

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

Rebecca T Disler

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

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 Lockett, 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 Lockett, 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; Policies 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.

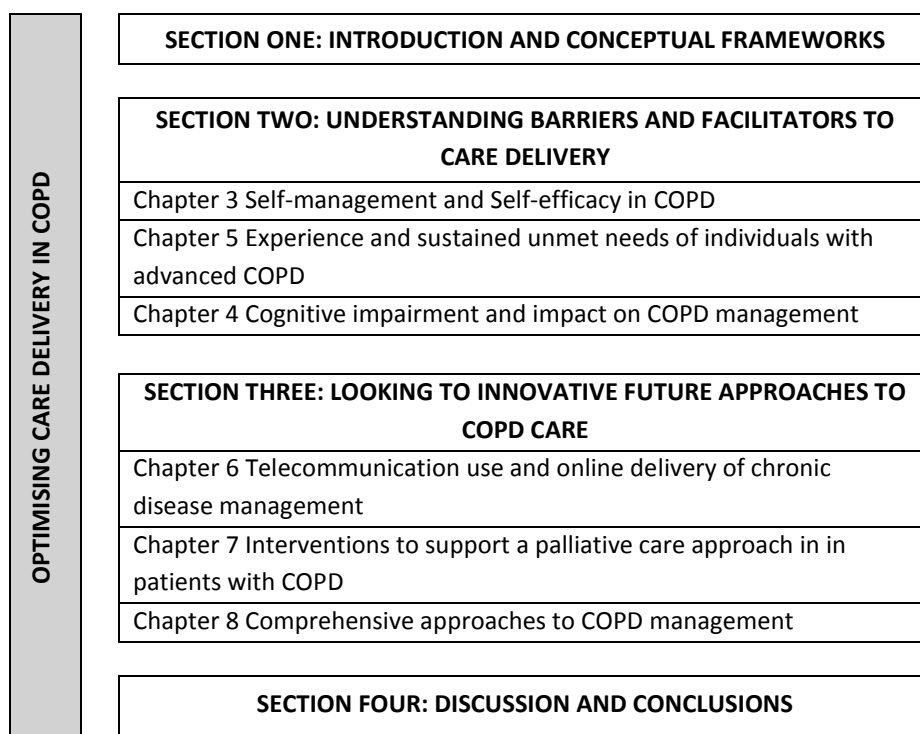


Figure i: Thesis structure

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

CERTIFICATE OF AUTHORSHIP AND ORIGINALITY	ii
ACKNOWLEDGMENTS.....	iii
PREFACE	v
LIST OF PEER REFEREED ARTICLES SUBMITTED FOR PUBLICATION DURING DOCTORAL TENURE	xi
AWARDS RECEIVED DURING DOCTORAL TENURE.....	xiii
CONFERENCE ABSTRACTS	xv
LIST OF TABLES	xvi
LIST OF FIGURES	xvii
DOCTORAL ABSTRACT	xviii
BACKGROUND	xviii
OBJECTIVES.....	xviii
METHODS	xix
FINDINGS.....	xix
CONCLUSIONS	xxi
SECTION ONE: INTRODUCTION AND CONCEPTUAL FRAMEWORKS	1
OPTIMISING MANAGEMENT AND CARE DELIVERY IN PEOPLE LIVING WITH COPD	2
CHAPTER 1: INTRODUCTION	2
BACKGROUND TO COPD	3
CHARACTERISTICS OF COPD.....	6
THERAPEUTIC MANAGEMENT OF COPD.....	10
SIGNIFICANCE OF THE RESEARCH PROBLEM	14
AIMS OF THE DISSERTATION	15
CHAPTER REFERENCES	16
CHAPTER 2: CONCEPTUAL FRAMEWORKS	25
THE CHRONIC CARE MODEL.....	25
SELF-MANAGEMENT	27
SELF-EFFICACY	30
COMPREHENSIVE APPROACHES TO CHRONIC DISEASE MANAGEMENT.....	31
CHAPTER REFERENCES	33
SECTION TWO: UNDERSTANDING BARRIERS AND FACILTATORS TO CARE DELIVERY	39
CHAPTER 3: INTEGRATED REVIEW: SELF-MANAGEMENT AND SELF-EFFICACY FOR COPD	40
EXTENDED ABSTRACT	40
BACKGROUND	40

OBJECTIVES.....	41
DESIGN	41
REVIEW METHODS	41
FINDINGS.....	41
IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH	42
CONCLUSIONS	42
EXTENDED ABSTRACT REFERENCES	43
Disler RT, Gallagher RD, Davidson, PM. Factors influencing self-management in chronic obstructive pulmonary disease: An integrative review, <i>International Journal of Nursing Practice</i> 2012; 49:230-242..... 46	
CHAPTER 4: METASYNTHESIS OF QUALITATIVE RESEARCH: EXPERIENCE AND SUSTAINED UNMET NEEDS OF INDIVIDUALS WITH ADVANCED COPD.. 59	
EXTENDED ABSTRACT	59
BACKGROUND	59
OBJECTIVES.....	60
DESIGN	60
METASYNTHESIS METHODS	60
FINDINGS.....	61
IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH	62
CONCLUSIONS	62
EXTENDED ABSTRACT REFERENCES	63
Disler RT, Green A, Lockett T, Newton PJ, Inglis SC, Currow DC, Davidson PM. Experience of advanced chronic obstructive pulmonary disease: Metasynthesis of qualitative research. <i>Journal of Pain and Symptom Management Journal of Pain and Symptom Management</i> , 2014; 46: 6: 1182-1199..... 67	
Disler RT, Green A, Lockett T, Newton PJ, Inglis SC, Currow DC, Davidson PM. Unmet Needs in Chronic Obstructive Pulmonary Disease: A Metasynthesis Protocol <i>International Journal of Research in Nursing</i> 2012; 3: 15-20..... 85	
CHAPTER 5: PATIENTS' ATTITUDES TO COGNITIVE IMPAIRMENT AND TESTING IN CHRONIC OBSTRUCTIVE PULMONARY DISEASE: FOCUS GROUP STUDY 91	
EXTENDED ABSTRACT	91
BACKGROUND	91
OBJECTIVES.....	92
METHODS	92

FINDINGS	93
IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH	94
CONCLUSIONS	95
EXTENDED ABSTRACT REFERENCES	96
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. <i>COPD: Journal of Chronic Obstructive Pulmonary Disease</i> . Under Review.99	
SECTION THREE: LOOKING TO INNOVATIVE FUTURE APPROACHES TO COPD CARE 117	
CHAPTER 6: TELECOMMUNICATION USE AND ONLINE DELIVERY OF CHRONIC DISEASE MANAGEMENT IN COPD 118	
EXTENDED ABSTRACT	118
BACKGROUND	118
OBJECTIVES.....	119
METHODS	120
FINDINGS	120
IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH	121
CONCLUSIONS	122
EXTENDED ABSTRACT REFERENCES	123
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. <i>Interactive Journal of Medical Research</i> . 2015; 4: 1. 127	
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. <i>COPD: Journal of Chronic Obstructive Pulmonary Disease</i> . Under Review.143	
CHAPTER 7: INTEGRATIVE REVIEW: INTERVENTIONS TO SUPPORT A PALLIATIVE CARE APPROACH IN PATIENTS WITH COPD 165	
EXTENDED ABSTRACT	165
BACKGROUND	165
OBJECTIVE	166
DESIGN	166
METHOD	166
FINDINGS.....	167
IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH	167

CONCLUSION	168
EXTENDED ABSTRACT REFERENCES	169
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 <i>International Journal of Nursing Studies</i> 2012; 49: 1443-1458.	173
Disler RT, Inglis S, Currow DC, Davidson PM. Palliative and supportive care in COPD: research priorities to decrease suffering. <i>Journal of Pulmonary and Respiratory Medicine</i> 2012; 1:1-3.	189
CHAPTER 8: COMPREHENSIVE APPROACHES TO CHRONIC OBSTRUCTIVE PULMONARY DISEASE MANAGEMENT.....	192
EXTENDED ABSTRACT	192
BACKGROUND	192
OBJECTIVES.....	193
DESIGN	193
METHODS	193
FINDINGS.....	194
IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH	194
CONCLUSIONS	195
EXTENDED ABSTRACT REFERENCES	196
Disler RT, Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. <i>Cochrane Database of Systematic Reviews</i> . Under editorial review.....	197
Disler RT, Inglis SC, Davidson PM. Non-pharmacological management interventions for COPD: an overview of Cochrane systematic reviews. <i>Cochrane Database of Systematic Reviews</i> PROTOCOL 2013, Issue 2. Art. No.: CD010384. DOI: 10.1002/14651858.CD010384	280
SECTION FOUR: THESIS DISCUSSION AND CONCLUSIONS	290
CHAPTER 9: DOCTORAL DISCUSSION.....	291
UNDERSTANDING THE BARRIERS AND FACILTATORS TO CARE DELIVERY	293
LOOKING TO INNOVATIVE FUTURE APPROACHES TO CARE	295
LIMITATIONS OF THIS DOCTORAL THESIS	299
IMPLICATIONS FOR POLICY, PRACTICE AND FUTURE RESEARCH	300
CONCLUSION	301
DOCTORAL DISCUSSION REFERENCES.....	303
BIBLIOGRAPHY:	315

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, Lockett 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, Lockett 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
- 2015 **Disler RT**, Inglis SC, Davidson PM. Cochrane overview: Comprehensive approaches to COPD management. TSANZ May 2015. *Respirology*. 2015; 20: 111.
- 2015 **Disler RT**, Spiliopoulos N, Collins M, Inglis SC, Currow DC, Davidson PM. Attitudes to Cognitive Impairment and Testing in Patients with Chronic Obstructive Pulmonary Disease: Focus Group Study. C107. New interventions and outcomes in pulmonary rehabilitation, American Thoracic Society Conference, Denver 2015: A5291, 10.1164/ajrccm-conference.2015.191.1_MeetingAbstracts.A5291
- 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

Table 1:1 Characteristics of final two years of COPD	8
--	---

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

Integrative review Table 1 Literature supporting conceptual model	49
---	----

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

Metasynthesis Table 1 Search Strategy	69
---	----

Metasynthesis Table 2 Characteristics of included studies	73
---	----

Metasynthesis Table 3 Themes identified in synthesis of 22 studies on lived experience of COPD and illustrative quotes	75
--	----

Metasynthesis Protocol Table 1 Search Strategy	87
--	----

CHAPTER 5 COGNITIVE IMPAIRMENT IN COPD

Focus Group Study Table 1 Patient demographic characteristics	112
---	-----

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

Survey Study Table 1 Respondent demographic characteristics	130
---	-----

Survey Study Table 2 Access and use of technology	131
---	-----

Survey Study Table 3 Online access, concerns and currently used sites .	134
---	-----

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

Integrative review Table 1 Characteristics of final two years of COPD.....	174
--	-----

Integrative review Table 2 Factors that determine quality end of life care	176
--	-----

Integrative review Table 3 Summary of approaches to support palliative care approach to end-stage COPD.....	175
---	-----

CHAPTER 8 COMPREHENSIVE APPROACHES TO COPD MANAGEMENT

Overview Table 1 Characteristics of included Cochrane Reviews.....	256
--	-----

Overview Table 2 AMSTAR ratings for each Cochrane Reviews.....	257
--	-----

Overview Table 3 Quality of evidence in included Cochrane Reviews....	259
---	-----

Overview Table 4 Summary of comparisons within reviews	211
--	-----

Overview Table 5 Results by individual review	260
---	-----

LIST OF FIGURES

CHAPTER 1 INTRODUCTION

Figure 1.1 Thesis structure.....	2
Figure 1.2 Mixed model approach to care in respiratory disease	14

CHAPTER 2 CONCEPTUAL FRAMEWORKS

Figure 2.1 The Chronic Care Model	26
Figure 2.2 Taxonomy of COPD Disease Management	32

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

Integrative review Figure 1 Model of conceptual elements of self-management in COPD	51
Integrative review Figure 2 Flow chart of studies from search to inclusion	51

CHAPTER 5 METASYNTHESIS OF QUALITATIVE DATA

Metasynthesis Figure 1 Flow chart of data synthesis.....	70
Metasynthesis Figure 2 PRISMA Flow cart of students from search to inclusion	71
Metasynthesis Figure 3 Relationship between themes	72
Protocol Figure 1 Flow chart of studies from search for inclusion (Medline example)	88
Protocol Figure 2 Flow chart of data synthesis	88

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

Survey study Figure 1 Internet access and use survey.....	141
---	-----

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

Integrative review Figure 1 Flow chart of studies from search to inclusion	175
--	-----

CHAPTER 8 COMPREHENSIVE APPROACHES TO COPD MANAGEMENT

Overview Figure 1 Taxonomy of COPD Disease Management	262
Overview Figure 2 Studies flow diagram.....	262

DOCTORAL DISCUSSION

Figure 9.1 Thesis structure	292
-----------------------------------	-----

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.