 0.78; 95% CI 0.38 to 1.57) [140,146]. The heterogeneity was high ($I^2 = 53\%$) in the longer term follow-up studies, which was noted to reflect the positive effect in favour of integrated disease management in van Wetering et al 2010 [50] compared to no effect seen in Sridhar 2008 [146].

Emergency department presentations were reported in six studies [20,57,64,133,144,150] with data pooled from four studies (1161 patients) [20,57,64,150]. No difference was found between the integrated disease management groups and those receiving usual care, with a high heterogeneity noted (OR 0.64; 95% CI 0.33 to 1.25, $I^2 = 71\%$). Similarly, intention-to-treat sensitivity analysis of two studies showed a mean difference in favour of the control group (MD 0.49; 95% CI 0.36 to 0.67, $p < 0.0001$, $I^2 = 0\%$). Three studies were excluded from pooled analyses due to lack of reported data [133,139,144]. Two of these individual studies found no statistically difference in emergency department presentations between the integrated disease management group and the usual care [133,139], however one study did find that emergency department presentations were reduced in favour of those who participated in the intervention group (0.45 ± 0.83 for intervention group, 1.58 ± 1.96 for control group; $p = 0.0001$) [144].

Patient reported breathlessness was reported by four studies on the MRC Dyspnoea scale [133,136,140,151]. The results from three studies were able to be pooled (345 participants) [133,140,151] as the results from Gottlieb [136] were not published. Breathlessness was reported as statistically improved but not clinically relevant in the integrated disease management group compared with control (MD 0.30; 95% CI -0.48 to -0.11, $I^2 = 0\%$, $P < 0.001$). Three studies (145 participants) measured breathlessness using the Borg scale, however, similar to the results in the MRC, no significant difference in breathlessness was observed in the pooled results between those who received integrated disease management compared to usual care (MD 0.14; 95% CI -0.70 to 0.98, $P = 0.74$, $I^2 = 39\%$) [135,136,145].

Functional capacity was measured on six minute walk in seventeen studies. In those studies with short term follow-up of up to 12 months, fourteen studies (871 participants) data was pooled with those receiving integrated disease management exhibiting a statistically and clinically significant difference in six minute walk when compared with usual care (MD 43.86, 95% CI 21.83 to 65.89) [130]. There was high heterogeneity detected ($I^2 = 83\%$). Two studies (184 participants) with long term follow-up (12 to 24 months) showed a statistically significant but not clinically significant improvement in six minute walk when intervention was compared to usual care (MD 16.84; 95% CI 3.01 to 30.67) [136,140].

Review authors conducted subgroup analyses for six minute walk in relation to type of control group, study setting and dominant study component. Six minute walk statistically and clinically improved when those receiving integrated disease management were compared with those receiving usual care without any other component (MD 46.59, 95% CI 19.68 to 73.51, $P = 0.0007$) [135,136,138,140,141,143,145,147,149,151]. Pooled analysis of the four studies that included a control in which participants received optimal medication management or a single education session found no difference between the intervention group and the control (MD 35.99; 95% CI -5.34 to 77.31, $P = 0.09$) [81,131-133].

Statistically and clinically significant improvements in six minute walk were seen in both those individuals who participated in integrated disease management through primary care (seven studies, 427 participants, 45.16 metres (95%CI 8.65 to 81.67, $P = 0.02$)) [81,132,135,136,140,147,151], secondary care (seven studies, 438 participants, 49.18 metres (95% CI

14.28 to 84.08, P = 0.006) [133,138,141,143,145,149,151], and tertiary care (one study, 35 participants, MD 85 metres (95% CI 30.43 to 139.57)) [131].

In relation to dominant program component, in the twelve studies (653 participants) that included exercise as their main component pooled analysis showed a statistically and clinically significant improvement in six minute walk compared with control (MD51.47, 95%CI 26.53 to 76.40).[130]. No significant effect was found in the one study that focused on tailored education sessions (MD 0.40; 95% CI -39.64 to 40.44, P = 0.98) [133] and in another that focused on GP and nurse follow-up (MD 3.50, 95% CI -28.31 to 35.31, P = 0.83) [149].

Maximal exercise capacity using a cycle ergometer test was used to measure functional capacity in four studies (298 participants). All studies statistically improved in maximal exercise capacity when intervention was compared with usual care (MD 6.99, 95% CI 2.96 to 11.02, P < 0.0001).

TAXONOMY OF DISEASE MANAGEMENT

A standardised disease management taxonomy [30] has been applied to provide a narrative summary of the components of comprehensive disease management. It is hoped that using such a framework will guide discussion and increase the utility of the review by increased understanding of intervention intensity and duration and workforce requirements [30]. This is critical in achieving research translation efforts as well as standardisation of outcome assessment and benchmarking.

Many of these discrete interventions are complex in both design and delivery and require distillation of essential elements: e.g. the type, frequency and level of intervention intensity as well as description of the workforce type and scope. Using a pre-specified and standardised taxonomy may assist in providing information to health providers and consumers in design of effective and appropriate interventions for COPD management [8,30] (Figure 1). Understanding the most efficacious organisation, timing and sequencing of these interventions within a disease management approach, as well as resource requirements for these approaches are of high interest internationally and will inform policy, health care decisions and future research [6-8,30]. We will summarise information on the multi-component interventions used in COPD disease management, including: patient population; intervention content, personnel delivery, method of communication, intensity and complexity of intervention, the setting and environment and outcome measures [30].

The recent review of evidence for integrated disease management by Kruis [38] has made an overt attempt to include information in relation to the above domains as part of their inclusion criteria for integrated disease management, classifying their included studies according to the Cochrane Effective Practice Organisation of Care Group (EPOC) taxonomy of interventions as well as patient directed intervention such as self-management and education. The updated review of self-management for COPD by Zwerink [7], while not using an organisational taxonomy as such, did also report the components and features of each intervention in detail and called for greater consensus on intervention components to and the use of a guiding framework to improve consistency and comparison of future studies. The other included reviews provided differing levels of information in relation to the taxonomy domains.

Patient population

All reviews sought to seek evidence for interventions in a patient cohort, and specifically in those individuals with a documented diagnosis of COPD as confirmed by: spirometry result according to the GOLD criteria [7,36,38] or British Thoracic Society criteria [40]; or as confirmed diagnosed by a clinician [37,39,152].

Comorbidity as a contributing factor was discussed by three reviews. Jeppessen (2012) and Zwerink (2014) both discussed the high incidence of comorbidity in COPD including comorbid conditions (cardiovascular disease, diabetes, mental health) and socioeconomic and non-clinical issues (frailty partner and carer, social isolation, and low socioeconomic status) and the marked impact this would have on the outcomes such as hospital readmission and ability to self-manage [7,153]. The impact of comorbidity is increasingly important [7] and as noted by both Zwerink and Jeppessen, future interventions must be responsive to these additional to factors with interventions tailored to meet the needs and facilitate successful intervention in individual disease impact.

Intervention Content

Intervention content with the included individual studies was described in some detail across all reviews. The intervention requirements did vary depending on the context of the review, however they also varied within the context of a comprehensive approach to disease management with some reviews requiring specific components to be integrated into a structured program [7,38] and others accepting single component interventions such as prescribed endurance exercise [37].

The recently updated review of self-management in COPD by Zwerink [7] described clear inclusion criteria that required programs to involve an iterative interaction between the health provide and patient over more than two contacts and with the inclusion of at least two of the following components: smoking cessation, self-recognition and self-treatment of exacerbations, an exercise or physical activity component, advice about diet, advice about medication or coping with breathlessness. Similarly, the recent review by Kruis et al [38] reported on the components and number of components contained in each integrated disease management intervention within the context of 'a multi-faceted response, including different elements (e.g. smoking cessation, physiotherapeutic reactivation, self-management, optimal medication adherence) targeted at the patient, professional or organizational level.'

The remaining studies described their intervention within the context of the major component, the review by Wong et al [27] of home outreach nursing programs for example focused on disease and self-management education, case management and care coordination in the form of nurse delivered home outreach programs. Similarly Jeppesen et al's [39] review of home outreach focused specifically on interventions that included assistance with medication and condition management in the post-acute period. Lacasse [36] and Puhan's [37] reviews on the efficacy of pulmonary rehabilitation described or reported the exercise component involved in the program and did note if there was education in the included study characteristics tables. Finally, McLean's [152] review on telehealthcare interventions in which the delivery of care and health professional decision making was facilitated through a telehealthcare mechanism, with description including for example: education, physical and social assessment, access to call centre, videoconferencing, and physiological monitoring.

Peer support was the only pre-identified element of the taxonomy that was not raised in intervention components, however, this is likely due to the context of the interventions themselves. Regardless, peer and social support are key factors in COPD support and management [6] with consistent reporting of this element useful in future reviews.

Delivery Personnel

Delivery personnel was addressed directly in two reviews, with Kruis et al [38] describing the number of disciplines involved in the intervention as part of the results discussion as well a detailed description of the disciplines involved in each study as part of the characteristics of included studies tables. Similarly, Wong provided a detailed description of the nurse specialist role in their review on home-based outreach nursing programs. Zwerink et al, Jeppesen et al and McLean et al [7,39,152] did not mention delivery personnel or included disciplines as part of the review narrative but did provide detailed information as to the delivery personnel involved in the interventions as part of the characteristics of included studies tables; including such disciplines as: Clinical specialist nurse, pulmonary rehab nurse, respiratory therapist; physiotherapist; dietician; GP; case manager, clinical psychologists, exercise practitioner, certified COPD educator. Lacasse et al and Puhan et al [36,37] did not report the included disciplines, however there was some detail available in the included studies themselves.

Given the focus on multidisciplinary and integrated care, it is increasingly important to understand the resourcing required for program delivery, including staffing. It is important that we understand those disciplines that are key to successful program delivery to ensure benchmarking and high quality delivery of care.

Method of Communication

Communication of the study interventions varied depending on the focus of the review with the majority implementing a face to face interaction through either small group or individual consultation. Jeppesen et al's [39] and Wong et al's [27] reviews of hospital at home and home outreach nursing, for example, were structured around individual face to face interaction supported by telephone contact. Similarly the reviews on pulmonary rehabilitation [36,37], while not reporting this directly, relied on face to face interaction either in a small group or at individual level as reported in the individual studies themselves. The more recent reviews by Zwerink et al [7] and Kruis et al [38] the mode of communication is reported both within the narrative of the review as well as in detail in the characteristics of included studies tables. Finally, the review of telehealthcare [152] required the content to be delivered through within an online platform in the form of telephone interaction, internet based delivery, use of a specialist network and videoconferencing.

Intensity

The majority of reviews described the duration, frequency and sequencing of interventions [7,27,36-39]. The duration of follow-up was also reported with Kruis et al Kruis 2013) separating those under up to 12 months and up to 24 months for analyses and reporting purposes. McLean described the intervention and follow-up in detail but did not report intervention intensity [152].

Complexity

Program components varied depending on the context of the review, however they also varied within the context of a comprehensive approach to disease management with some reviews requiring specific components to be integrated into a structured program. Wong et al [27], Jeppesen et al [39]and McLean et al [152] focused program components on the mode of delivery. Wong et al's (Wong) review for example, focused on disease and self-management education, case management and care coordination delivered in the form of nurse delivered home outreach programs; Jeppesen et al's [39] review of home outreach included program components that included assistance of a specialist nurse in the delivery of home medication and condition management in the post-acute period; and McLean et al's (McLean) review on telehealthcare interventions in which the delivery of care and health professional decision making was facilitated through a telehealthcare mechanism. Lacasse et al [36]and Puhan et al's [37] reviews on the efficacy of pulmonary rehabilitation included a single program component such as prescribed endurance exercise, although the presence of education and psychological support was noted in the included study characteristics tables.

The sequencing and how different components contributed to outcome was not a focus amongst the reviews, reflecting the Cochrane approach in seeking a specific intervention versus placebo as the highest level of evidence. Zwerink et al's[7] recent review however did analyse studies with head to head interventions as separate analyses as part of their recent updated review, looking at the impact of self-management compared with self-management with an additional program component or varying levels of intensity.

Environment

The environment of the interventions was determined by the intervention structure, for example in the Hospital at Home and Home Based Nurse Outreach reviews [27,39]. Similarly, McLean et al's [152] of telehealthcare, while recruiting from inpatient, outpatient and community settings, the interventions themselves were delivered into the individuals home through a phone based or internet based platform. The remaining four studies delivered pulmonary rehabilitation, self-management or integrated disease management in the in-patient, outpatient or a combination of both. In regards to reporting, Kruis et al [38], Zwerink et al [7]and Puhan et al [37] discussed the environment in which the studies were undertaken as part of their results and discussion narrative and additionally noted the location of the intervention within the characteristics of included studies tables. The detail of the environment was not discussed or reported in the older review of pulmonary rehabilitation interventions for COPD by Lacasse et al [36] but this data was available in the publications of the included studies themselves.

Outcome Measures

Clinical outcome measures were, in the main, restricted to core outcomes relevant to the central intervention component. Kruis et al [38] did allow for much broader outcome inclusion which reflected the integrated disease management approach under review and included all outcomes identified by this overview: HRQoL; all cause hospital admissions; emergency department presentations; patient reported breathlessness and functional capacity. All other studies reported HRQoL using varying measures, but most consistently SGRQ and CRQ. Hospital admissions and emergency presentations were reported in all other studies besides Puhan et al [37] who reported length of readmission rather than presentation and separation, and Lacasse [36] who reported neither. Functional capacity was reported by the majority of reviews as six minute walk or incremental shuttle walking test amongst other measures, but was not included as a primary or secondary outcome measure in Jeppesen et al [39] or McLean et al [152]. And finally, only Kruis et al [38] documented patient reported breathlessness as an outcome measure. Considering the impact of COPD on the individual, and the acknowledged limitations of current HRQoL measures [154-156], the integration of a patient reported symptom measure should be considered for future understanding of disease impact and efficacy of interventions on the lived experience for this patient group.

Process outcomes in regards to coordination of the program were reported in varying forms. Patient satisfaction was reported as a secondary outcome in four of the reviews, Jeppesen et al [39] and McLean et al [152] as patient satisfaction, Wong et al [27] as caregiver satisfaction and Kruis et al [38] as patient and caregiver satisfaction with program and health care provider. Study completion was reported in the narrative description of interventions in all but one review and varied in reporting from dropout rates [7,36,38]; total days of care delivered [39] and study withdrawals [37,152]. Finally the economic impact of program delivery was also discussed as a secondary outcomes in five of the included reviews with health costs and health economics discussed in three reviews [37,39,152] and use of health facilities including GP visits and medical costs reported in two further review [7,27].

It is difficult to achieve consistency in reporting measures due to the differences in target interventions, however, as articulated by Kruis et al in regards to integrated disease management, comprehensive approaches as required 'a multi-faceted response, including different elements (e.g. smoking cessation, physiotherapeutic reactivation, self-management, optimal medication adherence) targeted at the patient, professional or organizational level. … have been developed to improve effectiveness and economic efficiency of chronic care delivery [157] by combining patient-related, professional-directed and organizational interventions [158,159]' (p7). As such, it is important that future studies, and therefore reviews, look to process outcomes such as patient satisfaction and economic efficiency, in developing efficacy and sustainable health care delivery.

DISCUSSION

Summary of main results

Seven Cochrane Reviews were included in this Overview of Systematic Reviews including 116 trials across the included reviews [7,27,36-39,152]. The overwhelming majority of trials compared the intervention with usual care (93, 80%), self-management versus usual care provided by a general practitioner for example. The remaining studies compared one form of the intervention with another in regards to intensity of intervention (exercise endurance intensity or duration) or in terms of delivery mechanism (face to face versus internet based delivery). The interventions within this overview are discussed within the following categories: Based on the following comparisons: “ What works,” “What may work”, and “Insufficient evidence to make a judgement”.

WHAT WORKS

Pulmonary rehabilitation

Participants receiving a structured pulmonary rehabilitation program had a higher HRQoL on both disease specific HRQoL measures (13 trials, 1002 participants) and a marked improvement in functional capacity based on six minute walk (16 trials, 669 participants). Patient reported breathlessness were not reported in this systematic review but again showed significant improvement in favour of those receiving pulmonary rehabilitation across four individual studies (168 participants) that did report this data.

The review authors did note the variation in pulmonary rehabilitation setting, duration, exercise intensity and intervention components. Understanding under which circumstances pulmonary rehabilitation is most effective is paramount in the clinical context and in the allocation of resources.

WHAT MAY WORK

Self-management programs

Participants receiving self-management had a statistical improvement in HRQoL in all domains of the SGRQ (10 studies, 1413 participants), however only the impact domain reached clinical significance. In subgroup analysis a positive effect of the self-management interventions group was also seen in interventions without exercise component. Functional capacity (6 studies, 259 participants) did improve on six minute walk and would meet the newly reported MCID of 25 metres [97] however the difference between groups was not statistically significant and a high level of heterogeneity was noted. The inclusion of a prescribed exercise program may have by the key contributor to the change in distance walked with the two studies showing negative results, and like the cause of heterogeneity, attributing this to the lack of exercise intensity in the program. Patient reported breathlessness was observed to statistically improve based on modified MRC (3 studies, 175 participants), however the clinical significance is unclear. The review authors propose that this change may reflect learning around coping strategies during self-management education that may reduce anxiety when faced with shortness of breath during activities [160]. There was no effect from the self-management interventions compared with control on; functional capacity using six minute walk (6 studies, 673 participants); all-cause hospitalisations (6 studies, 1077 participants) and varied response to emergency presentations in individual studies given these could not be pooled due to methodological differences (5 studies 1318 participants).

The self-management updated review also included studies that compared one type of self-management with another type of self-management to understand which mode of delivery or combination of components may be most effective (6 studies, 579 participants). Between group analyses were not possible due to difference in study approach and components. While literature supports the integration of behavioural change techniques in varying forms [22,161], this did not appear to have an impact across the studies on HRQoL or hospital admissions. However the authors note the lack of consensus as to what constitutes behavioural change components and suggests future studies are guided by established frameworks such as the taxonomy of behaviour change techniques by Michie et al [162].

Similarly, exercise programs and the use of action plans were difficult to analyse and showed no statistical significant impact on sub-group analysis. The review authors suggest this might be a case for the use of a self-management training program is sufficient without a standardised exercise program.

Hospital at Home programs

Those participants, who received hospital care through a Hospital at Home program, following admission for an acute exacerbation of COPD, were reported as having a significantly reduced readmission rate compared with those participants who remained in hospital and received usual care (8 studies, 870 participants). Emergency department presentations were similarly significantly reduced in those randomised to the home care program in a single study including 222 participants. While HRQoL was did significantly improve (3 studies, 432 participants), reporting and reliability of data was questioned leading the review authors to conclude that there was very limited evidence overall for the positive impact of Hospital at Home on HRQoL.

Pulmonary rehabilitation in the form of exercise interventions following acute exacerbation of COPD

Pulmonary rehabilitation following acute exacerbation of COPD is noted by the authors of this review to be an effective intervention to reduce the risk of hospital admissions (five studies, 250 participants) and clinically improve HRQoL (six studies, 320 participants) and exercise capacity (8 studies, 449 participants) in individuals following acute exacerbation of COPD compared with those who received usual care. However, the interventions differed markedly between studies within program core components, duration of intervention, timing of intervention implementation and consequent participant acuity.

Four of the nine studies provided endurance exercises as the only part of the intervention [104-107]. This level of engagement would not be recognised as pulmonary rehabilitation following the American Thoracic Society/European Respiratory Society statement that highlights the need for behaviour change and education as part of a comprehensive intervention to promote psychological as well as physical health [163]. Additionally, while the majority of studies commenced exercise or pulmonary rehabilitation either while an inpatient or within a week of discharge, two studies based in the outpatient setting required individuals to have been without exacerbation for at least four weeks or within a year of a previous pulmonary rehabilitation program [102,104]. Patient acuity did vary as noted and also in the inclusion of a study of individuals currently being treated for acute respiratory failure in intensive care. The duration of the interventions included in meta-analyses also varied with from 10 days to six months.

There was marked heterogeneity noted in the study results (I^2 varying from 0 – 93%) and while the authors note this is did not reflect methodological or program differences there is a question as to whether the compounding influence of differences in intervention content, duration and patient acuity, make it difficult to assess the overall impact of exercise programs or pulmonary rehabilitation following acute exacerbation.

Integrated disease management

Twenty six studies were included in the review of integrated disease management programs. Disease specific quality of life measured on CRQ showed a significant effect across all domains with pooled data of four studies (148 participants) with short term follow-up showing statistical and clinical improvement in all four domains of the CRQ [81,131,147]. Two studies (149 participants) with long term follow-up were additionally pooled and demonstrated positive statistical and clinical significance in emotional and mastery domains when follow-up continued to 24 months [145,146]. However, disease specific quality of life measured on SGRQ did not show a significant clinical effect in favour of the intervention in the pooled data of thirteen studies (1425 participants) with short term follow-up (up to 12 months) [130] or in the two studies that reported SGRQ as part of their long term follow-up (12 to 24 months) [136,140]. High heterogeneity was noted in the pooled analysis for short term follow-up and consequently subgroup analysis was undertaken. Separating groups by allocation concealment and blinding of outcome assessment had no impact, however a clinically significant effect was seen when studies were excluded based on recruitment and baseline imbalance bias, and when two studies were analysed based on intention to treat.

Pooled subgroup analysis based on nine studies (744 participants) where the control did not include any other component, again showed a positive impact of intervention in SGRQ. No effect was seen when studies with mono-disciplinary treatment in addition to control were included, suggesting that the addition of an integrated approach does have a quantifiable positive impact in this context. Subgroup analysis of SGRQ based on program setting reported a positive statistical and clinical impact in those programs set in primary care but not within the seven studies undertaken in the secondary care setting. A clinically significant impact was also seen those studies with a randomised controlled trials, which was not seen in studies with single cluster randomised controlled trials. Subgroup analysis based on program component showed no improvement in those studies with self-management as the core component (four studies, 942 participants), but did show and improvement in those studies that focused on exercise training (six studies, 373 participants). Maximal and functional exercise capacity both improved significantly in those who received integrated disease management in comparison with usual care. Those studies measuring functional capacity had a high level of heterogeneity and when sensitivity analysis was applied this effect lost statistical and clinical significance. No significant difference was seen when studies were grouped according to setting, dominant component or type of control. No difference was seen when integrated disease management was compared with control in relation to generic quality of life, all cause hospital admissions, emergency department presentations, or patient reported breathlessness.

Overall there is evidence for integrated disease management in improving disease specific quality of life and in exercise capacity in studies where this is a dominant component. However, lack of reporting across studies, heterogeneity, the impact of subgroup impact and lack of impact in longer term results, suggest that greater consensus of study components, reporting and methodological rigour are required to avoid bias and improve the intervention replication and translation.

Telehealthcare

In comparison with usual care, those participants who received management delivered through telehealthcare were reported to have significantly less hospital admissions (4 studies, 285 participants). Hospital admissions were reported to significant change in a single study that compared videoconferencing within an integrated program with usual care plus education and home visits (1 study, 157 participants), but was not reported as significantly different in hospital admissions between an internet based dyspnoea self-management program and a face to face program (1 study, 39 participants). Emergency department presentations were significantly reduced when COPD self-management program delivered through a telehealth systems were compared with usual care (2 studies, 185 participants), in studies that compared telehealthcare with usual care plus education and home visits (1 study, 157 participants) and in a study that provided three month telephone follow up compared with usual care (1 study, 56 participants).

Participants also had a minimally clinically significant improvement in quality of life in comparison to those receiving usual care (3 studies, 420 participants). A minimally clinically significant improvement was also reported for HRQL when a web-based dyspnoea management program was compared with a face to face dyspnoea management program (1 study, 39 participants).

Breathlessness and functional capacity were not discussed as part of the Cochrane Systematic review of telehealthcare interventions [15], however, daytime breathless did not significantly improve in an individual study that compared a home theophylline monitoring system with usual care (1 study, 11 participants) or when an internet based dyspnoea self-management program was compared with a face to face program (1 study, 39 participants). Similarly, functional capacity was reported as having no significant improvement in a single study that compared COPD self-management program compared with usual care (1 study 139 participants), but was significantly higher in those who participated in the online arm of the study investigating dyspnoea self-management program (1 study, 39 participants).

INSUFFICIENT EVIDENCE TO MAKE A JUDGEMENT

Home care by outreach nursing for chronic obstructive pulmonary disease

Home care delivered by respiratory nurses was reported to significantly improve HRQoL when compared with usual care when measured using the SGRQ (4 studies, 691 participants) and the Dartmouth Primary Care Cooperative (1 study, 96 participants). However contradictory results were reported in two studies that measured HRQL through the Sickness Impact Profile (2 studies, 467 participants) and in studies that used the SF-36 (2 studies, 278 participants), however data from the study with negative results did include individuals with congestive heart failure in addition to COPD. There was no significant reduction in hospital admissions in those participants receiving home based care (5 studies, 636 participants). Emergency department presentations were similarly not statistically significantly different in those individuals receiving home-based care in the three studies (3 studies, 435 participants), however a single study did report a significant decrease in presentations (1 study, 191 participants). No significant difference in functional capacity was reported when comparing those who received a home-based nursing care intervention and those receiving usual care (2 studies, 323 participants). Patient reported breathlessness was not discussed as part of the Cochrane Reviews or reported in the included studies.

Overall completeness and applicability of evidence

Seven studies were included in this overview of comprehensive non-pharmacological of non-pharmacological, non-surgical and non-device approaches for the management of COPD. There remains strong evidence for the implementation of pulmonary rehabilitation and gaps in research evidence to definitively state that self-management, hospital at home, pulmonary rehabilitation exercise programs following acute exacerbation, integrated disease management and care delivered through telehealth platforms have a sustained and overall positive impact on disease progression and patient experience. Clarity and consensus of intervention components and the use of standardised measures will allow for better cross study comparisons in the future.

WHAT MAY WORK

Self-management programs

Participants receiving self-management had a statistical improvement in HRQoL in all domains of the SGRQ (10 studies, 1413 participants), however only the impact domain reached clinical significance. In subgroup analysis a positive effect of the self-management interventions group was also seen in interventions without exercise component. Functional capacity (6 studies, 259 participants) did improve on six minute walk and would meet the newly reported MCID of 25 metres [97] however the difference between groups was not statistically significant and a high level of heterogeneity was noted. The inclusion of a prescribed exercise program may have by the key contributor to the change in distance walked with the two studies showing negative results, and like the cause of heterogeneity, attributing this to the lack of exercise intensity in the program. Patient reported breathlessness was observed to statistically improve based on modified MRC (3 studies, 175 participants), however the clinical significance is unclear. The review authors propose that this change may reflect learning around coping strategies during self-management education that may reduce anxiety when faced with shortness of breath during activities [160]. There was no effect from the self-management interventions compared with control on; functional capacity using six minute walk (6 studies, 673 participants); all-cause hospitalisations (6 studies, 1077 participants) and varied response to emergency presentations in individual studies given these could not be pooled due to methodological differences (5 studies 1318 participants).

The self-management updated review also included studies that compared one type of self-management with another type of self-management to understand which mode of delivery or combination of components may be most effective (6 studies, 579 participants). Between group analyses were not possible due to difference in study approach and components. While literature supports the integration of behavioural change techniques in varying forms [22,161], this did not appear to have an impact across the studies on HRQoL or hospital admissions. However the authors note the lack of consensus as to what constitutes behavioural change components and suggests future studies are guided by established frameworks such as the taxonomy of behaviour change techniques by Michie et al [162].

Similarly, exercise programs and the use of action plans were difficult to analyse and showed no statistical significant impact on sub-group analysis. The review authors suggest this might be a case for the use of a self-management training program is sufficient without a standardised exercise program.

Hospital at Home programs

Those participants, who received hospital care through a Hospital at Home program, following admission for an acute exacerbation of COPD, were reported as having a significantly reduced readmission rate compared with those participants who remained in hospital and received usual care (8 studies, 870 participants). Emergency department presentations were similarly significantly reduced in those randomised to the home care program in a single study including 222 participants. While HRQoL was did significantly improve (3 studies, 432 participants), reporting and reliability of data was questioned leading the review authors to conclude that there was very limited evidence overall for the positive impact of Hospital at Home on HRQoL.

Pulmonary rehabilitation in the form of exercise interventions following acute exacerbation of COPD

Pulmonary rehabilitation following acute exacerbation of COPD is noted by the authors of this review to be an effective intervention to reduce the risk of hospital admissions (five studies, 250 participants) and clinically improve HRQoL (six studies, 320 participants) and exercise capacity (8 studies, 449 participants) in individuals following acute exacerbation of COPD compared with those who received usual care. However, the interventions differed markedly between studies within program core components, duration of intervention, timing of intervention implementation and consequent participant acuity.

Four of the nine studies provided endurance exercises as the only part of the intervention [104-107]. This level of engagement would not be recognised as pulmonary rehabilitation following the American Thoracic Society/European Respiratory Society statement that highlights the need for behaviour change and education as part of a comprehensive intervention to promote psychological as well as physical health [163]. Additionally, while the majority of studies commenced exercise or pulmonary rehabilitation either while an inpatient or within a week of discharge, two studies based in the outpatient setting required individuals to have been without exacerbation for at least four weeks or within a year of a previous pulmonary rehabilitation program [102,104]. Patient acuity did vary as noted and also in the inclusion of a study of individuals currently being treated for acute respiratory failure in intensive care. The duration of the interventions included in meta-analyses also varied with from 10 days to six months.

There was marked heterogeneity noted in the study results (I^2 varying from 0 – 93%) and while the authors note this is did not reflect methodological or program differences there is a question as to whether the compounding influence of differences in intervention content, duration and patient acuity, make it difficult to assess the overall impact of exercise programs or pulmonary rehabilitation following acute exacerbation.

Integrated disease management

Twenty six studies were included in the review of integrated disease management programs. Disease specific quality of life measured on CRQ showed a significant effect across all domains with pooled data of four studies (148 participants) with short term follow-up showing statistical and clinical improvement in all four domains of the CRQ [81,131,147]. Two studies (149 participants) with long term follow-up were additionally pooled and demonstrated positive statistical and clinical significance in emotional and mastery domains when follow-up continued to 24 months [145,146]. However, disease specific quality of life measured on SGRQ did not show a significant clinical effect in favour of the intervention in the pooled data of thirteen studies (1425 participants) with short term follow-up (up to 12 months) [130] or in the two studies that reported SGRQ as part of their long term follow-up (12 to 24 months) [136,140]. High heterogeneity was noted in the pooled analysis for short term follow-up and consequently subgroup analysis was undertaken. Separating groups by allocation concealment and blinding of outcome assessment had no impact, however a clinically significant effect was seen when studies were excluded based on recruitment and baseline imbalance bias, and when two studies were analysed based on intention to treat.

Pooled subgroup analysis based on nine studies (744 participants) where the control did not include any other component, again showed a positive impact of intervention in SGRQ. No effect was seen when studies with mono-disciplinary treatment in addition to control were included, suggesting that the addition of an integrated approach does have a quantifiable positive impact in this context. Subgroup analysis of SGRQ based on program setting reported a positive statistical and clinical impact in those programs set in primary care but not within the seven studies undertaken in the secondary care setting. A clinically significant impact was also seen those studies with a randomised controlled trials, which was not seen in studies with single cluster randomised controlled trials. Subgroup analysis based on program component showed no improvement in those studies with self-management as the core component (four studies, 942 participants), but did show and improvement in those studies that focused on exercise training (six studies, 373 participants). Maximal and functional exercise capacity both improved significantly in those who received integrated disease management in comparison with usual care. Those studies measuring functional capacity had a high level of heterogeneity and when sensitivity analysis was applied this effect lost statistical and clinical significance. No significant difference was seen when studies were grouped according to setting, dominant component or type of control. No difference was seen when integrated disease management was compared with control in relation to generic quality of life, all cause hospital admissions, emergency department presentations, or patient reported breathlessness.

Overall there is evidence for integrated disease management in improving disease specific quality of life and in exercise capacity in studies where this is a dominant component. However, lack of reporting across studies, heterogeneity, the impact of subgroup impact and lack of impact in longer term results, suggest that greater consensus of study components, reporting and methodological rigour are required to avoid bias and improve the intervention replication and translation.

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It is difficult to achieve consistency in reporting measures due to the differences in target interventions, however, as articulate by Kruis et al in regards to integrated disease management, comprehensive approaches as required 'a multi-faceted response, including different elements (e.g. smoking cessation, physiotherapeutic reactivation, self-management, optimal medication adherence) targeted at the patient, professional or organizational level. … have been developed to improve effectiveness and economic efficiency of chronic care delivery [157] by combining patient-related, professional-directed and organizational interventions [158,159]' (p7). As such, it is important that future studies, and therefore reviews, look to process outcomes such as patient satisfaction and economic efficiency, in developing efficacy and sustainable health care delivery.

QUALITY OF EVIDENCE

The overall evidence of data in the included reviews was of high quality and represented a low risk of bias; however, this quality did vary.

The majority of included trials provided information to allow for assessment of quality based, however there were a number that did not report important information across the quality assessment domains, and in some cases there was unavoidable a high risk of bias as a consequence of convenience or cluster sampling in clinical settings. Given the nature of all interventions, blinding participants from the intervention was not possible.

There is clear need for improved consistency and clarity in methodological and outcome reporting across studies to allow for future high quality comparison. As part of this, there is a need for consensus on operational definitions and as part of this articulation of the essential and evidence based components which are required for high quality care delivery. Finally, consensus as to the outcomes most appropriate for comprehensive interventions into COPD so that future research can strive for patient satisfaction and economic efficiency, in developing efficacious and sustainable health care delivery.

POTENTIAL BIASES IN THE OVERVIEW PROCESS

There is potential bias in all syntheses of research material. To reduce bias we undertook a systematic and a priori approach so that the overview process is transparent and replicable [35]. The search strategy was developed in consultation with the Cochrane Airways Group and was undertaken through the Cochrane *Database of Systematic Reviews.* Inclusion, exclusion and data extraction were carried out by two independent reviews with a third reviewer checking data accuracy and consistency as well as adjudicating over any disagreement. Quality of included reviews was assessed against the AMSTAR rating [32] and quality of evidence in included reviews was assessed using GRADE and the risk of bias tool developed by the Cochrane Collaboration [33].

The field of management of COPD is continually evolving with new studies published regularly. There is opportunity for bias in all reviews that the data extraction has not captured the most recent evidence, and we are aware that there are currently reviews in protocol form and that the current included reviews will be updated over time. We plan to check data regularly in collaboration with the Cochrane Airways Group and update the overview as necessary in light of new information.

AGREEMENTS AND DISAGREEMENTS WITH OTHER REVIEWS

- All reviews are carried out with a high quality and systematic approach to data presentation and interpretation; as such there are few disagreements that we could find between our own views from this broader context.
- The purpose of an overview is to give provide clinicians, policy makers or informed consumers with a summary of the evidence over several interrelated topics, and with close reference to the full reviews on which it is based. This review additionally seeks to explore and discuss the components of comprehensive and integrated disease management in which there is still lack of consensus. It is hoped that this review will be taken within that context [33].
- In using a taxonomy of disease management, or similar framework, we recommend that there be clearer articulation of the presence and impact of the interdisciplinary personnel involved in intervention delivery and the intensity and complexity in regards to sequencing of components. One constant issue is the need for consensus on operational definitions and articulation of the essential, evidence based intervention components. There is also a need for broader discussion of outcomes such as patient satisfaction and economic efficiency so that future intervention delivery targets those outcomes most efficacious and sustainable within this patient cohort.

AUTHORS' CONCLUSIONS

Implications for practice

- Pulmonary rehabilitation remains a highly efficacious and important intervention in the management of COPD.
- Self-management, hospital at home, pulmonary rehabilitation exercise programs following acute exacerbation, integrated disease management and care delivered through telehealth platforms all had impact in some but not all key outcomes for individuals' HRQoL, hospitalisation and emergency department presentations and functional capacity. Additionally, there remains evidence both for and against home care by outreach nursing.

- Heterogeneity across study design and reporting of results often restricted meta-analyses across the majority of studies.
- Clarity and consensus of intervention components are required as is the use of standardised measures to allow for across study comparison.

Implications for research

- COPD is a complex and debilitating condition that requires individuals to actively engage in a variety of comprehensive and complex self-care management activities.
- In recognising the complexity and potential burden of these interventions, it is imperative that we have clear evidence as to those that are most efficacy and those that produce sustainable positive impact in this group of patients.
- There is a need for clearer articulation and consensus on essential intervention components
- Impact on frequency and overall healthcare utilisation must remain a key focus and endpoint in future research.
- Additionally, patient and caregiver satisfaction and the impact on disease experience should be considered beyond HRQoL measures.
- A standardised taxonomy will allow for clearer guidelines as to intervention requirements and allow for replication and translation.

ACKNOWLEDGEMENTS

- We thank the Editorial Staff of the Cochrane Airways Group for their help and ongoing support.
- The authors would like to acknowledge the assistance of Sabine Allida and Hiba Deek in cross checking data extraction and data entry.
- The authors would like to acknowledge the authors of the Pulmonary rehabilitation in COPD Cochrane Systematic Review for providing additional information in the preparation of this overview.

SOURCES OF SUPPORT

- Rebecca Disler is Doctoral student supported by the University of Technology, Sydney.
- Rebecca Disler was awarded the 2014 Lung Foundation Australia/Australian Satellite Cochrane Airways Group Scholarship of $2500 to assist with the completion of this Cochrane Overview
- Dr Sally C Inglis is supported by a Cardiovascular Research Network Life Science Research Fellowship supported by the Heart Foundation and the NSW Office for Medical Research (CR 11S 6226).

CONTRIBUTIONS OF AUTHORS

All authors contributed to the development of the title registration, overview of methods, development of selection criteria, decisions on the organising framework and development and writing of the protocol.

DECLARATIONS OF INTEREST

There are no conflicts of interest in this overview.

Table 1 Characteristics of included Cochrane Systematic Reviews

Review title	Date of search	No. Studies included (No. Patients included studies)	Inclusion criteria for 'Types of Participants'	Comparison interventions (no. studies)	Summary of quality of evidence in reviews (risk of bias)	ROB Approach
Self-man for COPD (Zwerink 2014)	Review content assessed as up-to-date: 31 August 2011.	29 studies in 14 countries (Turkey, Canada, Germany, Spain, USA, UK, Netherlands, Norway, Egypt, Iran, France, Sweden, New Zealand and Japan), between 1995 - 2011 (3850 participants randomised, 2954 included in analyses).	Patients with a clinical diagnosis of COPD with symptoms and meeting agreed spirometry criteria (i.e. forced expiratory volume in one second (FEV1)/forced vital capacity (FVC) < 70%) were included (GOLD 2010). Patients with asthma as a primary diagnosis were excluded.	Self-management was compared with usual care in 23 studies. In one of these studies (Coultas 2005), two intervention groups and one usual care group were used. In meta-analyses, both intervention groups were compared with the same usual care group, resulting in one extra comparison (Coultas).	Sequence generation: 17 studies (low risk), 9 studies (unclear), 3 study (high risk). Allocation concealment: 15 studies (low risk), 10 studies (unclear), 4 study (high risk). Blinding of participants: 29 studies (unclear). Blinding of outcome assessment: 12 studies (low risk), 13 studies (unclear), 4 studies (high risk). Incomplete data: 17 studies (low risk), 6 studies (unclear), 6 studies (high risk). Selective reporting: 1 study (low risk), 26 studies (unclear), 2 studies (high). Other bias: 27 studies (low risk), 1 study (unclear), 1 study (high)	Cochrane Approach: We assessed the risk of bias according to recommendations outlined in the Cochrane Handbook for Systematic Reviews of Interventions (Cochrane Handbook) for the following items. 1. Random sequence generation. 2. Allocation concealment. 3. Blinding of participants and personnel. 4. Blinding of outcome assessment. 5. Incomplete outcome data. 6. Selective outcome reporting. 7. Other bias. For each included study, two review authors (MZ and TE or MBK) independently assessed for all items above whether a high, low or unclear risk of bias was present. Unclear risk indicated that insufficient detail of what happened in the study was reported; that what happened in the study was known but the risk of bias was unknown; or that an entry was not relevant to the study at hand. Each judgement was supported by a short description of what was reported to have happened in the specific study.
Hospital at home (Jeppesen 2012)	Review content assessed as up-to-date: 22 February 2012. The CAGR was searched up to February 2012. The additional databases were searched up to October 2010.	8 trials in 5 countries (Australia, Denmark, Italy, Spain and UK) between 2000 -2008 (870 patients were randomised, 369 included in analyses).	We included patients with a diagnosis of COPD with an acute exacerbation presenting to an emergency department for treatment.	Hospital at home versus Standard inpatient care (8 studies, 369 patients). Patients randomised to in-hospital care would be treated as usual and at the discretion of the hospital medical team.	Random sequence generation: 6 studies (low risk), 2 studies (unclear). Allocation consequence: 7 studies (low risk), 1 study (unclear). Blinding-objective outcome: 8 studies (low risk), Blinding -subjective outcomes: 8 studies (high risk). Incomplete outcome data: 7 studies (low risk), 1 study (unclear). Selective reporting: 7 studies (low risk), 1 study (high risk). Other bias: 6 studies (low risk), 1 study (unclear) and 1 study (high risk).	Cochrane Approach: We assessed the risk of bias for all included studies using the five criteria recommended in the Cochrane Handbook for Systematic Reviews of Interventions Higgins 2011.

Table 1 Characteristics of included Cochrane Systematic Reviews cont.

Review title	Date of search	No. Studies included (No. Patients included studies)	Inclusion criteria for 'Types of Participants'	Comparison interventions (no. studies)	Summary of quality of evidence in reviews (risk of bias)	ROB Approach
PR in COPD (Lacasse 2006)	Review content assessed as up-to-date: 15 June 2006. Edited with no change to publication in 2009.	31 trials in 14 countries (Australia, Belgium, Canada, China, Denmark, Germany, India, Israel, Netherlands, NZ, Spain, Sweden, UK and USA) between 1976 – 2006 (1597 patients randomised, 1322 included in analyses).	We included randomized controlled trials in which more than 90% of patients had COPD defined according to the following criteria: (1) a clinical diagnosis of COPD; (2) one of the following: (a) best recorded Forced Expiratory Volume after one second (FEV1)/Forced Vital Capacity (FVC) ratio of individual patients < 0.7; (b) best recorded FEV1 of individual patients < 70% of predicted value.	Rehabilitation versus usual care (11 studies, 292 patients). Short-term rehabilitation programs/ unsupervised programs.	Allocation concealment: 28 studies (low risk), 2 studies (unclear), 1 study (high risk). Assessor blinding: 12 studies (low risk), 11 studies (unclear), 8 studies (high risk).	Cochrane Approach: We assessed the quality of each trial following the Cochrane approach using the methods detailed in section six of the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2008).
Tele-health for COPD (McLean 2011)	till January 2010	10 trials in 5 countries (Canada, China, Italy, Spain and USA) between 1990 - 2009 (1307 patients randomised, 1188 included in analyses)	COPD, as diagnosed by a clinician, with no exclusions on the basis of age, gender, ethnicity or language spoken.	Usual care	This has 10 trials included but has and inclusion table of 12 trials! Also there is a table of a study half missing (Garcia-Aymerich 2007)	Cochrane Approach: We assessed the quality of each trial following the Cochrane approach using the methods detailed in section six of the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2008).
PR for exacerbations (Puhan Milo 2011)	Till March 2010	9 trials in 7 countries (Belgium, Canada, Germany, Ireland, Italy, New Zealand and the United Kingdom) between 1998-2010 (509 patients randomised, 389 included in analyses)	COPD patients after in- or out-patient care for acute exacerbation. More than 90% of study participants were required to be COPD patients.	usual care (no physical exercise program)	Random sequence generation: 4 studies (low risk), 5 studies (unclear). Allocation concealment: 4 studies (low risk), 5 studies (unclear). Blinding-hospital admissions: 6 studies (unclear), 3 studies (high risk). Blinding - HQOL: 9 studies (high risk). Blinding-mortality: 9 studies (low risk). Blinding - walk test: 1 study (low risk), 5 studies (unclear) and 3 studies (high risk)	Cochrane Approach: We assessed the risk of bias for all included studies using the five criteria recommended in the Cochrane Handbook for Systematic Reviews of Interventions Higgins 2011.

Table 1 Characteristics of included Cochrane Systematic Reviews cont.

Review title	Date of search	No. Studies included (No. Patients included studies)	Inclusion criteria for 'Types of Participants'	Comparison interventions (no. studies)	Summary of quality of evidence in reviews (risk of bias)	ROB Approach
Home outreach nursing (Wong 2012)	Till November 2011	9 trials from 4 countries (USA, UK, Australia and Canada) between 1987-2006 (1381 patients randomised, 1258 included in analysis)	We included participants with chronic obstructive pulmonary disease, as defined according to pulmonary function test findings, consistent with British Thoracic Society criteria	routine care, without respiratory nurse/health worker input	Random sequence generation: 7 studies (low risk), 2 studies unclear). Allocation concealment: 4 studies (low risk, 4 studies (unclear), and 1 study (high risk). Blinding: 9 studies (high risk). Incomplete outcome data: 7 studies (low risk), 2 studies (unclear). Selective reporting (2 studies (low risk), 5 studies (unclear) and 2 studies (high risk). Other Bias: 7 studies (low risk), 1 study (unclear) and 1 study (high risk)	Cochrane approach
Integrated disease management (Kruis 2013)		26 trials in 11 countries (US, Denmark, Canada, Australia, Netherlands, UK, Sweden, Spain, Brazil, New Zealand and Japan) between 1996-2011 (2997 patients randomised, 2523 included in analysis)	People with a clinical diagnosis of COPD according to the GOLD criteria were included: people having chronic respiratory symptoms (i.e. coughing, sputum or dyspnoea) and a limited post-bronchodilator forced expiratory volume in one second (FEV1) to forced vital capacity (FVC) ratio of < 0.7. Severity of airflow obstruction was classified using the GOLD stages of 2009 (GOLD 2009). All GOLD stages were accepted. Studies including participants with other diagnoses than COPD were only eligible if the results of participants with COPD were available separately.	Usual care	Random sequence generation: 19 studies (low risk), 7 studies (unclear risk). Allocation concealment: 14 studies (low risk), 8 studies (unclear risk) and 4 studies (high risk). Blinding participants: 25 studies (high risk), 1 study (low risk). Blinding outcome assessors: 9 studies (low risk), 10 studies (unclear risk) and 7 studies (high risk). Incomplete data: 19 studies (low risk), 6 studies (high risk) and 1 study (unclear risk). Selective reporting: 21 studies (low risk), 5 studies (high risk). Other potential threats to validity: 2 studies (8%)	Cochrane approach

COPD: Chronic obstructive pulmonary disease
PR: Pulmonary rehabilitation

Table 2 AMSTAR ratings for each Cochrane systematic review

	Zwerink 2014	Jeppesen 2012	Lacasse 2006	McLean 2011	Puhan Milo 2011	Kruis 2013
	Self-man for COPD	Hospital at home	PR in COPD	Telehealth for COPD	PR for exacerbations	Integrated disease management
1. Was an 'a priori' design provided	Yes	Yes	Yes	Yes	Yes	Yes
2. Was there duplicate study selection and data extraction?	Yes	Yes	Yes	Yes	Yes	Yes
3. Was a comprehensive literature search performed?	Yes	Yes	Yes	Yes	Yes	Yes
4. Was the status of publication used as an inclusion criteria	Yes	Yes	Yes	Yes	Yes	Yes
5. Was a list of studies (included and excluded) provided?	Yes	Yes	Yes	Yes	Yes	Yes
6. Were the characteristics of the included studies provided?	Yes	Yes	Yes	Yes	Yes	Yes
7. Was the scientific quality of the included studies assessed and documented?	Yes	Yes	Yes	Yes	Yes	Yes
8. Was the scientific quality of the included studies used appropriately in formulating conclusions?	Yes	Yes	Yes	Yes	Yes	Yes
9. Were the methods used to combine the findings of studies appropriate?	Yes	Yes	Yes	Yes	Yes	Yes
10. Was the likelihood of publication bias assessed?	Yes	Yes	Yes	Yes	Yes	Yes
11. Was the conflict of interest included?	Yes	Yes	Yes	Yes	Yes	Yes

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Table 3 Quality of evidence in included Cochrane Systematic Reviews

	Sequence generation assessed (% studies low risk)	Allocation concealment assessed (% studies low risk)	Blinding of participants, personnel and outcome assessors assessed (% studies low risk)	Incomplete outcome data assessed (% studies low risk)	Selective outcome reporting assessed (% studies low risk)	Other potential threats to validity assessed (% studies low risk)
Self-man for COPD	17 studies (58.6%)	15 studies (51.7%)	12 studies (41%)	17 studies (58.6%)	1 study (3.2%)	27 studies (93%)
Hospital at home	6 studies (75%)	7 studies (88%)	8 studies (100%)	7 studies (88%)	6 studies (75%)	6 studies (75%)
PR in COPD	52 studies (81%)	27 studies (42%)	32 studies (50%)	38 studies (59%)	13 studies (20%)	50 studies (78%)
Telehealth for COPD	5 studies (50%)	2 studies (50%)	3 studies (30%)	2 studies (20%)	2 studies (20%)	2 studies (20%)
PR for exacerbations	30 studies (94%)	14 studies (44%)	0 studies (0%)	23 studies (72%_	2 studies (6%)	27 studies (84%)
Home outreach nursing	7 studies (78%)	4 studies (44%)	0 studies (0%)	7 studies (78%)	2 studies (22%)	7 studies (78%)
Integrated disease management	19 studies (73%)	14 studies (54%)	10 studies (38%)	19 studies (73%)	21 studies (81%)	2 studies (8%)

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Table 5 Results by individual review

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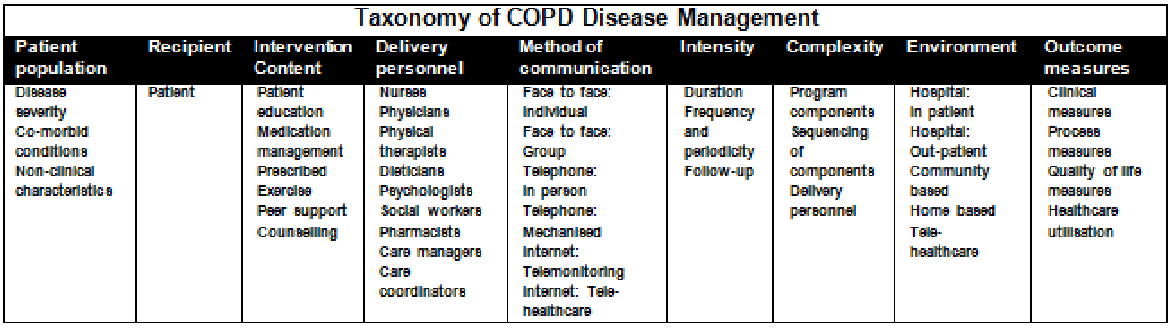
Self-management in COPD, 29 studies, 3850 participants			
4.1 Self-management versus usual care	Outcome	No of studies (participants)	Results
	HRQoL - SGRQ	10 (1413)	MD -3.51, 95%CI -5.37 to -1.65, p<0.001
	Hospital admission	6 (1077)	OR 0.77, 95% CI 0.45 to 1.30
	Patient reported breathlessness- MRC	6 (570)	MD -0.83, 95% CI -1.36 to -0.30
	Functional capacity- six minute walk test	8 (673)	MD 33.69m, 95% CI 9.12 to 76.50, p= 0.12
Hospital at home in COPD, 8 studies, 870 participants			
4.3 Hospital at home versus usual care	Outcome	No of studies (participants)	Results
	Hospital admission	8 (870)	RR 0.76, 95% CI 0.59 to 0.99, p= 0.04
Pulmonary rehabilitation for COPD, 31 studies, 1348 participants			
4.4 Pulmonary rehabilitation versus usual care	Outcome	No of studies (participants)	Results
	HRQoL- CRQ	13 (1002)	Fatigue MD 0.92, 95% CI 0.71 to 1.13, p<0.00; Emotion MD 0.76, 95% CI 0.52 to 1.00, p<0.001; Mastery MD 0.97, 95% CI 0.74 to 1.20, p<0.001; Dyspnoea MD 1.06, 95% CI 0.85 to 1.20, p<0.001
	HRQoL- SGRQ	6 (384)	Total score MD -6.11, 95% CI -8.98 to -3.24, p<0.001; Impact MD -6.27, 95% CI -10.08 to -2.47, p<0.001; Activity domain MD -4.78, 95% CI -7.83 to -1.72, p<0.05
	Functional capacity- six minute walk test	16 (669)	MD 48m, 95% CI 32 to 65
Pulmonary rehabilitation following exacerbations of COPD, 9 studies, 509 participants			
4.5 Pulmonary rehabilitation following exacerbations versus usual care	Outcome	No of studies (participants)	Results
	HRQoL- CRQ	5 (259)	Fatigue domain MD 0.81, 95% CI 0.16 to 1.45; Dyspnoea domain MD 0.97, 95% CI 0.35 to 1.58
	HRQoL- SGRQ	3 (128)	MD -9.88 95% CI -14.40 to -5.37
	Hospital admission	5 (250)	OR 0.22, 95% CI 0.08 to 0.58
	Emergency department presentations	1 (42)	MD 0.14, 95% CI 0.3 to 1.5, p= 0.01
	Functional capacity- six minute walk test	6 (300)	MD 77.70m 95% CI 12.21 to 143.20
	Functional capacity- endurance shuttle walk test	3 (128)	MD 64m 95% CI 41.28 to 87.43
Telehealthcare for COPD, 10 studies, 1188 participants			
4.6 Telehealthcare intervention versus usual care	Outcome	No of studies (participants)	Results
	HRQoL- SGRQ	3 (420)	MD -6.57 95% CI -13.62 to 0.48
	Hospital admission	1 (1307)	OR 0.46 95% CI 0.33 to 0.65, p<0.00001
	Emergency department presentations- telehealth system	2 (379)	OR 0.40 95% CI 0.22 to 0.71 and OR 0.47 95% CI 0.24 to 0.89

Table 5 Results by individual review cont.			
	Emergency department presentations- specialist independent network		OR 0.27 95% CI 0.11 to 0.66
Telehealthcare for COPD, 10 studies, 1188 participants cont.			
4.6 Telehealthcare intervention versus another type of management program	Outcome	No of studies (participants)	Results
	HRQoL- internet based dyspnoea self-management program	1 (38)	MD 0.5, p<0.001
	Hospital admission	1 (157)	OR 0.45 95% CI 0.24 to 0.86
	Emergency department presentations	1 (157)	OR 0.47 95% CI 0.24, 0.89 and OR 0.27 95% CI 0.11, 0.66
Home care by outreach nursing for COPD, 9 studies, 1381 participants			
4.7 Home care by outreach nursing versus usual care	Outcome	No of studies (participants)	Results
	HRQoL- SGRQ	4 (585)	MD 2.60 95% CI -4.81 to -0.39, p= 0.02
	HRQoL- SIP	2 (453)	Physical scores MD 3.90 95% CI 1.50 to 6.30, p<0.01
	Hospital admission	5 (593)	Peto OR 1.01 95% CI 0.71 to 1.44, p= 0.17
	Functional capacity- six minute walk test	2 (292)	MD 5.05 95% CI -15.08 to 25.18, p= 0.062
Integrated disease management for COPD, 26 studies, 2997 participants			
4.6 Integrated disease management versus usual care	Outcome	No of studies (participants)	Results
	HRQoL- SGRQ short term follow-up	13 (1425)	MD -3.7 95% CI -5.83 to -1.59, p<0.001
	HRQoL- SGRQ long term follow-up	2 (189)	MD -0.22 95% CI -7.43 to 6.99, p= 0.95
	HRQoL- CRQ short term follow-up	4 (148)	Dyspnoea MD 1.02 95% CI 0.67 to 1.36, P < 0.0001; Fatigue MD 0.82 95% CI 0.46 to 1.17, P < 0.0001; Emotion MD 0.61 95% CI 0.26 to 0.95, P < 0.0005; and Mastery MD 0.75 95% CI 0.38 to 1.12, P < 0.0001
	HRQoL- CRQ long term follow-up	2 (149)	Emotion MD 0.53 95%CI 0.10 to 0.95, P = 0.02; Mastery MD 0.80, 95% CI 0.37 to 1.23, P < 0.01
	Hospital admission- short term follow-up	2 (266)	OR 0.62 95% CI 0.36 to 1.07, P = 0.49
	Hospital admission- long term follow-up	2 (283)	OR 0.78 95% CI 0.38 to 1.57
	Emergency department presentations	4 (1161)	OR 0.64; 95% CI 0.33 to 1.25, I^2 = 71%
	Patient reported breathlessness- MRC	3 (345)	MD 0.30; 95% CI -0.48 to -0.11, I^2 = 0%, P < 0.001
	Patient reported breathlessness- Borg scale	3 (145)	MD 0.14; 95% CI -0.70 to 0.98, P = 0.74, I^2 = 39%
	Functional capacity- six minute walk test	14 (871)	MD 43.86, 95% CI 21.83 to 65.89
	Functional capacity- cycle ergometer test	4 (298)	MD 6.99; 95% CI 2.96 to 11.02, P < 0.0001

COPD: Chronic obstructive pulmonary disease

PR: Pulmonary rehabilitation



Taxonomy of COPD Disease Management								
Patient population	**Recipient**	**Intervention Content**	**Delivery personnel**	**Method of communication**	**Intensity**	**Complexity**	**Environment**	**Outcome measures**
Disease severity Co-morbid conditions Non-clinical characteristics	Patient	Patient education Medication management Prescribed Exercise Peer support Counselling	Nurses Physicians Physical therapists Dieticians Psychologists Social workers Pharmacists Care managers Care coordinators	Face to face: Individual Face to face: Group Telephone: In person Telephone: Mechanised Internet: Telemonitoring Internet: Tele-healthcare	Duration Frequency and periodicity Follow-up	Program components Sequencing of components Delivery personnel	Hospital: In patient Hospital: Out-patient Community based Home based Tele-healthcare	Clinical measures Process measures Quality of life measures Healthcare utilisation

Figure 1 Taxonomy of COPD Disease Management

Adapted from the American Heart Association, Krumholz HM, Currie PM, Riegel B, et al. A taxonomy for disease management: A scientific statement from the American Heart Association Disease Management Taxonomy Writing Group. Circulation 2006; 114.

COPD: Chronic obstructive pulmonary disease

PR: Pulmonary rehabilitation

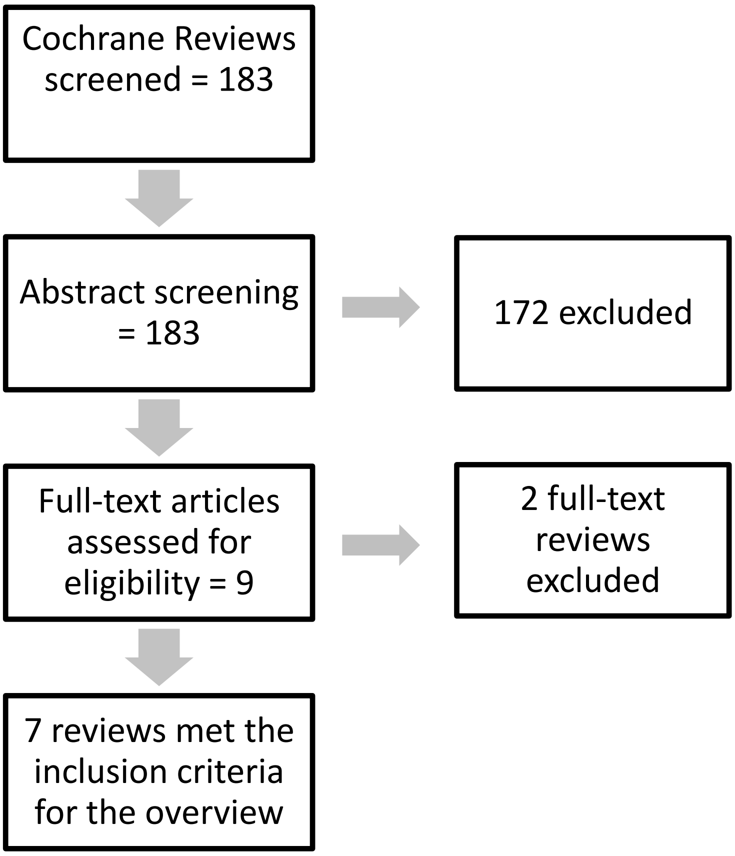


Figure 2 Study flow diagram

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Disler RT, Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. *Cochrane Database of Systematic Reviews* **PROTCOL** 2013, Issue 2. Art. No.: CD010384. DOI: 10.1002/14651858.CD010384

Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews (Protocol)

Disler RT, Inglis SC, Davidson PM

This is a reprint of a Cochrane protocol, prepared and maintained by The Cochrane Collaboration and published in *The Cochrane Library* 2013, Issue 2

http://www.thecochranelibrary.com

TABLE OF CONTENTS

[Overview of Reviews Protocol]

Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews

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Editorial group: Cochrane Airways Group.
Publication status and date: New, published in Issue 2, 2013.

Citation: Disler RT, Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. *Cochrane Database of Systematic Reviews* 2013, Issue 2. Art. No.: CD010384. DOI: 10.1002/14651858.CD010384.

ABSTRACT

This is the protocol for a review and there is no abstract. The objectives are as follows:

To a) summarise the evidence, b) identify gaps in the evidence base and c) describe elements of non-pharmacological, non-surgical and non-device interventions for the management of COPD using a standardised taxonomy for disease management adapted from the American Heart Association (Krumholz 2006).

BACKGROUND

Description of the condition

Chronic obstructive pulmonary disease (COPD) is the fourth most common cause of death internationally and accounts for 3.5% of total years lost due to disability (World Health Organisation 2004). This highly burdensome condition impacts on 80 million people and their families globally. It is characterised by non-reversible airflow limitation in conjunction with progressive debilitating symptoms and systemic effects (Global Initiative for COPD (GOLD) 2010). Increases in bio-fuel use and smoking, particularly in developing countries, are set to increase the prevalence of COPD globally by 30% by 2030 (Buist 2007; Mannino 2002; World Health Organisation 2004).

Despite optimisation of pharmacological treatments such as inhaled medications, a large proportion of individuals with COPD continue to have inadequately managed symptoms and unmet psychosocial needs (Bausewein 2008; Disler 2012; Effing 2007). Comprehensive approaches to disease management that engage “multiple therapies into a patient-centred plan of care” (Make 2003) are necessary to meet these healthcare needs (Craig 2008; Make 2003; Monninkhof 2003).

Description of the interventions

Key non-pharmacological interventions such as pulmonary rehabilitation and self-management programmes are central to COPD management and are highlighted in international COPD management guidelines (ATS/ERS 2011; Global Initiative for COPD (GOLD) 2010; National Institute for Clinical Excellence 2012). Chronic diseases such as COPD require a comprehensive approach to disease management (Make 2003), potentially incorporating a range of diverse non-pharmacological, non-device and non-surgical intervention strategies. The intervention strategies discussed in this overview, and defined below are: pulmonary rehabilitation; self-management programs; action plans as an integrated strategy and management guideline; telehealthcare; and outreach programs (ATS/ERS 2011; Bausewein 2008; Effing 2007; Global Initiative for COPD (GOLD) 2010; Kruis 2011; Lacasse 2006; Make 2003; McLean 2011; World Health Organisation 2004).

Pulmonary rehabilitation

Pulmonary rehabilitation focuses on building exercise capacity, disease and nutritional education, and psychological coaching. (ATS/ERS 2011; Celli 2004; Global Initiative for COPD (GOLD) 2010; National Institute for Clinical Excellence 2012; Nici 2006). Pulmonary rehabilitation is defined as “an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities. Integrated into the individualized treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimize functional status, increase participation, and reduce health care costs through stabilizing or reversing systemic manifestations of the disease.”(ATS/ERS 2011).

Self-management programs

Self-management programs are defined as “any formalized patient education programme aimed at teaching skills needed to carry out medical regimens specific to the disease, guide health behaviour change, and provide emotional support for patients to control their disease and live functional lives” (Effing 2007). Patients with COPD experience high symptom burden and poor health-related quality of life, and are required to manage their condition over extended periods (Bourbeau 2003). Evidence suggests that self-management education programs that target skills to assist patients in coping are likely to reduce hospital admissions in patients with COPD, but there is heterogeneity in current studies (Effing 2007).

Action plans as part of an integrated strategy and management guideline

Action plans are defined as “the use of guidelines which outline self-initiated interventions (such as changing medication regime or visiting the general practitioner or hospital) which are undertaken appropriately in response to alterations in the state of the patients’ COPD (e.g. increase in breathlessness, increased amount or purulence of sputum) that suggest the commencement of an exacerbation” (Turnock 2005). Patients who receive early intervention for exacerbations of COPD symptoms are shown to recover sooner and experience better quality of life with ongoing optimal management (Wilkinson 2004). Action plans have been shown to be effective in early intervention in asthma management; however the evidence for their efficacy in COPD has been limited (Gallefoss 1999; Turnock 2005).

Telehealthcare

Telehealthcare is a rapidly expanding field in healthcare and chronic disease management (Inglis 2010; McLean 2011). Telehealthcare in COPD is described by a recent Cochrane Review as “using technology such as telephones, video cameras and the Internet to allow people to stay at home and communicate with a nurse or doctor when they have a period of increased breathlessness” (McLean 2011). Considering the housebound status of people with advanced COPD and the frequency with which patients access acute health services as the disease progresses, telehealthcare has particular applicability in this population (McLean

2011). Telehealthcare has great potential in the resource-limited future of modern health care.

Outreach programs

Outreach programs are those interventions that "comprise home visits by a respiratory nurse or similar respiratory health worker, to facilitate health care, provide education, provide social support, identify respiratory deteriorations promptly and reinforce correct technique with inhaler therapy" (Wong 2012). Delivery of care in the community targets those patients who are housebound or frequently reliant on acute services in the advanced stages of COPD. Outreach programs strive to maintain optimal management of disease and assist patients in self-management behaviours, as well as regular monitoring and early intervention in condition deterioration. A recent Cochrane systematic review found that this type of intervention does improve health -elated quality of life; however the current studies are heterogeneous in their approach (Wong 2012).

Why it is important to do this overview

Chronic diseases such as COPD require a comprehensive and multi-dimensional approach to disease management that incorporates a range of integrated intervention components, for example exercise rehabilitation with self-management education (Global Initiative for COPD (GOLD) 2010; Make 2003; World Health Organisation 2004).

Many of these discrete interventions are complex in both design and delivery, and require distillation of essential elements: e.g. the type, frequency and level of intervention intensity, as well as description of the workforce type and scope. Using a pre-specified and standardised taxonomy may assist in providing information to health providers and consumers in design of effective and appropriate interventions for COPD management (Krumholz 2006; Make 2003). Understanding the most efficacious organisation, timing and sequencing of these interventions within a disease management approach, as well as resource requirements for these approaches, are of high interest internationally and will inform policy, healthcare decisions and future research (Disler 2012; Effing 2007; Krumholz 2006; Make 2003).

This overview will summarise evidence for non-pharmacological, non-surgical, non-device programs for the management of COPD, highlight the current gaps in knowledge, provide recommendations for how best to report outcomes for these complex interventions and inform future program improvement and design. Specifically, we will investigate the evidence for pulmonary rehabilitation, self-management programs, action plans as part of an integrated strategy and management guideline, telehealthcare and outreach programs.

OBJECTIVES

To a) summarise the evidence, b) identify gaps in the evidence base and c) describe elements of non-pharmacological, non-surgical and non-device interventions for the management of COPD using a standardised taxonomy for disease management adapted from the American Heart Association (Krumholz 2006).

METHODS

Criteria for considering reviews for inclusion

Types of reviews

We will include reviews published in the *Cochrane Database of Systematic Reviews* (CDSR) that examine non-pharmacological, non-surgical, or non-device strategies for the management of COPD. This overview seeks to assess the evidence published in the original Cochrane systematic reviews and will not seek to update these reviews. However, specific information about intervention components may be sought from trial reports and individual researchers.

Types of participants

People with a clinical diagnosis of COPD according to the definitions in the original reviews.

Types of interventions

We will include non-pharmacological, non-surgical, non-device intervention strategies for the management of COPD within a comprehensive and multifaceted approach, specifically: pulmonary rehabilitation; self-management programs; action plans as an integrated strategy and management guideline; telehealthcare; and outreach programs. We will exclude reviews of surgical treatments and treatment devices as outside of the scope of this overview, for example non-invasive ventilation, continuous positive airway pressure and lung volume reduction surgery will not be included.

Types of outcome

The following outcomes will be discussed and reported if present within the included Cochrane systematic reviews:

Primary outcomes

- Health-related quality of life (any validated measure)
- All cause hospital admissions
- All cause emergency department presentations

Secondary outcomes

- Patient-reported breathlessness (any validated measure)
- Functional capacity (any validated measure)

Search methods for identification of reviews

We will search the *Cochrane Database of Systematic Reviews* on *The Cochrane Library* (latest issue) using the search strategy in Appendix 1. We will not apply date or language restrictions. All protocols for ongoing reviews will be noted in the 'Studies awaiting assessment' section for possible inclusion in future updates of this overview.

Data collection and analysis

Selection of reviews

Two authors (RTD, PMD) independently will assess Cochrane systematic reviews as being 'for exclusion', 'for inclusion', or 'potentially eligible' on the basis of title and abstract. We will locate full texts for Cochrane reviews judged as 'eligible' or 'potentially eligible' and two independent authors (RTD, PMD) will judge their suitability for inclusion against the inclusion criteria. In the instance of disagreement a third review author will adjudicate.

Data extraction and management

Two review authors (RTD, PMD) will independently extract data from included Cochrane reviews and a third author will check all extracted data for accuracy and consistency. We will collect extracted data using a customised electronic data extraction form. The data extracted will include review objectives, participant information, primary outcome measurements and limitations noted in the review. Quality of included reviews (using AMSTAR) and quality of evidence in included reviews (using GRADE and risk of bias) data will be extracted for assessment of overall methodological quality. In addition, we will extract details of the following elements for discussion: intervention content; delivery personnel; method of communication; intensity and complexity of intervention; setting and environment; and outcome measures (Krumholz 2006; Ryan 2011).

Dealing with missing data

Outcomes will be discussed and reported if present within the included original Cochrane Systematic reviews. If any information from the reviews is unclear or missing, we will access the published reports of the individual trials and contact individual researchers.

Assessment of methodological quality of included reviews

Quality of included reviews

Two review authors (RTD, PMD) will assess the methodological quality of the included reviews independently using the 'assessment of multiple systematic reviews' (AMSTAR) measurement tool (Shea 2009). Disagreements will be resolved by a third author. We will not exclude Cochrane reviews on the basis of methodological quality.

Quality of evidence in included reviews

Two review authors (RTD, PMD) will assess the quality of evidence presented in the included reviews using the GRADE assessment tool and through assessment of risk of bias of the included evidence. We will retrospectively apply the risk of bias tool and GRADE the evidence from trials in individual systematic review where this was not done previously (Higgins 2011).

'Summary of findings' tables

We plan to prepare several summary tables. Summary tables will present data extracted on the characteristics of included reviews; the methodological quality of included reviews (AMSTAR ratings); the quality of evidence in included reviews (GRADE and risk of bias); and a summary of primary outcomes reported in included reviews - by intervention (pulmonary rehabilitation, self-management programs, action plans as part of an integrated approach, telehealthcare, and outreach programs). We will summarise information on the multi-component interventions used in COPD disease management using an adapted standardised disease management taxonomy. This 'elements of multi-component interventions' table will include the following content: intervention content, delivery personnel, method of communication, intensity and complexity of intervention, setting and environment, and outcome measures (Krumholz 2006).

Data synthesis

We do not anticipate that we will be able to perform quantitative data analyses. Therefore we will present a narrative summary of results for the individual reviews and primary outcomes. For future updates of this overview we may perform quantitative data analysis of interventions across reviews for the primary outcomes if data permit.

We will present narrative descriptions of the evidence for non-pharmacological, non-surgical, non-device interventions for COPD using two comparisons: intervention versus placebo, and intervention A versus intervention B (e.g. self-management versus standard care or self-management versus action plans). This descriptive approach to summarising evidence is similar to the successful approaches seen in the Cochrane overviews of pain management for women in labour (Jones 2012) and of consumer-oriented interventions for evidence-based prescribing and medicines use (Ryan 2011).

We plan to adapt and apply a standardised disease management taxonomy to organise the discussion (Table 1). We hope that the use of such a framework will guide discussion and increase the utility of the review for decision-makers by promoting increased understanding of intervention intensity and duration and workforce requirements (Krumholz 2006).

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* *Indicates the major publication for the study*

ADDITIONAL TABLES

Table 1. Taxonomy of COPD Disease Management (Adapted from the American Heart Association (Krumholz, et al., 2006))

Patient Population	Recipient	Intervention content	Delivery Personnel	Method of Communication	Intensity	Complexity	Environment	Outcome measures
• Disease severity	• Patient	• Patient education	• Nurses	• Face to face:	• Duration	• Program	• Hospital:	• Clinical

Table 1. Taxonomy of COPD Disease Management (Adapted from the American Heart Association (Krumholz, et al., 2006)) *(Continued)*

• Co-morbid conditions • Non-clinical characteristics		• Medication management • Prescribed exercise • Peer Support • Counselling	• Physicians • Physical therapists • Dieticians • Psychologists • Social workers • Pharmacists • Care managers • Care coordinators	Individual • Face to face: Group • Telephone: In person • Telephone: Mechanised • Internet: Telemonitoring • Internet: Telehealthcare	• Frequency and periodicity • Follow-up	components • Sequencing of components • Delivery personnel	Inpatient • Hospital: Outpatient • Community based • Home based • Telehealthcare	measures • Process measures • Quality of life measures • Healthcare utilisation

APPENDICES

Appendix 1. Search strategy: *The Cochrane Library*

#1 MeSH descriptor Pulmonary Disease, Chronic Obstructive explode all trees
#2 MeSH descriptor Lung Diseases, Obstructive, this term only
#3 COPD:ti
#4 (obstruct*) near/3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*):ti
#5 (#1 OR #2 OR #3 OR #4)
[Limited to Cochrane Database of Systematic Reviews]

CONTRIBUTIONS OF AUTHORS

All authors contributed to the development of the title registration, overview of methods, development of selection criteria, decisions on the organising framework and development and writing of the protocol.

DECLARATIONS OF INTEREST

None known

SOURCES OF SUPPORT

Internal sources

- University of Technology, Sydney, Australia.

RD is a doctoral student supported by the University of Technology, Sydney.

- National Health and Medical Research Council, Australia.

SCI is a post-doctoral research fellow supported by the National Health and Medical Research Council of Australia (NHMRC Grant ID 472 699).

- National Heart Foundation, Australia.

SCI is a post-doctoral research fellow supported by the National Heart Foundation of Australia.

External sources

- No sources of support supplied

NOTES

None.

SECTION FOUR: THESIS DISCUSSION AND CONCLUSIONS

CHAPTER 9: DOCTORAL DISCUSSION

This thesis has sought to understand how we can optimise care delivery in chronic obstructive pulmonary disease (COPD). Specifically, the thesis has sought to: understand the underlying factors that influence and challenge individuals' experience of living with COPD and their ability to manage their condition and engage with health care services; conceptualise how can we better address unmet needs and facilitate the transition from chronic to the end stage disease; and conceptualise innovative, multifaceted and tailored approaches that optimise care delivery and healthcare utilisation while meeting the needs of the individual.

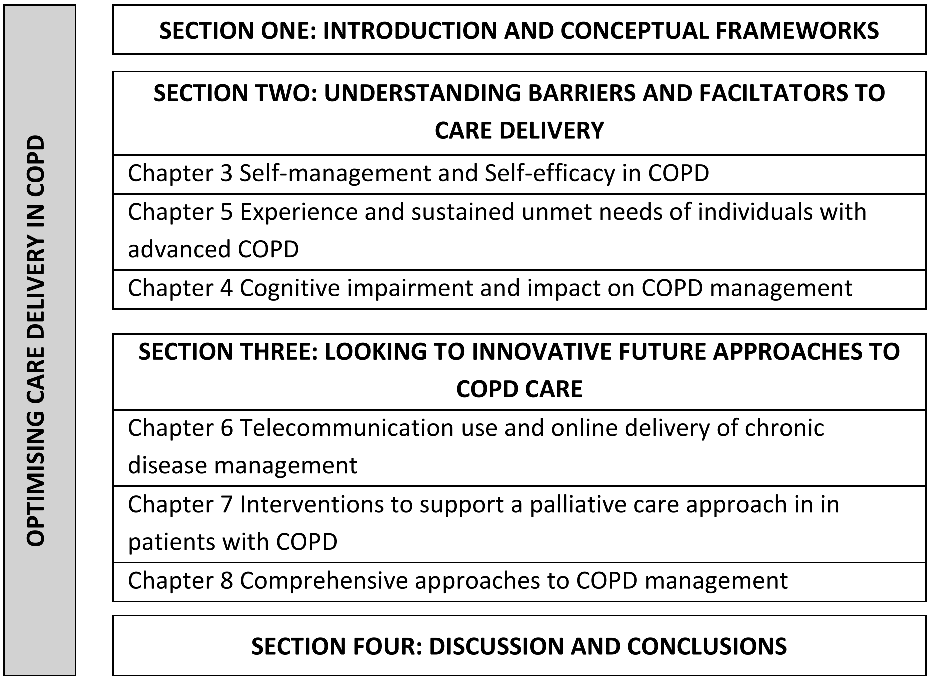
COPD is a substantial problem with clear documentation of the marked symptom burden and barriers to COPD care, yet solutions are less evident. The Chronic Care Model identifies the needs of the patients and their families as the focus of care and the need for coordination of care, evidence-based practice and cross-sector collaboration to achieve optimal outcomes [1-3]. An emerging body of data underscores the importance of this collaborative and multifaceted approach and is currently a focus of clinicians and policy makers in hospital avoidance. Nurses play a prominent role in this through planning and coordinating the complex care for individuals with COPD. Understanding the challenges to care delivery will act to inform health professionals and policy makers in the optimal care delivery approaches that provide sustained positive impact for individuals with COPD.

The interrelated studies presented in this thesis have sought to understand how we can optimise care delivery in COPD, and specifically to understand the underlying factors that challenge patient's ability to manage their condition and to conceptualise how innovative and multifaceted approaches to disease management can address the limitations of traditional care delivery and meet the needs of the individual (Figure 1).

The importance of collaborative and multifaceted approaches to care has been a key theme throughout this thesis and was informed by the Chronic Care Model [1-3] and the Comprehensive Approaches to Chronic Disease Management frameworks [4-6]. The concepts of self-management [5,7-9] and self-efficacy [10-12], and the need to support patients in developing confidence for managing their disease within their own context [1-3], have similarly informed the conceptual development of every study included in this doctoral work. The over-arching conceptual element of this study has been the focus on person-centred care and the need to support individuals across the illness trajectory from diagnosis to death. Whilst self-management, and some instances behaviour change, is the key focus in early stages of disease trajectory, in the later stages of the disease care focusses on a supportive care strategy. Nevertheless, across the care trajectory person-centred care is a central tenet that incorporates the following factors:

- Assessing the needs of individuals and working with them to recognise their strengths and adapt their lifestyle to enable self-care and independence.
- Affording individuals dignity and respect.
- Providing coordinated care providing evidence based treatment options.
- Fostering personalised care.

As a consequence, several conceptual frameworks have informed the development and theoretical design of the individual studies included in this thesis and have assisted in study design and interpretation of findings. These aspects are most clearly elucidated in the Chronic Care Model [1-3].



OPTIMISING CARE DELIVERY IN COPD

SECTION ONE: INTRODUCTION AND CONCEPTUAL FRAMEWORKS

SECTION TWO: UNDERSTANDING BARRIERS AND FACILTATORS TO CARE DELIVERY

Chapter 3 Self-management and Self-efficacy in COPD

Chapter 5 Experience and sustained unmet needs of individuals with advanced COPD

Chapter 4 Cognitive impairment and impact on COPD management

SECTION THREE: LOOKING TO INNOVATIVE FUTURE APPROACHES TO COPD CARE

Chapter 6 Telecommunication use and online delivery of chronic disease management

Chapter 7 Interventions to support a palliative care approach in in patients with COPD

Chapter 8 Comprehensive approaches to COPD management

SECTION FOUR: DISCUSSION AND CONCLUSIONS

Figure 9.1 Thesis structure

UNDERSTANDING THE BARRIERS AND FACILTATORS TO CARE DELIVERY

Gaining understanding of the challenges to self-management of COPD and the sustained unmet needs of individuals, acts to inform the design of future healthcare interventions, systems and policy that are reflective of the needs of the individual [5,13,14].

Barriers and facilitators to COPD self-management

The majority of COPD care occurs in the community by patients and their families. Engagement with self-management and development of self-efficacy have been shown to assist patients to control their symptoms, slow disease progression, and improve health related quality of life [15-17]. Understanding the barriers and facilitators that individual's face will assist health professionals in better supporting patients in actively participating in this core element of COPD care[18-21] and in undertaking the naturalistic decision making that requires patients to interact with knowledge, experience, skill, and values to interpret and implement self-care [5,7-9].

Studies have been undertaken to explore discrete foci around self-management but few have attempted to link those things that influence self-management in COPD as an overreaching and coherent model. The integrative review undertaken as part of this thesis identified that there are diverse physical, social, cultural, psychological and existential issues experienced by patients [5]. An overriding theme that emerged was that individual's commonly find the requirements of self-management burdensome and disruptive and often in conflict with pleasurable, life activities [22-27]. While the physical aspects of COPD are well recognised, the existential determinants, such as social isolation, are seen to have a high impact on the individual, but are rarely acknowledged or addressed in practice [5]. Provider characteristics, socioeconomic status and support, and health literacy, were all noted to influence patients' condition, but scant literature explored the direct influence on quality of life or individuals' ability to self-manage [26,28-305,28,29,31].

Support for collaborative self-management has been recognised as a vital component for increasing continuity and quality of chronic illness care in the future. [2,3] Regular access to this expert advice around symptom management, problem solving and coping techniques are necessary for patients to make self-management decisions with increased confidence [24,26,32-37]. Collaborative care between individuals and health providers, and strengthening of relationships between primary, secondary and tertiary care, are essential to assist individuals in accessing resources and transitioning through the health system [33,34,3835,39]. Understanding the diverse factors that contribute to self-management is important in developing interventions tailored to the needs of the individual's, and to support interaction with health and social systems [5,23,24,26,27,38].

Cognitive impairment

Cognitive impairment is increasingly recognised to influence self-management behaviours in chronic illness, yet is infrequently considered in delivery and planning of care [14,40-43]. Cognitive impairment is attributed to systemic respiratory, vascular and inflammatory effects as well as ageing and comorbidity burden in COPD and occurs in 77% of individuals [40-43]. However, the prevalence and impact of cognitive impairment on patients ability to manage their condition is likely underestimated given screening has previously relied on generic tools, such as the Mini-mental State exam, not necessarily suited to changes in high level functioning [40,43]. Domain focused cognitive testing and interventions that address decline in cognitive function have the potential to improve patients' ability to cope and adjust to living with COPD [14,43].

Of concern was that participants in the qualitative study as part of this thesis appeared to be unaware of the connection and high prevalence of mild cognitive impairment in relation to their COPD. Contrary to anecdotal concern that raising issues around cognition would be distressing to individuals with chronic disease, participants in this study voiced that cognitive testing would be considered just another part of routine care if offered, and were in fact eager to access cognitive testing and supports if available [14].

Regardless of the context of COPD, participants were in fact already engaging in strategies to help maintain cognitive function and remember their self-management activities as part of their normal lives [14,40-43]. The work to manage the varied, complex and ever changing medications regimens associated with chronic illness was a resounding theme for participants in the study. A key concern on discussion, was that individuals who did have cognitive impairment would be of high risk of inaccurate medication behaviours and this would have dangerous consequences.

Optimisation of disease management, including decision making in the context of complex medication regimens, is essential in symptom control and slowing of disease progression [44-46]. Understanding the influence of cognition on self-management will furthermore assist health professionals in recognising and addressing cognitive impairment as an underlying influence on individuals' engagement with and adherence to healthcare regimens [14,43]. Cognitive change must additionally be recognised as a key issue to be addressed when designing interventions to optimise health care delivery and utilisation [14,43].

Sustained unmet needs of individuals with COPD

Despite advances in management and optimisation of treatments, a large proportion of individuals with COPD continue to have inadequately managed symptoms, unmet psychosocial needs and limited access to supportive services [5,17,47 13,48-53]. The metasynthesis of discrete qualitative studies provided a collective voice and important insight into the broader experiential perspective of living with COPD over the past two decades [13,48,54-57]. This amalgamation highlighted the ongoing and yet unmet psychosocial and existential needs of individuals and a disconnection with society in an increasingly 'shrinking world' [13,25,31,48,54,58-69]. Loss of hope and meaning have a marked impact on individuals' experience of illness and resilience to engage with management techniques, yet they have a limited presence in management models and quantitative outcome measurement [64,67]. Preparation for end of life is equally recognised as important [70,71] and while the barriers and facilitators for initiating end of life discussions are increasingly understood, there is limited evidence of innovations to address the lack of proactive discussion [13,70,71]. Individuals with COPD experience well established and ongoing needs. Future care must look to solutions that address the variety of symptoms and complex experiences of individuals with COPD [13,72-7413,48-50,75].

LOOKING TO INNOVATIVE FUTURE APPROACHES TO CARE

The complexity of individuals' symptoms and experience, in addition ageing and comorbidity burden suggest the need for comprehensive approaches and optimisation of current care with a broad based symptom focus [13,48,72-7476]. The latter parts of this thesis sought to look towards the future of COPD care delivery and in particular: consensus around multifaceted and tailored approaches to disease management; approaches to care that facilitate the transition from chronic to progressive chronic disease; and how current innovations and trends could inform COPD care delivery that address issues of access and improved utilisation of available health services [77-79].

Comprehensive and multifaceted approaches to COPD management

The complex and progressive healthcare needs experienced in COPD require comprehensive approaches to disease management that engage 'multiple therapies into a patient-centred plan of care' [77,78,80-82]. The Cochrane Overview of systematic reviews undertaken and presented in this thesis, collated the evidence for the key multifaceted interventions associated with COPD management. The overview again confirmed the established strong evidence that pulmonary rehabilitation improves quality of life and lessening disease burden [77,78], however noted that only mixed evidence existed for a positive effect of self-management, hospital at home, pulmonary rehabilitation exercise programs following acute exacerbation, integrated disease management, care delivered through telehealth platforms and home care delivered by outreach nursing services [77,78]. Intrinsic heterogeneity in study design, intervention components, outcome measures, and the lack of a consistent control, inhibits understanding of the most effective interventions for sustainable positive impact in COPD [5,17,47,77,78,80-82]. Articulation and consensus of operational definitions and essential intervention components, and the use of standardised measures, will allow for better cross study comparisons in the future [77,78,83-85]. A standardised taxonomy will allow for clearer guidelines as to intervention requirements, so that future research can strive for patient satisfaction and economic efficiency, in developing efficacious and sustainable health care delivery [77,78,85,86].

Interventions to support a palliative care approach

There is increasing recognition that supportive care should be used in the management of life-limiting conditions during the acute, chronic or terminal phases [49-52,79,87,88]. Palliative care is highly appropriate for end-stage COPD, yet, individuals with this condition have limited access to palliative and end-of-life care [49-52,79,87,88]. The difficulty in prognostication in the end-stage of COPD, due to the fluctuating and episodic decline of the disease [52,89-91], is a well-established barrier for patients with end-stage COPD when accessing palliative care services [49,50,52,89,91]. However, these challenges are not a valid argument for avoiding provision of effective end of life care, given that only 30% of men and 24% of woman with a diagnosis of severe COPD survive five years [92], and 50% of people with COPD die within two years of their first acute admission, and 50% within one year if they require non-invasive ventilation for management of acute respiratory failure [93-95].

The integrative review as part of this thesis found that although literature concerning discrete elements of management is present, there are limited data discussing the comprehensive and collaborative approaches necessary to address the complex and multivariate needs of end-stage COPD patients[79]. A key overriding principle throughout the review was the role of provider communication in ensuring patient access to services and interventions in the management of end-stage COPD [70,79,96-99]. Evidence indicates that providers acknowledge that most patients are unaware of the terminal nature of COPD and the need for timely advance care planning, however few initiate such discussions [49,70,79,100]. Difficulty in estimating the terminal phase of COPD and lack of communication around end-of-life planning has been a well-documented barrier to appropriate timing of conversations and consequently the referral of patients to palliative care [52,71,79,96,101-105]. Training is required to support providers in commencing advance care planning discussions.

The complex needs experienced by patients with end-stage COPD, and the subsequent variety of associated interventions, demonstrate the need for a systems approach to care such as that seen in palliative services [50,79,101,106-108]. A 'mixed management model' such as that seen in palliative care provides a flexible system that allows for active management in combination with planning for the final stages of life [79,109-111]. A collaborative palliative care approach would encourage collaboration across health services and specialities, and assist patients in utilising available supports to manage the demands of their disease while maximising involvement and enjoyment in pursuits that give them pleasure [24,52,53,101,112,113]. Health reform and further research are required to ensure the provision of supportive palliative care which is responsive to the needs of patients, provider and health systems [79].

Innovative technological approaches to healthcare delivery

Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and economically sustainable approaches to support patients with chronic illnesses, such as COPD. Current care approaches are episodic and expensive and reach only a small proportion of the population [114-117]. Decreased mobility further inhibits chronically ill patients from accessing these programs [114,115]. These challenges inhibit access to information related to coping as well as social support networks [114-118]. Access to online health information and support is well established in the United States of American [119], but is commonly used internationally [120-125]. The introduction of e-health (health care delivery through internet and telehealth communications for surveillance, health promotion and support of management) and mHealth (monitoring, personal digital assistants, and other wireless devices) are altering the collaboration and interaction between consumers and health providers [126-128]. Asynchronous forms of health interaction, such as through email or discussion boards, have the capacity for individuals to pose questions of their provider without having to wait for a formal consultation, and thereby access self-management and condition support that meets their ongoing needs [129,130].

The two data studies completed as part of this thesis showed that the majority of respondents engaged in regular computer, smart phone and internet use, including accessing and browsing health sites and information. Participants in the focus group study reported noted that the online environment is already a common aspect of the modern landscape. Participants in both studies were already interacting with peers and health professionals using a range of media [119-121,131,132]. Online healthcare delivery, moderated sites and direct health provider interfaces, were viewed as providing convenient, timely and easily accessible support and information, currently difficult to obtain through traditional face to face sources. Individuals additionally noted the benefit for individuals who are isolated by debilitation or geographical barriers and in particular the benefit of peer support and sharing through these platforms [133] [119-121,133]. Computer literacy training and access to computers also need to be addressed to meet the needs of a generation of already engaged and empowered health consumers [119-121,131].

Long-term progression of disease and associated self-management requirements necessitate the need for accessible and convenient avenues to obtain ongoing treatment and peer support. The increased social well-being, enhanced self-management and self-efficacy and sense of belonging and normalcy offer important benefits in the context of prolonged disease duration [119-121,131]. Utilising online healthcare delivery may be an important adjunct to traditional forms of healthcare [119-121,131,132]. Healthcare professionals have an opportunity to optimise care delivery by directing individuals to trusted and accurate health information [119-121,133]. Further research is required into the socioeconomic and physical benefits of such approaches particularly in those who have limited access to face to face health support.

LIMITATIONS OF THIS DOCTORAL THESIS

Undertaking a series of discrete studies has limited the capacity for this thesis to implement a complex intervention. However, the comprehensive and holistic approach undertaken has allowed for depth of understanding into the underlying factors that challenge individuals' experience of living with and self managing their COPD and how we can optimise healthcare delivery and utilisation by conceptualising innovative and multifaceted approaches to disease management. Increasingly the development of successful health care interventions requires substantial formative development. These individual studies are congruent with the development phase of complex interventions [134]: the understanding gained from this thesis will be paramount in informing the development of efficacious, complex and multifaceted interventions in the future.

The methodological limitations of the individual study approaches have been discussed in the studies in detail, and additionally the depth of discussion in published material has at times been influenced by journal word limits and style requirements. However, these do not detract from the comprehensive understanding of these complex issues provided by a series of discrete yet interrelated studies of the approaches to and patient experience of COPD management. Rigour, reliability and cogency have been supported throughout by the systematic and transparent approaches to each study, with the use of independent investigators and expert panel discussion to develop and confirm understanding and emergent themes.

What this thesis has clearly shown is that there remain clear gaps in research around the optimal care delivery and utilisation of available services in supporting patients with COPD. It is exciting to think that postdoctoral study will draw on this work to allow for greater understanding and implementation of interventions to provide comprehensive and tailored approaches to COPD care.

IMPLICATIONS FOR POLICY, PRACTICE AND FUTURE RESEARCH

Ranking fourth as a cause of death worldwide, economic costs associated with COPD are only expected to increase as the population ages. Social costs include significant disability as reflected in daily symptoms, poor physical functioning, social isolation, and caregiver burden. Despite advances in management and optimisation of treatments, there are well established and ongoing needs which have not markedly improved over the past two decades [49,50,75]. In optimising care delivery and healthcare utilisation, it is important to consider the impact of provider influence, socioeconomic status, cognition and health literacy [5,28,29,3114,46-49]. Additionally, while the physical aspects of COPD are well recognised, the existential determinants, such as social isolation, are seen to have a high impact on the individual, but are rarely acknowledged or addressed in planning care delivery [5]. The measure of success and effectiveness of interventions remains strongly based on health related quality of life, health utilisation and mortality data. Consequently these outcomes continue to inform and drive policy and practice development [135]. There is potential to capitalize on our understanding of the ongoing needs of individuals with COPD in developing consumer driven interventions and reframing health service delivery to address the underlying needs of this population [56,57,136].

Improvements in the complex and multivariate needs of individuals with COPD must be driven through comprehensive and systems approaches to care delivery [77,78,80-82]. The intrinsic heterogeneity in the components included in the different programs and the way program success is measured challenges the evidence for these multivariate interventions [77,78]. It is imperative that we have clearer articulation and consensus on essential intervention components for high quality care delivery [5,17,47,77,78,80-82]. Using a pre-specified and standardised taxonomy may inform health providers and consumers in design and development of future interventions for COPD management [81,86].

The transition from chronic to chronic progressive COPD requires active management to be combined with planning for the final stages of life [71,103,104]. Challenges in prognostication, and the limited recommendations provided for end-stage care in international COPD guidelines, are likely contributors to the lack of palliative and supportive care delivery in individuals with COPD [49-52,79,87-91,137]. Improving providers' confidence in initiating end-of-life discussions, through training in approaches to end-of-life conversations and available services, would assist in the utilisation of advanced care planning and system interventions [71,103,104,138]. In addition, collaboration between primary, secondary and tertiary care should be strengthened to improve delivery of care across different parts of the health system [33,35,38,39].

Finally, current care approaches are episodic and expensive and reach only a small proportion of the population [114,115,117,118]. The long-term tasks of self-management and overall burden of disease, provide a compelling argument for accessible and convenient avenues for patients to obtain ongoing treatment and peer support. Communication tools are already a pervasive component of healthcare delivery and will increasingly influence future healthcare delivery in COPD and other chronic conditions [120-122,131,139,140]. The new generation of empowered health consumers expect health care systems that accommodate their changing needs and preferences [120,121,131]. Innovation in delivery approaches, such as those seen in asynchronous online health delivery platforms, may be an important adjunct to traditional forms of healthcare [119-121,131,132]. Further research is required into the socioeconomic and physical benefits of such approaches particularly in those who have limited access to face to face health support.

CONCLUSION

There is clear documentation of the marked burden and barriers to COPD care, yet solutions are less evident. This thesis has sought to understand how we can optimise care delivery in COPD. Issues of healthcare access, increasing health costs and the need for improved health outcomes drive the search for more effective and economically sustainable approaches to support patients with chronic illnesses, such as COPD. Future COPD care must be delivered through multifaceted and comprehensive approaches that tailor care to the socio-psychological needs, and associated health literacy of the individual. Collaborative care between individuals and health providers, and strengthening of relationships between primary, secondary and tertiary care, are essential to assist individuals in accessing resources and moving between different parts of the health system [33,34,3835,39]. The long-term tasks of self-management and overall burden of disease provide a compelling argument for accessible and convenient avenues to obtain ongoing treatment and peer support, such as those seen in asynchronous online health delivery platforms. It is hoped that in understanding the factors that influence individuals engagement with care delivery that the work in this thesis will act to inform new and innovative delivery approaches that work to address the varied needs of individuals with COPD and that engage patients with health professionals and peers in supportive and collaborative relationships.

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