A GOOD LIFE, DESPITE MY TROUBLES:
AN EXPLORATION OF QUALITY OF LIFE IN
OLDER PEOPLE WITH CHRONIC
OBSTRUCTIVE PULMONARY DISEASE

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Quality of Life in COPD

Abstract

The purpose of this hermeneutic study was to explore the conceptualisation of quality of life for older people with Stage IV (end-stage) Chronic Obstructive Pulmonary Disease (COPD). Eleven people aged between 63 – 89 years living in a large rural centre in New South Wales, were recruited through a local Respiratory Coordinated Care Program to participate in narrative-style interview. Audio and video recording were transcribed verbatim and analysed using an inductive thematic analysis to identify core ideas and themes. The analysis and interpretation of the text was underpinned by Gadamer’s philosophy of hermeneutic phenomenology (1975; 2004) and the Gadamerian-style research method proposed by Fleming, Gaidys, and Robb (2003).

The thematic analysis revealed four core themes: ‘Accepting Change’, ‘Mind over Matter’, ‘Being in the World Together’, and ‘Quality over Quantity’. In accepting the changes occurring in their bodies, as opposed to the diagnosis and label of COPD, the participants spoke of an identity grounded in their past experiences of both suffering and change. It was from this identity as a person both subject to, and capable of change that they fought to maintain independence in the face of mounting dependence. Critical to their acceptance of, and adaption to, change was their use of self-regulatory coping strategies to establish control over their symptoms. This in turn fed into a cycle of change and adaption that built confidence to face future change with resilience.

There were implications of the ongoing change on their core familial relationships, as this is where the burden of physical care lay. These implications manifested not only in the way they coped with increasing disability and burden, but in their decision making processes regarding their future, particularly Advanced Care planning. The drive to maintain independence, and in so doing, protect their loved ones from the full emotional and physical impact of COPD, sat at the core of the participants’ understanding and expression of quality.
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of life; that it was not just their own quality of life, but the quality of lives of those they loved.
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Acknowledgements

This thesis would not have been possible without the support of my supervisors, Dr Judith Crockett, who has steered the ship calmly through endless storms and Associate Professor Deborah Burton, who started me on this Respiratory journey on my first day of University fourteen years ago. Many thanks also to Dr Judith Gullifer and Professor Ann Bonner who provided integral moments of necessary, and timely guidance. Thanks also go to those who have walked this path before and with me, providing counsel and encouragement: Associate Professor Maree Simpson, Dr Sarah Hyde and Chontel Gibson.

To ‘Bernadette’, without whom I would have not been able to hear such magnificent and honest stories; the quality of your care for your patients should serve as a lesson to us all in the power of respect, empathy, and wisdom.

To the emotional ballast in life, my husband Richard Southwell, my mother Meredith Yabsley and my beloved family and friends who have lived this project with me, there are no words. To Ben, the one who was, for just a moment in time, and to the little one who is on its way, you remind me of what life is actually about; this project would not be what it is if I were not your mother.

I dedicate this work to the eleven people who blessed me with their story, from which I learn and from where I teach.
Small Deeps

We are too complicated.
We seek God here, there and everywhere.
We seek God in holy places, in books,
in rules, regulations, rites and rituals.
We seek God in pomp and glory and ceremony,
in relics and statues
and visions and shrines.
We seek God in Popes and Fathers and saints.
Ah, like lost bewildered children,
we seek outside the God
who waits to be found
in the small deeps
of the human heart.

From Edwina Gately,
There Was No Path So I Trod One (1996, 2013)
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Certificate of Authorship

I hereby declare that this submission is my own work and to the best of my knowledge and belief, understand that it contains no material previously published or written by another person, nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged. I agree that this thesis be accessible for the purpose of study and research in accordance with normal conditions established by the Executive Director, Library Services, Charles Sturt University or nominee, for the care, loan and reproduction of thesis, subject to confidentiality provisions as approved by the University.

Phillipa Southwell

29th March 2017
Prologue

My name is Phillipa, but everyone calls me Pip; even my mother when I’m in trouble. I have dark hair, dark eyes and occasional dark moods. Everything else about me is average - age, height, weight, features. I don’t use ‘average’ as a negative; I am happy with average. I have a husband, a son and one on the way - I work full time and they are at home. I miss out on our son’s music and swimming lessons, cuddles and chaos, but in all reality, I like to be an adult; and my husband is the very essence of capable and patient. We have a little house, chickens, and a dog. Average, and deeply, deeply happy.

I like to think of myself as one of those Christians that you don’t mind being friends with. My theology isn’t bigger than yours, your sin isn’t bigger than mine, so let’s get another cup of coffee so we’ve got enough time for you to ask that question you’ve always wondered about.

I never meant to be a scientist, and never meant to work in the Respiratory field - I’m not sure anyone ever intends to work in respiratory, but those who fall for it, tend to fall deeply. I completed an Honours degree whilst working as a Respiratory Scientist at a large paediatric hospital in Sydney, Australia. The study was a purely quantitative assessment of the lung function of teens with Cystic Fibrosis (CF). The testing procedure took about an hour to complete, including significant waiting periods, where I would sit, wait and inevitably chat with them. What I remember most was learning about life with CF, and the unbeatable sense of hope those young people held for their lives. Even then, I knew that research in the future would always involve being in relationship with people, preferably without the statistics. In leaving Sydney for rural New South Wales, CF research was ruled out of the question for pragmatic reasons, but relationship was not.

When this project was initially proposed, it was a far cry from where it is today - different methodology, different ideas, different me. What I was given with that initial idea, was the
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freedom to explore these and other ideas, to wander in the wilderness of literature and find my way through. In creating space for me to discover my place within this project and my identity as a researcher, I have learned to create space for others and for myself.
Chapter 1

Focus of the Inquiry

*It is the simple act of storytelling*  
*that illuminates the darkness.*  
*An image, a string of words*  
*that accesses places beyond consciousness.*  
*It is truth spoken from a damaged soul*  
*that warms the heart.*  
*The expression of another’s pain*  
*that has the power to heal.*  
Janine Browne  
Illuminate the Darkness from *In My Room*’ (2010)

Rationale for the Study

I distinctly remember the day my grandfather set his pants on fire. He had come to look after us while my parents were away and was hiding in the garden, smoking. So desperate to hide what he was doing when I found him, he pocketed the lit cigarette. His trousers must have been a polyester blend - they melted rather than burst into flames. He spoke with me kindly for a few moments, but when the thick chain of black smoke rose from his pocket I was sent away post haste.

Fast forward ten years, the cigarettes and asbestos had both done their work and we knew he only had months to live. When he should have given up cigarettes, instead he gave up pretence. I had known about the smoking all my life but had never seen him do it, it was a challenge to sit with him and see little else. I was 17 and didn’t understand as much as I do
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now - the smoking gave him something to do with his day, something to do with his hands, allowed him to listen rather than talk, and comfort until the end.

My grandfather remains central to my own experience of family. Fifteen years after his death he remains the patriarch of the family, and each year he becomes more perfect in our memory. As a family, we all experienced his disease and his death, and it marked us, but we remember more fondly the sugar stewed in rhubarb for dessert or the day he lost his swimmers in the surf and had to be rescued by my aunt. His legacy was more than his final year.

Within the field of health, we talk of ‘health-related quality of life’, we try to encapsulate what it is and how it can be preserved, even extended. My own experience is that quality of life is bound in love and relationship, purpose and meaning. As scientists, we use scales and tools and questionnaires to try and understand better, and faster, these experiences; but love and relationship, purpose and meaning are nearly impossible to assess objectively. As these concepts and constructs change with the times and the individual, so every now and then, it is important that we pause our measurements long enough to humbly ask the people who have lived this experience: ‘of all these things I believe to be true, is any of it true for you?’

**Phenomenon of Interest**

As the core construct underpinning this inquiry, *quality of life* incorporates the positive and negative aspects of life and provides an understanding of how experience and time influence how the individual perceives their existence and environment (WHOQOL, 1995). It is comprised of a blend of internal (personal) and external (environmental) factors; subjective experiences and objective observations (Ashing-Giwa, 2005; Fernández-Ballesteros, Arias-Merino, Santacreu, & Ruvalcaba, 2012). The assessment of quality of life is used in geography, sociology, epidemiology and politics, although how it is applied varies between
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disciplines. As such, there are a number of discipline-specific interpretations. Of particular relevance to this research is health-related quality of life (HRQL), which explores the positive and negative aspects of life that directly influence a person’s experience and perception of their own health (Farquhar, 1995).

Historically, the model of HRQL used in chronic disease management by the medical community relied on a biomedical model which focused on physical health as pathology progressing uni-directionally into disability (Fernández-Ballesteros et al., 2012; Gerson, 1976). That assumption is to be approached with some caution as it negates the role of assistive therapy, and ignores the subjectivity of the self-assessment, the ability of subjects to cope or adapt, and the individualistic nature of perceived HRQL (Ahmed, Mayo, Wood-Dauphinee, Hanley, & Robin Cohen, 2004; Zhang et al., 2012).

The biomedical framework of HRQL is now universally refuted in light of the work by those such as Engel (1977) and the WHO International Classification of Functionality, Disability and Health (Chan, Gelman, Ditchman, Kim, & Chiu, 2009). HRQL has now been pushed away from an exclusively medical model to incorporate psychological and sociological influences. Thus, HRQL was redefined by Schwartz, Andresen, Nosek, and Krahn (2007) as “a perceived state of health of an individual, group or population that reflects the degree to which a person is able to participate physically, emotionally and socially, with or without assistance” (p.530). Just as importantly, it now focuses on the patient perspective rather than objective observation (Bernhard, Lowy, Mathys, Herrmann, & Hürny, 2004). Bernhard et al. (2004) also suggested in their work with people being treated for colon cancer, that to the client, HRQL is not a stagnant concept, rather, the concept changes with time and experience. The theory that HRQL is not fixed, but a flexible frame of reference influenced by a continual process of adaptation, is yet to be explored in people with Chronic Obstructive
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Pulmonary Disease (COPD), which is the pathological context from which quality of life will be explored in this project.

There has been a notable increase in interest and publications regarding COPD and HRQL in the last 15 years, despite the lack of consensus on definition or guiding frameworks. Weldam, Schuurmans, Liu, and Lammers (2013) provide an interesting definition in their comprehensive review of the topic, as the “individual’s perception of the position in life or life satisfaction, affected in a complex way by physical health, psychological state, level of independence, social relationships and personal beliefs” (p.689). Despite this holistic working definition, they go on to suggest that its measurement should be contained to the realms of physical, psychological and social function, in line with the WHOQOL working party (1995).

However, there is only a weak association between standard markers of COPD progress, like lung function, and HRQL in COPD, so it is currently viewed as an important and complementary measure of health status, used routinely in disease monitoring and clinical research (Pickard, Yang, & Lee, 2011; Weldam et al., 2013).

The premise of this project was initially informed by Albrecht and Devlieger’s (1999) conceptual work regarding the disability paradox where “…in practice, patients’ perception of health, wellbeing and life satisfaction are discordant with objective measures of health status and disability” (p. 978). The misalignment between actual and perceived health and the view that HRQL must continue to reduce over time disallows consideration of the perspectives of the patients who have adapted to their situation despite impairment. In exploring the idea of paradoxical quality of life assessment in COPD, notions of successful or healthy ageing (Young, Frick, & Phelan, 2009), disease specific models of quality of life (Dignani, Toccaceli, Guarinoni, Petrucci, & Lancia, 2015), and adaptive models of quality of life such as Response Shift Theory (Sprangers & Schwartz, 1999), were all used to inform the current research design. Being open to differing approaches to the interpretation of quality of
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life and HRQL, prompted this exploration of their meaning, value and role in the lives of people who were not only living with Stage IV COPD, but also ageing.

Research by Habraken, Pols, Bindels, and Willems (2008) described the patient journey of palliation in COPD, and in the process, highlighted the lack of insight into current measures and understanding of HRQL provided to clinicians caring for their patients towards the end of their life. The research spoke to the nature of illness perception and the identity of the individuals as people who did not perceive themselves to be ‘sick’. These considerations raise questions as to whether there could be alternate warning systems to indicate either end of life or referral to palliative care services, and whether a clearer understanding of how patients conceptualise their illness and their quality of life could affect the way people are cared for.

Research exploring HRQL in people with end-stage COPD is limited primarily to its quantification through a variety of questionnaire tools. The scope of the existing research opens the way for the exploration of how population groups conceptualise the quality of life. Further, how quality of life is understood in light of the lived experience of older people in Australia with advanced COPD remained to be explored from a qualitative perspective prior to this study.

Purpose of the Study

This project aimed to explore the constructs of quality of life, and HRQL, through the insights and experiences of older people with Stage IV (advanced) COPD. To do this, I posed the question: How do older people with Stage IV COPD conceptualise health-related quality of life? With the participants, I explored the individual’s conceptualisation of both health-related and global quality of life as well as factors that mediate them in the presence of ageing and functional decline through the telling of their ‘COPD Story’.
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Background

The scientific literature that informs the Focus of the Inquiry (Chapter 1) and Context of the Inquiry (Chapter 2) were explored at two discreet time periods within the research process. Literature pertaining to COPD prevalence, burden, severity and trajectory as well as constructs of Quality of Life, Disability, and Successful Ageing were explored prior to the data collection phase. It was this knowledge that informed the development of the research question and challenged my own assumptions, particularly regarding disease versus disablement. Late in the interpretive phase, the literature included in Chapter 2 was explored, creating evidence-based context into which the findings would sit. A wide range of keywords were used to search within Scopus, Google Scholar and the CSU Library Catalogue (CSU Primo). Searches were generally refined to a five year period from the date of the search, although more historical searches were required at times.

Chronic Obstructive Pulmonary Disease

COPD is defined by the Global Initiative for Chronic Obstructive Lung Disease (GOLD) as:

“a common preventable and treatable disease… characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients.” (Vestbo et al., 2013)

Used as an umbrella term for a number of orphan respiratory conditions displaying similar features, primarily post-bronchodilator flow limitation, COPD traditionally encompasses emphysema (the destruction of alveoli) and chronic bronchitis (increased mucus production for 3 months a year for two consecutive years) (COPD-X, 2014; Rennard & Drummond, 2015; Vestbo, 2014). COPD is most commonly associated with smoking history, although complex causality associated with exposure to noxious particles, alpha 1 antitrypsin
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deficiency and history of respiratory illness are linked to the development of COPD (Chitkara 
& Hurst, 2012) The incidence, prevalence and mortality of COPD in Organisation for 
Economic Cooperation and Development (OECD) countries has been declining since the late 
1980s although the trends in women and people ≥75 years of age lag behind the rates of 
decline seen in men (Rycroft, Heyes, Lanza, & Becker, 2012; Yang et al., 2016). 
Australian forecasts to 2025 continue to demonstrate this declining trend (Erbas, Ullah, 
Hyndman, Scollo, & Abramson, 2012). Presently, the national prevalence for stage II (mild) 
COPD in people ≥40 years is 7.5% and 29.2% in those ≥75 years (Toelle et al., 2013) 
although this may underestimate prevalence in rural and remote areas of the country (COPD- 
X, 2014). Despite a favourable outlook, COPD remains a significant health concern and 
financial burden world-wide and in Australia (Rycroft et al., 2012). 

**COPD as a Disease of Ageing and Accelerated Lung Ageing**

With normal ageing, the lung will undergo senescence beginning around the age of 25. This 
process results in gradual decline in pulmonary function and increased pulmonary 
inflammation. As the adaptive immune system ages, there is an upregulation of pro- 
inflammatory regulators meditated by the innate immune system as well as structural changes 
to the epithelial and parenchymal tissue of the lung (Ito & Barnes, 2009; Mercado, Ito, & 
Barnes, 2015). Immunologically, COPD mimics, albeit at an increased rate, the age- 
associated changes seen in the lung in response to exposure to pollutants, noxious gases and 
cigarette smoking. Increased oxidative stress within the system can trigger an exaggerated 
inflammatory cascade, resulting in COPD being accepted as a disease of accelerated ageing 
of the lung, with the capacity to induce premature ageing within the systemic vascular system 
(Ito & Barnes, 2009; Mercado et al., 2015; Sharma, Hanania, & Shim, 2009; Vogelmeier & 
Bals, 2007). With the insidious and slow progression of COPD, there is little surprise that
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accelerated lung ageing occurred with increased prevalence associated with age, and increased disability in the older population (Fletcher & Peto, 1977; Ito & Barnes, 2009; Toelle et al., 2013).

**Stage IV COPD**

For the purposes of this study I have used the GOLD I - IV classifications of severity based exclusively on the lung function cut-off points for the severity classification of clients, as this was the severity classification used by the recruiting service at the time of the study. Stage IV COPD is classed as ‘very severe’, with the ratio of Forced Expiratory Volume in one second (FEV₁) to Forced Vital Capacity (FEV₁/FVC) <0.7 and FEV₁ < 30% predicted (GOLD, 2011). Additionally, the diagnosis of respiratory failure or clinical signs of right heart failure can result in patients being categorised at this level. Stage IV COPD is associated with increased rates of weight loss and anorexia, cor pulmonale and secondary pulmonary hypertension, as well as increased rates of depression and anxiety (Matte et al., 2016; Pauwels & Rabe, 2004).

An obvious flow-on effect of high rates of symptom burden, complications and comorbidities are complex intervention regimes. Table 1.1 provides an overview of the current recommended medication-based interventions for people with advanced COPD in Australia. In additional to a gamut of pharmacological strategies, pulmonary rehabilitation is known to have positive effects on physical and psychosocial wellbeing (Janssen et al., 2016; Vaghegginini et al., 2016).
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**Table 1.1 Overview of Pharmacological Management of Stage IV COPD adapted from the Australian COPD-X Guidelines (Yang et al., 2016).**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Therapeutic Aim</th>
<th>Indications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short and Long Acting</td>
<td>Relief of bronchospasm and shortness of breath.</td>
<td>Long-Acting: twice a day</td>
</tr>
<tr>
<td>Bronchodilator</td>
<td></td>
<td>Short-Acting: as required</td>
</tr>
<tr>
<td>Steroidal Preventer</td>
<td>Reduce inflammation within the airways</td>
<td>Twice a day, often in combination with a long-act. bronchodilator, inhaled</td>
</tr>
<tr>
<td></td>
<td></td>
<td>deliver device</td>
</tr>
<tr>
<td>Oral Corticosteroids*</td>
<td>Reduce systemic and pulmonary inflammation</td>
<td>As required, tablet</td>
</tr>
<tr>
<td>Oxygen</td>
<td>Manage hypoxaemia and associated complications</td>
<td>As required, often up to 15 hours a day, generally from oxygen concentrator/</td>
</tr>
<tr>
<td></td>
<td></td>
<td>portable cylinder via nasal prongs</td>
</tr>
<tr>
<td>Antibiotics*</td>
<td>Treatment of pulmonary infections</td>
<td>As required, tablet</td>
</tr>
<tr>
<td>Diuretics</td>
<td>Relief of pulmonary and systemic oedema</td>
<td>Daily/twice daily, tablet</td>
</tr>
</tbody>
</table>

*Medication kept in the home as part of COPD Action Plan for self-management to prevent escalation of exacerbations.

There was a paucity of literature regarding the characterisation of advanced COPD, and little outside the palliative care paradigm. In comparing people with stage IV COPD to end-stage lung cancer, COPD patients reported an average of 14 symptoms, particularly breathlessness and drowsiness, and greater rates of depression than anxiety. Whilst symptomology and burden were on par, the significant difference between the two cohorts is the duration of suffering, which was on average 482 days longer for people with COPD (Bausewein et al., 2010). Additionally, in their study of people with severe COPD, Park (2015) found an increase in the number and frequency of symptoms over time, with dyspnoea being the
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primary cause of physical decline and drop in health perception. It was, however, the combined burden of multiple symptoms that caused a decline in not just physical ability but also social functioning.

Central to an individual’s ability to manage the impact of and change associated with severe COPD is their ability to self-manage and self-regulate. *Self-regulation* is defined by Brandt (2013) as the “process of monitoring the effects of action and choosing subsequent behaviours” (p. 12). Grounded in social cognitive theory (Clark, Janz, Dodge, & Sharpe, 1992), self-regulation is central to disease self-management as it is considered the process by which knowledge is translated into action.

Research into the impact of self-efficacy training showed improvement in symptom distress for people with Stage I-II disease (Jonsdottir, 2014), increased peak expiratory flow post-exacerbation compared to controls (Kuo et al., 2013) and decreased unplanned physician visits in both groups (Jonsdottir, 2014; Kuo et al., 2013). Chen, Liu, Shyu, and Yeh (2016) found people with COPD engaged in cyclical self-regulation whereby they mastered skills to control breathlessness using a ‘trial and error’ process. Whilst primarily intrinsically motivated, they noted there was significant capacity for health professionals to assist in the development of knowledge and skills that would play into this cycle of adaption, and to promote quality of life. Examples of self-regulatory strategies used in COPD include pace reduction and breaking up of tasks to prevent or minimise breathlessness and fatigue (Brandt, 2013; Falter, Gignac, & Cott, 2003), modification of the use of medication in response to changing symptoms, management of air quality and alleviation of emotional distress using medication and avoidance (Brandt, 2013).
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Disease Trajectory and Mortality

The trajectory towards death in COPD is typified by a gradual decline in health status, punctuated by exacerbations that may require hospitalisation, as also seen in a number of chronic conditions such as heart disease and renal disease. This is opposed to the decline typically seen in end-stage cancer, where there is a marked decline in health status in the last weeks of life or in those with frailty and dementia, who experience ‘prolonged dwindling’ (Kalowes, 2015; Seamark, Seamark, & Halpin, 2007; Suissa, Dell'Aniello, & Ernst, 2012).

An acute exacerbation is defined by the Australian Lung Foundation as “an event in the natural course of the disease characterised by a change in the patient’s baseline dyspnoea, cough, and/or sputum that is beyond normal day-to-day variations, is acute in onset, and may warrant a change in regular medication in a patient with underlying COPD” (Abramson et al., 2014). In the landmark study by Suissa et al. (2012) 73,106 people with COPD were tracked over a 17 year period to quantify the natural history of the condition from the time before their first exacerbation. Suissa et al. (2012) concluded that the disease course worsened with every hospitalised exacerbation, and every exacerbation increased the risk of death, particularly if exacerbations were occurring in quick succession. Whilst post-exacerbation mortality rates are decreasing in COPD, they still considered high in comparison to other chronic conditions. This may be associated with COPD patients being older, having high rates of comorbidity and the nature of advanced respiratory disease (Almagro et al., 2014).

Adding to the complexity of care in COPD is the salience of other conditions over COPD for people with multi-morbidity (two or more chronic conditions), which has been established within the literature (Ansari, Hosseinzadeh, Dennis, & Zwar, 2014; Harris, Dennis, & Pillay, 2013; Pinnock, Steed, & Jordan, 2016). The complexity of management of multiple conditions lies in the capacity for other conditions to mask the signs of deterioration (Pinnock et al., 2016), as well as increase the increased intricacy of interventions and therapies,
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dramatically impacting the individual’s capacity to self-manage their conditions (Ansari et al., 2014). Ansari et al. (2014) found in an Australian population that only 29% of the research participants prioritised their COPD over other chronic conditions.

The degree of uncertainty associated with trajectory, and complications associated with comorbidity and individual health priorities, all affect referral and transition to palliative care in COPD (McVeigh et al., 2014) and create ‘prognostic paralysis’, where the inability to pinpoint the time when referral should be made results in the referral never being made (Epiphaniou et al., 2014). Clinicians also expressed difficulty in deciding when to initiate these end-of-life and transition of care conversations at the same time as patients not wanting to ‘bother’ their care staff with concerns of this nature during visits (Mousing, Timm, Kirkevold, & Lomborg, 2014). From the Australian perspective, Cumming, Boreland, and Perkins (2012) noted an absence of palliative services in many areas of non-metropolitan New South Wales. This meant generalist palliation was often provided by primary health and community nurses, who reported feeling ‘ill-equipped’ for the emotional and psychosocial demands placed on them in providing this level of care.

Other barriers included geographical isolation, affecting access to specialist care and professional development, the complexity of care required to be delivered by staff who already have a large scope of practice, and importantly, the clouding of social and work boundaries when health professionals provide care for neighbours, family and friends in smaller regional and rural centres. The potential impact of effective palliative care on care management of people with advanced COPD is clear, although how implementation of this care is achieved in non-metropolitan centres remains complex. With limited research into the experience of effective generalist palliative care provision in people with advanced COPD living in rural and regional areas, the question is raised: How can quantity of life and quality
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of life be facilitated? And before considering attempting their facilitation, it must be asked, what do people with COPD define their quality of life to be?

**Advanced Care Directives in the Australian Context**

The research took place in a rural city in the state of New South Wales (NSW), Australia. As legislation and definition of advanced care directives, plans, and planning differ between each of the Australian states and territories, the follow information relates directly to the state in which the research was conducted. According to the Australian National Framework for Advanced Care Directives (ACD), an ACD is defined in NSW as a ‘common law document that records a person’s future preferences for health care but does not appoint a substitute decision-maker (2011, p. 13). The directive is the formal reporting of an advanced care plan and is specifically designed to be separate from and different to treatment plans written by medical practitioners. Within the Australian context, ACDs are written by the patient and can encompass much more than just end-of-life preferences, including preferences due temporary or partial loss of capacity. The documentation is explicitly designed to encompass personal, medical and residential values and preferences regarding the provision or withholding of formal and informal care. Critical to the development of an ACD is the understanding that the person is autonomous and decides for themselves what constitutes quality of life.

In addition to a NSW ACD, it is preferred for people to nominate Enduring Guardians and Powers of Attorney (POA). An Enduring Guardia is defined in NSW as a person appointed to make personal, lifestyle and medical decisions on your behalf. This guardianship is only activated at the time of the individual incapacitation. A Power of Attorney, however, has legal authority to manage financial affairs (NSW Government, 2017). This is often overlap in people appointed as Enduring Guardian and POA, but this is not required or always the case.
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In light of these definitions, the Guardianship Act of 1987 mandated that a person’s next-of-kin (closest living relative) has no legal authority to give substitute consent for medical decisions. Instead, A Person Responsible is generally identified. This person is preferentially (and in legal order) an appointed guardian, such as an Enduring Guardian, a spouse or de facto spouse, the person’s primary care-giver or a close friend or relative. Health professionals may apply to the Guardianship division of the NSW Civil and Administrative Tribunal for independent decision-making should a Person Responsible not be found (COTA NSW, 2015).

Disability and the Disability Paradox

The term disability is defined here as the ‘gap between a person’s capabilities and the demands of the environment’ (Pope & Tarlov, 1991), although it is acknowledge that this is a contested space. The Disability Cascade established by Nagi in 1965 was the first modern conceptual framework describing the progression of disease to disability. This cascade recognised the clinical and functional factors that affect an individual’s progression towards disability, but had a number of limitations in its scope, particularly its lack of incorporation of the social influences on health and disability, as well as its unidirectional nature. This work was critical, however, in underpinning the development of a wide range of functional and social frameworks to describe and classify disability. The most widely accepted framework currently is the WHO International Classification of Functionality, Disability and Health (ICF) (World Health Organization, 2016), the goal of which is to create an enabling framework that highlights the functionality of the individual rather than the limitations (Chan et al., 2009).

The movement from purely medical to functional, and then social models of functionality, can be integrated into Nagi’s pathway of pathology, impairment, functional limitation and
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disability with the individual’s social and physical environments. When integrated, the model allows factors such as assistive technology, access to care and pharmacotherapy to be considered as enabling factors that will influence the impact and severity of a disability.

Engel’s 1977 ‘biopsychosocial’ model incorporated the client’s adaptive and coping mechanisms into the framework whilst Leidy’s 1994 Functional Outcomes model allowed for bi-directional movement within the reworked framework to account for the natural and therapeutic ups and downs of living with a chronic health condition.

Chan et al. (2009) stated that “the social model [of disability frameworks] has the greatest potential to help people with disabilities to live with dignity as functioning and valued citizens in society”, but due to the complex nature of the concept of ‘disability’, still recognized that no single model of understanding or classification has yet been able to encompass all the physiological, functional, personal and environmental factors that impact upon the progression of a disease into disability.

In 1999, Albrecht and Devlinger published a conceptual work on the disability paradox, stating that for people with significant disability “…in practice, patient’s perception of health, wellbeing and life satisfaction are discordant with objective measures of health status and disability” (p. 978). The misalignment between actual and perceived health status and HRQL, was grounded in the individual’s capacity to adapt to their situation despite impairment and irrespective of societal expectations of them. In their critique of QoL conceptualisations, Moons, Budts, and De Geest (2006) reminded readers that health and science literature is replete with examples of researchers using the terms ‘quality of life’, ‘health status’ and ‘functional status’ interchangeably. By equating one to the other, quality of life is then based on the assumption that to have good health is to have good quality of life. This is consolidated by the consistent measurement of ‘health status’, labelled as health-related quality of life and assessed using a deficit model, inferring loss.
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In measuring HRQL instead of quality of life in people with a health concern, Moons et al. (2006) asks readers to challenge the assumption that an individual with a health concern can differentiate the aspects of their life that are influenced by their health from those that are not. Additionally, any assessment based on that defined group being directly compared to a ‘healthy’ population, who are generally assessed using more holistic and positive measures of overall quality of life, must be considered methodologically flawed. As the measurement of HRQL is constrained to indicators of physical, psychological and social well-being, there is a tendency to overestimate health impact and under-estimate the influence of ‘non-medical phenomena’. In light of this stand point, and the historical tendency to assume that poor health is poor quality of life, there is little wonder that the disability paradox exists (Moons et al., 2006).

Only one study has been conducted regarding the disability paradox at the end of life. Conducted in the hospice setting, Kutner et al. (2003) found evidence of the disability paradox, reporting that despite being at the end of their life, the 66 participants generally reported strong spiritual connection, hope and reduced anxiety or fear of death. The fear they exhibited mainly related to how their death would affect their families but overall, both quality of life and general positivity remained. This insight into the capacity for people at the end of their life to retain hope and reduce anxiety, despite the loss of functional capacity, warrants the exploration of this idea in the context of severe COPD, where there has been no research conducted regarding the disability paradox or psychosocial adaption to functional decline.

Broadening the discussion on HRQL

Beyond the three core domains of HRQL (physical, psychological, and social wellbeing), there are additional domains that become salient to the individual such as spirituality and/or
sexuality, or to specific groups based on the disease process, including appearance and symptomology (Sprangers & Schwartz, 1999). Many of the factors that will influence perceived health can be measured objectively and undergo interpersonal comparison (e.g. functional performance) but increasingly the literature shows that it is the influences that can only be measured subjectively (pain, fatigue and HRQL) that are affecting perceived health, quality of life and the process of adaption to disability and chronic illness (McPhail & Haines, 2010).

A number of models of HRQL have been suggested in the literature and used in HRQL research. In the systematic review by Bakas et al. (2012), the quality of commonly used HRQL frameworks were evaluated independently and within the wider literature. The research found that three-quarters of HRQL research revolved around one of three framework references. Bakas et al. (2012) was clear to state that HRQL was a multidimensional construct based on subjective (physical, psychological, social, and spiritual) and conjective (emotional, cognitive, economic, cognitive) domains. The use of different definitions across different research paradigms and disease states complicates the use of HRQL in practice and research. But it is here, in its innate complexity and idiosyncrasies that we best align the conceptualisation, assessment and role in disease management to the values, experiences and needs of the individual.

Paradigms such as the disability paradox should serve to pique the interest of researchers in the field of COPD management to explore how people with COPD conceptualise their own quality of life and HRQL. In exploring this, specifically during the prolonged end-of-life stage associated with the condition, there is the capacity to more deeply understand, and in so doing, potentially influence the nature and efficacy of care provided during that period to more closely align to the wishes and needs of the individual, in their own context.
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**Conceptual Models of HRQL**

Since 2009, there has been an explosion of new conceptual models of quality of life and HRQL that are specifically contextualised to different disease and lifestyle states. Within the contexts of chronic disease or ageing, there is no standard set of symptoms, complexities, adaptions or interventions that will serve to improve the experience of the every population group, thus there is no silver bullet when it comes to defining or assessing HRQL. Instead, research has explored how the construct of HRQL can be moulded to fit different groups in different ways and for different reasons (Anthony et al., 2014).

For example, conceptual models of quality of life have been developed in sarcoidosis (Victorson, Cella, Grund, & Judson, 2014), heart failure (Grady et al., 2015), multiple myeloma (Baz et al., 2015), sickle cell anaemia (Treadwell, Hassell, Levine, & Keller, 2014), adults with congenital or early deafness (Kushalnagar et al., 2014), and systemic lupus erythematosus (Gallop et al., 2012). As the model varied for the condition, the rationale for its development tended to vary also. Whether addressing treatment issues, HRQL measurement, assessment of adaption, or increasing understanding and service provision, the conceptual models tended to focus on the symptom burden of the condition as reported by patients and clinicians. Whilst the actual symptoms differed between groups, what emerged from each study was how highly rated factors such as emotional distress and social limitation were listed as primary causes of concern for the participants, again highlighting the multidimensional nature of HRQL (Gallop et al., 2012; Grady et al., 2015; Kushalnagar et al., 2014).

A conceptual model for COPD in the context of nursing has been suggested by Dignani et al. (2015), who completed a systematic review of 75 articles regarding quality of life, COPD and nursing, published 2008 - 2013. Using Rogers’ evolutionary concept analysis, an inductive analysis process designed to pinpoint the current consensus on an issue using a systematic
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review of the literature, the following conceptual model of quality of life was developed (Figure 1.1).

Figure 1.1 A conceptual model of the concept quality of life in COPD context. Source:
Adapted from Dignani et al. (2015).

The model identified a range of antecedents (events or themes that exist before the concept (HRQL)), attributes (clusters of characteristics that make it possible to identify situations that can be categorised under the concept) and consequences (events that occur after or as a result of the concept) (Dignani et al., 2015, pp. 6 - 7).

Antecedents to quality of life in COPD included a range of subjective and objective factors as listed in Figure 1.1. Of particular relevance are the antecedents of ‘patient’s personal ability’ and ‘conditions that negatively affect quality of life’ as it is from these subjective perspectives that the authors acknowledge the impact of personal attributes such as coping strategies, self-management and resilience as mitigating factors in the individual’s perception of quality of life. In addition to this, mental health, co-morbidity, symptom control and exacerbation all play a role in quality of life conceptualisation and actualisation.

In identifying the core attributes of quality of life in COPD, the authors note the difference between definitions of quality of life and HRQL, namely that quality of life could be
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perceived as a more holistic framework for the experiences of the individual, as it incorporates not only the health dimensions of quality of life, but overall life experiences, happiness and meaning in life (Bentsen, Rustøen, & Miaskowski, 2012). Dignani et al. (2015) broke the attributes into two distinct characteristics: those ‘related to patients’ and those ‘related to meaning’. Patient-related attributes were identified as subjective (perceptions of health, emotions and well-being) or objective (functional capacity and symptom burden), providing a framework for future researchers to understand the disease-specific implications of COPD on HRQL. Importantly though, this model allows for the exploration of ideas of the importance of the concept, the significance of the understanding and experience of quality of life to the individual and their sense of meaning. In deepening health professionals’ understanding of quality of life and HQRL, there will still be a time and place for objective assessment of the health-specific aspects of quality of life. The approaches used to facilitate quality of life at the end of life, must stem from that deeper understanding of the concept, the disease and the individual.

In discussing ‘consequences’, Dignani et al. (2015) saw quality of life as a consequence opposed to a construct with consequences. When looking at issues specifically pertaining to the patient, factors are divided into intrinsic (e.g. symptoms) and extrinsic elements (e.g. device use), creating an approachable framework for health professionals to understand modifiable aspects of the COPD experience that may improve overall quality of life. At the core of the Rogers’ methodology is the idea that a concept in never complete, but should instead be considered recommendations for further research (Tofthagen & Fagerstrøm, 2010).

The currently proposed conceptual model for quality of life in COPD has the capacity to serve as a springboard for explorations into patient perception of quality of life in end-stage COPD, its mediators and how their experiences relate to existing disability, ageing and adaptive theories. The model suggests that it “attempts to create a basis for further
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investigation and development. Continued research into quality of life, its definition, assessment, and impact, is needed to understand the experience of COPD patients and implement effective and efficient nursing care.” (Dignani et al., 2015, p. 9). What remains to be explored is how this conceptual model marries with the lived experience of older people with Stage IV COPD as well as how psychosocial adaption may alter the linearity of the model.

**Philosophical Perspective**

The theoretical underpinning of interpretive phenomenological analysis began with the likes of Kant, Hegel and Brentano in the 18th and 19th centuries. Their work became the foundation for Edmund Husserl’s phenomenological philosophy, which espoused that the pure essence of a phenomenon could be elicited, through ‘rigorous and unbiased’ study, as well as the temporary suspension of preconception and assumption, and use of reductionism. Despite his evolution towards transcendentalism, through Genetic Phenomenology, Husserl’s descriptive phenomenology would ultimately become his legacy and the framework from which the likes of Heidegger and Merlou-Ponty, both students of Husserl, would build their philosophies (Bower, 2013; Converse, 2012; Theodorou, 2015).

Phenomenology is considered to have eight ‘arms’, although only three are widely used and accepted; descriptive (Husserlian), interpretative or hermeneutic (Heideggerian) and existential (Merlou-Ponty). It is the hermeneutic tradition that is foundational to this project. Where Husserl aimed to describe the phenomena as a way that made it generalisable, Heidegger focused on understanding the ‘being’ of the object and prioritised understanding the meaning of ‘being’ over epistemology or Husserl’s focus on the ‘essence’ of the phenomena (Converse, 2012). From a social science perspective, this can mean exploring the lived experience of a person though their accounts of subjective experiences, with the
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researcher aiming not to describe the experience, so much as to understand how that person has made sense of their world. This assumes that the individual has undertaken self-reflection and meaning making, a direct contrast to Husserl, who focused on the pre-reflexive and passivity of consciousness (Barthold, 2012; Lawn, 2006).

Dilthey, an early pioneer of hermeneutics, argued for the importance of both meaning and interpretive research, in social research (Crotty, 1998; Holroyd, 2008). Whilst not rejecting positivist methodologies, that is those methodologies that involved scientific, logical or mathematic verification, both he and Schleiremacher disputed positivism’s ability to allow for full understanding of human phenomena. Building on this, Heidegger sought to understand the meaning of what it was to be human and be in the world (Dasien), despite believing this meaning could never be fully revealed. This belief was contrary to Hessurlian phenomenology which was noted for the use of bracketing or reductionism, where it was deemed possible for the researcher to acknowledge and then step outside their biases to observe a phenomena. Heidegger strongly refuted this position, believing that it was impossible to separate out our experiences related to the phenomenon under study, as those understandings were central to the research process. Striking a more gentle compromise between the capacity of researchers to recognise and manage bias in the research setting, Hans-Georg Gadamer, a Heidegger student, specialised in hermeneutic research in the mid-20th century (Barthold, 2012; McManus Holroyd, 2007; Simms, 2015). Gadamer’s response to Heidegger’s question of the meaning of ‘Being-in-the-world’, was to ask instead how it was that we were in the world together. Gadamer’s magnum opus, Truth and Method (1975) is the cornerstone of current thinking in the field and identifies several core attributes of Gadamer’s Philosophical Hermeneutics: prejudice and tradition, and situatedness and the fusion of horizons.
Prejudice & Tradition

Heidegger espoused that it was only through assumption and experience, termed fore-knowledge, one could engage in the hermeneutic reflection, as without one’s own context, one could not contextualise new information coming from a text. This fore-knowledge included the acceptance of both the assumed and shared understanding of meanings of words and language, and the capacity to come to a text without any reasonable or predetermined understanding of it. It is through fore-knowledge of the meaning of language that one transfers meaning to the text, and incorporate this new meaning into our understanding (Simms, 2015). The power of language to denote meaning is learned experientially, long before speech is mastered. The capacity to link word to object, object to experience, experience to meaning and assumption creates a cyclical process of meaning-making within our social context. Commonality of language allows the individual to share meaning through dialogue, and critically, know and predict the world around them through their perception of conformity and cohesion; through tradition (Regan, 2012).

This understanding of how we are born into language, and the depth of tradition and assumption bound within it, must then shape how one approaches a text or person. Thus, it is imperative that one is prepared to hear, read or experience something new that will shape that fore-understanding. In taking this approach, one is required to be sensitive to the ‘otherness’ of the text; that is different, and comes with its own fore-understanding, and allow it to assert its truth against one’s own (Gadamer et al., 2004; Simms, 2015).

Gadamer used the term ‘prejudice’ to encapsulate the fore-understanding and fore-knowledge that allows an individual understand their own context and tradition. Whilst the term has taken on a negative connotation since Enlightenment, Gadamer preferred the pre-Enlightenment definition, ‘a judgement rendered before all the elements that determine a situation have been finally examined’ (p. 273). It is important to differentiate here that
Gadamer’s ‘prejudice’ is that based in authority, rather than over-hastiness, or coming to a false judgement as per the current legal understanding of the term (Gadamer et al., 2004).

If the researcher is not fully aware of their prejudices, they cannot be fully appreciative of the ‘otherness’ of the text. A common way someone can be bound by ‘hidden prejudice’ is to be blinded by tradition - the historical reality of being. As Gadamer et al. (2004) discussed, it is easy to be blind to one’s own tradition as ‘long before we understand ourselves through the process of self-examination, we understand ourselves in a self-evident way in the family, society, and state in which we live’ (p. 278).

Gadamer believed that a person could never fully escape or fully comprehend their own tradition, but that did not mean it could not questioned or changed. Tradition serves as a background, a counter point from which enquiry and inquiry stem and we can never be fully free of it, as with prejudice. Secondly, ‘to embrace tradition is to make it one’s own by altering it’ (Barthold, 2012, para. 28), highlighting that it is through activity, not passivity, that we can develop new understanding.

In understanding prejudices and tradition, it is possible to come to a state of belonging - where the bond that enables a person to want and to be able to seek understanding, from a text or another person, can be achieved through the commonality of tradition and language. The tension that is created between the familiarity of the other and its strangeness, creates the impetus for questioning. As Gadamer stated:

> It is in the play between the traditionary text’s strangeness and familiarity to us, between being a historically intended, distanced object and belonging to a tradition. The true locus of hermeneutics is this in-between (Gadamer et al., 2004, p. 295).

It was also in his discussion of Truth that it was possible to come to an understanding of aletheiology as it related to my tradition and to the ‘strangeness’ of exploring philosophical literature for the first time. My own aletheiology, or understanding of truth, has dramatically
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influenced my interpretation of this study and its findings. In short, Gadamer argued that there is no singular Truth, merely our different perceptions of truth (Lawn, 2006). I would argue that my perception of truth is that there is a singular Truth, a belief grounded in my own personal faith, whilst freely accepting that this is my perception of truth. This has shaped the study design and result interpretation, as I have always looked at the participants and their stories as the two of us coming to a shared understanding of our perceptions of the truth. Similarly, using an exegetical approach in relating to the interview transcripts was a source of comfort, as through my own tradition, I have been conditioned from a young age to pull chapters, stanza, sentences and words of biblical text apart to better understand their meaning and their application to my life.

**Situation & Fusion of Horizon**

Gadamer requires that perception of the way one interacts with and interprets a text, will be affected by situation or historical situatedness, a fixed standpoint where tradition exerts its socio-cultural influence over the individual (Code, 2010). Grounded in prejudice, tradition, and historical situatedness, each develops a ‘horizon’, a single and finite viewpoint that exists in that moment of time. The horizon is further influenced by our present condition; culture and society, as well as our expectations for the future. It is in comprehending these limitations, the boundaries of horizon, Gadamer encourages the reader that they can begin to move outside them (Barthold, 2012; Gadamer et al., 2004).

What looks to be achieved in hermeneutic research is to understand a personal horizon, knowing that it moves and changes as a person does, using it to create bonds with others’ horizons and so facilitate a shared understanding. This fusion of horizons is not about one horizon dominating the other, or a total overlay of the two; to ‘walk a mile in another’s shoes’ is not theoretically possible within the Gadamerian tradition (Barthold, 2012). Rather, it seeks
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to come to a shared understanding of various perceptions of the truth, learning from each other, through dialogue. According to Gadamer, this transformative and continually dynamic process “requires all horizons to change; neither one’s own horizon nor that of the other is left intact” (1975, pp. 306-307). Barthold (2012) added as two horizons are able to come together, they cannot become a fixed singularity.

But if there are not two reified horizons, neither is there a single, bounded horizon that occludes difference. Fusion refers to the active and the on-going nature of understanding—not a static, hegemonic unity. Any unity wrought by understanding is its effect—not its cause. Furthermore, such unity will never be total: understanding refers to a process not a final end (para. 33).

The journey to understanding and embracing the Gadamerian Hermeneutic Phenomenological methodology, for this project, was one bound in dialogue with the text. From an ontological perspective, I can come to terms with Heidegger’s’ Dasien, being in the world, when it is framed in the context of how I am in the world, and that is together through language and dialogue. In understanding the nature of prejudice, tradition and situation, the opportunity to be open to others is created, allowing a fusion of horizons that has guided a shared understanding of what it is to live with advanced COPD.

Scope and Critique

This project was conducted within the context of the COPD experience of older people living in a specific geographic region of rural New South Wales, Australia. The design phase of the project included discussion regarding whose experience should be included in the research. At the time, and to this day, the decision not to formally include the voices of the participants’ informal or formal care-givers is one I stand by. This was not a decision made due to the lack of significance of those voices in the discussion of quality of life. Instead, those voices were deemed so important, they warranted further research both at the level of
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the individuals and from the perspective of the care-giver/care-receiver dyad, and so sit outside the scope of this project.

There were several implications of the recruitment location being exclusively from a single local health network in the Central West of New South Wales. Recruitment was facilitated through an existing and non-compulsory health service which may have biased recruitment towards individuals who had accepted high level, disease-specific health support through the Respiratory Coordinated Care Program. True to the nature of Phenomenology, a small sample of the population was sampled for the research, although the group represented approximately one-fifth of the RCCP cohort. The demographics of the group, whilst reflective of the RCCP demographic break-down, were not necessarily representative of the general Australian demographic of people with Stage IV (Yang et al., 2016), with all participants being Caucasian and the inclusion of more female participants than male.

In line with the chosen methodology, the interpretation of the research data was mine; it is therefore only one interpretation, grounded in my bias and prejudice, as opposed to all possible interpretations of the text. In light of the nature of the sampling and the individuality of the interpretation, I urge caution before generalising these findings and encourage the reader to come to their own interpretation of the research before applying them to their own context.

The limitation of language has been an additional concern within this project, as every reader will bring their own prejudice to terms such as identity and acceptance. More complex is the language of quality of life itself, with health literature, health professionals, and participants using terms such as quality of life and health-related quality of life interchangeably. This is made more complex by the lack of clear definition of the terms. I admit to falling victim to the confusion of terminology at times and in so, asking for the participants to discuss quality
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*of life* rather than specifying *health-related quality of life*, before coming to a fuller understanding of the difference between the two constructs myself. Thankfully, the participants led me through such informative and enlightening narratives of their lives that I can see my own limitations more clearly and will strive to do better in the future.

**Significance of the Study**

Stemming from the recommendations Habraken et al. (2008), that there is a lack of understanding of the measures of quality of life for people with advanced COPD, this project aims to add to the body of quality of life/HRQL literature specific to COPD. Further, this project offers a uniquely Australian perspective in exploring the experiences of people living in rural areas, who experience significant access limitations to specialist Respiratory or Palliative Care services. As such, research of this nature is integral in assisting health professionals engaging in the care of older people with advanced COPD through the exploration of factors that influence HRQL in this group. This study aims to explore not only ‘what’ HRQL is but how the individual comes to their conceptualisation, potentially providing insight into how who can better facilitate good quality of life through the life course as well as at the end of life. In light of the geographical context of the research, my interpretation is influenced by a desire to work within existing health care services, supporting the men and women at the coal face of COPD management in rural areas to be supported and equipped to walk with our clients and their families through the end of life without fear.

**Thesis Overview**

This chapter has introduced the core constructs, literature, theoretical and philosophical frameworks that underpinned this research. The following chapters will discuss the scientific literature that provide a wider context for the research findings (Chapter 2) as well as how
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Gadamer’s Hermeneutic Phenomenology was applied to the study design, implantation and analysis (Chapter 3). The findings of the inquiry are discussed in Chapter 4 as a series of Pen Portraits introducing the eleven participants, which leads into a detailed interpretation of the four core thematic chapters (Chapters 5 – 8) of the study: ‘Accepting Change’, ‘Mind over Matter’, ‘Being in the World Together’, and ‘Quality over Quantity’. Chapter 9 includes a discussion of those themes and their relationship to the established literature.
Chapter 2

Context of the Inquiry

This chapter will critically analyse the literature influencing and surrounding my own pre-understandings of living as an older person with Stage IV COPD. While issues pertaining to COPD, the strategies employed to manage symptoms, and disease trajectory and mortality were discussed in Chapter 1, in this chapter, the focus will be on the core relationships that are present in the care of people with COPD, formal (i.e. health professionals) and informal primary care-givers (generally a spouse or member of the immediate family). Raised here, too, are the external issues that complicate care provision, in COPD and quality of life, including issues of rurality and communication.

The Role of Health Professionals in Facilitating Quality of Life at the End of Life

Whilst literature exploring the experiences of generalist community nurses providing end of life (EOL) care in rural practice is limited, there is continuity of findings within North American and Australian research. As these health professionals strive to provide the best EOL care for people in their communities, preferably in the home, they are severely impacted by several limiting factors. A primary limiting factor is the degree of multiskilling required to provide holistic care to all members of their community. Specialist nursing skills are required by those needing palliative care, and there are significant issues in accessing relevant and cost-effective training without adequate staffing to cover workload. Furthermore, competing demands exist in providing continuity of physical, psychosocial and emotional/spiritual support in increasingly large, diverse and complex caseloads (Kenny & Allenby, 2013; Reed, Fitzgerald, & Bish, 2015). Additionally, from the Australian perspective there are barriers to care associated with the geographical distances required to provide in-home support (Kaasalainen et al., 2011; Reed et al., 2015).
Nurses reported that these barriers led to, and were complicated by, late referral to their services, disallowing the development of the kind of relationships that best facilitated effective EOL care. As health professionals grapple with the institutional and pragmatic limitations of their workload, capacity to understand and execute the wishes of the individual may well be compromised (Reed et al., 2015). This may also be compounded by issues of confidence in approaching conversations about existential, psychosocial and emotional questions, and managing patient distress, both of which require time, privacy and a fearlessness for what may be discovered in the process of listening and counselling (Keall, Clayton, & Butow, 2014). Rural nurses’ primary request in delivering effective end of life and palliative care was increased education and debriefing opportunities, as the emotional and potential legal implications of isolated and unsupported practice are primary stressors (Keall et al., 2014; Reed et al., 2015).

A primary barrier to effective communication at the end of life is fear from the health professional that they will diminish the individual’s sense of hope, as noted in the literature on hope in Heart Failure (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011; Gadoud, Jenkins, & Hogg, 2013). Yet the established literature suggests that empathic and direct communication of prognosis can be a source of hope for people and families at the end of life (Philip et al., 2012; Robinson, 2012). Prognostic information may allow the individual to reconceptualise their construct, setting goals and looking to a future that has as much quantity and quality as can be expected, rather than aiming for a cure. Further, the reshaping of more achievable goals to focus on meaning, value and relationships with loved ones can significantly improve the individual and group experience of the end of life (Duggleby et al., 2012). The challenge for health professionals is the balance of hope and reality, communicating truth with a gentleness that allows the individual to balance hope and reality.
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in a way that reflects and respects the individual’s right to autonomy and beneficence (Olsman, Duggleby, et al., 2014; Olsman, Leget, Onwuteaka-Philipsen, & Willems, 2014).

What is critical in facilitating and sustaining hope from the perspective of the health professional is that the bond between the two parties required to achieve this must be built on trust and through empathic and authentic relationship. It is in this place that there is the greatest impact to facilitate or destroy hope. In the context of COPD, this involves working with the ongoing ‘tension of maintaining hope and negotiating the reality of illness and its consequences’ (Philip et al., 2012, p. 816).

**Dyadic Coping, Burden and Reciprocity within the Family Unit**

Dyadic Coping refers to the strategies a couple uses to cope with adversity together, aiming to maintain and/or restore “individual and couple homeostasis, well-being and couple functioning” (Meier, Bodenmann, Morgeli, & Jenewein, 2011). Within the working relationship, balance is created through acts of reciprocity, where physical, psychological, social and emotional needs are met in a ‘give-and-take’ manner. This does not imply that the balance is necessarily equal, but that each partner’s needs are being met sufficiently by the other. Over time, with the progression of COPD, the ability of people with declining health to sufficiently reciprocate for care-provision becomes increasingly difficult (Vaske et al., 2015).

There are four modes of dyadic coping: supportive, common, delegated and negative. Within the COPD literature, couples tend to shift from supportive dyadic coping mechanisms where the couple works together to manage the declining health of one partner through acts of reciprocity, towards a delegated model, where tasks are gradually handed from the partner with COPD to the partner in good health (Vaske et al., 2015). This shift is understandable in the context of declining functional capacity and increasing care demands, but relies particularly on effective ‘stress communication’, the ability to express need and the emotional
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impact of that need on the other member of the dyad, with the intent of stress reduction. It is critical that in a reasonable transition to an unevenly distributed dyadic coping mechanism such as delegated coping, both partners are communicating stress effectively. Meier et al. (2011) concluded that the shift to delegated coping was not associated with disease severity. Quality of life is facilitated for people with COPD as they are able to delegate effectively to their partner, with care-givers increasing their own quality of life if the delegation is communicated clearly and with respect and gratitude for the role-change. In both cases, poor stress communication has been shown to decrease quality of life in COPD (Vaske et al., 2015). Importantly, increased intimacy through deepened communication is known to increase quality of life for care-givers of people with COPD, serving as a primary source of satisfaction in the end-of-life care situation. From the care-receiver perspective, improved communication and emotional support has been shown to replace the performance of physical tasks, allowing the care-receiver to reciprocate within the relationship and maintaining a form of balance in the give and take nature of a couple.

Communication is also associated with better management of stress and more effective use of resources within the dyad (Meier et al., 2012). Important to consider in the discussion of dyadic coping is the role of gendered societal expectation in the transition from supportive to delegated coping. Changes to the traditional gender roles and responsibilities may challenge preconceived ideas of masculinity and femininity in a way that inhibits the dyad from adapting to change and communicating need effectively (Clarke & Bennett, 2013; Helgeson & Zajdel, 2017; Shuttleworth, Wedgwood, & Wilson, 2012).

**Mutual Protection & Stress Communication**

Spouses acting as primary care-givers is not a new phenomenon. The COPD literature has established that they take on this role through a sense of duty, societal expectation, but also as
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an extension of the marital obligation ‘until death do us part’ (Vaske et al., 2015, p. 851).

Vaske et al. (2015) reported in a longitudinal study of dyadic coping in COPD that couples, and care-givers in particular, tended to want to protect their loved one from strong emotions, effectively placing their care-givers in an ‘emotional straight-jacket’ and preventing them from communicating stress. This was commensurate with Bergs (2002), who identified emotional-straight jacketing as a barrier to effective communication for wives caring for husbands with advanced respiratory disease, as they avoided inducing respiratory distress. The follow-on from the breakdown in communication was a perceived weakening of the marriage associated with not only loss of sexual, but emotional intimacy.

Similarly, Meier et al. (2012) found that stress-communication, by care-givers of people with COPD was much lower than both the person with COPD or in control dyads. This was linked to an intentional reduction in communication by the care-giver to prevent emotional distress and the exacerbation of symptoms associated with dyspnoea-anxiety-dyspnoea cycle.

Psychological distress in care-givers was associated with decreased overall quality of life and increased rates of care-giver depression (Meier et al., 2011) as the care-givers walk the fine line between their ability to take on the burden of care and their own coping capacity (Nakken et al., 2015). As care-givers are silenced through ‘emotional straight-jacketing’, not wanting to affect their loved-ones’ sense of hope and the difficulty and complexity of the content matter that needs to be communicated, so too, can be the care-receivers be silenced. This mutual protection, where each person in the family tried to prevent the other from being ‘exposed to a harmful situation (words/actions)’, has been reported in other respiratory conditions, such as Lung Cancer (Noble, Price, & Porter, 2015).

In the changing balance from supportive to delegated dyadic coping, care-givers are required to take on an increasing volume of tasks, which also increases in complexity over time. At the same time, care-receivers find it difficult to reciprocate within the relationship, in order to
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maintain a homeostatic relationship. At the end of the day, neither member of the dyad is willing to communicate stress, increased need or fatigue, leading to a downward trajectory of couple’s functioning and overall quality of life (Vaske et al., 2015).

**The Care-Giver/Health Professional Relationship**

With informal care-givers providing the bulk of physical care and psychosocial support to people with chronic disease and at the end of life, it is not surprising that their need for information is often more than the individual with the condition (Chen, 2014). Despite this, there is very little current literature exploring the relationship between family and informal care-givers, and health professionals (Chen, 2014; Grant, Cavanagh, & Yorke, 2012; Northouse & Northouse, 1988; Robison et al., 2007). Within the context of family care in nursing homes, Robison et al. (2007) noted that both partners in this relationship (health professionals and families of residents) expressed difficulty communicating with the other. Health Professionals reported that dealing with the families of residents was one of the most stressful aspects of their role. Stress was attributed to both insufficient time for effective communication with families and the perception of unrealistic expectations being placed on them by family members. This was compounded by racial, cultural and socio-economic differences between staff and the families. Correspondingly, families often felt hesitant to comment on the care of their loved ones due to fear of negative repercussions on them and despite often having ideas and suggestions regarding ways to improve their loved ones’ experience.

As mentioned earlier, family members and care-givers tended to under-communicate health information with their loved one to protect them from prematurely or inadvertently inducing emotions and distress. It could be suggested that this mutual protection acts as a barrier to effective communication between families and health professionals, as many of their
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interactions are conducted with the individual present, by chance and without planning (Northouse & Northouse, 1988). In addition to this, many of these conversations, particularly surrounding advanced care planning, are conducted during or in direct response to a critical incident or crisis moment, when nerves are raw and emotions heightened (Kaasalainen et al., 2011).

The erratic and informal communication pathway between health professionals and primary informal care-givers can dramatically affect the provision of care for the individual, as a greater onus for information seeking is placed on the family. This is compounded by families not wanting to ‘bother’ busy staff, as the information they require has already been given to the patient. The communication barrier serves additionally to disallow opportunities to build trust and rapport between the care-giver, family and health professionals. At the same time, relaying information in this ‘Chinese whisper’ way, has the capacity to cause confusion and misunderstanding between the care-giver, family and health professional. As family expectations and knowledge have significant influence on patient decision making, there is significant scope for communication interventions to be put in place to better facilitate communication between this often disparate triad (Chen, 2014; Garland, Bruce, & Stajduhar, 2012; Northouse & Northouse, 1988).

This care dyad can be complicated in different cultures, where the family and health professionals collude to hide information about diagnosis and prognosis from the individual as a protective mechanism (Marzano, 2009). Whilst information withholding is common practice in Italy, the inability for health professionals to be truthful with their patients in Australia it is a known barrier to care and cause of psychological distress for the health professional (Noble et al., 2015).
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The Palliative Care Trial conducted by Horton et al. (2013) uses patient and care-giver education as well as early enrolment in an integrated palliative care service to facilitate the goal of a comfort oriented management and home-death for people with advanced COPD. Whilst none of the participants who died during this study period were able to die in their homes, importantly, none were in ICU or ventilated at the time of death, a valued goal for people with COPD and their families within the context of the trial. The study found that as symptoms escalated prior to death, care-givers felt forced to rely on an Emergency Department admission to hospital as they questioned their capacity to cope with the degree of dyspnoea and distress their loved one was experiencing. It was through careful planning between the care triad, that the individuals had their advance care plans enacted in a way that allowed their death to be as controlled and comfortable as possible despite, or may be because of, hospitalisation.

Summary

This chapter reviewed the complexities of COPD management from the context of the people closest to the individual from a care perspective. In understanding the nature of communication between the triad of health professional, care-giver and the individual with COPD, we can explore the experience of those individuals in light of their relationships (Figure 2.1).
Figure 2.1 A summary of the barriers to communication established through chapter 2, between the three partners in a care triad, the care-receiver/patient, the primary informal care-giver and the health care professional.

Considering Gadamer’s ontology of being in the world together and through shared language, it is critical that we understand some of the horizons that have influenced how the individual perceives, experiences and copes with COPD. The following chapter will discuss how that process of exploration took place in light of Gadamer’s philosophy of hermeneutics.
Chapter 3

Methodology

Introduction

This chapter details the processes used to design this study, and gather, analyse and interpret participant stories regarding the conceptualisation of quality of life for people with advanced COPD. Using the Gadamerian-style Research Method proposed by Fleming et al. (2003), this chapter will discuss how the research was designed according to the principles of Hermeneutic Phenomenology, including the role of reflexivity in the research journey. The process of participant recruitment and informed consent, as well the conduct of research visits will be outlined. Included is participant sampling and evidence of saturation to defend auditability, and the documentation and communication of the research processes and decision making (Fleming et al., 2003), and establishing trust (Lincoln & Guba, 1985). The chapter will conclude with an in-depth discourse of the process of data analysis, linking the principles of Hermeneutic Phenomenology and Gadamerian-style Research Method to the interpretation of participant stories in this project.

Reflexivity and the Research Process

Before the discourse surrounding methods used to establish credibility and rigour within each phase of the project can begin, the role of reflexivity in the research process must be discussed, for it is reflection, and interpretation of such, that sits at the heart of hermeneutic research as described by Koch and Harrington (1998):

“By returning to our personal history we can raise our situation to consciousness in order to monitor the way in which it deals with texts and traditions. Such reflexivity is the critical gaze turned toward the self and the making of the research product” (Koch & Harrington, 1998, p. 888).
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Reflexivity, defined by Smith (1999, p. 360) as ‘the ability to critically examine and use previous experiences to influence future action’ is integral within phenomenological analysis to both understand a personal horizon and the way it influences praxis, and to develop and demonstrate rigour within the research process (Smith, 1999; Spence, 2016). When considering both credibility and rigour, Gouldner’s 1972 definition focuses on the importance of truth within reflexivity, where the researcher cannot seek to discover truth, but rather sees truth as stemming from the knower’s experience with, and in the world (Hibbert, 2013), aligned with Gadamer’s alethiology.

To differentiate, reflection, (as opposed to reflexivity) when conceptualised through the lens of Disembodied Cognition theory, suggests the process of learning involves creating links between data from the external world and linking it to the ‘inner world’. This process is thus, influenced heavily by social context as the learner observes an experience, conceptualises it in theoretical terms and develops strategies and hypotheses to test against later experiences.

The shift from reflection to reflexivity occurs when it is not so much the external world being observed and conceptualised, but the self. At the heart of reflexivity is Heidegger’s Dasien, understanding how it is we are in the world, and how we are in relationship with others and our social context. Reflexivity moves past the point of reflection when goal ceases to be learning about the experience, but becomes understanding the essence of who we are, how we relate to others and how we create context and identity through those experiences (Reynolds, 2017).

The idea that researcher reflection and reflexivity are part of the data is not new to hermeneutics, as the methodology assumes pre-assumption, prejudices and bias cannot be bracketed, contrary to Husserl’s phenomenology. Gadamer further stated that prejudice is a pre-condition to truth, not an obstacle to it (Smith, 1999). Thus, my own reflections of both
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experiences and self, throughout the project are grounded in cultural and historical situatedness, and bound by personal values, interests and experiences (Appendix A).

To understand the way this has come into the design and implementation, for this project, and to interpret its data, I needed to understand my own prejudices and the horizon that would inform the research findings. It was in this ongoing and iterative self-critique that I could be open to other voices in the research, and so better understand my personal values and perspective (Koch & Harrington, 1998; Smith, 1999; Spence, 2016).

Lincoln and Guba (1985) identified credibility (faithfulness to the text), fittingness (applicability within alternate contexts) and auditability (documentation of decision making by the researcher) as their underpinning constructs in establishing rigour in qualitative research. Whilst strategies such as member checking (i.e. triangulation, peer-review, returning data to participants) are valued methods to achieve this, it is critical that reflexivity is used by the researcher to demonstrate rigour. Self-scrutiny through continued questioning, contemplative thinking and reflective writing allows the researcher to continually engage with their changing understandings (Koch & Harrington, 1998; Smith, 1999).

Reflective and reflexive passages are included within the thesis to alert the reader to how my own experiences, assumptions and prejudice have informed the design and interpretation of the participant’s narrative. These passages also serve to highlight the impact the research process on my way of thinking and being. Additionally, a detailed overview of the reflexive strategies used throughout the project is included in Appendix A, as articulation of the process, and findings of self-scrutiny, serve to open the reader to greater understanding and has the capacity to influence perception of research quality and trust in the researcher. Be it the place of the reader or the researcher, it is through understanding one’s own
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preconceptions, assumptions and prejudice that they can more fully immerse themselves in the narrative of the text, drawing meaning as much from its same-ness as its otherness.

**Gadamerian Hermeneutic Phenomenology**

Gadamer never published a method for the application of philosophical hermeneutics to health science research. Rather than outlining a set of rules to follow, as is the positivist tendency within the scientific method, Spence (2016) suggested that it was more critical for students of hermeneutic phenomenology, the philosophical hermeneutic methodology, to ‘remain faithful to the spirit of the underlying philosophy’ (p.6). In addition to the tenets of Gadamerian hermeneutics discussed in Chapter 1, there are three additional dimension of Gadamer’s work that have influenced this research most profoundly; understanding through dialogue, *Spiel* and the hermeneutic circle.

**Understanding through Dialogue**

Intersubjectivity is defined as the attention given to the experience of others; to enter another’s’ lifeworld, that is, their social and cultural reality (Crepeau, 1991). Of course, The value of striving for intersubjectivity through both observation and dialogue is the aspiration to understand the intended meaning of the speaker’s words and actions. Interpretation of such will only ever be an approximation of that intended meaning as in reflecting on another and their experiences, interpretation will perceived through the lens of one’s own lifeworld. When comparing intersubjectivity to the philosophy of Gadamer, the ‘other’ and the despite to understand and question otherness sits at the forefront of enquiry. Yet a shared co-location facilitated by a similar social context allows the interpreter to better understanding sameness, which highlights otherness (Crepeau, 1991; Hooker, 2015; Regan, 2012).

Gadamer espoused that knowledge comes through language, whilst understanding comes through dialogue, even if that dialogue is with yourself (Fleming et al., 2003). Thus, it is
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critical to the paradigm that one is ‘open to conversation with others’ as it is in this space that one is able to disagree, learn and reframe their temporal thinking. It was through dialogue in and with reflective journals, critical friends and supervisors that it was possible to begin to articulate my prejudices and tradition with the goals of being open to the experiences of the participant interviewees. It was through dialogue with the participants, their transcripts and the established literature that it was possible to shape a personal understanding of the lived experience of people with advanced COPD. In aiming to best reflect and embody Gadamerian Hermeneutic Phenomenology, strategic decisions were made to encourage rich and authentic dialogue. A narrative interview style was used to promote a more natural dialogue with the participants. A critical friend was engaged to provoke and challenge fore-understanding and prejudices as part of the fore-grounding, that is, the critical self-examination of articulating prejudice and tradition, prior to and throughout data collection (Simms, 2015).

Speil

The word speil is translated to the English ‘play’. There are many attributes to Gadamer’s discussion of play and its impact on dialogue, but Spiel was one of the first Gadamerian concepts that encouraged a commitment to this way of thinking. Essentially, dialogue between two people moves from being a mere conversation to something richer when the ‘players’ lose themselves in the game of dialogue, and the time spent together understanding each other becomes fun. The analogy of playing a game is extended further when considering the balance the player must achieve between taking a game seriously, and understanding that it is ‘just a game’ (Simms, 2015). In the same way, it was important to establish a relationship where both the seriousness of the content and the collegiality of the conversation were appreciated, further recognising the spoken words were being told at a time, place and within a historical context that were finite. From the perspective of the data collection phase of this
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project, to appreciate the participants’ stories, trust needed to be established that recognises a common bond of tradition that may have sat outside the allocated questions, and should be enjoyed as part of the journey of understanding (Gadamer et al., 2004; Simms, 2015). When there was a sense of play within the interviews, the stories tended to ramble on, without much interviewer interjection, and the depth of sharing changed.

In Laurel’s interview the depth of sharing resulted in a 20 minute conversation about custard, which flowed into her divulging true feelings about fear, spirituality, and death that had only been brushed over in the previous interview. This sat counterpoint to an interview where the emotional barriers were simply not able to be broken down and Spiel was never achieved. In the case of Evan, there was only superficiality in discussions about complex issues, and he was easily distracted from the primary conversation, a sign that he was and would not necessarily immerse himself in the dialogue, and so nor could I.

The Hermeneutic Circle

‘Hermeneutics’ is derived from the Greek, *Hermeneutikos*, which means ‘to interpret’. More broadly, hermeneutics refers to the capacity of the interpreter to expand knowledge and understanding through language, and more specific to Gadamer, dialogue. The process of interpretation manifests clearly in Gadamer’s approach to the hermeneutic circle. This cyclical process of pre-understanding, experience and reflexivity is characterised by the movement between the parts and the whole of the text. This movement involves using prejudice and tradition to inform the contextualisation of that text to create meaning, and that meaning will inform how text is broken down into its parts. In turn, those parts will influence the understanding of the whole (Spence, 2016). This circle allows continual challenge of interpretation, revealing hidden or layered prejudices and allowing new insights, from the parts, to peel away layers and cause the whole to deepen the understanding of the experience
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(Austgard, 2012; Fleming et al., 2003; Stenner, Mitchell, & Palmer, 2016). In being constantly open to the text, challenging assumptions of the text and engaging with new revelations and experience of language, the text can be ‘re-awakened’ by the reader. The effect of this re-awakening is not just to understand the intended meaning of the speaker, or the phenomena, but how the reader experiences and resonates with the language. In balancing the fusion of horizons, that is, the coming together of the narrative of the speaker and the interpretation of the reader, the hermeneutic circle calls for the constant openness to the text. Whilst meaning derived from this openness is initially based on assumptions of shared meaning, it is driven more by the exploration of text that challenges those assumptions (Regan, 2012). How this was achieved within the study is discussed in depth, from a theoretical, method and reflective stand point, throughout this chapter.

A Gadamerian-Style Research Method

As Gadamer never published a method of his own, several philosophers and social science researchers have proposed various research methods that embrace hermeneutic phenomenology (Colaizzi, 1978; Diekelmann, 1992; Koch, 1996; Van Manen, 1997), specific methods ascribed to Gadamerian hermeneutics (Fleming et al., 2003; Koch, 1996; Koch & Harrington, 1998; Turner, 2003) and Heideggerian/Gadamerian Hermeneutics (Koch, 1996; Maggs-Rapport, 2001; Whitehead, 2004). Whilst Diekelmann (1992) would suggest a team approach to manage bias, Gadamerian positive notions of the impact of bias. Comparatively, Colaizzi (1978) would suggest that all data should be taken back to the participants for validation, Gadamer would argue that the goal in returning to the interviewee would be too increase understanding. Turner (2003) noted within the gamut of hermeneutic methods, there was a distinct lack of guidance on the application of data analysis according to philosophical orientation in general, let alone Gadamerian principles.
Within each method, there is to be found inherent strength and limitation. It is the work of Fleming et al. (2003) that is the focus of this investigation, as it aims to reflect Gadamer’s epistemology, referred to as the *Gadamerian-style Research Method*. This chapter will discuss at length the practical application of Gadamerian hermeneutics to social research, beginning with the limitations outlined by De Witt and Ploeg (2006) and reconciled through the work of Lincoln and Guba (1985). Their work approached Gadamer from a nursing perspective, breaking the research process into five parts that relate to his understanding of research, prejudice and language.

In their critical evaluation of the Gadamerian-style Research Method, De Witt and Ploeg (2006) commented that the way the method linked the question and purpose of research to Gadamerian philosophy, as well as its reliance on the original work of Gadamer, were strengths of the research design. The demonstration of credibility as a form of rigour was not clearly established, however, Weiland (2012) and Della Ratta (2015) demonstrated how embedding the work of Lincoln and Guba (1985) or Holloway and Wheeler (1996) into Gadamerian-style Research Method can serve to evidence rigour within the research process, despite the limitation of the method. The following section describes how Fleming et al. (2003), in combination with Lincoln and Guba (1985), informed the process of research design, integrating the theoretical standpoint, researcher practice and supporting evidence.

**Deciding on a Research Question**

Gadamer espoused that there could be no understanding without questioning, so to gain a deep understanding of phenomena, the researcher must learn to question (Gadamer et al., 2004). Further to this, the research question should guide the exploration and interpretation of the entire research process and give sense to hermeneutic research (Barthold, 2012). The research question for this project was developed to be intentionally broad: ‘How do older
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people with Stage IV COPD conceptualise health-related quality of life?’ This overarching question was designed to allow participants to interpret the concept for themselves and provide stories and insights that may have sat outside the researcher’s prejudices and assumptions. As detailed in a written reflection in April 2016, during the data analysis phase, I was able to come to a greater understanding of how the design of the question had been influenced by personal assumptions and pre-conceptions. This increased understanding also allowed for more detailed questioning into the topics and issues that the participant discussed (Harris, 2014).

The development of the research question was possibly the most difficult step in taking ownership of this research. What began as a project exploring the link between exercise tolerance and mental health in multiple chronic disease states, a project conceptualised by the original supervisors, became a wandering in the wilderness - for three years. Exploring the literature regarding COPD, it emerged slowly that the COPD experience was governed by much more that physical and mental health; and it was the ‘much more’ that had actually captured my imagination. As the project morphed, several things changed: the team, the scope, my tone and my commitment.

What seems a simple question: ‘how do people with Stage IV COPD conceptualise quality of life?’ is not. It is layered in years of reading, of not understanding, of searching, of ideas - good and bad. This question, as simple as it is, asks me to step back from my own assumptions about what makes a good life; to explore an idea without any other goal but to ask the question. Written Reflection, April 11th, 2016

The research question links to the theoretical framework as well as personal understanding of issues affecting the lives of people with advanced COPD. In this way, the question is linked to my pre-understanding of the area of study, which needs to be critically examined and reflected upon as part of the research journey and in defence of its credibility.

Identification of Pre-Understandings

Fleming et al. (2003) suggested two methods to assist researchers in articulating and understanding their pre-understanding, which have been called journaling and critical friendship for the purposes of this study. There were a number of strategies used to capture reflexivity, identify pre-understandings and acknowledge where bias has influenced the
project. To identify and challenge personal prejudices, as well as chronicle their change over time, a detailed journal, beginning prior to the data collection phase, became a series of reflective annotations and recorded reflections through data collection and analysis. In addition to this, practices like meeting regularly with a critical friend (SH), supervisors (JC, DB, JG) to discuss their understanding of the project, reflecting on the experience of data collection and thoughts on data analysis of voice recorded interviews, all contributed as a disciplined part of the overall strategy. The interview sessions were transcribed and analysed as part of the data analysis process to monitor change over time in prejudice and understanding (Austgard, 2012; Fleming et al., 2003). The interpretations of these reflections were woven throughout the results as well as the discussion chapters of the thesis.

Gaining Understanding through Dialogue with Participants

For Gadamer, the goal of dialogue was never to debate, but to move towards mutual understanding, even if consensus wasn’t reached; it asks good-will of both parties to reconcile understanding and connect (Barthold, 2012). Methodically, dialogue between the researcher and the participant needed to stay within the realm of the subject matter and the researcher was required to request justification for the views of the participant. As such, Fleming et al. (2003) infer a semi-structure interview style dialogue in their proposed method, although a narrative style of interview was used in this project (Harris, 2014). The choice to use narrative interviews was made to better facilitate interpretation (Rolfe, 2014) and is not novel to hermeneutic research (Harris, 2014). Personally, this choice reflects an inherent desire to be heard. As a person who thinks and speaks quickly, there was a concern that using a method such as semi-structured interviews would result in speaking over the participants, or to think so hard about the next question that no one was listening to the answers they were providing. Gadamer spoke of the humility required to engage effectively
in dialogue that comes from the self-understanding that we ‘know that we don’t know’ (Fleming et al., 2003). This methodological choice had two primary aims, to respect the participants as experts in themselves, and ensure that voices seldom heard were not drowned out. One of the first reflections recorded, after transcribing the initial interview, drew out the concern that it would be possible to talk over the participants, and the tangible evidence that this had not been so, served as encouragement to continue in this way, dramatically shaping future interview styles over the coming months.

I was really proud of myself, in transcribing the first hour [of Camilla’s interview], there are pages of text, it’s her speaking for a really long time, and I did it! I was able to bite my tongue! In the second hour I bit my tongue less and it became dialogue between the two of us, or the three of us at times. Recorded Reflection, March 18th, 2015

According to Barthold (2012), ‘dialogue requires a humble playfulness in which we get caught up and lose ourselves in the connection with another’. There were times where building relationship was more critical than collecting data. One participant, Valerie, had commented in her first interview that I would occasionally check my handwritten notes before asking a question. This prompted the challenge to maintain eye contact while listening to her story in the next interview, and engage with her in conversations with active listening techniques, demonstrating to her the importance of her stories.

Part of developing understanding, through dialogue with the participant, is the notion of temporality, that a statement said in the moment is important, but is transient (Fleming et al., 2003). To allow for Gadamer’s assumption that understanding is dependent on historical situation and that all dialogue is temporal, the research method suggested by Fleming et al (2003) specifically edicts that multiple interviews should be conducted with a participant. Thus, To gain greater understanding of the participant’s horizon, as it was appropriate, interviews were conducted over two visits separated by approximately one week. This
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allowed for exploration of ideas and reflection to be tested, as well as revisiting core questions a second time. It also allowed participants to think on the questions asked and respond to them, adding omitted responses or requesting that information provided be removed from the transcript. Additionally, one participant retracted a statement from their initial interview and requested it not be included in any way in the project findings. This data collection process allowed for my own pre-understandings to be influenced by the previous interview and dialogue with the text, playing into the cyclical nature of understanding in which pre-understanding shapes the perception of an experience, which influences subsequent understanding. Both Gadamer and Fleming et al. (2003) concede that this dialogue and fusion of horizon could continue indefinitely, with full understanding never being achieved, thus pragmatic decisions regarding saturation were made, as outlined in Appendix D.

Gaining Understanding through Dialogue with the Text

‘Text’, from a hermeneutic standpoint, is considered to be more than just written text. It may also include any audio/visual recordings, observation and field notes, and written notes made about the interview situation. Understanding is also gained by feeding the transcripts, and/or summary of the initial analysis, back to the participants or conducting follow-up visits. Due to the health limitations of the research group, i.e. that is was likely a return visit was not feasible months after the initial visit, transcripts and the initial summary were returned to the participants for checking, authenticity and comment (Fleming et al., 2003). The four stages of analysis (the naïve reading of the ‘whole’, exploration of the ‘parts’, movement back to the whole, and establishing trustworthiness) to continue the process of gaining understanding are discussed in detail in the Method of Thematic Analysis section.
Establishing Trustworthiness

As previously mentioned, Lincoln and Guba (1985) have outlined criteria for establishing trustworthiness in qualitative research, that can be applied directly to Gadamerian-style research (Della Ratta, 2015; Weiland, 2012). They identify auditability, fittingness and credibility as the three core constructs of trustworthiness. Clear documentation of the research process, as well as evidence of analytical decision-making (auditability), were kept in the form of progress reports and milestone documentation for the supervising University. Researcher journaling and supervisory/critical friend meeting notes and recordings were also used to detail progress and decision making. Direct quotes are used throughout this document to established credibility through the direct representation of the stories of the participants. Whilst idealistically, according to Gadamer, trustworthiness is also establish through objectivity and authentic representation of text, it is recognised that in trying to convey the meaning of each participant, the results of this study represents a shared understanding of meaning, as all data collected and interpretation will be influenced by a personal horizon (Fleming et al., 2003). For Gadamer, the balance between faithful representation and prejudice strikes at the heart of his beliefs on ‘truth’, that there is no statement that is universally true, as no statement can be free of prejudice (Fleming et al., 2003; Simms, 2015)

Gaining Ethical Approval

This study was approved by the Charles Sturt University Human Research Ethics Committee (CSU HREC) (2013/129), the Greater Western Area Health Service (GWAHS) HREC (HREC/13/GWAHS/61) and Bathurst Health Service Ethics Committee (SSA/14/GWAHS/132).

Copies of the Ethics Approvals attached in Appendix B.
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**Reporting of Critical Incidents**

An amendment was sought and approved by CSU and GWAHS HREC’s for the use of data from Participants 2 and 11, in April and July 2016 respectively, as they did not meet the study inclusion criteria for age due to recruitment error. Details are provided in Table 3.1 and Appendix B.

**Recruitment**

Participants were recruited through the Bathurst Health Service (BHS) Respiratory Coordinated Care Program. The process of recruitment detailed here was prescribed by the Health Service and Area Health Service Human Research Ethics Council.

**The Respiratory Coordinated Care Program**

The Respiratory Coordinated Care Program (RCCP) at BHS coordinates the care of people with chronic respiratory diseases, including COPD, as well as oxygen therapy for people living in the Bathurst Region. The majority of clients enrolled with the service have Stage III or IV COPD, although the service is not limited to COPD care. Clients are supported with regular in-home medical review and assessment, with the RCCP Clinical Nurse Consultant (CNC) acting as the case manager for the multidisciplinary care team, including local General Practitioners (GPs), mental health services, community and ambulatory care staff, as well as social support services such as chaplaincy and social work.

During the design phase of the project, the RCCP CNC, referred to as ‘Bernadette’ throughout the study, was consulted to facilitate the recruitment and post-research support of potential participants. With the support of the Health Service Senior Management, requests were made that potential participants should be recruited through the service, by Bernadette, as she had the capacity to undertake purposeful recruitment, according to the needs of the study through her knowledge of each of the RCCP clients. In addition to this, all participant
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follow-up support, if required, would be facilitated through the RCCP in line with the case management approach of the service.

As there was a potential conflict of interest in Bernadette recruiting and caring for RCCP clients, several safe guards were put in place to prevent coercion at recruitment, as noted in the wider discussion of Ethical Considerations.

**The Invitation to Participate**

Potential participants were invited by Bernadette during a home consultation. This included being provided with a ‘Participant Invitation Pack’ (Appendix C), which included:

- A Letter of Invitation
- A Participant Information Sheet
- An Expression of Interest reply form
- A reply-paid envelope addressed to the researcher.

All further communication regarding recruitment was handled between the researcher and the participant. Although Bernadette was trained to be able to answer basic questions about the project, she was instructed to refer the client to the researcher for any in-depth questions, or questions she did not feel were appropriate for her to answer.

From this point, the general process of recruitment procedure followed:

- Potential participants contacted the researcher by phone/mail/email to discuss the project and participation
- A research visit was arranged in the person’s home, at their convenience
- At the time of the research visit, the researcher discussed the information sheet, and questions the participant had and the criteria required for informed consent (also Appendix C)
Table 3.1. Recruitment Outcomes

<table>
<thead>
<tr>
<th>Recruitment Outcomes</th>
<th>Number</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>RCCP Clients Approached</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Clients recruited and consented</td>
<td>11/12</td>
<td>One client accepted Participant Information Pack and contacted the researcher directly to refuse participation</td>
</tr>
<tr>
<td>Clients not recruited</td>
<td>1/12</td>
<td></td>
</tr>
<tr>
<td>Clients recruited outside of Inclusion Criteria</td>
<td>2/12</td>
<td>Two participants were recruited and a home visit conducted without the researcher knowing they did not meet the Inclusion Criteria for age. As the participants had made the time and effort to participate, the full research visit was conducted. An amendment was approved to the CSU and GWAHS HRECs to include the data collected in the research findings.</td>
</tr>
</tbody>
</table>

Consent

As part of the informed Consent process, participants were made aware of the personal and potentially sensitive nature of issues that may be discussed in their interview which could cause anxiety or distress, and that they could withdraw or terminate the interview at any time without consequence to their care. Participants were also required to consent to Bernadette being made aware of their participation for follow-up reasons.

Several consent options were provided relating to the recording and presentation of their interview data which were clearly outlined in the consent form (Table 3.2). These options were available to all participants, but were sensitive of cultural preferences relating to the
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recording of images, as later viewing of those images, which could include images of people who are deceased could be distressing.

Additional consent was requested from each participant about access to the research data upon or after their death. Whilst this did not affect their capacity to participate, it was included so that in the future, should the families of the participant approach the researcher to access the recordings, there was a clear understanding as to the wishes of the participant. This was particularly pertinent for participants who did not wish to receive their transcript and/or recordings at the time of the research (n = 3). To date, the researcher has not been contacted by any of the participants’ family members.
Table 3.2. Consenting Options and Preferences

<table>
<thead>
<tr>
<th>Consent for recording</th>
<th>Number</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed consent given</td>
<td>11/11</td>
<td></td>
</tr>
<tr>
<td>Video and Audio</td>
<td>6/11</td>
<td></td>
</tr>
<tr>
<td>Audio Only</td>
<td>5/11</td>
<td></td>
</tr>
<tr>
<td>No recording made</td>
<td>0/11</td>
<td></td>
</tr>
<tr>
<td>All transcripts and recordings sent to the participant</td>
<td>8/11</td>
<td></td>
</tr>
<tr>
<td>No transcript sent to the participant</td>
<td>3/11</td>
<td>1 Participant deceased</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 Participants specifically requested no transcript to be sent</td>
</tr>
</tbody>
</table>

Ethical Considerations

Issues of ethical concern for people highly dependent on medical care, particularly in terminal care research, focus on the consenting procedure, the consequences of participation/non-participation and the timeliness of research. Despite these concerns, it remains critical that people with a terminal condition, or in palliative care, have the opportunity to participate in research and have their perspectives heard. Ethical considerations fell under two main themes, those relating to recruitment and those relating to the data collection phase of the study.

Recruitment Considerations

At the request of BHS and the RCCP, Bernadette was engaged to participate in the recruitment and follow-up aspects of the project. As it became clear that participants were highly dependent on her care, procedures were put in place to protect participants from...
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coopercion or feelings of coopercion. Potential participants were made aware, through Bernadette and the research documentation, that:

- Participation was voluntary and participation, non-participation or withdrawal from the project would not affect the level of care provided by Bathurst Health Service or the RCCP
- Several options were available for participants to contact the researcher directly (phone contacts, mail slips and reply paid envelopes) that were not facilitated by the RCCP
- Should they opt to participate, RCCP staff would not be informed of their participation until after informed consent was given and the interview had taken place, and only to provide a follow-up call or visit. Further to this, staff was not provided access to the interview recordings or transcripts.

The participant information sheet clearly stated “Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the Bathurst Health Service and the staff caring for you.”

We were respectful of the right of every person to spend their own time as they choose, particularly in the context of palliative and terminal care. Arrangements for participant visits were made at the earliest mutual convenience, with all phone messages, letters or faxes from participants being responded to, via a phone call within one working day.

**Data Collection Considerations**

The narrative interviews conducted as part of this project covered issues such as ageing, quality of life, psychosocial wellbeing and living with COPD. It was possible in the discussion of these topics that issues of a personal or sensitive nature arose. As a result, there
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was a risk of anxiety or distress associated with the discussion of sensitive and/or private information. As part of the informed consenting procedure, participants were made aware of the potential discussion of sensitive and personal issues. They were also made aware that they could terminate the interview at any point. A contact list was provided to each participant, allowing immediate contact with their care team, and out-patient health services from Bathurst Health Service (Appendix C).

Further to this, Bernadette contacted each participant within 48 hours of each interview by phone or during a routine visit, to facilitate or provide any follow up support required by the participant. In light of the sensitive nature of these interviews, arrangements were made for the chief investigator to access the services of the CSU (Orange Campus) Student Councillor, if required.

People with COPD are at risk of negative health outcomes such as breathlessness, oxygen desaturation and cough that can be triggered by talking, posing potential risks for people being interviewed, over a period of time. The researcher had extensive work and research experience in interacting with people with chronic respiratory conditions, including those with severe disease, so understood that talking with these participants would be slower and require more breaks than other interviews. Those participants receiving oxygen therapy were encouraged to use this as they required. Participants were regularly reminded that they could take breaks at any time, terminate the interview completely or postpone to a later time/date for any reason. Alternately, the researcher could stop the interview if continuation was not in the best interests of the health of the participants.

The risk of transmission of cross-infection of pathogens between the researcher and participant was a potential risk, due to the high rate of chest infections in people with COPD as well as their weakened immune system. To prevent transmission from researcher to
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participant, the researcher ensured proper infection control was used, including hand hygiene and use of personal protective equipment, when required. The research protocol stipulated that in the event of the researcher or participant being unwell, the interview was postponed until the illness had cleared, although the need for postponement did not occur. To lower the risk of transmission from participant to researcher, all the researcher’s immunisations were up to date.

Due to the severity of the participant’s condition, it was appropriate for the interviews to be conducted in the home. To ensure the safety and ease of mind of the participant and the researcher, home visits were conducted according to Department of Family & Community Services standards for Working Alone or in Isolation (2015). Of particular relevance to the study visits are issues relating to:

- Communication: all visits were scheduled with the participant prior to the visit. Scheduling included reminders in relation to the securing of pets and smoking cessation, as well as arrangements for reminder calls and access to the property.

- Worker location/contact: a written record of the researcher’s location, arrival/return times, contact details and schedule were given to the School of Biomedical Sciences Administrative Assistant. The researcher had a mobile phone on their person at all times during the visit.

- Identification: the researcher presented their CSU Staff Card on arrival and had it visible at all times during the visit.

- Travel: the researcher used their own private, comprehensively insured vehicle, for the purpose of research visits, and assumed all responsibility for travel.
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Data Handling

One cardinal expectation of the Gadamerian-style of research is that the researcher responsible for data analysis undertakes the research visit and preferably transcribes any interview transcripts as part of the dialogue between the researcher and the data (Fleming et al., 2003). All interviews were transcribed verbatim into a Word document by the researcher, correlated with relevant field notes and uploaded to NVivo 10. When possible, the first interview was fully transcribed before the second interview was conducted. A copy of the transcript and preliminary summary of the interview was sent to each of the participants for their review and comment.

All files were transferred from the recording device to a password protected computer in the researcher’s private office. Files were wiped from the recorder once transferred and a back-up made onto the password protected University database. Data are stored and will be destroyed in the following ways:

- Electronic Research data will be kept for a period of seven years on a password protected computer before being erased.
- All field notes were scanned and stored as electronic data. Originals were shredded and discarded.
- All original research documentation, including signed consent forms will be stored in a locked filing cabinet in the private office of the researcher for a period of seven years.

These procedures are in line with current CSU Policy on research data protection.

All participants were provided with a pseudonym that was linked to a re-identification list that was held by the researcher only. The research primary supervisor was made aware of the location of this file in case of emergency. Participant pseudonyms were used from the time of
transcription, through the data analysis and the presentation of research findings. Any audio-visual data used in the presentation of research findings were used with the expressed permission of the participant.

**Sampling of Participants**

**Sampling Strategies**

Qualitative sampling is considered less rigid than in quantitative research, as there is capacity for emerging theory and conceptual dimensions to influence the choice of participants in accordance with the needs of the study (Creswell, 2013). Selective or purposeful sampling, the selection of participants based on set criteria, is routinely used in qualitative research as the method allows the researcher to prioritise the recruitment. It is used to increase the capacity to collect the maximum volume of data within the scope of the study design (time available, theoretical frameworks, research foci and restrictions) (Coyne, 1997). This aligns with the hermeneutic methodology, where sampling focuses on the recruitment of participants both willing and able to discuss their experiences (Van Manen, 1997). Whilst purposeful sampling is most commonly used, current literature has accepted that a combination of sampling strategies may be the most appropriate strategy, dependant on the needs of the study. Theoretical sampling, more commonly associated with Grounded Theory methodology, is sampling based on analysis of data to validate variations in findings, confirm importance or meaning or patterns, and test facets of the theoretical framework (Coyne, 1997).

In the context of this study, aspects of theoretical sampling were used in line with Patton (1990) and Morse (1991), as a variation of purposeful sampling. The purposeful recruitment of participants in the initial stages of the study provided information-rich dialogue and generally exemplified the typical experience of living with advanced COPD. Theoretical
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sampling was then used to explore specific experiences (e.g. current smoker) or atypical experiences (e.g. atypical COPD diagnoses), to increase understanding across the breadth of the area of study.

Inclusion criteria (Table 3.3) utilised for the recruitment of participants were based on established criteria within the theoretical framework of successful ageing, as well as standardisation of disease severity according to national guidelines. The capacity to recruit was also considered. The use of preconceived, but reasonable criteria, allowed for the recruitment of participants who would actively engage with the researcher, providing data that would scope the core themes of the project.
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**Table 3.3. Inclusion Criteria, Amendments and Justifications**

<table>
<thead>
<tr>
<th><strong>Inclusion Criteria</strong></th>
<th><strong>Justification for Criteria</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>A person with a confirmed diagnosis of COPD, Stage IV severity</td>
<td>The phenomena being explored regards not just the diagnosis of COPD, but its severity rating. Severity was categorised by the recruiter according to existing medical records.</td>
</tr>
<tr>
<td>Aged 65 years or older</td>
<td>The model of successful ageing used as the theoretical framework for this research was validated in three population groups aged 65 years or older.</td>
</tr>
<tr>
<td>Able to communicate effectively in English</td>
<td>Participants needed to be able to engage in an active dialogue with the researcher in line with the principles of hermeneutic phenomenology</td>
</tr>
<tr>
<td>In the care of the Respiratory Coordinated Care Program (RCCP) at Bathurst Health Service</td>
<td>All recruitment and follow-up was facilitated by the RCCP</td>
</tr>
<tr>
<td>Is not acutely unwell (relative)</td>
<td>Recruitment for any participant who was acutely unwell was postponed until they were recovered to prevent deterioration or cross-infection.</td>
</tr>
</tbody>
</table>

**Modified Criteria**

<table>
<thead>
<tr>
<th><strong>Modified Criteria</strong></th>
<th><strong>Justification for Modification</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged 65 years or older</td>
<td>Two participants were consented despite not meeting the inclusion criteria for age. Ethics amendments were received from CSU and GWAHS for the use of this data.</td>
</tr>
</tbody>
</table>

Over the course of the data collection and transcription, naive reading and reflection, cases with specific or atypical experiences were sought (Morse & Field, 1995). The transition from purposeful to theoretical sampling was a conscious choice to explore aspects of COPD that had not emerged in the initial interviews. In exploring the rationale for recruitment with the RCCP CNC, priority was given to potential participants who would be able to share their experience with depth and enthusiasm.
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In the beginning it was about people who were engaging, who would kick you off... The first couple, yes, because I knew they would engage, and they are people who have a bit of a passion for sharing their story and I think you found with Gail and Valerie... I think in that regard, it was people who would engage. Interview with Bernadette, July 21st 2015

After eight interviews were completed, theoretical sampling was used to recruit the remaining participants. Two specific requests were made to the recruiter, that she recruited participants who she identified as ‘mal-adapters’ for any reason, and to explore concepts that had not emerged strongly in the previous interviews, particularly spirituality and religiosity. Three additional participants were recruited on the basis of perceived mal-adaption, due to mental health or smoking status. At the time of recruitment there were no participants identified that could be recruited to specifically explore the concepts of spirituality and religiosity. The tone of the interviews did change slightly at this stage.

I think they weren't that different. There were things about them that were different - the general story was very familiar, but they tended to have one core difference, such as still smoking... I was testing ideas on all the participants - using phrases like 'now what I've heard from your story was this... am I on the right track', which was about coming to a shared understanding. What I was probably hearing [in the theoretical sample participants] was less of the initial story - it was a little bit like trying to draw blood from a stone at times - Evan and Mae especially - they were laboured interviews. It may not look like it to see the transcript, but there was a lot of silence in the audio. Recorded Reflection, July 13th, 2015

Whilst the questions did not differ, there was an increased emphasis on how the participants differed from the initial cohort; why they were identified as ‘mal-adapters’, as noted in the recorded reflection.

Sample Size and Saturation

According to Mason (2010), sample size in qualitative research is determined by a number of factors including, but not limited to, the heterogeneity of the population, number of inclusion criteria, time and budget constraints, scope of the study, quality of the data, as well as study design and methodology. Sample sizes are generally quite small in qualitative research to reflect the thickness or volume of information collected as well as the volume of data that
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could be reasonably managed by the researcher (Dworkin, 2012). Whilst Creswell (2013) recommends a sample of 2 – 25 for phenomenology, Morse (2000) suggests at least 6 cases. These recommendations are generally smaller than those for other methodologies such as Grounded Theory (20 – 50) or ‘qualitative research’ in general (25 – 50). What is critical is that the sample size reflects the research aims and purpose and is line with methodological rigour, as opposed to more current trends in Doctoral research where larger samples are used to be on the ‘safe-side’ of a defensibility, in regards to this (Mason, 2010).

Within the scope of hermeneutic phenomenology, using set characteristics and variables to guide sampling is undertaken to a point. Unlike similar methods such as Interpretive Phenomenological Analysis, where heterogeneity of sampling is a priori, purposeful sampling is issued in the hermeneutic tradition to recruit ‘people who offer a picture of what it is like to be themselves, as they make sense of an important experience’ (Cohen, Kahn, & Steeves, 2000, p. 45). The generalisability of data sets goes against the core tenets of the methodology, where each interview and data set is seen as an interpreted construct created by the researcher and participant, where multiple realities and perspectives of truth are revealed (Laverty, 2003; Mapp, 2008).

Creating the time and space for a researcher and participant to work towards a shared understanding of the experience, through dialogue, ultimately affects the volume of data collected and participants recruited. To acquire the depth of analysis Gadamer demands, smaller sample sizes were necessary, respecting the stories heard and the researcher’s capacity to manage the volume of data, without resorting to generalisations and the ‘levelling of banality’, where text is so far removed from its context and temporality that it loses its authenticity and credibility (Laverty, 2003; Mapp, 2008; Whitehead, 2004).
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Ultimately, one of the major determinants of sample size was saturation, a highly contentious term in qualitative research, particularly outside the Grounded Theory paradigm, where it first emerged (Mason, 2010; O'Reilly & Parker, 2012; Strauss & Corbin, 1998). To date, there are limited guidelines for phenomenological methodologies to achieve adequate transparency and auditability, when making a claim of theoretical saturation (O'Reilly & Parker, 2012). There were a number of indicators of saturation, both at the level of the individual interview(s) and the whole data collection process. Specific to the cohort being studied, participant fatigue was one of the primary determinants of the length of the interviews. Appendix D contains a detailed table of evidence regarding decision making and saturation.

**Participant Overview**

Participant details are provided in Table 3.4, in order of their recruitment. There were 7 female and 4 male participants, ranging in age from 63 to 89. The period of diagnosis ranged from 32 years to two weeks prior to recruitment for the study. Nine participants were former smokers, with one being a current smoker and two having no smoking history.
Table 3.4. Study Participant Details

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Year of Diagnosis*</th>
<th>Work History</th>
<th>Living Arrangement</th>
<th>Approx. BMI*</th>
<th>Smoking History*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Camilla</td>
<td>82</td>
<td>1996</td>
<td>Professional</td>
<td>Married</td>
<td>21</td>
<td>Yes</td>
</tr>
<tr>
<td>Laurel</td>
<td>69</td>
<td>2009</td>
<td>Cleaner, Cook</td>
<td>Widow, lives alone</td>
<td>31</td>
<td>Yes</td>
</tr>
<tr>
<td>Clem</td>
<td>64</td>
<td>2004</td>
<td>Painter</td>
<td>Married</td>
<td>18</td>
<td>Yes</td>
</tr>
<tr>
<td>Gail</td>
<td>68</td>
<td>2011</td>
<td>Administrative Management</td>
<td>Single, lives alone</td>
<td>39</td>
<td>Yes</td>
</tr>
<tr>
<td>Ruth</td>
<td>68</td>
<td>1998</td>
<td>Manufacturing, Cleaning</td>
<td>Married</td>
<td>33</td>
<td>No</td>
</tr>
<tr>
<td>Vida</td>
<td>76</td>
<td>2015</td>
<td>Administration, Retail</td>
<td>Married</td>
<td>18</td>
<td>Yes</td>
</tr>
<tr>
<td>Valerie</td>
<td>73</td>
<td>2014</td>
<td>Retail</td>
<td>Widow, lives with sister</td>
<td>33</td>
<td>Yes</td>
</tr>
<tr>
<td>Geordie</td>
<td>71</td>
<td>2013</td>
<td>Farm-hand</td>
<td>Single, lived alone</td>
<td>17</td>
<td>Yes</td>
</tr>
<tr>
<td>Mae</td>
<td>68</td>
<td>1982</td>
<td>Cleaner, Driver</td>
<td>Married, lives with husband, son and grandson</td>
<td>41</td>
<td>Yes (current)</td>
</tr>
<tr>
<td>Evan</td>
<td>63</td>
<td>2011</td>
<td>Driver</td>
<td>Married</td>
<td>24</td>
<td>Yes</td>
</tr>
<tr>
<td>John</td>
<td>89</td>
<td>Not reported</td>
<td>Professional</td>
<td>Married</td>
<td>Not reported</td>
<td>No</td>
</tr>
</tbody>
</table>

* Self-reported measure
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Data Collection

Data Recording

Interviews were recorded either using a digital voice recorder and/or digital video camera. Participants were able to opt for which recording method was used, based on personal or cultural preferences. The rationale for the visual recording of data, in this way, was due to the impact of breathlessness in COPD on the ability to communicate and the importance of body language in communication. It was felt that to accurately present the participant’s story, they must be given the opportunity to present it for themselves i.e. to use visual as well as audio data. To use only transcripts could misrepresent much of their journey. Details pertaining to the handling and storage of data are listed previously in Data Handling.

Demographic Data

As the nature of Gadamerian-style research is conducted with a ‘conversational’ style, a list of basic demographic questions including basic demographic data (age, weight, height, BMI) and COPD-related health questions (smoking history, work history, current medications and co-morbidities) were asked to ‘break the ice’ with participants and develop relationship between the participant and the researcher before the interview began (Appendix C).

The ordering of the questions on the demographic sheet was slightly modified in the interviews, to work up to questions regarding smoking history, rather than begin with them. Instead, the less threatening question about work history was broached first, then co-morbidities and medications. Some participants provided lists of
medications to be included in their documentation, whilst others self-reported their medications.

**Interview Phase 1**

According to Flick (2006), narrative interviews were used as an alternative to the traditional semi-structured interview, routinely used in biographical research, although more commonly associated with a Grounded Theory approach. Phase 1 of the narrative interview was asking a generative narrative question, to stimulate the telling of the participant’s ‘story’. It is important that the question has topical specificity and the period of the biography is relatively defined, as this grounds the content to context and generalizable circumstances. The question was generally worded ‘**can you tell me your story from the time you first thought something was wrong with your breathing?**’, although the exact wording depended on the context of the conversation. From the researcher perspective, this phase involved little more than active listening, note taking and occasional clarifying questions. Depending on the participant, this phase took anywhere from a few minutes (Valerie, Mae) to an hour (Camilla), with the starting point of the stories ranging from birth (Camilla) to the first exacerbation (Clem).

**Interview Phase 2**

Phase 2 is commonly referred to as ‘narrative probing’. When the participant had finished telling their narrative, follow-up questions were asked from the researcher notes, to elicit further detail or meaning from specific points in the narrative. Questions included ‘in regards to x, could you tell me a little more about what that was like/what happened/how that affected you?’

As demonstrated in Gail’s discussion about taking care of herself.
Interviewer: You talked about, last week, how your quality of life is getting out of bed in the morning, getting up and doing things for yourself like washing yourself, doing the dishes, that kind of stuff. When did something like having a shower become your priority, as opposed to an assumption?

Gail: *It became a priority when I first came out of hospital for the first time, you know, on oxygen and it would have been very easy for me not to have a shower every day, so easy but I choose to do it… Some days my breathing’s not good enough to enable me to do that, so I’ve got to do it in little bits… Chunks…*

*Yeah (laughs). I used to shower twice a day; I don’t even contemplate that anymore (laughs, coughs).*

Do you think those decisions are affected by your experience with your mum?

No. No, because I never had any experience… Dad took care of all that stuff.

Gail

On reflection, it was in this phase of the interview, that the dialogue became closer to the *Spiel* Gadamer talks about, as noted in the post-interview reflection recorded after Camilla’s follow-up interview.

That was fun - it got easier when it became a conversation. I felt it was very medically driven at the start, which may be a limitation of the question; it was interesting to see how far back her story started... Recorded Reflection, March 16th, 2015
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In other situations, additional dialogue that was not relevant to the study was purposefully omitted. Transcription resumed, if and when, the dialogue returned to the focus of the study.

**Interview Phase 3**

In the final phase of the interview, the ‘balancing phase’, questions that were highly specific to the area of study were asked to deduce meaning and theory. At this point of the interview, the participant is considered and ‘expert and theorist of themselves’. Questions included:

- Can you tell me what you understand of the term quality of life?
- Can you tell me about how you/your life have/has changed over the course of this disease?
- Can you tell me how your (physical health / emotions / spirituality or religion / mood) affects your quality of life?

There were two primary aims of this phase. These were to to ask direct questions of the participants from the theoretical framework, raising issues not previously mentioned, as well as creating space for open reflection at the end of the interview. For Valerie, who did not see faith or spirituality as an issue in her life, it was important to clarify whether she did not consider it important at all, or it simply hadn’t come to mind throughout the interviews.

Pip: …can you tell me how… does COPD affect your faith and spirituality, or does faith and spirituality affect the way you experience COPD?

*Valerie: No, because I don’t think of it that way, to be honest; that side of it has never, ever entered my mind; I’ve never been a person that’s gone to church, even though I believe in God. But I never think about it that way, I
never think of spirituality at all, actually. No, it doesn’t, for the want of a better word.

Method of Thematic Analysis

Fleming et al. (2003) suggested a process for analysing data using the hermeneutic circle, which included examination of the whole, the parts, and the movement back to the whole from the parts that is critical to Gadamer’s philosophy and the Gadamerian-style Research Method. In a similar way to Husserl’s descriptive phenomenology, which deduces the ‘essences’ of the phenomena, the researcher must explore the meaning of the ‘whole’, as this will influence the understanding of every other part of the text. This can be done, in part, through the transcription process and is sometimes referred to as the ‘naive reading’ where the researcher gains an understanding of the wider lens of each participant’s story and the collective of stories (Appendix F). From there, line by line the researcher aims to expose meaning from every sentence and story. From this exploration, themes are developed that demonstrate the depth of the researcher’s understanding and are influenced by the researcher’s prejudices. In the same way, the prejudices of the researcher should be analysed in light of the emerging themes.

The emergent themes must be related back to the meaning of the whole text to complete the hermeneutic circle. This is a critical step specific to Gadamer, as other hermeneutic philosophers, particularly van Manen (1997) do not include this phase of data analysis. Within the Gadamerian tradition, both the meanings derived from the initial naive reading affects the examination of the parts, and the understanding of the parts, alter the understanding of the whole and the parts in turn (Barthold, 2012). In addition to the movement between the whole and the parts, the researcher
must show evidence of the shared understanding established between the researcher and the participants, most commonly achieved by using passages of the original text that demonstrate this. These passages should have been, and were, included in the research report as evidence as well as evidence of the decision making and development of thematic codes through the analysis process (Appendix E). This is also critical to the establishment of trustworthiness and truthfulness of the research findings.

**Moving through the Cycle of Thematic Analysis: A Reflection**

The cyclic movement between the whole and the parts became a rhythm throughout the data analysis phase. At first it felt quite erratic, as though I didn’t know where to look next, but on reflection it was possible to see that when it was hard, I didn’t know where to look, I needed to shift from one space to another, from the whole to its parts. This movement added richness and depth, whilst movement from parts to the whole enabled the re-evaluation of the larger themes and meanings. This to-ing and fro-ing became a conditioned response to the struggle, and so with time, I became more comfortable that when grappling with an idea, a quote, the flow of a chapter, it followed that I simply needed a change of perspective.

The first view of the ‘whole’ came as I reached saturation during the data collection. Sitting in a participants’ lounge room, thinking ‘I’m so busy linking his story to other stories that I am not listening properly, my head is full, I need to stop if I’m going to respect each story’. As each interview was transcribed, generally before the follow-up meeting, my thinking shifted from the whole to the parts, drinking in each word as it was heard, listening to each story fresh. Learning my tendency to remember the idea of a story but not necessarily the fine details, and finding that
those fine details were easily muddled and reshaped to fit the predisposed mould I had cast for this project, facilitated a heavy dependence on those original transcripts, to avoid misrepresenting the participant stories. Variations between annotated throughout the transcription process and recorded reflections when I retold stories to supervisors made it abundantly clear that I had the capacity to glean the essence and meaning of a story long before remembering its finer nuances accurately. These nuances, of course, went on to inform my naïve interpretation of future interviews and transcripts.

Over the period of data collection and transcription, a six month period of living in the individual words and phrases of the participants, a sense of where the larger project was going and some preliminary ideas of themes developed. This movement back to the ‘whole’ - a much more comfortable place, served as motivation to spur the project on through the overwhelming task of coding. These preliminary ideas, the (very) naïve reading, was only ever written in pencil, per se (Appendix F). It was grounded in my thoughts and insights and a gut feeling about the interviews , as they were experienced on the day, and as they were analysed during the transcription process Importantly, the essence of those gut reactions is still present in the final themes and discussions of the project, but only as essences. They morphed into bigger, clearer, wiser themes only when moving back to the parts and I took each participant, line by line, through their story.

I used an inductive coding method - essentially eleven transcripts and a blank NVivo page. Over time 54 nodes¹ were established signalling different areas of discussion (Appendix E). In my bias, the nodes were often inherently positive, labelled

¹ Node: a thematic coding folder within the NVivo software in which quotes, references and text pertaining to the code are filed together
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‘Maintaining Independence’, for example. Over time these labels became much more neutral - as ‘Maintaining Independence’ began to cover discussions surrounding the loss of independence or the perception of independence, it became simply ‘Independence’. The nodes were designed to be large and generalised to capture sweeping ideas and maintain the context of the statement, so often multiple paragraphs of the text from an interview was cross-coded into upwards of 10 nodes, as the roll of the sentence(s) could not be broken and one idea could not be inherently separated from the next, yet. Most interviews ended up being coded over 120 times into at least 40 of the nodes.

Working through each transcript, line by line, was definitely an exploration of the ‘parts’, although as I moved from transcript analysis to node analysis, exploring what each node had to say about a core idea, I remained in the ‘parts’. It was about this time that, with a preference for the ‘big picture’, I struggled to see where the project was going. There were days when it felt like the ‘whole’ would never be - it was too elusive and irretrievable, not able to be found again. My initial ideas where not always what the participants wanted you to hear. It was slow work, but the participants were persistent with their message.

As the nodes were broken down further, there were times where I realised that I had coded nonsense. This happened particularly in the ‘Denial’ node. A sense of denial had been so strong through the interviews but when tone of voice was lost in transcription and context was lost by taking text out of its natural dialogue, references that inferred denial were lost too. This was because themes like denial run not in individual sentences, but through entire stories, generally in the contradictory statements that are made as the participant opens up over time. It was back to the transcripts with pen and highlighter to find what was lost.
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Over time, and particularly through the larger nodes of Family and Coping Strategies, the ‘whole’ resurfaced - fresh-faced and grounded in the actual words of the participants, leading to the refinement of the project’s Concept Map (Appendix F) that facilitated the development of Chapter 4. At last, the big picture.

As each chapter evolved according to that concept map, the goal was to use the participant voices to facilitate an understanding of their stories - a fusion of horizons, as it were. At times through the process, I have felt like I was butchering their stories, by cutting sentences from their context. The reader and the participants can be assured, however, they have put up a strong fight and I have worked hard to allow these eleven participants to walk others through their experiences, as well as my new understanding of them. Several of the themes which emerged from the data had a natural narrative, where I felt like I was not in control of how the story would come together, I was simply coordinating a linear flow on paper. Others have been more of a struggle, where for days on end, I asked ‘where is the story?’, ‘what does this mean?’ and ‘how do I explain this clearly to someone else?’

In written reflections the words ‘argh!’ and ‘ugh!’ appear very regularly. Above my desk are post-it notes that say silly things like ‘how does this demonstrate equilibrium?’ and ‘you are writing a results chapter, not a discussion’; little reminders that the participants are in charge and I am simply the messenger. These notes are all triggers to ask myself ‘are you looking at the part, should you be looking at the whole?’ or vice versa. They are also triggers to remind myself that this project is a shared understanding between all of us.
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Conclusion

The data collection method used in this study is based on Gadamer’s hermeneutic phenomenology, using the Gadamerian-style research method suggested by Fleming et al. (2003). Participants were asked to tell the story of their COPD journey, using a narrative interview technique, which allowed them to direct the flow of the interview and to respect them as experts of their own lives (Flick, 2014). The following chapters detail the participants stories, their analysis and interpretation, with the goal of understanding their conceptualisation of HRQL and the factors that mediate it, through the use of the hermeneutic circle (Fleming et al., 2003).
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Chapter 4

Context of the Research Findings

The purpose of this hermeneutic phenomenological analysis was to explore the conceptualisation of quality of life by older people with advanced COPD. The participants’ stories gave insight into the far reaching implications of their condition, not just on their activities and functional capacity, but their identity and core relationships. COPD was seen as an accepted part of their identity, the response to which was considered one dimension of a multifaceted individual to be metered against a lifetime of experiences. As such, COPD and its implications were perceived as one contributor to global quality of life.

The inductive thematic analysis revealed four core themes within the participants’ narrative: ‘accepting change’, ‘mind over matter’, ‘being together in the world’ and ‘quality over quantity’ (see table 4.1). The first two themes focus on the internalisation of COPD, how it shapes and is shaped by identity and acceptance, and then how those intrinsic mechanisms enable a range of coping strategies that facilitate independence and resilience in the face of change. The third theme, ‘being in the world together’ goes on to explore quality of life and the lived experience of COPD, in relationship with others, how COPD affects relationships and how those relationships influenced the participants’ perception of their situation and quality of life. With the insights of the three previous themes, ‘Quality over Quantity’ explores the way quality of life was defined with how it was discussed by the participants.

Habraken et al. (2008) wrote about the ‘silencing’ that occurs for people with COPD at the end of their lives. As a researcher, the goal was to ensure that voices seldom
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listened to were able to be heard. This chapter begins with a series of Pen Portraits, so that each voice can be heard as the voice of an individual, in their context.

Table 4.1 Overview of the structure of the Research Findings

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</table>

The Voices

An overview of the participant demographic is provided in Table 3.4. In addition to that information, this chapter will introduce the participants from my own perspective as a researcher.
Bernadette and I met at a University residential school many years ago. She was the student that would answer the question, volunteer, and rally the troops - a relief for any weary teacher, to have a student that could keep the momentum when their own is flagging. She had come to respiratory nursing, the way most of us come to respiratory practice - through rare opportunity and a well-recognised need. We spoke about my research for the first time on the day of her graduation. It was stinking hot, we were in our academic dress standing in a gazebo that seemed to provide a disproportionate volume of shade to the amount of heat it trapped, but I had an idea to run by her. She liked it. She liked the idea that her patients might have their stories heard, she had great patients with great stories.

Bernadette recruited each of the participants for this study. Without her, I would have never made it through Ethics, let alone a single front door. She had spent years building relationships with these and so many other people with COPD, walking them through their final stages. Her patients trust her, and went on to graciously extend that trust to me.

Every story contained in the data reflects Bernadette’s presence in the lives of the participants, and their family. As an outsider looking in, I could see clearly that the care she provided for her clients had directly affected the way each individual perceived their situation. Would the stories told have been different if Bernadette was not their nurse? Of course they would. Would my interpretation of those stories been different? Of course it would. Bernadette served as a point of consistency throughout the narratives, which can be seen as a limitation of the work. More importantly though, Bernadette’s consistency lit the way for an interpretation based
on the provision of care that the participants truly appreciated: her empathy, her capacity to provide timely and gentle guidance, and her ability to respect every person as whole and valued.

Camilla

Camilla met me at the door - my first interview. A beautiful multistorey home filled with pretty things to dust, and stories to be told. She reminded me of my great aunt more than I should admit. She looked at least 10 years younger than her 82 years. Everything about Camilla was poised; her hair and makeup, her dress, her shoes, her home. Small, delicate, considered; I was glad I had taken the time that morning to put on pantyhose. Every story was considered, but there were many of them. We spoke for over two hours on that first visit. When the recording stopped, she apologised for her scratchy voice - she didn’t always sound like this. She missed her old voice.

Throughout the interview, Camilla’s husband only left the room to answer the phone. He was as big as she was small, and had nowhere else to be but to listen to her stories, interject occasionally and keep an eye on me. They had had many ‘lives’ together: children, careers, tragedy, joy and now COPD. As she began to fatigue he drew me in with his own stories, changing my line of sight if only long enough to allow her to cough, spit and regain composure without me seeing. He was her body guard and I could not ask him to leave, lest she went with him.

Camilla wove her way in and out of adventures all morning and I devoured them whole, enjoying the ride. She spoke at length about the people in and through her life, distancing the story from her own world. It would take many more months and interviews to realise that the world she created with words was, in fact, a beautifully
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constructed façade, built over years, deliberately, but not necessarily consciously.
For all her activity on social media, there were no photos. For all the effort she put into her presentation, she did not leave the house anymore. For all her past adventures, she had submitted to the boredom of the day. I was glad I didn’t figure this out until much later.

Clem

Clem was old beyond his years. He was only 64 but was weary in the way many elderly are weary. He was on the couch in the TV room, every 30 seconds or so, shifting his body from the hips to sit back or rest forward on his walker, resting exhausted respiratory muscles, fatiguing the others in turn. Breathing was hard work but he didn’t wear his oxygen and listening to him, I wished he would.

We were in the family home where he lived with his wife, who wandered past the room intermittently and eventually settled on the armchair across the room to add her ‘two cents’. She had retired early to care for Clem and didn’t regret it, but she had too much energy for this house. She hacked at weeds in the garden, redirecting that energy toward the garden instead of Clem; getting angrier at the futility of the situation with every passing season.

Clem’s speech was laboured, husky and quiet but he had points to make and he made them. He missed his old life, and mourned the retirement he should have been having. At times he spoke as though he was already dead, especially when he talked about his grandkids and what they’d remember of him. Clem’s story was one of denial. He was not interested in the COPD, he had other health issues that slowed him up, if not for them, he’d be up, around, breathing, walking, doing - ‘this CO… whatever you call it’ would not touch him.
Clem died a year after I met him. His wife commented at the time of his death that she was ‘too young to be a widow’.

**Gail**

Gail’s story was a story of hope, of defiance. The first two interviews with Camilla and Clem were so disparate that I was wondering if I was on the right path at all but Gail, Gail spurred me on to honestly believe that there was so much that could be done to improve the experience of people with COPD, and that those improvements must be bound in relationship.

It was a freezing cold that day, despite the fact it was only early autumn - we were both rugged up and drinking tea at the dinner table. Her little apartment was exactly what she need it to be; homely, comfortable, easy to keep, loved. She was portly with silver hair, she took good care of herself and so did others; they had seen that she was absolutely worth the effort.

Gail’s life was heavily affected by her COPD and its psychological toll took priority over the other co-morbidities, of which there were a few. She took ‘the anti-depressants’, although she wasn’t sure that they did anything.

Gail lived in a residential village for over 55’s. She was their social director for a while, which suited her personality; friendly, organised, decisive, no tolerance for fools. I thoroughly enjoyed every moment I spent with her. When asked about family she had none - never married, no children. When asked again, she admitted she had created her family, a combination of old friends from far away and new friends that have become more like sisters than neighbours. On her blue days, and she had them, they’d stop in, get barked at, and respond ‘well then, I’ll be back later’. She returned the love accordingly.
Laurel

Laurel was small, round and soft. She wore cat-eye glasses and flannelette pyjamas with no apology. There were no mirrors in her house, she didn’t want to ‘see how fat I’ve gotten’. Despite this, she was swamped by her armchair, the kind of chair that was good for napping by my own standards. Her whole life was within a metre of this chair. The kitchen, the TV remote, oxygen, medications, knitting, and junk mail there was no flat surface or carpet to be seen, again with no apologies. I was on her turf and she’d do as she pleased. I took an instant liking to her spirit.

Laurel was happy with her station as a ‘shut-in’, as those whom she needed, came happily through the door on a regular basis. She mourned her husband, but did not let this grief get in the way of uncompromising love and spoiling of her remaining family. She loved big and hard. Laurel’s need was to be needed.

Laurel had buried many people, endured much hardship and lived with more than one chronic disease. It was remarkable that throughout the telling of these stories, she still laughed freely, generally at herself, and I wondered how people learned to do this; laugh instead of cry.

She was a great and therapeutic cook - it was primarily how she tied her family to her, although I felt they’d come whether she fed them or not. At one stage, we had a 20 minute discussion about how best to make baked custard - she used cold milk, I used warm. As long as there was no curdling of eggs, we decided it didn’t matter.

Ruth

Ruth and I sat directly across from each other at the dinner table the size of a card table; designed for two. She had a nervous giggle and every sentence was laden with terms like ‘and yeah’, ‘and that’ and ‘um, like’. To transcribe, there were entire
sentences that made no sense, but to listen to, it’s just that the words simply tumbled out, rather than flowed from her. She was nervous, unsure that she would be of any help to me.

Her husband was in the house, but not with us. He made himself busy in the next room and never really acknowledged that I was there. Sitting in the next room with the radio on, he was not listening to our conversation, nor was he ever out of earshot. Their home looked like a home that has raised many children and built up a lifetime of photos and things in a way that you can only put them together as they are created, not planned. She revelled in the small things. She admitted she loved being around people, even to sit quietly in the corner and watch life happen.

Ruth’s COPD was as a result of Rheumatoid Arthritis. The fingers of one of her hands were seemingly pinned to her wrist in that uncomfortable, arthritic way. The physical impact of the arthritis was monumental but she claimed it was the breathing that slowed her down. She did not prioritise one condition over the other but saw her body, mind and their problems as a single entity, with whatever was flaring the priority.

I walked away from the interview amazed at how over a lifetime, two people could love each as much as Ruth and her husband. It was the deep, slow-burn kind of love that lasts, mixed with the girlish delight of your first crush - her face lit up when she spoke about him. I felt as though in giving in to the amount of care she required from him, she had fallen for him anew, he was her Florence Nightingale. I guessed this was adaption but I wasn’t sure if it was healthy.
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Vida

Vida’s home was a large Federation home in the centre of town, beautifully styled and neatly presented, her husband was vacuuming for almost the entire first interview. Monday was cleaning day and he wasn’t a spring chicken anymore. These things took time.

Vida was the definition of petite. I don’t think she was always that petite though, her clothes were good quality, ironed, a size too big. We sat in a light filled family room towards the back of the house. The walls were covered in paintings and overflowing bookcases. Vida was an artist. She didn’t paint too much anymore because of the fumes but she was excited about her work that was about to be exhibited locally.

When I asked her how she would ‘paint COPD’, she lifted her hand to an invisible canvas, one finger pointing, spiralling tighter and tighter, moving away from her, stating ‘the only thing I can think of is a line... eating me up as it went through, you know, going in and in and in and in, and eventually grasping all, everything...’

Vida didn’t get out much but deeply appreciated the friends that have hung in there, visiting and calling. She didn’t want to get out that much but wished her family would put up more of a fight when she refused their invitations. Her husband wandered through the room occasionally but did not participate until the camera was turned off, curiosity got the better of him and he wanted to know what I was doing with all this ‘stuff’. Vida insisted that I must be bored listening to all these stories. She acknowledged that whilst not bored, her limited social life had made her boring to others.
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Valerie

Some people get up to greet you at the door, some spouses do it. Some people shout for you to come in, as though they are confused as to why you would knock, which was the case with Valerie. From the outset, Valerie wanted me to know that what she was going to tell me was the honest truth, and I believed her. She was honest and unabashed, with a wry humour, a lot more like one of the boys than a lady but then again, so am I. She, and I are the kind who can give and receive an off-colour joke in the spirit in which it was meant or swear without offending, because it was the right word to use to make the story sing.

Valerie’s husband passed away a little while back. Of all the ways you don’t want to go, he did it - dwindling in a nursing home, semi-conscious, uncomfortable, waiting. It was some consolation that his family were there constantly, but only some. This affected Valerie’s view on the living of life and the process of death. It was in speaking with her that I was able to come to the realisation that this project was not about talking to people who were dying, about dying, but talking to people who are living, about living.

Her life had been one of tragedy, change and adaption. Learning to cope after the car accident that prevented her playing national level sport meant that there was never a question that she would survive breast cancer. Her cure to COPD was simply to keep on keeping on - get in the car and go on holidays, oxygen concentrator in tow.

Geordie

Geordie lived by himself in a one bedroom apartment. He sat there in his pyjamas, unshaven with a wrestling match on the TV; forgot to put his teeth in. He apologised for all of this in time, and turned the TV off. I never asked a participant to do things
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like turn the TV off, despite the difficulty it would cause listening back to the recording. For Geordie, and others, television was a companionable background noise that was part of the music of the day.

Geordie was comfortable in his big recliner rocker and I was perched on the edge of the couch. He wasn’t a big guy but you could tell he’d worked hard, outdoors, his entire life. Between us was some clutter, a clear plastic tub full of medications, books, TV guides and an army of remote controls. The house was tidy.

Geordie sucked and chewed constantly on a Nicobate inhaler in a habitual way - he perched it between his fingers at times to tap the non-existent ash. I would suggest he was a relapsing-remitting smoker. It’d been eight months since his last smoke but he’d do it again in a moment if it wasn’t so bad for him. On my second visit, the house smelt like day-old smoke - I asked him how his quit attempt is going, to which he replied ‘fine’. His voice was a smoker’s voice but it was also lyrical, musical. He was a willing story teller, and seemed to enjoy having company.

Geordie was the first participant to die. I do not have permission to tell you that story but I encourage you with the idea that it happened on his terms.

Evan

Evan was the youngest person to participate. I felt as though he was also the angriest; the deeply repressed kind of anger that sits in your bones and makes you old. We sat in the front room of the house, the formal lounge, and were alone, his wife was at work. She worked full time and he did not.

Evan provided a different perspective to most others, whilst they mostly retired before the COPD took hold, COPD put a stop to his work, paid and unpaid. It brought to an end a number of joyful things in his life and he seemed to have to give
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up the nice things, woodwork or the golf club, to conserve energy to do the mundane, housework or the like, to make it up to his wife for sending her off as the breadwinner.

He had a calm exterior, always considering the question before answering, and never giving more than I’d asked, and I had to ask a lot. I think his dog had extra-sensory perception, as soon as I was getting somewhere, the little darling would appear out of nowhere for a pat and the chain of thought was lost.

Unlike any other participant, I never felt like I was able to break down the wall that he had built around himself. I commend myself for being able to put people at ease, read them in a way that allows them to open up, but not that day. We were both uncomfortable and the visit, all of it, was conducted in just over an hour. I wasn’t welcome there.

**Mae**

I sat outside Mae’s house for a while, ringing the doorbell, knocking, calling out ‘hellooo’. A phone call eventually got me in the door. Mae lived with her boys, an invalid husband, adult son, teenaged grandson and dog. No wonder nobody heard my polite window-tapping.

Mae was purposefully recruited for the study as someone who actively smoked, a ‘mal-adapter’. An assumption I unknowingly lived by was that smoking with COPD, equated to not coping. Mae helped me realise that we all have our poison, mine was sweet coffee, hers was cigarettes; they help us get through our day and soldier on.

The house was cluttered, the table cluttered, the couch she slept on, cluttered. Mae was dressed comfortably and sat sipping with her diet coke for the duration. She was polite, but not particularly friendly - ready for a fight, because she was so used to
being preached at. When I said I would not judge her for her actions - namely her smoking; she seemed genuinely surprised and warmed up almost immediately.

The paradox of Mae’s situation was that she had built a system of adaptive mechanisms that allow her to function in her family, but these systems would not be considered healthy in any regards; smoking to reduce anxiety or sleeping on the couch because lying in a bed makes you claustrophobic. Neither of these things was really okay, but they got her through. The fact is that she has had a hard life, and she was still having one. As unhealthy as these strategies appeared, they allowed her to remain in her home despite her worsening health, caring for her family much longer than a weaker soul could. She kept her husband out of residential care, her grandson out of unsafe living situations, her son out of unemployment. She could ‘shut up shop’, live with her daughter, quit smoking, be happy, and lived longer, but instead, she did what was required of her. Full credit.

John

John’s was the last interview I conducted. I was tired of stories, they were becoming blurred. It was a relief to step into his home, knowing this was the end. He spoke with the gentle and undulating timbre of a well-educated, polite man, the kind that wore his heart on his sleeve. John was tall and thin but not fragile. He was almost 90 and reminded me of my paternal grandfather, Pa, who was equally gentle, considered, and full of heart. I waited and listened as he caught his breath after answering the door; inhale a lot, exhale a little, inhale a lot, exhale a little, inhale a lot, exhale a little, purse the lips and deflate like a balloon – identical to Pa. If I closed my eyes, I was a child on summer holidays at the family farm. I felt less like a researcher and more like a granddaughter asking her grandfather for the family
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history. He was generous enough with me, to share the kind of stories one does not
tell their actual grandchild.

Throughout the interview, John regularly lost his composure, becoming tearful as he
spoke about the way his health has affected his capacity to provide for his family. He
was a man of great duty, a gentleman, never the kind to acknowledge the ‘black dog’
that had taken hold.

As I left, I began to regret not staying for a cup of tea to chat afterward but it was
right to leave this beautiful afternoon to memory. Of all the stories, John’s affected
me the most emotionally. To sit within the story during the hours of transcribing,
coding and analysis, it was his story that made me the saddest, nostalgic, because it
was so familiar.

**Pip**

I am an innate optimist. I see life through a prism of colour, of opportunity, of
privilege. At the point at which I was interviewing each of the participants I had
never truly lost, or grieved. I have now. Life is less shiny, but no less beautiful, and
no less purposeful. In fact, maybe it is more so. Of all the bias I brought into each
interview, most notable was my belief that there is purpose to be found in every
dimension of life; in the everyday mundane as in the extraordinary. Secondly, it was
and is my bias that we are all whole people, all of the time – as every fibre of out
being is interconnected, so to is every dimension of our lives. This means that the
lines theorists and health professionals construct between our physical,
psychological, social, emotional, spiritual and all other dimensions are mirages. They
disappear the moment we search for them. So, we are never fully capable of
separating the dimensions of what makes us, us; to talk about one dimension is to
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include all the others in one way or another. I discovered this for myself when I tried to bracket myself assumptions and bias from the research process, a naively optimistic fancy. To be present in an interview, to play through dialogue was not possible if I left my true self, all of it, at the front door of the participant’s house.

I took all of this into each interview with me, this assumption that there was more to life with COPD that just breathe in, breathe out, repeat. This optimism blinkered me at times to travelling down the path of the less comfortable conversations. It meant that stories carried the essence of denial, but not evidence. It meant that ageing became about looking backward, rather than forward; a good story, well told, is easier for a stranger to share than partially formed thoughts that reflect a fear for the future. These were opportunities missed, and lessons learned. Thankfully, their stories are no less powerful or meaningful for my limitations.

Whether it was right or wrong to assume these things, I did it. It flavoured the dialogue, my understanding and my interpretation of each narrative. I consider this to be the greatest strength and greatest limitation of the qualitative paradigm; the humanity of it all. As a result, the stories told by the participants spoke of who they were, as much as who they now are, or who they would become. There is a temporal nature to their experience, a strong sense of timeline, of identities formed before we crossed paths, and now shaped by their current experiences. This shaping included, but was not limited to, being older and being breathless. It was the participants’ hope as well as their ability to look past their present experience for greater meaning that allowed me, in my own time of desperate sadness, to remember that there is purpose in the everyday mundane as there is in the extraordinary.
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Chapter Summary

This chapter has provided an overview of the research findings that will be described in the subsequent chapters. Additionally, the chapter introduced the eleven participants whose voices are used throughout the remaining chapters and sections of the thesis in addition to my own narration and interpretation of their story. Allowing the participants to speak for themselves is critical in research of this methodology, as it is only through the expression of their voices that true authenticity can be achieved, and only through the combination of their voices with my own, that historical horizons and the fusion of those horizons be demonstrated (Fleming et al., 2003). This exploration begins with the participants discussion of change, identity and independence, and how those constructs are shaped over a lifetime as well as by COPD.
Accepting Change

As the first theme, ‘Accepting Change’ revolves around the participants’ identities, as a modifiable construct, shaped by their world, their sense of self and now influenced by COPD. Baptista, Galvão, and Pimentel (2014) defined acceptance as ‘recognising and understanding the limitations and losses causes by [a] disease’ (p.33). Despite the deficit language of the definition, acceptance of illness was said to be considered as a positive variable that was critical to an individual’s capacity to adapt to their condition.

This theme is broken into four sub-themes (Transcendence, Identity, Hope, and Independence) to navigate how the participants accept change (Table 5.1). The participants’ past and present experiences of ill-health, suffering and change shaped the way they framed their ‘COPD story’. This reflected their identity as people who were both subject to and capable of change (Transcendence). As such, COPD was considered not as a source of sickness but a source of change that lay outside both their understanding and control (Identity). The ability to accept the changes occurring in their bodies without accepting the label of COPD manifested as a hope and defiance, again shaped by past experiences of surviving against the odds (Hope). From this hope, the participants articulated their desire for independence in the face of declining functional capacity (Independence). It was their ability to accept change, adapt to it and learn from past experiences that allowed them to reinforce a cycle of acceptance where new experiences of adaption created greater hope and defiance, and adaption that would maintain independence despite the mounting impact of COPD symptoms.
In describing how the participants understood their identity, the scene is set for how they, as individuals, respond to the changes and challenges of COPD independently (Mind over Matter, Chapter 6) and in relationship (Being in the World Together, Chapter 7).

Table 5.1 ‘Accepting Change’ Themes and Sub-Themes

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Transcending Suffering

Each of the participant narratives covered past and present experiences that informed the individual’s perceptions of COPD and quality of life. At the core of these stories was the idea of accepting ongoing change as a natural part of life, a core attribute of self-transcendence (Duggleby et al., 2012). Acceptance of change was demonstrated as they reflected on past experience of adaption, allowing many to contextualise their current experience, seeing their suffering in the wider context of their life. The lens through which they reflected on their situation included their daily experience of COPD, and past experiences of suffering and ill-health, both lived out and vicarious.

The participants expressed confusion regarding their condition, yet despite their misunderstandings, were fully cognisant of the changes that were happening in their bodies. This was demonstrated, in part, as an understanding of the variability of their symptoms from day to day and general decline in function over time, without necessarily understanding the mechanisms by which those changes were occurring. When seen in the light of past experiences and the context of an entire life, the changes that were occurring in and to their bodies were accepted with the same inevitably as ageing.

The daily experience of COPD

There was a temporal awareness of a range of acute COPD symptoms. Breathlessness was identified by each of the participants as the most frequent and burdensome symptom, particularly in the way it limited activities; as Valerie described,

*If you’ve got COPD, people would be aware that you are going to be out of breath when you’re showering, when you go to the toilet… when you get*
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dressed, when you do walk, can’t walk because, well, you just can’t walk;
walk out to the letter box and back and you’re (puffing), you know. Valerie

In addition to the impact of breathlessness, other symptoms noted included cough (Gail), congestion (Laurel), difficulty swallowing (Clem) and difficulty sleeping (Geordie, Mae), although none of these symptoms appeared regularly across all stories. In contrast to the literature no participant listed COPD-related pain as a symptom (Joshi, Joshi, & Bartter, 2012; Wysham, Cox, Wolf, & Kamal, 2015). Laurel did explain that there was pain associated with COPD but this was restricted to COPD complications as opposed to the disease process itself.

There’s no pain attached, unless you get a cold or a cough, or you break your ribs, well, then there’s pain. Laurel

In addition to Laurel’s description of COPD-related pain, there was an occasional interplay between conditions that had negative complications, such as Ruth’s dental decay being masked by the continuous morphine patches used to manage pain associated with Rheumatoid Arthritis or Camilla’s inactivity which inflamed her bursitis.

The experience of nine of the participants, who did not identify pain as an issue, was in contrast to Ruth and Clem, whose daily life was affected by ongoing pain associated with their Rheumatoid Arthritis and Osteoporosis respectively. For both Ruth and Clem, exacerbations of their co-morbidities influenced their perception of their health more than the presence of COPD, with Ruth acknowledging the accumulative effect of co-morbidities in determining her health priorities. Similarly, Clem maintained his Osteoporosis was the source of his impairment and that COPD didn’t really factor into his functional limitation.
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*My biggest problem is not being able to get around because of other problems, not so much the breathing. If I could walk, I'd be right. But I can't walk, I can't support my own weight.* Clem

Clem’s management of multiple chronic health conditions was not an isolated experience, as each of the participants were affected by at least one co-morbidity, with 38 self-reported co-morbidities being identified across the eleven individuals. These ranged from diabetes to trigeminal neuralgia and included depression and/or anxiety in ten instances, excluding Valerie. It became clear, that for some participants, there were very clear health priorities in managing these conditions, in conjunction with their COPD.

Clem’s prioritisation of Osteoporosis over COPD sat in direct contradiction to Camilla, whose COPD sat at the forefront of her health priorities, as was indicated when she ‘forgot to mention’ her bursitis, dermatitis and glaucoma until the second interview, despite direct questioning. Camilla considered them ‘ordinary everyday things that are not a great deal of importance.’ This quantification must be considered in light of the existing literature on multi-morbidity, where COPD is generally considered quite low on a list of health priorities for the individual (Ansari, Hosseinzadeh, Dennis, & Zwar, 2014; Eckerblad et al., 2015; Harris, Dennis, & Pillay, 2013). Ruth suggested that it was not a fixed set of priorities, however, whatever was ‘flaring up’ was the priority for her, adding fluidity, and so complexity, to the hierarchy of conditions and their management.

In experiencing symptoms, their day to day variability, was considered important, as symptom severity tended to determine the quality and mood of the day. This variability was part of the participants’ overall understanding of the condition, as one
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aspect they constantly factored in; that there would be good days and bad, and one would do what one must to have more good than bad. ‘Good days’ and ‘bad days’ were typically measured in activities that could be achieved with minimal breathlessness and fatigue, as described by Geordie.

Oh yeah, some days I feel good, you know, I can get up and, well, not run a mile; job to walk from here to the toilet, but ah, you wake up, you feel really good and other mornings you wake up and you feel as though, gosh, do I really have to get up? ‘Specially when it’s cold and you’re snuggled down in bed’. Geordie

Rather than Geordie’s ‘good days’ and ‘bad days’, Camilla spoke about the ongoing decline in health and increase in symptoms ‘day by day’, which was met with little sympathy by her General Practitioner (GP).

I’ve got no infection, nothing particularly wrong, but all of a sudden my lungs are much worse; and they were. And [the GP] said, ‘well, and they’re going to get a lot worse yet.’ Camilla

Both Camilla’s awareness of her declining health and Geordie’s discussion of the variability of symptoms demonstrate that participants were aware of the changes in their bodies, both significant and subtle. This daily awareness of change was not however perceived in isolation. Instead, the overall experience of COPD was contextualised to a lifetime of change and imbued into their identity, as a person who could grappled with the daily experience of COPD, whilst simultaneously accepting that this struggle was simply a part of a life.
Building perspective over a lifetime

Through their stories, each of the participants described their perceptions of their place in the world, establishing their identity as being part of something bigger than themselves, and bigger than COPD. Understanding their place in the world allowed them to create a sense of perspective of their current situation, in the context of their whole life, as they compared and contrasted past and present experiences of change, success, failure and suffering.

In relating current experiences of COPD to others, they created a frame of reference in which they understood and interpreted their present circumstance. John was able to reflect on the nature of suffering, over the course of his life, in his definition of ‘quality of life’. Appreciating that he had had a ‘very good life’, John defined quality of life as a global and fluid construct that reflected the breadth of a life, and so rated his life well ‘despite the troubles I’ve had’. Whilst acknowledging COPD as a serious health concern, John’s reflection placed COPD in the context of his whole life rather than as his whole life. Similarly, Valerie asserted herself as an individual who would overcome COPD, as she had overcome conditions in the past. In comparing her health to that of her now deceased husband and others with COPD, Valerie perceived herself as ‘one of the lucky ones’, as she was still able to perform activities that facilitated quality of life and provided joy and confidence, despite her symptoms. With her past serving as motivation to continue pursuing the quality of life she desired, Valerie could also look to others around her to add to her understanding of the present and future.

Loss of social connectivity and shrinking life-world are recognised consequences of breathlessness and fatigue in COPD. With the decline in social network comes the
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perception of loss of usefulness and effectiveness as a person (Gullick & Stainton, 2008; Leidy & Haase, 1999). Whilst acknowledging the declining size of their social networks, there was a committed sense of connectivity to the communities in which the participants lived, and the nation to which they belonged. This was often expressed as a concern for the future of others, particularly family, and a sense of duty about their civic responsibilities, again hallmarks of self-transcendence (Duggleby et al., 2012). More than any other participants, John and Camilla, the oldest participants, spoke of their tendency to reflect on the state of the nation (Australia) and exercise concern for others, and in the process of doing so, demonstrated elements of transcendence.

John became distressed when considering the plight of vulnerable communities, associating this increased degree of concern with his advancing age.

_I worry tremendously about the people who sleep on the streets and the Aborigines; people are doing a lot for them, but they get rejected... You worry about all these things as you get older, as you get nearer the grave and you hope you’re doing the right thing._ John

Similarly, Camilla spoke passionately about her mother as a suffragette in the United Kingdom, which affected her perception of quality of life to a construct that ‘extends to the country, and what happens to it’. Self-transcendent views and actions are more commonly ascribed to older people (gero-transcendence) (Tornstam, 1996) or to those acutely aware of their own mortality (Reed, 2008). For many participants, spirituality featured as a mechanism by which they built a sense of perspective and interpreted the changes they experienced.
In those who identified as religious and/or spiritual, it was seen as a source of comfort as well as a larger frame of reference. In speaking about her relationship with God, Ruth spoke about her prayer life, admitting that she resorted to begging God that ‘everything will come alright’ despite believing that the request was both immoral and futile. Ruth’s experience of God was as of an entity larger than herself, with the power to control her future. There was a dichotomy in her discussion of prayer, in the persistence, despite the fact she did not believe that her request would be answered. Despite the seeming futility of the action, Ruth continued seeking that relationship as an acknowledgement of her faith in bigger things, as a source of comfort and effectively placing control of her future in another’s hands. In doing this, Ruth was able to distance herself from her situation whilst simultaneously accepting change as a divine experience. By placing the responsibility of health outcomes on ‘another’, she was able to accept that declining health was inevitable and out of her hands. Interestingly, health improvements were not linked to her faith but the skill of health professionals.

Ruth’s experience was quite different to Laurel’s agnostic spirituality. Laurel’s experience of her husband’s death and subsequent spiritual experiences had reframed her understanding of dying, death and the afterlife. Having never been a religious person, her growing spirituality had prompted a dialogue within her family about dying, wherein fear had been eliminated and dying was perceived as a source of hope for the future. As such, Laurel had demonstrated self-transcendence in the way she accepted death as a part of life. The worry that remained with her was held exclusively for the welfare of her family, as opposed to herself. The following case study uses Laurel’s story to explore the role of transcendence and spirituality in facilitating both the acceptance of change, and change itself. As Laurel and her
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family came to terms with her husband’s death, their combined and growing sense of spiritual connection to him, allowed them to not only accept his death as a normal part of life but reduce anxiety about dying and developed greater emotional connections between the three generations of Laurel’s family.

_Spirituality and Death – Laurel_

In the 18 months preceding the research visit, Laurel’s husband of 49 years had died. Towards the end of his life, each spouse had taken on the role of primary carer for the other as the health of both declined. At the time of his death, Laurel was flagged ‘at risk’, due to serious concerns for how she would take care of herself and how long she would survive her husband.

_I’ve had a bit of a big adjustment too, since my husband passed away, you know. He was my carer, he was my life, he was my partner, and it’s been a very, very bad; it’s been a bad time adjusting._

Despite the devastation of her loss, Laurel exceeded all expectations - even her own. This was due, in part, to the increased role her adult daughter played in her care but also the resilience Laurel showed in increasing her role within the family, and a deepening spirituality. As the interview rolled on, I broached the idea of religion, spirituality and faith, from which Laurel began to talk through her spiritual beliefs. She did not identify as being religious but there was a strong sense of agnostic spirituality to her story. It was from this belief system that Laurel saw purpose in her life and suffering, as well as a way to cope with what was happening to her and others.
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You’ve got to believe, that’s how I’ve survived over all these years... I believe in there’s a here-after, I believe there’s a place we’re to go. I believe you’re put on this earth to do something, regardless of what you do, you are put on this earth for it and I just believe. I don’t go to church, I don’t preach, but I believe.

Laurel was quite reserved in our initial discussions regarding spirituality. This only became apparent when the topic was revisited in the second interview, and the dialogue had become more conversational. At this time, Laurel began to speak more openly about her spiritual connection to her husband.

I do miss my husband, I do miss him immensely, but we have fond memories and we talk a lot about him, because we always say that he’s around... The day that he passed away there was a rainbow over our daughter’s house. It was a big rainbow. And people that come, they said, it was just right over [my daughter’s] house, this big rainbow and we had ‘Somewhere Over the Rainbow’ played at his funeral, and you know, to this day rainbows come everywhere... And even the boys (grandsons) will say ‘guess what I seen today Nan? I seen a rainbow, Poppy’s around again.’ You know, they, they don’t, they’re not frightened of it, sort of thing, they think he’s around, but he’s around, the old bugger. (Laughs)... But he still shouldn’t have gone, he was naughty. But he’s around.

Whilst her husband’s death was considered premature and devastating, it had served to change the family dynamic to one of increased intimate sharing, particularly around taboo topics such as death. In opening the channels of dialogue with her family, they have used symbolism and spirituality to move on from her husband’s
death and look to her own end of life with greater positivity and openness, drawing comfort from their experiences and each other.

_We laugh a lot about it, the old bugger, he’s around; he is. And the kids are feeling the same, you know, and it’s a good feeling, it’s not a scary; you know, before, you wouldn’t talk, people wouldn’t talk about things because it’s too scary, but the children are even talking, they’re not frightened of death... it’s a satisfaction to know that he’s around ... A comfort, because... he wasn’t one who believed but now I think he does, he’s there, he believes and he’s trying to get through to us to say, ‘I do believe Fred’, as he called me. I do believe and that’s how I accept it. I suppose everyone has different ways, a lot of people have bitterness and hatred but you know, but I don’t, I just have as ‘he’s there’, and I cannot wait to go and meet him._

There was a renewed sense of hope through this connection, that her husband was okay, and that death was okay. Laurel expressed no fear in death or dying - she did not wish to be mourned, the only remaining fear was that she cannot protect her children and grandchildren from further loss.

**Summary**

Laurel’s story highlighted the way participants saw themselves in the context of their whole life, and as part of a greater whole. The way participants established their historical context revealed how they were able to, or at least begin to, transcend their present suffering. This was demonstrated by the concern for others, acceptance of death as a part of life and the integration of past experiences into their perception and acceptance of the present and the future, and so their ongoing adaption to the changes they were experiencing in their health. These discussions allowed the
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participants to establish the historical context of their lives before engaging with their ‘COPD story’.

Identity as a Means of Acceptance

Identity of illness is described within the literature as the ‘greater experience of illness of symptoms as a result of illness’ (Weldam, Lammers, Heijmans, & Schuurmans, 2014, p. 3). Whilst measures of illness perception play an important role in the assessment and management of people with COPD, the participants’ perspectives would suggest that illness perception and identity of illness is more than just their ‘experience of symptoms’. Instead, we join the growing chorus of literature in which people with COPD define their own identity; as people who are ‘not sick’ (Habraken et al., 2008; Jensen, Esmailzadeh, Holm, Anderson, & Lien, 2015), but rather people who has lost the capacity to breathe. The participants’ sense of identity was, instead, grounded in their perception of self and the illness, the impact of ageing and past experiences of change, both positive and negative. From these perspectives, the participants were able to discuss the nature of change and how it played out in their lives, seeing it as inevitable and ongoing but not necessarily associating change with COPD or smoking.

As COPD shaped identity, so too did identity shape the participants’ understanding and acceptance of COPD. The rate of change, its frequency and severity all played into how readily COPD-related change was accepted. What is important to note about the acceptance of change in relation to identity was that whilst acceptance of change was considered part of themselves, their story and ageing, this did not equate to taking responsibility for disease development or the label of COPD.
Perceptions of self and illness

Despite the volume of co-morbidities, the severity of COPD and the impact of symptoms, only Ruth and John perceived themselves to be sick or unwell. As previously stated, Ruth attributed that status to a number of conditions, not specifically COPD while John ascribed it to heavy medication use rather than directly identifying as being unwell from COPD. Alternate participant responses seemed to revolve around their own experiences of ‘sick’, as suggested by Laurel.

*I don’t feel sick, it’s not a ‘sick’ thing; it’s just you can’t breathe... Sick means going to bed and laying there and saying you can’t get up because you’re just so, you know, squeamish in the stomach, that’s what the word ‘sick’ means to me.* Laurel

Rather than identifying the ongoing symptoms of COPD as sickness, they were perceived as a source of impairment, regularly being compared to disability (Gail), a thing to be managed (Valerie), being ‘unfit health-wise’ (Evan) or a ‘damn nuisance’ (Laurel). Three participants (Clem, Gail, Laurel) independently used the metaphor of amputation when discussing the impact of COPD on their life or how their health was managed. In essence, the participants saw themselves as having an acquired physical impairment, as any other amputee would. By comparing their lungs to an arm or leg, they suggested that the participants did not see COPD as an enemy, but as a part of their identity. For Clem, the perception of COPD as missing a part of himself, was key to his acceptance of his circumstance.

*It’s just an acceptance of the way things are. Like if you had one arm, you’ve only got one arm - or you’ve got one arm missing.* Clem
Seeing COPD as a fundamental change to bodily function rather than an illness was influenced by the insidious nature of the condition, where people had been gradually worsening over such a protracted period that they had seen it as a part of themselves, and as part of getting older. Both John and Valerie noted that despite considerable health concerns and incidents in the past that things simply start to ‘niggle’ over time.

*I’ve had breast cancer; a mastectomy. I had a car accident... other than a couple of other smaller things, you know, Osteoporosis... all the other niggly things, I suppose you have when you get to 78 (laughs).* Valerie

Valerie’s description of ageing accepted that major health incidents were considered inevitable as she got older, and so too would be death. Ongoing decline associated with ageing was included into end of life care and planning, with participants factoring their age into their decision making, independent of their health status. Their choices suggested that they had considered themselves to have lived long enough (John, Ruth), or that in the choice between saving the young or the old, the young were to be favoured (Mae, Geordie). When looking back over a long, happy life, John sense of achievement allowed him to broach death comfortably.

*I’m 89 and ah, don’t think anything can be gained from [being resuscitated]... it wasn’t hard for me to say I didn’t want to be resuscitated. As I said, I’ve had a long life, a good life, a lovely family, so what else can you ask?* John

John’s ability to see his suffering in the context of his whole life and his advancing age, demonstrated the ability of the participants to maintain their identity as an individual who was undergoing continual and holistic change, and not just the
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changes associated with their condition. Even as one of the two participants who identified as being unwell, John refused to let that aspect of his self-perception overtake the experiences of a life time, in determining what ‘a good life’ was and means to him.

Evidence of the acceptance of change was demonstrated in the way the participants internalised their symptoms and functional decline. Rather than seeing COPD as a disease that was added to their experience of life, the changes they were experiencing were considered one aspect of who they were as an individual; subject to both change, and ageing. Their acceptance, grounded in their past experiences of suffering and change as well as their understanding of the variability within the day to day experience of COPD, allowed them to internalise COPD as a core element of their ever-changing identity. The process of internalisation was influenced by the individual’s experience with change in the past, with adaption often being discussed as a learned skill and conditioned response to adversity.

In discussing identity and acceptance, the means, frequency and rate of change which had been experienced, both in the past and currently, were all associated with COPD. Laurel’s gradual change over time helped her see COPD as a part of her identity, stating ‘I’ve had it for so long that it’s just part of me.’ Both Laurel and Valerie’s stories sat in direct contrast to the experiences of Clem and Evan, in the way they experienced, interpreted and accepted functional change. The following case study compares Valerie’s story to that of Evan and Clem, demonstrating how Valerie’s history of survival created a ‘culture of overcoming’, in her life. This was in contrast to Evan and Clem’s rapid and unexpected decline in health, which was met with universal frustration, as well as anger from Evan and resignation from
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Clem. The case study illustrates both the power of developed resilience over time as well as the emotional implications of that resilience, or lack thereof.

Learning to adapt – Valerie, Clem and Evan

In exploring how the participants underwent the process of acceptance and adaption to COPD, it was Valerie’s story that best exemplified how a lifetime of needing to adapt, eased the way for adaption to COPD. In her experiences of illness, loss and suffering across her life meant she had significant practice in creating a new sense of normal for herself and her family. There was a determined consciousness about her decision making in times of change that allowed her to move in a different direction as required, which was generally forward. After a serious car accident 30 years prior, Valerie had given up national level sport representation as she ‘couldn’t handle the fact that I wasn’t as good as I used to be’, which she described as feelings of frustration and depression. It was the experience of managing these negative emotions and dealing with loss that changed the way she approached change throughout the rest of her life, confident in the fact that she was able to adapt to anything in the future as well.

I always thought that I was always going to get over it (breast cancer) and with this (COPD), it hasn’t worried me a lot, except the fact that my lifestyle has changed a little bit, but I just accepted it, you know. Yeah, I always seemed to be able to do that, accept everything that’s happened to me, like when my husband died, well he’s probably better off, because he was so sick and never got out of bed; just accepting the fact, I think it’s helped me all the way through, actually. Valerie
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In looking at those critical incidents, Valerie seemed to seek out the positive, assuming that she would survive breast cancer, and knowing that her husband was ‘better off’. These ideas clearly shaped the way she managed her priorities and COPD, seeing herself as ‘lucky’ for being able to continue on with her life despite the reduction in pace and spontaneity, and the modifications required to achieve goals. This capacity to adapt to ongoing change brought about a sense of peace, that whatever change comes next, as Laurel called it, ‘the next hurdle’ would not be insurmountable, but there to be cleared. That knowledge also served as a motivation for Valerie to keep living life to the fullest each day as decline was inevitable.

*I just don’t want to be sitting here ‘til I’m 90 doing absolutely nothing, to me quality of life means being able to get out and enjoy yourself and do things you like doing.*

What happens for you, when you get to that point…?

*That I have to stay home? I’ll accept it. I’ll accept it, and I’ll be sitting in this chair watching that TV, watching the football... Valerie*

Valerie’s story sat in contrast to many of the participants' stories, although Clem and Evan’s struck a particular chord. While Valerie has undertaken rolling change over time and mastered her ability to adapt to it, Evan and Clem, the youngest participants, a diagnosis, retirement and the initial exacerbation all came relatively quickly after a lifetime of good health, affecting the way they perceived disease onset. For Clem, it was his initial exacerbation that time-stamped when he perceived that the COPD ‘came from’.
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I had a cold and couldn't shake it. After about three weeks, the doctor kept saying, you've just got the flu, you've got the flu - but I had pneumonia and I spent 11 days in ICU. And that's where it came from. Clem

In later discussions, Clem described his increasing difficulty managing stairs at work due to breathlessness, suggesting that he did not link those symptoms to the beginning of his COPD journey. For Evan, the initial exacerbation, retirement and diagnosis were in very recent memory, with strong emotions still quite raw. This was made worse by the swapping of family roles which came with premature retirement, creating ongoing tension in Evan’s relationship with his wife.

I was driving forklifts in a freezer and I was finding that I was, when I would drive in, I was losing my breath, and this was before I was on oxygen or anything, see, I'd get in there and I wouldn’t be able to breathe ...having shifted the (family) roles, virtually, where I was the primary earner, like I used to bring in the most money and [my wife] still worked, but she only worked three or four days a week, from home mainly, and now to switch it where I’m now at home all the time and [my wife] goes out to work to bring the money in, is sort of fairly hard to get used to.

What was it like?

Not working? Oh, murder... Evan

There was a sense of grief for Evan and Clem, that they would not have the retirement they had looked forward to. This was not echoed in the other participant’s stories, maybe due to the amount of time that had elapsed, potentially allowing them to accept the idea of a new or different kind of retirement. Of the eleven participants, only the male participants reported being medically retired in
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their 50s, against their preferences. Whilst the impact of gender was not explored specifically within this study, and did not appear directly as part of the inductive analysis of the data, it is suggested that explorations of gendered experiences of retirement, change and acceptance in COPD is warranted.

In addition to the influence of their place in the world and spirituality, the difference between stories from Valerie’s to Clem and Evan’s again shows the effect of a lifetime of experiences. In this case, past experiences of health-related change, the rate of change over time and socio-economic implications of those changes influence how participants understand and accept the change happening to them.

**Accepting change without accepting responsibility**

Whilst the participants could comment honestly on how they had adapted and accepted the changes that were happening to them, and their families, as a result of COPD, this did not equate to accepting diagnosis or involvement in its pathogenesis.

As opposed to discussing traditional medical models of the disease state, participants tended to discuss COPD with an air of confusion, highlighting the variability of experiences they had witnessed over time, from other patients, health professionals and care-givers.

Gail was the only participant to offer her definition of COPD as a ‘range of illnesses’; specifically, bronchiectasis and asbestosis but not emphysema or chronic bronchitis. Her definition was drawn from her experience with other people with those conditions, and her perception was that their symptoms and quality of life were ‘entirely different’ to her own.
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Confusion about the condition was widespread, and ranged from not understanding the experience of others to difficulty remembering the acronym or using medical terminology. When asked about her ‘chest’ Valerie responded that she didn’t have problems with her chest, stating ‘it’s more my lungs than anything else’, where Vida referred to COPD as ‘UCD’ and Clem, ‘CO-whatever-you-call-it’. This lack of understanding about the condition seemed to relate more to an unwillingness to learn more as opposed to insufficient health education. When probed about seeking more information about the condition, Vida commented that she could if she wanted, but had unconsciously chosen not to.

*I’ve never looked it up on the computer, put it that way, so I mustn’t [want to know about COPD]. Yeah, actually one of my sisters started to tell me, when I told her, started to tell me that ‘they say that…’ I said, ‘I don’t want to know, B’.* Vida

What was particularly interesting in the diagnosis stories was the number of participants whose diagnosis was contested (Ruth, Gail, Vida, John), affecting both the way support was provided (John) and creating doubt as to whether the diagnosis was correct at all (Gail).

*I know that my disease is progressing and of course, I don’t fit in any of the boxes. I suppose Bernadette told you that, I’m an anomaly… Bernadette and I are convinced it [is] something else as well, but I don’t know what. But whatever it is can’t be changed, so I don’t worry about it.* Gail

In comparison to the confusion or apathy towards the disease process, what was slightly better understood about living with COPD was the process of dying; that it wouldn’t be the COPD that killed but its complications, which were to be avoided at
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all costs. The way in which the participants spoke about their health suggested that COPD was perceived more as the way in which they would grow old, and likely die. Rather than being seen as a diagnosis or disease set aside from their identity, COPD was instead seen as a source of change.

Overwhelmingly, the participants’ development of COPD was related to smoking, with all but two participants, John and Ruth, being current or former smokers. Participants with a smoking history tended to buffer their smoking history with other possible causes, offering a wide range of theories regarding their personal aetiology. This included references to heredity (John) or work and hobby exposure to particulates and noxious gases (Laurel, Mae, Geordie, Clem). Camilla acknowledged the impact of smoking on her respiratory health but did not accept that the 100 cigarettes a day she smoked were to blame entirely.

...the weakness in the lungs started when I was a baby... [The doctor] said ‘you would have got emphysema eventually even if you never smoked, but it would have been very late onset’; but he said ‘all things being equal, the fact that you were a heavy smoker, you brought it on earlier’... Camilla

One of the only times rurality featured, in the discussion of the COPD experience, was in relation to work opportunities. This was noted by Clem, but the idea seemed to follow through with other participants whose work opportunities were limited to manufacturing (Ruth), farming (Geordie) and cleaning (Laurel, Mae). Many participants also noted the work safety conditions through their working years may have contributed to their exposure. Whilst most participants could see the effect of smoking and workplace exposure, Mae could not, blaming her work exposure to
cleaning products exclusively, which could speak to why she continued to smoke despite her diagnosis.

*I think I know where I got me emphysema, it was from working with Government cleaning and I used to go into the toilets and I’d splash around ammonia - wasn’t very good. Mae*

Mae’s description of causality may be interpreted to be minimising her contribution to, or responsibility for, her COPD (Hansen, Walters, & Wood Baker, 2007). Bailey, Montgomery, and McMillan Boyles (2009) however, suggest a less common interpretation of the nature of complex causal explanations, provided by people with COPD. Whilst acknowledging the role of smoking, many health professionals seem to negate the impact of other contributing factors, thus promoting the argument that COPD is a disease of ‘poor lifestyle choices’. A wider perspective of the argument would instead consider the implications of work in hazardous environments, living in industrial communities and the reality that the participants would have taken up smoking before health implications of smoking were known. This interpretation lies closer to the experiences described by the participants of this study, who identified lack of career opportunities (Clem), as well as poor understanding of the health impact of smoking at the time of uptake (Geordie, Camilla) amongst but not exclusively as the cause of their COPD. Camilla, who combined a history of poor respiratory health with smoking history, openly accepted responsibility for her COPD, despite providing a complex and life-spanning description of alternate potential causes. The follow-on effects of complex causality and smoking history played out in Clem’s story, who described being routinely dismissed by health professionals because of his smoking. Whilst intubated during an exacerbation, Clem
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was referred to publicly as a ‘bloody idiot’ by a junior physician, reflecting the stigma of smoking and COPD within some of the health community.

Summary

In perceiving themselves to be people who were not sick, the participants identified themselves as people who were subject to, and accepting of, the changes that were occurring in their bodies as a process of disablement. As their description and understanding of COPD would imply, however, their acceptance did not necessarily extend to the acceptance of the label of COPD, nor their complicity in its development. The internalisation of COPD-related change into their identity created a unique psychosocial reality, facilitating a sense of hope, and defiance, of COPD that guided the way they maintained their independence, thus reinforcing their capacity to accept further change.

Hope as a Manifestation of Identity and Acceptance

One outcome of accepting change, without necessarily accepting the label of or their role in their own COPD, was the sense of defiance the participants had in regards to their condition. It was clear from the stories that few participants denied the negative impacts of COPD on their life and lifestyle but many chose to not let COPD control their remaining years. Initially coded as ‘defying COPD’, these discussions cross-coded heavily with the ‘Denial’ node. What became clear was that this defiance was a marker not of denial through ignorance or avoidance but a denial grounded in hope - that they would fight on to live and another day. For Gail, this meant choosing to control symptoms rather than letting them control her, whilst Camilla took every day as a blessing. This hope included planning for the future (Camilla, Geordie, Valerie) and hope for a cure (Gail).
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You just can’t give up because medical science has... see how far it’s come with other diseases, one day, maybe in my life time, they’ll find something.

Who knows, but if you don’t live in hope, you may as well not live. Don’t you think? If you don’t have hope, you’ve got nothing. Gail

Gail’s sense of hope reflected more than just hope for a cure, however. She went on to discuss hope in the context of future decline. There was a sense of a peace from several participants that it wouldn’t always be as good as it is at the moment, even if, at the moment, it wasn’t as good as they’d prefer. For Valerie, this served as motivation to do what she could while she could, identifying her core priority as ‘getting out’. In leaving the house she overcame the urge to give in to her symptoms, as ‘if I don’t do these things now, then I will definitely not do anything else’. For Geordie, the desire was to set, and achieve, the kind of goals that would create a sense of hope personally, and within his family.

I made a deal with [my grandson], if I get to 75 he gets a motor car. I don’t know where I’ll get the money from, but that’s beside the point. But you know, I think you’ve got to have, you’ve got to have aims and things to keep you sort of occupied more than anything else. Geordie

When comparing the goals set by Valerie and Geordie, there is significant difference in the achievability and time frame of those goals. Where Valerie strived every day to achieve her goal of getting out of the house through careful planning, Geordie’s was set years into the future and was not necessarily financially possible. Whether the goal was set in the present or the future, both served as a motivating force; to do as much as they could to maintain quality of life and relationships, while they could.
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Acknowledging the current challenges in the ‘conceptual clarification’ of the construct, hope can differentiated into the goal-seeking phenomenon or as a wider psycho-spiritual construct defined by Lu and Cui (2016) as ‘an experience of a sense of purpose and meaning in life and a feeling filled with infinite possibility in life’ (p.2). In the limited literature discussion of psycho-spiritual hope in the context of COPD, Lowey, Norton, Quinn, and Quill (2013) found that hope, especially for the future, was grounded in past experiences of ‘bouncing back,’ and future aspirations to maintain their current level of health. This was expressed in the participants’ recounting of smoking cessation, their ability to overcome adversity was central to their beliefs that COPD was simply what was next.

Defiance breeds defiance

In exploring the mentality of defiance, throughout the participant’s stories, there were many parallels between their attitude to COPD and experience with defying poor health in the past, as seen in Valerie’s story. Another area where many participants had demonstrated and learned from the power of defiance, was in the area of smoking cessation. Without negating the impact smoking had on their health, the participants often felt a fondness towards it. They seemed to want to help me, a person who had always known that smoking was bad for one’s health, know how enjoyable smoking was, especially before its consequences were known. For some participants, there was an element of peer pressure in smoking that you were ‘weird’ if you didn’t do it (Gail) or that you smoked to fit in (Vida) but most commonly, people smoked because they loved to smoke, and because it was simply what they did. Camilla and Mae both described using smoking as a primary coping mechanism for stress, leading Camilla to be ‘mentally convinced that I wouldn’t be able to give it up.’ Excluding John and Ruth (non-smokers) and Mae (current smoker), each of
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the participants had waged war, at some time, against their smoking habit, and there was a definite sense of pride when they recalled their victory, especially when they surprised even themselves, as in Valerie’s story.

*I tell you what, I honestly didn’t think I would be able to [quit]; I didn’t think that I’d have the will power to do it. I honestly was so proud of myself for doing it (‘cold turkey’)… I am impressed myself for doing it that way, honestly I am. I really am.* Valerie

Many participants ended up quitting ‘cold turkey’ - a badge of honour, although Vida and Geordie battled with nicotine replacement therapy and other strategies, finding the process much more difficult and taking multiple attempts. The most common trigger for a successful quit attempt tended to revolve around declining health, either theirs or a loved one’s. This was particularly effective if partnered with an extended hospital admission, when six of the participants managed to quit completely. Interestingly, it was seldom that the admission was associated with COPD, as in Clem’s story where the five week hospital admission was due to a broken hip.

The participants spoke of many emotions that influenced their experience of COPD but only ever raised the emotion of pride twice; pride in their children, and pride in themselves for winning the battle against this addiction they enjoyed. It was through these kinds of experiences that participants knew that they were capable of fighting against an unrelenting force, and succeeded; COPD simply being the next thing on the list.

These past successes did assist in the facilitation of hope for the participants, although their outlook for the future was not necessarily based on those experiences.
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Valerie’s experiences of surviving multiple potentially life-threatening health events, as well as the emotionally traumatic death of her husband, had shaped her response to COPD, as the next thing to be overcome.

**The reality of hope and decline**

Olsman, Leget, Duggleby, and Willems (2015) found that both hope and hopelessness could co-exist in people with severe COPD and heart failure. Geordie’s story reflected this paradox; at the same time as he was able to set goals for the future with his family and talk about his hope for a cure, he acknowledged that he was too old for that cure to impact him. Comparatively, Lowey et al. argued that hope in the future was about maintaining a ‘status quo’ of health, as the idea of unbearable symptoms was, in itself unbearable (2013). For Vida, there was a very real articulation of her fear for the future and inevitable decline, expressed with a more ubiquitous sense of hopelessness than the likes of Geordie, Valerie or Gail. In looking to the future, many participants spoke with a great sense of hope but this was balanced with the reality that their health would not stay as it currently was, in contradiction to Lowey et al.’s findings. Instead, the participants metered hope and goal-setting driven by their experiences and innate optimism with their, albeit limited, understanding of what dying with COPD looked like.

Vida’s understanding of her declining health gave a sense of peace in was happening to her day by day. She commented that her future was outside her control and so not be over-thought. This was, perhaps incongruously, coupled with the dread of uncertainty for the future, associated with how much worse her COPD would get and how much longer she would be alive. As a result, Vida was the only participant to make reference to suicide, that she had contemplated it as a result of fear and
uncertainty, but could not give up living in the present and more importantly for her, could not reconcile her religious beliefs with that action.

_The future; um, well, I’d like to think I had one, but on the other hand, I think I don’t, because I don’t really want to go through years, years and years of this… I couldn’t go through the future just getting worse and worse, I don’t think, but then I suppose I’ll have to. You know, in other words, I have thought of suicide, but not, only lightly, this stage and really ruling it out because it’s a sin anyway, to take your own life, so you know, that’s that side of it, but I just hope God will be kind, probably, just letting each go, taking each day as it comes, like an alcoholic._ Vida

It was the participants’ ability to acknowledge the changes occurring in their bodies, and for most, continue on a path hopeful for the future that signalled their acceptance of their situation, without necessarily submitting to its negative attributes. For others, acceptance manifested as resignation to COPD but even for the likes of Clem and Vida, there was an appreciation of what was in the present despite a lack of sense of future.

**Summary**

Both hope for the future, and defiance of COPD, were integral to the participants’ experience of COPD. As body function changes were woven into the individual’s identity, so too were the memories of past battles and successes. These memories were powerful enough for a number of participants to live in hope for a reasonable future, set goals and have ambitions, whilst simultaneously understanding that the changes they were experiencing would continue, taking what was left of their functional capacity away from them. For some participants, however, acceptance
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came less through the hope-inevitable decline dichotomy, rather manifesting itself as resignation-based acceptance. Still, each of the participants, whether by hope or resignation, set themselves the challenge to maintain those aspects of their identity that reinforced hope, thus allowing them to continue to understand and accept the ongoing nature of change. At the heart this cycle of adaption was the need to be, and to be seen to be, independent.

The Choice to be Independent

Critical to the participant’s sense of self was their ability to maintain activities and tasks that played into their identity. As a result, the participants constructed their story in a way that demonstrated their worth, despite their health; that they were still participatory members of family life. Laurel’s sense of self and happiness was grounded in her role as family matriarch, cooking and providing for her family. Her story was evidence of her need to be needed and loved, fulfilled in her provision for her family. When asked, what allowed her to stay independent, it was not a description of her physical ability but the ability to be present and useful within her family.

[My daughter] has her own business and everything now, and that’s what we [moved to Bathurst], to help her out and that’s what I feel; that I’m not letting her down because I’m like this, that I’m not letting her down, I’m still doing things. Laurel

Independence for Laurel was not about physical ability but engaging emotionally in those core relationships. She achieved this by providing emotional and physical support to her daughter’s family in a way that allowed her daughter to continue her career. Independence however, looked very different for participants like Clem,
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whose family identity was based in serving his family, performing physical tasks for his family, as his gift to them. Clem described a typical day five years ago, as ‘I'd be down at one of the boy's places on the ride on mower or on a tractor’. The accumulative effect of Osteoporosis and side effects of prednisone meant that Clem was no longer able to bear weight, or more importantly for him, drive.

_I had to stop driving. If I stop at a set of lights I couldn't hold the clutch in with my left leg, and I'd start quivering and I was frightened that my foot would slip off. We could have solved that with an automatic but I didn't want to go that far because of the eyesight through the Prednisolone, made it not a safe thing to be doing anyway, but that's about the only thing._ Clem

In light of Laurel and Clem’s stories, where joy and purpose lay in such differing pursuits, Gail commented on the individualistic nature of independence as well as joy and purpose. She didn’t mind if someone chose to stay home, but that was not for her, and neither option precluded the other from having quality of life.

_I think your quality of life is what you make it to be yourself, to be honest, if you’re happy just to sit around and that’s it for the rest of your life, you know that’s your choice. But I choose not to do that, I do everything in my power to do something every day, but sometime it gets the better of me and I can’t do it._ Gail

Gail’s ‘choice’ to engage with activities that required effort was a small example of how independence was influenced by declining functional capacity. The participants’ capacity to undertake self-care (e.g. showering, toileting), valued activities (those that contributed to their sense of self), and home-care/community mobility (e.g. cleaning, shopping) were compromised. Loss of many of these activities became a
source of deep emotions; frustration, depression and grief. These emotions weighing heavily for Gail, knowing that her condition was life-limiting.

_I still get down sometimes, but you know, and I think it's only natural._

_Because you know that this is a life limiting disease and it's also an activity limiting disease and that's hard._ Gail

To maintain a balance between independence and energy conservation, a hierarchy of priorities emerged throughout each story, which mirrored the participant’s desire to retain a level of physical independence. There were certain tasks however that seemed more important to each participant, reflecting their interests, their relationships with family in particular, and things that brought joy to their lives. There was also a tendency for these valued activities to revolve around family and allow participants to maintain their role within the family dynamic, despite not being able to achieve all the physical tasks they would have before the onset of COPD.

_As long as I am still needed, and I think I am, as far as the children are concerned, I'm still needed, you know. As long as [my daughter] doesn’t get a cooking course, I’ll be right._ Laurel

Valued activities and home-care/community mobility shared a commonality in that they were often activities associated with high energy expenditure that could cause considerable fatigue to the individual. The difference between the two lay in the participants’ willingness to fatigue themselves to participate in a valued activity, at the expense of home-care/community mobility. Ruth noted that she was no longer able to leave the home to shop for groceries but was willing to leave the home to eat out with her husband. Whilst eating out was an exhausting process, both she and her
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husband were willing to exert themselves to achieve it, leaving the shopping to her husband, at another time.

Well I, when I used to go do the shopping and things like that... now we try and make every Wednesday a lunch day and ah, I can go on that (scooter) to [a restaurant] and I can go in on that had put it up along the table and you know, eat and that, saves me walking and that. Ruth

There seemed to be a hierarchy of priorities for task performance. Home-care/community mobility tasks easily able to be performed by others or where assistive technology was available, were seen as the least important (shopping, cleaning, walking) and thus deprioritised most readily. By preserving energy this way, more energy was given to valued-activities, although with time, the number, frequency and magnitude of those tasks also reduced. What was saved for the last to be given away, thus given the highest priorities, were the most intimate of self-care tasks, particularly showering and toileting.

I came out of hospital and I couldn’t do anything, I couldn’t even wash myself, I couldn’t shower, I couldn’t move. It was most degrading to have somebody come [shower me]. Laurel

It is important to note that it was the participant who decided what was considered ‘home-care’ and what was a ‘valued activity’, particularly in the case of cooking; while Laurel prized cooking as the most important aspect of their identity, Geordie was entirely happy to live off frozen dinners and ice-cream.

In exploring ideas and narratives regarding independence in COPD, Falter et al. (2003) associated the perception of independence with the degree of disablement, but
more importantly, with adaption, stating that compensatory and optimisation-based adaptive strategy used to facilitate independence did so, in part, by building confidence. The critical link between interventions that facilitated independence lay in the nature of the task being achieved, in particular, personal care and community mobility. The prioritisation of self-care tasks within the participants’ stories was very strong. Discussions regarding showering elicited some of the strongest emotional response, with Camilla describing showering as ‘a question of absolute determination’ and eight other participants reflecting on the negative emotional and relational consequences of not being able to shower alone.

**Chapter Summary**

Each participant, in turn, shared stories that helped me understand who they were before, and because of COPD. It was through a greater understanding of their motivations and who they saw themselves to be, that I could come to understand how they had adapted to functional decline over time. The participants saw themselves actively within their life-world, despite a diminishing social network. Their complexity was grounded in culture, spirituality, community and family. Within these social constructs, however, there was still an individual with a desire for independence, in the face of heightening dependence, who used personal resources, lived experiences of change, and their hope in things greater than themselves, to create a sense of perspective, in their lives, and regarding their current situation.

In setting priorities to facilitate independence, the participants continued to experience successes that played back into a cycle of acceptance; success triggered increased confidence, confidence which allowed further goal setting and
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achievement which led to more success. In this way, participants were able to accept changes, including functional decline, continually modifying aspects of their identity. The pragmatic responses to these changes are discussed in the following Chapter, ‘Mind over Matter’.
Chapter 6

Mind over Matter

When participants spoke of their identity in relation to COPD, they spoke of internalisation and acceptance that came with ongoing decline in capacity over time. Accepting their situation, as part of who they were, facilitated a range of pragmatic and intrinsic responses to change (Table 6.1). These adaptions became more conscious and deliberate over time, signalling an increasingly cognisant ‘mind over matter’ approach to living with COPD. The ability to self-regulate through change was as critical, if not more so in establishing the balance of mind over matter, as it was to manage the ‘body’. The way extrinsically mediated medical interventions were communicated to the individual had significant effect on the uptake and perceived efficacy of the therapy. Effective symptom management, combined with their intrinsic responses to change, was seen in the way participants spoke with a sense of future, hope and defiance; that the mind was in control of the body.

This relationship between body, mind and spirit became more pronounced in times of stress, when those self-honed regulatory skills were insufficient to combat overwhelming physical and psychological symptoms. This triggered feelings of frustration, fear and a loss of control or sense of future. Despite, or possibly to spite these dark times, the participants continued to wage an internal war on their symptoms, to regain the upper hand over their body.
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Table 6.1 ‘Mind over Matter’ Themes and Sub-Themes

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**Self-regulation as a primary coping mechanism**

When exploring the implications change had on their performance of priority tasks, valued activities and home-care/community mobility, the ‘slow and steady’ narrative was woven through the participants’ stories, demonstrating their capacity to modify high-priority tasks they wished to retain. There was some evidence of these tasks being replaced rather than modified. Interestingly, this emerged primarily with the men, who seemed to be able to substitute some valued activities such as sex (John),
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driving (Clem), sport attendance (Geordie, Evan, Valerie) and smoking (Geordie) to a degree that made them comfortable; not the same, but enough.

I used to love football. I’d travel miles to go to a football match, but now it’s on TV I can see the same game, I can sit in comfort; I don’t have to worry.

Geordie

By replacing the task, energy was conserved and anxiety allayed, as Geordie noted. More commonly however, a task was modified through self-regulation of pace, specifically pace reduction. In doing this, participants not only facilitated task completion but allowed themselves to be in the moment of task performance - to enjoy the task itself, or to enjoy not having another person involved.

Conscious Choices to Prevent Physical and Emotional Distress

There were quite specific ways in which participants regulated the pace of life. This included planning activities in more depth, lowering expectations of what could be achieved, taking breaks and establishing routine. Invariably, these strategies were initiated as insidiously as COPD itself. As Vida alluded to, this process was subconscious adaption to increasing limitation.

...it was probably maybe 10 years ago that I started to notice that I got, I got a bit breathless by the time I’d finished the shopping, and very tired, you know I had to have a sleep when I got home from shopping and things like that… did something to make it get easier, you know, unconsciously do things like, ah, if I found I got too breathless to walk down to the shops one way, I went another way, or I stopped and looked in a window, you know, things
As Vida indicated, participants became more considered in their approach to self-regulation over time and with increasing symptoms. They did this by making plans about how they would achieve tasks days before the actual event, including breaks whilst performing tasks, either pausing mid-task or taking a more substantial break, as they broke the task into chunks (Geordie). In Geordie’s description of vacuuming, he had learned to take half hour breaks between ‘little bits’ as he didn’t have the energy to do more. Whilst the whole process would take longer, he recognised that it didn’t matter how long it took in the end, as much as that it was done independently.

*I’m learning more each day, do you get what I mean? Like you learn to when you’re doing things do a little bit, stop, do a little bit, stop- don’t rush in and say ‘oomph, ooh beauty, you know’. Geordie

Whilst frustrating, the process was indicative of a larger response to change, in which taking breaks was considered a normal and sustainable way of maintaining independence. Laurel described the process she undertook to prepare a large meal for her family, taking many days to get it together. By preparing aspects of the meal ahead of time, she was able to better enjoy the company of her family, at the time of the meal without undue fatigue or breathlessness. Similarly, Valerie commented that she had lost a lot of spontaneity in her travel, as she had to make provision for oxygen cylinders.

*Now you kind of have to organise yourself, so you, you are organising things two or three days in advance... I’ve got to make sure I’ve got two bottles of oxygen to take and you know... Valerie
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Both tasks, cooking and travelling, were deemed some of the most important in the respective participant’s lives, providing joy and social connection. While there was more planning, and days of work to prepare, the activity was deemed worth the effort. Both Laurel and Valerie accepted the compromises they had to make to continue in their valued activities. Geordie expanded on this acceptance, discussing the longer term consequences on his well-being from lowering his expectation of what could be achieved in the day. By resetting goals, there seemed to be a reduction in his overall levels of frustration. Importantly, Geordie wasn’t removing his goals completely, or handing over all responsibility to another but was simply being more gracious in accepting how much could be done in a day. The result for Geordie, was a drop in the number of ‘bad days’ he experienced in the preceding year, as he chose to slow his pace of life down, which he acknowledged prevented frustrations and getting ‘flustered’ so often. Whilst this strategy worked well for Geordie, Evan and his wife were still coming to grips with how lowered expectations would affect their daily life. Instead of decreasing frustration, it served, instead, to cause greater tension between the couple.

*Say I do 10 jobs around the house during the day, okay? And my wife comes home and picks the one I didn’t do, right? Forget the other ten, right, she walks in and has a look around; might notice the other 10, doesn’t say anything about them, and picks ‘I thought you would have put that basket of clothes away today, or folded them’, or something, like, yeah, well, I didn’t have time. ‘Why? What did you do all day?’ And I just get, I just don’t bother.* Evan
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In reflecting on the difference between Evan and Geordie’s response to achieving less in the day, there are a myriad of reasons why their responses were so disparate, including but not limited to, differences in duration of illness and adaption, and the impact of reduced activity on a spouse. One cannot negate Evan’s relatively short duration of illness, coupled with the changing roles associated with his wife being the family breadwinner, in the way he and his family have experienced these changes, and the emotional response change elicited.

To remedy or mitigate the physical and emotional impact of change, a number of participants reported using ‘safety net’ strategies to optimise their ability to maintain activities that played into their sense of identity. These interventions and requests for help were used to alleviate the risk of isolation and anxiety, and were generally associated with single participants. Geordie described going to the club several times a week.

*You tend to want to be with somebody when you go out because, it’s not a fright, how would I, it’s not fear, it’s ah… it’s like a, like a dummy to a baby, you just need to have somebody there that if you feel crook or something you can say, look can we go now, or get a cab and well go home.* Geordie

There was a tendency to see medication and oxygen in this way, as Valerie described.

*The oxygen in a bottle, which I take with me, is more a security blanket, I feel.* Valerie

Past negative experiences of being ‘caught out’ with symptoms, as well as fear of embarrassment or not being able to cope in a public setting, all played into the development of safety strategies. As a result, some strategies, such as not going out
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alone (Geordie), using social support systems (Mae) or using oxygen prophylactically before going out (Valerie) allowed the participants to maintain tasks. Camilla however, had given up driving and social commitments rather than pursuing adaptive safety behaviours. These strategies, as with pace reduction and taking breaks, were largely implemented using trial and error, and so become self-regulatory mechanisms of coping.

**Self-Imposed Restrictions**

In addition to pace and expectation reduction, participants set about other ways of taking and maintaining control of their daily life. This played out, functionally, as the implementation of fixed routines and self-imposed lifestyle restrictions. As the participants responded to changes in their body functionality and situation, routine featured as a strategy of self-care to maintaining daily activities, which reflected the new, reduced pace of the day. Routines were used primarily to control the morning, when the bulk of self-care tasks were competed. Clem added that routine was not only used to manage symptoms but also to stay out of the way while other household tasks were being completed.

*I don't get up first thing - I mean I could be awake, I woke this morning at 5 o'clock, but I don't get up... I stay in bed, have breakfast in bed, I stay there, so I don't get in the road... From actually swinging out of bed to being dressed and cleaned up and here having a cup of coffee, it might take an hour, it might take a bit more. Because I only do it in short stints because I run out of puff. Clem*

By creating a known routine throughout the morning, Clem perceived that he was helping his wife, by not adding to her workload at the busiest time of her day, as well
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as being able to perform self-care independently, at his own pace. Participants had learned over time that if they did not implement strategies, like pace reduction, there was a sense of retribution; payback for doing too much in the day. Gail commented that the people around her knew this and acted to protect her from the exhaustion, while Vida commented that there was an inevitable rest day after a day of activity. Valerie’s experience was slightly different in the way she did not experience this ‘payback’ for physical exertion but rather for risk taking, such as going out at night or during winter.

*When winter comes, on Thursday night, I will not go out. I will not do that in the winter time, because it’s just too cold and you can’t take the risk of getting pneumonia...* Valerie

Participants spoke about prophylactic measures they took to avoid illness and exacerbations. Valerie and Mae both avoided poor weather conditions, as they saw them as an exacerbation trigger. This meant, for both women, missing out on much loved outings they associated with their quality of life, such as bingo (Valerie) and road trips (Mae). As a way of reducing risk of illness or exacerbation, participants created restrictions regarding when they could leave the house or engage with others, particularly during the night-time, winter and in poor weather. These restrictions were almost unanimously enforced by all participants. When questioned, John was at the point that night time was considered 'bad weather’, so ubiquitous had they become, in his mind.

*Do you go out in bad weather?*

*No, I don’t go out at night.* John
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Limitations imposed by the weather were quite varied, from preventing deterioration in health (Clem, Geordie), to difficulty getting around (Ruth). These limitations had very real consequences on the social lives of the participants, as Gail commented, but were imposed none the less with the goal of maintaining health and preventing exacerbations. Likewise, John and Mae both tried to avoid hospital, seeing the admission, rather than being just an exacerbation, as a life threatening experience. Mae described getting ‘panicky’ at the idea of being hospitalised, as in previous admissions she had been encouraged to be ventilated, which she perceived as ‘you normally don’t come out of it’. Of course, when winter passed and the weather calmed, there was a noticeable lifting of the spirit; spring seems not only to bring warmth, but freedom, which Mae described as a defining aspect of her quality of life.

I have got good quality of life when summer and spring come. The winter is not; stay out of the cold, and don’t get the flu! Mae

In addition to self-imposed boundaries, most participants actively tried to maintain a healthy diet, although all but Gail actively avoided any form of intentional exercise or pulmonary rehabilitation. Valerie and Geordie both recalled experiences of attending pulmonary rehabilitation, which led Geordie into an argument with the physiotherapist and refusal to complete the program, while Valerie commented ‘honestly, I don’t see any point in it, to be honest, I don’t see that I’d get any benefit out of it.’ Despite a wealth of literature that demonstrates positive impact of pulmonary rehabilitation for people with severe COPD on measures of physical functioning (Guell et al., 2006; Janssen et al., 2016), psychosocial indicators, care dependency (Janssen et al., 2016), functional independence and quality of life (Vagheggi, 2016), Valerie chose instead to continue engaging in valued
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activities such as visiting the club and seeing her family, seeing them as her own form of rehabilitation.

Summary

Self-regulation of pace, routine, and activities sat at the heart of how the participants adapted and accepted change. Beginning with sub-conscious changes to their activities, each participant became more cognisant of how they managed activities in and over time. In striving to control core aspects of their life and care, each participant asserted their will, as an individual, as to how they wanted to live. Whilst lowering goals and expectations is seen in ageing literature, to reduce help-seeking and health outcomes (Sarkisian, Prohaska, Wong, Hirsch, & Mangione, 2005), here the participants were able to maintain a sense of control over their daily lives and how they engaged with others. By establishing routine, reasonable goals, and being gracious with themselves as to what they were capable of, the participants began to establish a mind-body balance approach to coping with change. In working towards controlling the controllable, the participants’ stories focused first on the psychosocial strategies and responses they had in place, before engaging in a dialogue about the practical and interventional strategies they used, such as oxygen and medication. Even then, taking control of their body and its symptoms was not seen as a goal in and of itself, instead a means to continue doing what they loved.

Controlling Symptoms as a Secondary Coping Mechanism

Critical to the success of regulatory and pragmatic responses to change was the ability to reduce symptoms and their impacts. To achieve this, participants used the kinds of medical interventions that are most commonly associated with COPD management: oxygen therapy, medication and mobility assistance technology. What
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became salient throughout the narratives was not so much the impact of those interventions but the way in which interventions, and resultant change, was communicated and implemented by health professionals.

**Interventions as Change, Not Comfort**

Nine of the eleven participants regularly used long-term oxygen therapy to manage their COPD symptoms. For most participants, there was a clear impact on their experiences of breathlessness and exacerbations. Clem used his oxygen intermittently, expressing some confusion about when he should be using it. Despite intermittent use, he remarked that it made ‘a hell of a difference when I do something’.

In considering the positive impact of oxygen therapy, the practicalities of being on oxygen appeared to impinge heavily on its perceived benefits. Whilst required to perform an activity, its physical presence, limited functionality. Common limitations revolved around loss of access, with participants identifying difficulty with portability (Clem, Camilla), or the fear associated with running out (Gail) as some of the most common problems. Camilla described the frustration and disappointment that came from investing in a portable system that failed to meet her need. Geordie also noted that his social life was limited to the length of time the bottle lasted, which was always an unknown quantity.

*Well, you realise that, that sort of ah, you couldn’t do the things that you liked to be able to do, you know, ah; be like now, I couldn’t go out with the boys now, because those machines only last about 6 hours, well, you’re sort of restricted in that 6 hour period, ah, that’s a bit of a bug bear really...*

Geordie
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Vida’s experience of her diagnosis seemed to affect her use of oxygen, which was prescribed at the likely time of diagnosis and caused significant distress. It is not unreasonable to assume that the stress of being put on oxygen was enough for her to miss the fact that she was diagnosed at all. Despite over a decade of symptoms, six years under specialist care, and two years with the RCCP, she stated she was ‘only told a couple of weeks ago’ that she had COPD.

*I went to [a respiratory specialist] and oh, he put on a terrible turn... he started getting oxygen machines and all sorts of things, because evidently I was running on 67, but as far as I was concerned, I was normal (okay), yeah, so really I don’t, I can go with fairly low blood oxygen, but anyway, then I... after he, him, and he made me go on oxygen full time, I’ve never been off it since, you know. So before that I was doing normal things and I really think he frightened me into, you know, believing I couldn’t breathe initially, but now of course, I can’t.* Vida

Within her home, Vida used oxygen continuously but using oxygen to leave the house was a different matter. It was her husband who put this strategy in place, to manage her breathlessness and anxiety.

*I get anxious but [my husband] had sort of adopted a bit of a different attitude I think, like he brings... the portable oxygen machine, he brings it out and says put that on and says ‘I’ll go and get the car out’, and you know, that’s the attitude he’s been adopting and by the time I do that, I seem to be alright.* Vida

Whilst Vida didn’t comment directly on the cause that underpinned her anxiety, Laurel stated it was the activity associated with preparing to leave the house that...
triggered breathlessness and anxiety. Geordie and Valerie reported initially struggling with being seen on oxygen in public. In balancing oxygen dependence with system limitations, each of the participants had developed ad-hoc strategies to achieve their primary goals. Valerie’s story revolved heavily around the goal of getting out of the house. Over time and because of her supportive community, Valerie was able to overcome some of the emotional and physical barriers associated with oxygen use in public, to maintain her independence. This included staff at her club storing her cylinder overnight if she planned on returning the next day and offering assistance regularly and politely.

Implementing oxygen therapy was designed to assist in the control of symptoms but it was the beginning of a different kind of juggle that was to maximise the impact of the therapy and minimise its functional limitations. In a similar way, participants also had to balance medication regimen, dependence and side effects. Despite the complexity of medication regimes, participants tended to adhere to their medications for two reasons - either they worked, or they submitted to the regime and did ‘what they were told’ (Evan). If the medication was effective, in the short term, it was praised and used often, longer term medications, or medications with side effects, were met with more disapproval. John’s spoke about his dependence on nebulised bronchodilator and prednisone as the backbone of his day, and whilst relieving his physical symptoms, there also seems to be a psychological comfort or relief in controlling his medication. Routinely, participants had access to oral corticosteroids and antibiotics in the home, allowing them to self-medicate to prevent or reduce the severity of exacerbations. This strategy had been effective for Mae, who had stayed out of hospital for nearly three years ‘because I have, I have a plan, at home, I have antibiotics and I know if I get sick, I’ve got to take my antibiotics and my
Medication regimes and oxygen therapy were generally externally driven, facilitated by health professionals. These compensatory interventions sat closely aligned to the standard medical interventions prescribed for people with Stage IV COPD of all ages (Yang et al., 2016). The way they were implemented by participants, often without questioning efficacy and despite frustration, would suggest that the implementation of these interventions was extrinsically motivated and used to quite passively control the body.

*I’ve done what I can with Bernadette and with the breathing team down here, the COPD team down here just doing whatever I can that the experts like Bernadette say will be good for me.* Evan

For the participants, however, accepting ‘what’ll be good for me’, was more than just blithely doing what they were told. There was a relationship between how willing the individual was to accept an intervention and the manner in which that intervention was introduced. Judgements of interventional efficacy were often swayed by how the change in treatment was communicated. This is in line with the findings of Polinski et al. (2014) and Svavarsdóttir, Sigurdardóttir, and Steinsbekk (2015) who identified the capacity to build a trusting provider-patient relationship was key to medication adherence and the perception of a ‘good educator’, respectively. Polinski et al. (2014) also reported full disclosure of adverse effects and ‘cost sensitivity’, by the health professional, influenced adherence. More importantly, was the perception of shared decision making in the uptake of medication, which was also reflected in Ruth’s story, detailed in the following section.
Communicating Change is More Important than the Change Itself

More important to the participant's stories than the pragmatic nature of health intervention, was the way that intervention was introduced to them. Relatively isolated from Specialist care, the RCCP CNC and GP sat at the heart of care delivery for the participants. It was here that the effect of rurality and access to services was raised by the participants. Issues that were noted included the high turn-over of staff, particularly GPs, and the travel required to see a visiting Respiratory Specialist in a town 45 minutes from their place of residence. With increased responsibility placed on local GPs, Clem’s story reflected the volume of staff turn-over but more importantly that he appreciated how thorough and invested any GP was, about his care. This excerpt demonstrated how Clem prioritised being cared for at a holistic and relational level before a disease-specific level.

The last two, the fellow that I've got now is really good. And the lady prior to that - she’d check out a flaming blind pimple on your bum, she never missed anything. It was an hour and half, she would write off, or well over and hour, she’d write off her books if I had an appointment and I actually heard her say it to the staff, but she’s gone now. And this new bloke, he's really good. And the fellow at the hospital, he's passionate about breathing disorders. Clem

Gail stated openly that moving from a metropolitan to a regional centre was the best thing she could have done for herself and her health, because of the ‘community and the medical care I get here’. The positivity of the participants towards their care provision was a source of hope for each of them. Whilst each had their own anecdotes of sub-optimal care, a common thread through the stories was the impact of the home visits provided to them by the RCCP and how they had been
empowered, in that care relationship, to embrace new interventions and maintain control of their condition. Camilla and Vida’s stories demonstrated how the participants experienced change communication, and how that communication strategy influenced their willingness to respond to externally facilitated change, such as altering medication regimes.

As a part of the RCCP, the participants were supported in their homes by a specialist Respiratory Nurse, Bernadette. What became powerful, in the retelling of the participants encounters with Bernadette, was the trust they placed in her, stemming from relationship building over time. Bernadette was described by Gail as ‘the rock’ and without her, ‘I wouldn’t be alive’. More often, when discussing the positive impact of care in the home, it was not just the specific knowledge that Bernadette brought, but her continuity of care and the time taken with each individual and family. Participants looked forward, not just to her care but her company, supporting the idea that it is in and through relationship that quality of life and quality of care are achieved.

*I look forward to seeing her, she’s a lovely girl and she’s very helpful. She’s very proactive, rather than retroactive. She’s very generous with her time (cough) she probably does more to help me than all the doctors.* Camilla

The proactivity and advocacy, mentioned in Camilla’s story, was also important to Ruth. Bernadette advocated for her clients in two specific ways; creating a timely dialogue between the participant and GP at times of crisis, and providing therapeutic advice to modify existing treatments to assist participants to achieve goals and manage symptoms. As Ruth told the story of how her pulmonary and systemic
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oedema limited her ability to perform tasks, a simple medication change had
significant impact on Ruth’s quality of life.

For a long, long time I just had swollen feet and I just couldn’t; even though
I was taking Lasix... but it didn’t stop the swelling... Last year, Bernadette
said to me, why don’t you get onto Spiractin, and she said they do the same
job but it’s a different sort of tablet. And you know, my legs are so thin! ...I
just sort of stayed at home before that and I was dependent on [my husband]
a lot more because he sort of does all the cooking and that now, and ah, but I
mean, I am starting to get back into doing a little bit myself... Just by feeling
a little bit better with no fluid. Ruth

Interactions such as these showed that it was the combination of Bernadette’s
relationship building, and disease-specific knowledge that impacted the experience
of the participant. In discussing this event with Ruth later in the interview, she
commented that she appreciated being provided options and then the freedom to
make her own choices.

I’d rather decide but the suggestions that they make probably would be what
I want, you know, because you don’t know sort of some things you don’t
know what it’s about. They’ve going to sort of say something, and then you
know that’s it... Like, you’ve said a lot to me today which I normally
wouldn’t think about, but you make yourself think about it and that, so, yeah.
Ruth

The ability for Ruth to understand her choices, before making a decision, went on to
shape the way she saw the outcomes of that process. Part of the reason participants
appreciated Bernadette’s approach to their care, revolved around past experiences of
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Sub-optimal care. In times of crisis, Camilla spoke of how her General Practitioner made her to feel ‘written off’ and isolated, both due to the nature of her condition and her age. The way information was given to her in the past, left her quite upset and disheartened about her condition, assuming the worst of each subsequent physician.

But your general practitioner’s view anybody over the age of 50, I think, with ‘well what do you expect at your age?’ And they don’t really want to waste their time on people like me. I’m an embarrassment to them. There’s no way they can write out a script and make me better, so anything that goes wrong with me is to be expected and you don’t need to ask for help with it because you ain’t going to get any. Camilla

Vida and Clem reported similar incidents of being dismissed, regarding the insensitive delivery of critical information, which left Clem quite disheartened and hopeless, and Vida fearful of the treatment she required. In one specific incident, Clem’s wife asked to have a junior physician removed from Clem’s care after Clem was referred to as a ‘bloody idiot’ in front of his family for smoking, whilst unconscious and mechanically ventilated during a life-threatening exacerbation. How this undermined Clem’s wife’s trust, in the care provided to Clem at Hospital, became evident in the way she engaged with doctors for the rest of Clem’s life, making sure she was ‘dripping in jewellery’ at subsequent medical appointments, in an attempt to mitigate pre-judgement.

Camilla was quite realistic about understanding her health and how she had participated in its decline. Despite this, she had a very simple request of her health
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care providers that reflected her positivity towards life and the common request to be respected.

To me a little sugar coating might be a better option. I mean, yes, that’s probably quite true [I’m] not going to get any better, but she should perhaps put it a different way, if you know what I mean. Camilla

The way change and intervention was communicated to the participants was a significant determinant in how readily news and advice was taken up. Camilla, Clem’s wife and Vida all spoke about the lack of empathy and respect shown to them in specific instances, and how it left them feeling stigmatised or helpless.

Where Vida saw the initiation of oxygen therapy as the point of her demise, Ruth’s experience of changing medications was seen as a positive turning point, especially when countered with her mother's experience of COPD.

[Mum] didn’t have anything else, she had puffers; that’s all she had, you know, and I’ve got puffers and that at the moment, I used to have it every day, I had to have the nebuliser. But since this, the fluid’s gone down, I’ve gone without that. Ruth

While the process of adjusting therapies could been seen as months spent on the wrong medication and with frustration, instead Ruth saw it as a source of hope, allowing her to regain lost activities and reduce the care load she had placed on her husband. Ruth's story typifies the connection between mindset (the mind), symptom control (the body) and psychological and emotional responses to change (the spirit).

In adapting to COPD, Ruth, more than any other participant, was able to articulate the power of the ‘mind over matter’ in coping with a large number of health concerns. Moreover, her story reflected the potential for health professionals to challenge the
established equilibrium and bring about positive change through using their position of trust to create an environment of open communication and hope.

*Being open to (novel) adaption – Camilla & Mae*

Social Media was used widely amongst the female participants, which increased their sense of connectedness with family and friends. They were happy to use the social media platform quite voyeuristically, and enjoyed seeing photos of grandchildren, in particular. As a highly social person, Camilla no longer engaged with the outside world, she had cut her ties with community groups and activities on the basis of her COPD; from what could be heard, immediate family and care staff are the only people that come through her door any more. In lieu of a physical social life, she had instead created an online social/virtual world, to connect her with her family and friends on her terms.

*I keep in touch with people; I use Facebook and Twitter, all these various things. I’m a bit dicey about all this twitter business. I only just joined that the other day. I think it might be a mistake, it looks to me like its scandalous and I’m not interested in all those things...* Camilla

The pride that beamed from her as she spoke about her achievements and family was very nearly visible and linked directly to the use of technology to keep track and learn more. Social media had become integral in sustaining a social lifeworld for Camilla, Gail, Vida and Mae, in particular, but it was Camilla’s use that triggered the ‘red flag’ and indicated the negative impact of not having to leave the house. Reading between the lines of her interview, it was clear that the outside world was to remember the Camilla of days gone by, not to see the tubing, the breathlessness and the fatigue. Unsurprisingly, amongst all the uploaded photos, there is not one of her.
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Camilla provided a number of reasons as to why she had resigned from her public commitments but it was her desire to not be seen as unwell that underpinned these decisions. That she could maintain a presence in the lives of her children and grandchildren was of great meaning to her, but critical to her sense of identity was that the presence she maintained was one that sheltered them from the realities of her health.

As Camilla walked a fine line between adaption and denial, so Mae lived with a fine balance of mental health preservation at the expense of her physical health. The coping strategies Mae believed to be most effective would not necessarily be considered traditional, effective or in some cases, safe. Mae was recruited into the study once theoretical saturation had been reached but noticeable gaps still existed within the participant group, particularly someone still actively smoking despite their diagnosis. Mae was chosen as the participant’s pseudonym not only for its primary meaning ‘of the garden’, but for its secondary meaning ‘rebellious’, reflecting her decision to continue to smoke.

*I still smoke and I smoked from the time I was about 14... maybe about 20 a day, I tell the doctors 2, 3 a day.* Mae

In coding this portion of her story, there was a genuine conflict; is using smoking as a therapeutic intervention ‘coping’? This idea lay at the heart of COPD life for the participants; that you have to use whatever works, for as long as it works and because, in many cases, there is not enough time for more ‘traditional’ interventions to be put in place and become effective. As such, Mae used smoking to cope with her home situation, where she lived with an invalid husband.
I think I smoke because I get frustrated, get angry; get angry with [my husband] because we don’t get enough sleep around here. He’s up at; sometimes he’s up at 2.30 in the morning [and] up for the day, and then he’ll cat-nap in the chair... when I was away from them, I wasn’t smoking, I didn’t crave for it... I was living at my daughter’s place at [a nearby village], lived there for nearly two and a half months, yeah, ah, went cold turkey from the time I left... I think it’s just the habit, and when I used to get frustrated, I used to have a smoke.

...

Do you find that people sometimes are a bit judgemental because you still smoke?

Oh yeah, yeah... I feel like saying ‘fuck you, I can’t give it up’ (laughs hard). That’s it, the panic, that’s when the panic sets in (yeah?), thought of giving it up. That is when panic sets in. I gave it up for three months because I was that sick that I knew I had to, then I come home, must be, I didn’t smoke for a couple of days and then it was everything combined, I had, I just had to have one, but the panic of giving up smoking is worse. That’s sends you into (laughs), down the road.

What’s panic-inducing about it?

Probably not, not having me calm-er, yeah, not having that thing that makes me feel calm. I mean, I can go out and go for two hours, three hours, and not have a smoke, but then I’ve got to have one as soon as I get home... It’s panic mode, yeah. If someone said to me, you can’t have a cigarette now, I
would go into panic, grab me bag, grab me car keys, and take off to get a cigarette. Mae

This discussion made it clear that given the right circumstance, Mae could quit, and use other coping strategies but at what cost; the neglect of her husband, the loss of her role as the matriarch of the family? This is another example where a participant chooses quality over quantity, that she would rather live in her own home with her own trouble for less time than impart those troubles prematurely onto the rest of her family.

Both Mae and Camilla’s coping strategies, and more importantly the impetus behind them, serve as a reminder to health professionals that no one strategy can be assumed to be without fault, and no questionable strategy is automatically without merit. As communication serves as a pivotal determinant in the implementation of externally mediated interventions, it is important that communication be bi-directional. Without understanding the underlying process of cognition that drives decision making, both adding new interventions and trying to remove counter-productive coping strategies can only be perceived as more change for nothing more than the sake of change.

Summary

Functional decline associated with increased breathlessness and fatigue dominated the physical experience of COPD. To this end, a range of medications and oxygen therapy were used to control symptoms and prevent deterioration. These interventions became a way to control the body, although their perceived efficacy was discussed less in relation to symptom reduction, and instead, in light of the amount of effort required to maintain the treatment regime. Whilst medication and oxygen therapy were generally effective in alleviating symptoms, it was how change,
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i.e. initiation and modification of treatment regime, was communicated to the participants and facilitated, that appeared to be as important to the uptake and perceived efficacy of the intervention, as the therapy itself. The relationship established between the participants and their health care team had the capacity to do much more than simply manage symptoms but also the capacity to build or extinguish hope.

The connection of mind, body and spirit: “Enjoy the sunshine and tolerate the clouds”

In the theme ‘Accepting Change’, the participants discussed their sense of self and independence, in relation to their place in the world, their family and COPD. These aspects of their identity led to most accepting the changes that were occurring in their bodies. When the participants told their stories, they spoke with defiance and hope; they spoke of the future, as Camilla described.

*Quality of life to me, means that you want to get up every day and that you enjoy the sunshine and tolerate the clouds. But it means I’ve got [my husband] and his companionship, as long as I have that, I’m a very happy lady. I have a very good family, all achievers. I derive an enormous amount of pleasure from what my children and grandchildren and great-grandchildren do and achieve... quality of life is how you approach things each day. Do you enjoy living? Do you look forward to something? Yes I do...* Camilla

Camilla's description of quality of life highlights her determination to see herself as something more than her symptoms, and focus on the positive. There is a balance between her mind's will and the limitations of her body. It is important to Camilla's
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story to note that while she did not deny the physical impact of the condition, she also did not give into it. Her entire life story was one over overcoming and resilience. There were instances, however, when the mind over matter balance participants worked so hard to establish, did not hold. When recalling experiences of acute exacerbations and panic attacks, times when the body took over the mind, the tone of their dialogue changed dramatically, as the participants resigned themselves to whatever would come. In these times, the air of hope and defiance, so intrinsic to their identity of themselves as an individual, was lost. For some participants, that loss was momentary but for others, as previously discussed, that hope was less recoverable and so was replaced with resignation.

When the ‘Body’ Overtakes the Mind

When discussing acute exacerbations, participants tended to use language such as ‘pneumonia’, ‘being in hospital’ and being ‘sick’. These exacerbations sat as clear punctuations, or time markers, in their stories, as they were often able to recall how long it had been since their last hospitalisation or to measure time according to admissions. In describing these events, however, there was a sense of vagueness as though they were not fully cognisant during the period of acute illness. Laurel described the vagueness of her initial exacerbation as just seeing ‘faces around me and watching me and looking at me’, not fully comprehending why it was that the hospital ‘was in no rush to send me home’.

Exacerbations served as a primary source of fear in the lives of the participants, as it was during these times that they experience the most acute and frequent breathlessness, medical intervention and awareness, that it would likely be an
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exacerbation that ended their life. Where previously participants spoke with
defiance, Clem was open about his resignation of the inevitable.

This is the way it’s going to be. I can’t see into the future, but it doesn’t look
bright... I suppose, but the bottom line is, that it won’t be forever. You've got
to resign yourself to that fact. Clem

Ruth took the idea of resignation in the face of exacerbation a step further linking
apprehension about the inevitable, yet unknowable decline, to her Advance Care
Planning.

I think you’ve got to go through the process that we’ve all been through, you
know, you’ve got to, and I suppose you’ve got to think what’s got to happen
from here on out as well, to think, you know. That's why I’ve said in my will
that I do not want to be resuscitated and that, and you’ve got to sort of draw
the line somewhere. Ruth

During, and in response to times of acute exacerbation, times when the body's
decline was stronger than the mind's resilience, participants experienced what could
be considered for some a loss of hope and for others a gain in perspective; where the
idea of dying became more salient than the hope of the future. In looking at
exacerbations as times when the body conquered the mind, there were also
experiences when the mind gave in to the body, with similar implications in
lowering the participants’ identity as 'one who overcomes'.

As Clem’s interview progressed, his wife joined the discussion, and in so doing,
introduced the notion of ‘fear’. At no time in any of the interviews did a participant
raise this idea but during the follow-up questions, the topic was consistently
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broached. With the exception of Valerie, every participant who was asked responded that fear was a dominant force in their lives, although the source of the fear varied between individuals. There was fear of being overcome by a task (Laurel), breathlessness (Gail), and death (Ruth). As fear became a dominant emotional response to COPD, and its symptoms, it had a tendency to manifest as acute panic attacks. There is a well-documented physiological link between breathlessness and panic attacks in COPD, whereby they cycle off each other, the panic attack exacerbating the breathlessness, the breathlessness increasing the sensation of anxiety, defined as the dyspnoea-anxiety-dyspnoea cycle (Bailey, 2004). Geordie made direct reference to the positive feedback of breathlessness and anxiety experienced during a panic attack, which he directly associated with feelings of considering death as a way to end the attack.

I suffer from panic attacks because ah, sometimes you think you can’t breathe and... it’s very hard for people to understand that when you gasp for breath like that, it makes you panic... and that’s the frustrating thing about it - that you know it’s, you’re not going to die from the lack of oxygen because you’ve got it going through all the time, but, it gets to the stage that you think, is it all worth it, is the hassle worth it? Geordie

As with Geordie’s description, participants used strong negative language to express feelings of isolation in those moments. Ruth spoke about how anxiety ‘came with her’, so that she could never be free from it, and feeling as though she was ‘going mad’, while Geordie was frustrated not only by the attacks but with others’ response to him. It is in these moments, when even the most seasoned adapters asked themselves ‘is the hassle worth it?’ (Geordie). In exploring these stories from the
mind-body-spirit perspective, panic attacks did not appear to be a time when the body took over the mind, as much as a time when the mind gave in to the body.

The triggers for panic attacks were quite varied, although going out in public seemed quite common (Ruth, Vida) and a potential cause for social isolation. Mae’s panic attacks were triggered by lying down in bed, feeling claustrophobic. There was a sense of being out of control, in these moments, which ruminated with many participants. As Laurel recalled what it was to experience a panic attack, the concept of feeling out of control of your life was raised.

They’re the worst things that I think I’ve ever experienced… You’re just trying to get that breath into you, another breath into you, so you can get back to normal and the more you do it, the worse it gets, and then you fight it and you start to freeze up... It is one of the worst things I think... it’s so close to death it’s not funny. Laurel

Despite hope for independence and defiance, there came a point for participants, particularly Clem, Vida and Camilla, where the coping strategies, already in place, were no longer fully compensating for their declining health. Vida spoke about not noticing the wider implications of the disease anymore, as she was occupied with unrelenting acute symptoms not associated with an acute incident.

I suppose it has affected me, but it’s affected me in a way that I haven’t actually noticed that much, you know, because I’ve been thinking about the fact that I couldn’t breathe. Vida
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As the disease progressed, more and more simple tasks, such as meal preparation (Clem) and collecting the mail (John), were taken on by others, particularly family members, leading to feelings of frustration and guilt.

*One of the things I can’t do is to go out and get the mail and pick up the paper. My wife does that for me, so that’s one little thing that I don’t do that at all now and that’s, that’s every day.* John

As the care demands increased, so too did the emotional response to that situation, particularly feelings of burdensomeness, frustration and fear. Catastrophising, which is exaggerated negative thoughts about a trigger event or activity was demonstrated in way participants focused heavily on perceived threats to their breathing, be it going out or participating in activities (Solomon et al., 2015). Within COPD, catastrophic thinking regarding breathlessness and panic attacks is known to lead to fear-avoidance, which can be more disabling than the actual symptoms (Bailey, 2004; Willgoss, Yohannes, Goldbart, & Fatoye, 2012). Catastrophic thinking also includes poor perception the individual’s ability to control a threat or situation. As the participants perceived they had lost control over aspects of their life, their language shifted to a tone of blame, particularly self-blame, rather than defiance. At the same time they were asking more and more of the people around them, in regards to care needs, they were battling with their own guilt about whose fault their situation was.

*Emphysema is a ghastly disease, it really is. But there’s no use kicking and screaming, because I did bring most of it on myself. Nobody did it to me, I did it to myself. And I had enough knowledge to know better.* Camilla
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Each of the participants grappled differently with catastrophic thinking and fear-avoidance. Even during difficult times, some participants were able to restore the balance of mind over matter using a combination of medical intervention and self-regulatory behaviours.

Reclaiming the Upper Hand

For Clem and Vida, in particular, acceptance had become resignation but for most others, even in those times of acute distress, an internal battle was waged against submission and hopelessness. It was in these times that the internal dialogue, the participants’ inner voice came to the fore, as the mind fought to retake the control over the body. In taking control over fear, Gail noted ‘I think you’ve got to just talk yourself out of it virtually, ‘come on Gail; get yourself together’. Living independently, Gail routinely talked herself through frightening and stressful situations. This served to both distract her from the issue at hand but also to reason her way through a situation rationally, over-riding her tendency to panic. This was highlighted when describing an incident when her oxygen supply was compromised during a power failure.

The first time the power went off when I was on oxygen and I thought... to start off, there was a real fear then. And then I thought ‘think about this sensibly’ and I went and got the portable and put it on. Gail

Despite the fear, Gail used self-talk to navigate her way through a difficult situation. In addition to rationalising through self-talk, internal dialogue was used was as distraction during events, which did not seem to prevent an episode from occurring as much as help the participants through them. Laurel and Ruth both demonstrated
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this, with Ruth thinking of happier things such as grandchildren, and Laurel talking herself into distracting tasks she enjoyed, particularly cooking.

Most participants used regular anti-depressant and anti-anxiety medications to manage both ongoing and acute anxiety. Of the nine participants using medication to manage anxiety, only Laurel and Ruth reported that it helped in any way. More commonly, participants took the medication, as prescribed, despite the fact they didn’t believed it helped or worked. Instead, in talking themselves through an acute episode, it was the power of their mind that allowed them to regain control over their body. Using self-talk to rationalise themselves through panic attacks suggested that even in the most difficult moments, most participants were still initiating self-regulatory strategies to manage the situation, fighting the urge to let their mind lose to their body. Interestingly, Evan was the only participant who stated he had worked with a mental health professional to build these skills.

Research into the combined use of pharmacotherapy and psychotherapy, particularly Cognitive Behavioural Therapy (CBT), in COPD has had positive findings (Hynninen, Bjerke, Pallesen, Bakke, & Nordhus, 2010), although not always statistically significant impact (Farver-Vestergaard, Jacobsen, & Zachariae, 2015). The general consensus through a series of systematic reviews and meta-analyses would suggest that in addition to the standard pharmacotherapy for anxiety and/or depression for people with COPD, which is known for poor uptake, adherence, and tolerance (Yohannes & Alexopoulos, 2014), CBT or similar forms of psychotherapy should be provided as standard care in the management of mental health and psychological wellbeing in COPD (Farver-Vestergaard et al., 2015; Ouellette & Lavoie, 2017; Zwerink et al., 2014). In light of the findings of this research, I concur
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with the recommendations from each of the reviews, that further research is warranted in this area of study. Of particular relevance to this work is how early psychological intervention could potentially influence the development of the self-regulatory strategies used sub-consciously by people with COPD to manage constant, incremental change.

The self-regulatory strategies discussed throughout the participant stories were reflective of the current, albeit scarce literature on self-regulation in advanced COPD management. Ideas and strategies identified by Brandt (2013) in her seminal research on self-regulatory strategies in older people with COPD, were reflected strongly throughout this research. Those strategies, which included pace reduction and taking breaks, use of interventions and assistive technology, prophylaxis and trigger/risk avoidance, resonate within the wider COPD management literature on maintaining independence in COPD (Falter et al., 2003; Pinnock et al., 2016). In addition to these strategies, positive self-talk by the participants to regulate emotion and work through acute symptoms was evident, which has been identified as a panic control strategy within the COPD literature, although with limited discussion of its impact, efficacy or facilitation (Fraser, Kee, & Minick, 2006; O'Neill, 2002; Sassi-Dambron, Eakin, Ries, & Kaplan, 1995). Willgoss, Yohannes, Goldbart, and Fatoye (2012) commented that both self-talk and reflection on past experiences were used by people with stable COPD living, in the community, to both assess risk and avoid panic attacks. The use of self-talk during acute stress was key to re-establishing mid-over-matter control, with far reaching consequences in the acceptance cycle and the regulation of negative emotions, such as fear and distress.
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Summary

In times of acute physical and emotional distress such as exacerbations or panic attacks, the ability to regulate symptoms using both psychosocial and interventional strategies, was compromised. These experiences elucidated feelings of fear and resignation which, in the case of panic attacks, specifically had the capacity to increase the severity and impact of the episode. For some participants, the accumulative effect of critical incidents, and the emotional implications, had a negative effect on their resilience and hope. For others, however, the sense of defiance, key to their identity as a person with COPD, resurfaced as they engaged with self-initiated psychosocial strategies to regain control over their body. This cycle played back into the cycle of acceptance, where success bred confidence and confidence bred further success.

Chapter Summary

This chapter explored how the participants responded to the changes occurring around and within them. The participants discussed a range of self-initiated, self-regulatory strategies, in conjunction with medications and oxygen, to mitigate physical symptoms to maintain independence. The balance of mind over body was challenged in different circumstances, including acute exacerbations and panic attacks and difficult communication with health professionals. These negative experiences led some to a sense of hopelessness but led others to fight harder to defy the disease and re-establish the equilibrium required to maintain their identity and quality of life. In the following chapter, each participant’s identity, independence and response to change, will be explored in the context of their core relationships, as they shift from independence to growing dependence on others.
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Chapter 7

Being in the World Together

Previous themes have discussed the COPD experience in relation to the individual’s identity, sense of independence and how those attributes shaped their response to COPD. In weaving a narrative that reflects their sense of self being larger than their current situation, the relationships that are central to their lives must be considered (Table 7.1). In addition to their relationship with health professionals, discussed previously, the participants identified three core relationships that affect how they understood and coped with COPD; a spouse, adult children and now deceased parents.

The spousal relationship sat at the heart of adaptation to change, as spouses tended to receive the bulk of the handover of tasks, care and carriage of concern. In trusting another, in this way, the relationship shifts from one of lover to one of care-giver. This shift from marital interdependence to dependence triggers deep and simultaneous emotional responses, of gratitude and fear. Running deeper still, is the relationship of parent and child. Whilst accepting change in their marriage, there was a strong resistance, by a number of participants, to allowing their adult children to take on the anticipated physical toll, or emotional implications, of a physically deteriorating and weakening parent. This, for some, was grounded in their own experiences of caring for their parents or in-laws, a task most had performed willingly and well but had no intention of repeating as the parent. To compensate for their increasing disability, the participants engaged in acts of reciprocity to compensate for the burden they were and the burden they perceived themselves to be.
### Table 7.1 ‘Being in the World Together’ Themes and Sub-Themes

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### From Interdependence to Dependence

Of the eleven participants, all but Gail had been married. Seven participants were married to a living spouse at the time of the interviews, with their spouse acting as primary care-giver in six of those instances. As Vida alluded, there was a natural and gradual handover of home care tasks, and other activities of daily living (ADLs), to the primary care-giver, her husband.

*Initially, I still did everything, [my husband] did all the cleaning things, because I couldn’t vacuum before that, you know, I was having trouble, you know, vacuuming the whole house and certainly washing, the water and all that, I couldn’t cope with that, so [he] was doing that sort of thing then and I, we kept going for a fair while, because I’d do the dusting and those sort of things, the clothes and the ironing.* — Vida
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Her description of the transition confirmed it was the high energy tasks such as vacuuming, that were given over first, with other tasks being adapted and modified until they too, became overwhelming. In discussing this with Evan, whose wife was still in full time employment, there was a significant emotional burden associated with the handover of these tasks. To alleviate this stress, the family paid for additional support to achieve tasks he could no longer complete. Likewise, Mae did not expect her son, who was her primary carer to take care of the garden, a particular source of joy for her, in addition to home and personal care. To alleviate responsibilities of this task, as well as to continue to appreciate the garden, Mae hired a gardener in lieu of more traditional home care support. This choice reflected a dual desire, to remain engaged with valued-tasks and support her primary care-giver.

Clem and Ruth both discussed different aspects of being cared for by their spouse, each suggesting that there were clear links to their quality of life. Whilst Clem could see the impact he had on his wife’s life, he could see that they are in this together and he is probably alive because of her sacrifice, including her retirement to care for him.

_Without her I’d be lost. I wouldn’t have a quality of life and…it’s probably unfortunate she has to do that but she probably accepts that as much as I accept my problems and she accepts my problems as her problems. I don’t know. But, I probably wouldn’t be sitting here if she wasn’t happy to do what she does. But yeah, that’s about all I can say._ Clem

In line with existing literature regarding preferences for familial over professional care provision (Pinnock et al., 2014), Ruth went on to comment that she not only
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accepted the care her husband provided but she preferred it to professional medical care, despite the negative emotional impact. When asked how it felt to have her husband take care of her, she replied ‘dreadful’, yet she preferred his care to that of a paid health professional coming into her home, as she was able to trust him explicitly, and be certain of his presence when she needed assistance.

*I trust him because he’s here all the time, you know, and he sort of knows what’s going on, you know. Like, if I get into a panic attack and go like this (signals with arms) he knows not to say anything until I’m [calm].* Ruth

The weight of responsibility of requiring people to be present to take care of them, or take on the responsibilities previously held by the other, led to a range of emotional responses from a passive resignation to anger. It was frustration, however, that was the most common of the emotional responses. Laurel expressed frustration at her requirement for other people to assist her in cleaning the house, in that she could not do it for herself, but also that the job was not up to her standard.

*Ah, yeah, I get a bit annoyed because I can’t do housework because I can see it needs doing and there’s not a thing I can do, but I’m learning to live with that now. I mean, home care and that, they’re wonderful and they’re good, but they don’t exert themselves, but it’s the Claytons cleaning, it’s ‘the cleaning you have when you haven’t got cleaning’. So, I learn to shut my eyes now.* Laurel

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2 Claytons is the brand name of a non-alcoholic drink marketed through Australia and New Zealand throughout the 1970s and 1980s as ‘the drink you have when you’re not having a drink’. The term ‘Claytons’ is widely used colloquially in Australia to imply a sham or dummy article.
Where Laurel had become desensitised to trigger situations, Evan’s frustration at his inability to complete tasks was more likely to escalate to anger. The impact his impairment placed on his wife was an acute source of stress, as there was generally little he could do to support her except ‘put tea on’; insufficient reciprocation in his eyes.

Oh, oh, I get frustrated sometimes because of the things I can’t do… my wife mows the lawn around here, well that pisses me right off, you know, like she’s out there mowing the lawn and I’m sitting in here doing, putting tea on or some shit, but I see her out there mowing the lawn and go, no, that should be me doing that, and she comes in with a red face and sore ankles.

Evan’s experience raises two important issues. Firstly, the role of gendered societal expectation on the experience and severity of disability and secondly the implications of unequal reciprocity within the care dyad, as described in Chapter 2. In their review of the conceptual development of disabled masculinity, Shuttleworth et al. (2012) discussed the tendency for men to rely on a hegemonic definition of masculinity, associated with independence, autonomy and gendered power hierarchy, in the presence of acquired disability. An existential conflict is raised as this definition of masculinity is countered with a lived experience of increased dependency and perceived helplessness. In exploring disabled masculinity, from the perspective of men with multiple chronic conditions, Clarke and Bennett (2013) reflected the experience of living with chronic conditions was gendered, with men prioritising functional ability over appearance. Symptoms such as pain, fatigue and loss of strength challenged the participants’ ability to adhere to a hegemonic...
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definition of masculinity, although ultimately older men reported being ‘displeased with their failing physical abilities and increasing dependence, they were resigned and stoic about their health issues’ (p.344).

Evan, Clem, John and Geordie’s experiences all reflected disabled masculinity in one way or another. I would suggest that Evan’s response to his wife taking on traditionally ‘masculine’ tasks such as mowing the lawn, was a challenge to his identity as the breadwinner of the family and ‘man of the house’. His desire to maintain these tasks, however, was not universally associated with gender. Evan’s description, that he would ‘put tea on or some shit’, reflected his desire to reciprocate of his wife’s increased workload. This was achieved in and through hiring home support to alleviate cleaning tasks, however, existing literature would suggest that wives, in care-giver roles, generally prefer increased emotional intimacy, as reciprocation for physical task performance. Intersection of identity and adaption are evident within Evan’s story; the effect of gender on reciprocity and adaption to the shift of societal gendered roles are avenues for further research.

As Vida’s health has deteriorated, her husband has taken on much of the home-care and cleaning but her description suggests that the gradual decline in ability has also impacted her confidence to do other things. Immobility doesn’t just mean she can’t vacuum any more, she becomes anxious in leaving the house. Further, she expressed her concern in that being unable or unwilling to leave the house, she impacts on her husband’s ability to socialise and maintain his quality of life. The guilt associated with limiting her spouse’s social life, as he provides primary care, was reiterated by Ruth and Vida. In contrast, John actively encouraged his wife’s social life, as a means to get ‘a little bit of peace, at times’.
Because I don’t want to be a burden on them, you know, because I know I’m a burden on him, because he has stopped playing bowls, like he doesn’t need to but he said he wants to be here. Ruth

Additionally, Camilla gave up her ‘out of the home’ activities, in part, to alleviate the burden they placed on her husband.

Yes, so I just thought it was time to give it up, let someone else [be the organisation treasurer]... it still wasn’t fair to ask William, look he’s having trouble walking and to have to go the bank and bank the money every five minutes- it’s getting too much. Camilla

Camilla’s decision to step back from community life was reflective of her increasing symptom burden, as well as her acknowledgement that more and more of her commitments were being managed by her husband. With additional burden placed on their spouse, Camilla and all other participants, made decisions to cease activities completely or use paid assistance rather than increase the encumbrance on their spouse. The emotional implication of feeling burdensome included not only negative emotions but a deep sense of appreciation for the quality of the care they were receiving.

The changing face of marriage

Gratitude was particularly strong in married couples, and even more so when the husband was caring for the wife, the wives spoke with enamoured pride. Despite this, when describing their husbands, they tended to focus on their capacity to take care of them. This may signal that these women had fallen in love with a man who was no longer a lover, but a care-giver. Ek, Ternestedt, Andershed, and Sahlberg-
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Blom (2011) noted a similar phenomenon, whereby couples where one partner had advanced COPD described their relationships in the context of companionship. This was, in part, due to the loss of physical intimacy and sex but also as they each took up new forms of intimacy, associated with increased involvement by the care-giver spouse in the self-care of the partner. In describing her husband, the best Ruth could say was to describe how well he cares for her, whilst Vida’s very definition of quality of life was to describe what her husband did for her.

*I think quality of life is not too bad, you know, it’s sort of, well, I would watch an episode of Escaping to the Country every day while we have lunch and I come out in the morning and breakfast is on the bench waiting for me and and then [my husband] cooks dinner for me at night and I have a sleep in the afternoon and in the meantime I’ve always got a book, [he] goes to the Library and gets the books and ah, we’ve got plenty of DVDs if we wanted to watch a movie. Vida*

In interpreting these comments, there is potential to devalue the compliment being given to the care-givers, to see them as ‘only’ as providers of care. These comments, rather, reflected the genuine respect the participants had for their spouse, and the spouse’s ability to adapt to constant change. It was only Camilla and John, the oldest of the participants, that made the direct references to seeing their spouse as something different to just a care-giver, seeing them as friends and lovers.

*We’re very good friends, you know. We’ve been married nearly 66 years but we remain good friends.* Camilla

*[We had], I suppose, a normal sex life; gone through the window now, of course, yeah, but ah, you still ah, you still ah, interested in having a bit of a
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cuddle; a snuggle up, that how we reassure ourselves. I think we’re pretty normal. John

The shifting dynamic of marriage, moving away from physical intimacy toward care provision and the perception of burden, manifested itself in the fear of loss of the spouse who acted as their primary carer, and its impact on the widowed participants. For those with living spouses this fear emanated from the perspective of loss of care, as Vida described.

I get worried about [my husband] … from the point of view that if anything happens to him, then you know, I’d be stuck here, I wouldn’t be able to drive, but that sounds very cold... Vida

Vida and Ruth raised this but not in discussions regarding death, advanced care planning, or their relationships but rather, when the issues/triggers of fear or anxiety were raised with them. In those discussions, that event, of losing their husbands, was their prime example of their worst-case scenario. Vida was weighed down by the ambiguity associated with her lack of prognosis but this revolved more around whether her husband would be alive to see her through her final years, as opposed to what those years would look like, as a result of the COPD.

No one will tell you how long it takes to… to actually die.
I don’t think anybody knows…
That’s what I’m worried about.
You don’t want to go on for years?
Well, no. Not really. No, I don’t. No, that would be horrid. [My husband] would probably be gone, no, no, I think I would get depressed then.
If [your husband] went?
This fear sat in stark contrast to the widowed participants, Laurel and Valerie, who had, in reality, coped remarkably well since their husbands had died. For Laurel, in particular, it was the death of her husband that allowed her to build more intimate relationships with her remaining family and come to terms with her own death, as discussed previously. Similarly, the experience of Valerie’s loss allowed her to accept her condition and governs her perspective of how to live and die well.

He was so sick and never got out of bed... Lying in bed, he couldn’t even sit up. They had to lift him up and support him for a bath, so his lifestyle; and that’s made me stronger too, I think, because he had no quality of life at all, and I think... if I just had to lay there like that, what are you going to do, where’s your life and I think that’s why I push myself sometimes. Valerie

Whilst Ruth’s deepest fear was the possible loss of her husband, her story also suggested that should that come to pass, she too would have the capacity to live and age as successfully, as had Laurel and Vida. Each of the couples had learned to adapt to uncertainty and change, however, Ruth’s story, demonstrated that just as anxiety could dominate a relationship, so the relationship could learn to dominate anxiety. Instead of a story of fear, Ruth’s description of coming to terms with her anxiety, both of breathlessness and the risk of her husband’s premature death, became the telling of how she and her husband had worked together to build her confidence. This was already releasing her from her emotional and psychological dependence on her husband.

Well the anxiety sometimes comes with me; I think is the panic attacks... It started off when [my husband] got sick and I just thought, and I felt guilty
Ruth was able to articulate how that changing relationship was able to produce both
great love and great distress, both of which silenced her capacity to articulate her
concerns about her increasing anxiety. Her anxiety was triggered by a wide range of
factors, including concern for her husband. In trying to protect him from that anxiety,
which he was already heavily involved in managing, she was pushed to her breaking
point before admitting there was a problem.

At the same time, Ruth’s husband was enabling her anxious behaviours, without
judgement or challenging the idea that something wasn’t right. Whilst she had not
completely alleviated the symptoms of her anxiety, by working with her husband
rather than sheltering him, they, and their GP, were able to resolve many issues that
triggered her panic attacks and symptoms. This had a dramatic effect on the way she
began to understand her condition, and advocate for herself, in stressful situations
without depending on her husband directly. In situations where her husband could
have mitigated a panic attack, Ruth became able to communicate her needs with
others in a way that prevent episodes from occurring.

Well, it can happen but now I make sure I sit there and explain to [the health
professionals], or get them to explain to me what is going to happen. That’s
what I did when I went to the dentist; and I said, because they could see that
I was on that (walker) and I just sort of sat down and said, look, you know, if
this is going to happen, well, tell me what’s going to happen. Ruth

Ruth used her experiences of working with health professionals, and her husband, to
inform how she is to manage her anxiety. Similarly, Laurel and Valerie’s
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experiences of loss and suffering have shaped the way they experienced COPD. At times, I was also lucky enough to catch glimpses of how the care-givers felt about the process of being in relationship with their spouse. As the care-giver spouses challenged and affirmed their partners, they revealed different interpretations of living with COPD.

Hearing different voices – Clem’s Wife and Camilla’s Husband

At times spouses joined the discussion, most notably Camilla’s husband and Clem’s wife, allowing different voices, interpretations and perspectives to be heard, regarding COPD and its impact on marriage and lifestyle. Camilla and Clem’s spouses gave insight on the emotional impact of care, and COPD, on other people, as well as highlighting how different people interpret scenarios differently. It was, during these times, that I saw the dyad strive to understand each other and provide a snapshot of their shared horizon of experience. Camilla’s husband’s interjections challenged her generalised statements about how other people perceive her. In the following exchange, when discussing why they don’t go to the club anymore, Camilla stated they did not go because they had quit gambling but her husband challenged this statement, to which Camilla conceded that her breathlessness ‘frightens people and upsets them and that’s not fair; not fair to them and humiliating to me.’

Camilla conceded that she did not wish to humiliate herself, nor did she desire to make others uncomfortable seeing her breathless or distressed; that people being distressed by her breathlessness would likely only feed into the anxiety-breathlessness cycle. As a result, she had given up a number of obligations to community organisations to prevent others seeing her this way. For Camilla, who
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cared very deeply about the way she was perceived and the emotional welfare of the people around her, both of these factors influenced her choice to withdraw from community life. Additionally, it was through those challenges that I came to better understand Camilla’s tendency to shelter people from the whole truth about COPD. Whilst able to speak frankly about other sensitive topics, her discussions stayed focused in the past; it was her husband that continually brought her into the present talking about what it was like ‘now’, not just ‘then’.

In the same way Camilla discussed how she had withdrawn from her social life, Clem discussed the changes in his relationship with his family over the past 18 months. As a result of his COPD and Osteoporosis, he has gradually withdrawn from the physical labour he undertook to support his sons, as well as his driving. He spoke of this quite passively but late in the discussion, when his wife responded to how the changes affected his family, her fatigue and frustration became apparent. It is not just Clem mourning the retirement he wanted but his wife, too.

*Clem (Cl): I have an electric wheelchair that fits in the car when [my wife] goes shopping, I go with her and drive around, but like I said I used to walk, once. That’s the hard part at the moment. It's nothing to do with C-O, whatever it is. (Laughs).*

It was at the point that his wife raised her perspective that Clem opened up more about the emotional implications of COPD, and his wife introduced the construct of ‘fear’. This idea would permeate the rest of the interviews from that point forward and prompt the following written reflection, which described the impact of fear on identity, coping, and relationships; namely that it created an environment wherein
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those experiencing fear, rather than reaching out for help, would silence themselves and experience the fear in solitude.

No one spoke of fear except Clem’s wife. Thank goodness for her. From her suggestion, I knew to balance each of the participant’s stories by broaching the topic of fear, and in that time, all but one admitted the strangle hold it had on their lives. Yet, no story they told used the word directly up to the point I introduced it - fear was the elephant in the room. Adults aren’t supposed to be scared - we use different words when it’s an adult - anxiety, panic, worry; so, it seems different to what you felt in the dark, as a child. Yet, fear – of not being able to take another breath, of death, of losing a spouse - underpinned how COPD was perceived, experienced and managed. Things that were feared were given up first, and if they couldn’t be avoided they were managed dogmatically.

The thing about asking about fear - the question that got me the most information of all the questions - was that it was so simple. What came from that little question was heart-felt; for me, it was a truer characterisation of the COPD experience than any other idea presented, and allowed me to develop the findings of this thesis in a way that no other question could have. It was brave of Clem’s wife to raise the topic, brave of me to keep pursuing the idea and brave, of each individual, to be so honest in their response. Be encouraged, Bernadettes of the world - a little bit of bravery goes a long way. Written Reflection, September 2016

The data collection was designed to hear the stories of people with COPD, exclusively. When the idea of speaking with care-givers emerged at the point of research design, it was seriously considered but decided that so great was the need to hear their stories, it should be a project in and of itself. In listening to the interactions between the couples, there is scope for research exploring shared experiences of couples and other care dyads, such as patient and health professionals or parents and their adult children. Both Clem’s wife and Camilla’s husband’s stories were used with permission.

Summary

In accepting the care provided by their spouse, as an extension of the marital role, there were deep and far-reaching emotional implications. The blend of gratitude and
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fear, associated with increasing dependence, made clear the complexity of shifting from interdependence to dependence. Despite Vida and Ruth stating that the loss of their care-giving spouse was their worst-case scenario, there was a more universal fear, shared by the participants who were parents. It was clear that with any loss of a spouse, the more fearful possible result would be in the shift of care to their adult children. Dependence on your partner was one thing, dependence on your dependant was something entirely different.

Ageing Parents and Adult Children

Participants, with children and grandchildren, were clear to articulate their role in the family as a parent, even as their adult children were heavily involved in their care. Ten out of the eleven participants had adult children, grand and great-grandchildren. Whilst grandchildren served as primary sources of joy in their lives, there was an interesting dynamic established between participants and their adult children, who were often taking on an increasing caring role. This was demonstrated particularly by Laurel, who moved towns to support her adult child only to come under her daughter’s care within months of the move. Laurel would willingly participate in activities to foster the relationship with her daughter, despite the health implication, then hide severe deteriorations in health from that same daughter.

_I just got sick and went into hospital Christmas night after baking a big Christmas meal for everyone and I said to my husband, he said 'home?' I said yeah home; no, take me to the hospital, I’m not well. And that’s where I was for 7 weeks, very, very ill, I was... I had a collapsed lung, a germ in the lung, I had pneumonia, pleurisy, broken ribs and a stress fractured spine... Through a lot of perseverance and what have you ... I’m back at the stove._
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So, I'm cooking up a storm... and everybody was happy - Nanny’s back,

Nanny’s back at the stove and so that more or less what I do, I just sit and

knit and cook. Laurel

Laurel’s story highlights the way parents tended to hide symptoms from their families, which was relatively consistent throughout the participants’ narratives. No participant explicitly stated that they aimed to withhold information and symptoms from their family, instead choosing to under-express need until they were away from them. The propensity to hide symptoms from their children may stem from a sense of burden they felt in caring for their own parents but also contribute to the difficulty some families experience in understanding and recognising their parents’ limitations, as Geordie noted of his children.

They just don’t sort of get, they don’t think that dad should have this; dad should be, you know, dad should be dad and he should be able to do this and do that, but they don’t understand that dad just hasn’t got the energy anymore. Geordie

Parents, whilst reluctant to receive help from their children, did tend to reprioritise their social life to revolve around their children and grandchildren. Whilst this is a very normal aspect of ageing and family dynamic, avoiding symptoms and triggers had major implications on the way participants engaged in family activities and how they were organised. As the most physically active participant, Valerie recalled a time when she was included in all family activities, from meals to white water rafting but ‘now it’s, it’s impossible for me to do the things that they do... I’m in the situation with the oxygen, they can’t include me, you know, I mean, they ask me and I say no.’
Contradictory to Geordie and Valerie’s experiences, some family members were so accepting of the participant’s limitation that they could be termed ‘accepting to a fault’. This could be seen particularly in John’s story, who referred to his children as ‘looking after him like a piece of crystal’ or ‘a cream puff’. Alternately, Vida wished her family would persevere in encouraging her to participate in family activities.

quote
I’m not going to [my granddaughter’s] 21st, which I’d love to, you know, so, we decided that would be too hard... but everyone understands that I can’t, a bit too readily actually (chuckles)... I say ‘I can’t’, and they say, ‘oh we understand’ sort of thing which probably, I’d prefer if they talked me into it (chuckles), but anyway, that’s the way it is, you know, I mean, they probably think that they’re doing the right thing. Vida

despite his frustration, John’s sense of humour, in discussing these things, reflected the fact that when families are over-bearing or anxious, it is just part of being a loving family. ‘Black’ or ‘morose’ humour is known in chronic disease and COPD
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to alleviate psychological burden and facilitate quality of life (Lebowitz, Suh, Diaz, & Emery, 2011; Rzadkiewicz, Brâtas, & Espnes, 2016). Humour is often used by both people with terminal cancer (Rose, Webb, & Waters, 1997) and health professionals (Wanzer, Booth-Butterfield, & Booth-Butterfield, 2005), to create a sense of normalcy and diffuse tense situation, which appeared congruent with the experience of humour from and between the researcher and the participants in this project, such as John’s description of his family and the way COPD affected those relationships.

Irrespective of the degree of disability experienced by the participant, or how well limitations were comprehended, their identity as a parent remained at the core of both their identity and their quality of life.

...being able to do what I can do for the family and help them out. That’s why we came over here in the first place, to help out... and that’s what I feel; that I’m not letting [my daughter] down because I’m like this, that I’m not letting her down, I’m still doing things. Laurel

Most parents provided the context of why they sheltered their children from change, which related to their own experiences of ill-health, suffering and most importantly, their own experiences caring for their now deceased spouses, parents and/or in-laws, in multi-generational care. It is in understanding the generational experiences that the idea of perceived burden (as opposed to actual burden), came to the fore. More than being concerned for the actual burden being placed on their adult children at the time of the interviews, participants were distressed by the sheer risk that they could become a burden, as they had been similarly burdened by their own parents.
History repeating

When asked to tell their COPD story, some of the story-tellers’ stories spanned their entire life, from birth (Camilla), through childhood (Gail) and youth (John), to adulthood (Evan, Laurel), whilst the remainder began their story at the time of diagnosis or initial exacerbation. Five of the participants took me back to a history of poor health, and constructed their stories to connect the family of their childhood to their perception of COPD, illness and resilience. Shaping their own experience, of living with COPD, was not just their personal history of illness but the lives and deaths of loved ones, especially their own parents. Seven of the participants had taken an active role in the care of their parents. Evan’s story reflected the idea that the participants did not resent having to care for their parents but discussed that the volume of care required and how it fitted into their lives, was significant.

_I always say to anybody, that [my mother-in-law] came to our place for a three week holiday and stayed three and a half years... but she was a good old stick. Same thing, we were primary carers for my mum and primary carers for [my wife’s] mum._ Evan

Through their experiences of delivering complex care giving roles for ageing or dying parents, relatives and in-laws, the participants developed an empathy for, and protectiveness towards, their own care-givers. It was not simply how much was required of them, that shaped the participants understanding of being burdened. It was also how their loved ones coped with chronic disease and the end of life that influenced how the participants wanted to approach the end of their own lives. This was exemplified in both Ruth and Gail’s stories. For Gail, the experience of caring
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for her mother and grandmother provided a sense of perspective of how she did, and didn’t, want to live with a chronic disease.

*My grandmother, she was a very determined person... Nanna and I could both laugh at life - mum couldn’t.* Gail

With the two most important women in her life experiencing significant hardship, Gail had made a decision to follow her grandmother’s lead and approach life with a sense of humour and grace, so to not be the emotional burden her mother was at the end of her life. Instead, Gail’s approach to living is one of reciprocity, to give and take within her community.

*It's been a motto of mine, always treat people as you expect to be treated... it's what community living is all about - giving and taking.* Gail

As Gail’s worldview was shaped by her past experiences, so too was Ruth’s. As discussed previously, Ruth had nursed her mother through COPD, which led to an understanding of what a COPD death could look like, but also that because of advances in medication and technology, there was a sense of hope that her experience would be better.

*I suppose you’ve got to think what’s got to happen from here on out as well, to think, you know. That’s why I’ve said in my will that I do not want to be resuscitated and that, and you’ve got to sort of draw the line somewhere, and that. I seen my mother go through it... she was gasping for breath and at the time she had one of them great big masks, it was as if it was glued to her and I said to her, how can you stand that on your face, because I couldn’t stand anything on my face and she said, you do what you have to do.* Ruth
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Ruth made a direct connection between her experiences of caring for her parent and how it has shaped the way she wishes to control and experience her own death, through Advanced Care Planning. Her decision to put advanced directives in place stemmed in part from her desire not to suffer as her mother suffered but later she went on to discuss how her advanced care plan was in place to protect her daughters from that suffering.

*If it was me [to survive my husband], I would have to say, I would have to go into a place. I don’t want to sort of go to the girls because I don’t want to ah, you know; they’ve got their life and that. I know what they would say, but I would say, no, you’ve got to... you know.... Whatever happens, I would give up because you’ve been through so much. Ruth*

It was in the lived experience of being the adult child to an ageing parent, and in being the ageing parent of an adult child, that the participants came to understand the emotional weight of actual and perceived burden. To this end, the desire for parents to protect their children particularly, in light of their age and declining health, was not about the quality of life but quality of death. To live well, with COPD, became in part about dying well, with COPD, and in so doing protecting their children from the emotional distress of their inevitable deaths.

**The perception of burden and its influence on Advanced Care Planning**

There were a number of reasons why the participants chose their particular advanced care planning strategies, including moral reasons as Vida mentioned, or simply ‘being done’ at the end of a long, happy life (Geordie, John). John and Laurel commented on refusing curative treatments, at this stage of their life, as they had
lived their lives well and those opportunities should be saved for ‘the young ones’ (Laurel). Geordie was equally accepting of the impact of age on his survival.

*There’s nothing you can do about it, well, I suppose you can get a lung transplant, but I’m that old that it wouldn’t matter.* Geordie

More than this, however, the participants’ choices, for end of life care, were guided by their past experiences caring for parents and their desire to avoid the same situation for their adult children. For Ruth and Laurel, it was explicit that they would not live with their children when they were no longer able to live alone. For Laurel this was grounded in her own experience of caring for her mother in law, ‘Big Nanny’, who lived with the family for 33 years. As a result, she has put plans in place for her own funeral to avoid ‘any fuss’.

*I did not want to go, when I got sick, I did not want to go and live with my children. I said I’ve lived with my mother in law for 33 years, here we go again, and I am not going to put that on my kids… so I will stay here and live here until my time is up. Or, I will go into a home.*

*...*

*I’ve got a do not resuscitate, yeah, that’s all done. My funeral has been planned, I don’t want any service; I don’t want nothing... I’ve always said when I go, I don’t want any fuss, I don’t want the little ones crying and carrying on and you know, the sadness, just I’m gone. That’s it. Finished. No more.* Laurel

For Ruth, her choice was to protect the lives her daughters had built for themselves and reduce the emotional impact of her death. The advanced directives, in place for
both she and her husband, reflected her awareness that she was already a burden on her family, and was likely to become more of a burden, as time progresses.

*I don’t want to be a burden on [my daughters], you know, because I know I’m a burden on him...* Ruth

John’s reflections, on his end of life care, was the only reference from any participant articulating where he would want to die, preferably at home. This again, revolved around his perception of burden. Despite seeing hospital as a threatening place, he knew, in requesting to die at home, he would be adding a final burden to his family. This suggested he was prepared to compromise on his wishes for the place of his death to protect his family from more hardship.

*I’d rather not go to hospital, yeah, then again, that puts another burden on your family.* John

In addition to this, Mae was very clear that the burden of her death would not fall on her daughter’s shoulders, as the emotional burden of her father’s death had and still rested on hers, even decades later.

*Well, me dad... had a massive heart attack... and he said to the doctors, ‘why did you bring me back? I was floating and it was like Heaven’... So he cursed them until he died... and died a really bad death.*

...  
*Bernadette* knows that I don’t want to go on a ventilator, they can tell me, they told my older daughter; she said ‘mum, it will save your life’, I said no it won’t, I won’t come off it. Then you have to say ‘turn it off’, do you want that responsibility?’ I don’t want to leave my kids with that responsibility...
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*think it was just last week, my daughter and I had a talk about the machine*  
*and I said to her, no, look what happened to granddad... Let me breathe. If I*  
*can’t breathe, I die, but no machines so you have to turn it off.*  

Mae

It is important to note that whilst each participant knew their wishes and each had ‘Do Not Resuscitate’ (DNR) orders in place, only two of the 11 had actually acted to put in place Enduring Guardianship and Advanced Care Directives. This is in line with the current prevalence of Advance Care Directives (13.3% of the population), for people living within the state in which the study was conducted. No data was available specific to the uptake of advance care directives for people with COPD. Advanced Care Directives were more common for people with Enduring power of Attorney and Wills in place. The only demographic associated with higher rates of Advance Care Directives, however, was related to marital status, where single people, and people not in legally recognised relationships, were more likely than people in married/de facto relationship, to have a directive in place (White et al., 2014). Gail, the only never-married participant, was one of the two participants to have both an Advanced Care Directive and Enduring Power of Attorney in place, which reflected her desire to protect the people she loved.

*Constructed Family and Advanced Care Planning - Gail*

Gail had moved to Bathurst 2 years prior to her interview taking place, at the request of her now estranged niece. Her remaining living, also estranged family, were located several hours away. When asked about her family, she replied simply ‘I don't have a family’. After losing her fiancé in the Vietnam War, she was unique in the group, in that of all the participants she was the only one never to marry or have children. Instead, she had created her own family, the kind of family you build over a
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lifetime of friendships. She listed her residential community as her family, as that was the degree of support she received from them. In addition to a community of older people, who had accepted her as a sister, her oldest and dearest friends acted as her guardians, with their daughter, Gail’s ‘niece’, having Power of Attorney.

*I’ve got very close friends in [Sydney] - and her kids are like my kids, and [her daughter] K, who I call my niece, she’s got my power of attorney and enduring guardianship and everything like this.*

One striking element of Gail’s family is the differing nature of advanced care planning and communication about the end of her life, not present in many other stories. Where many other participants sheltered their biological families, from their COPD experience, Gail took a more active stance in how she planned her life and death. To that end, she had clearly and legally articulated her wishes to those people she trusted the most, rather than her next of kin, her brother. In making these choices, Gail was still aiming to protect those she loved most in the world, including her beloved neighbour.

*And [my neighbour]’s got keys, so she can always come in, but she said she’d never come in on her own, because I think she’s got a bigger fear than me of my disease.*

That’s an interesting idea. What do you think her fear is of your disease?

*One day she’ll come and in me on the floor or something. But I’ve told if that happens what to do - just ring [my niece]!*

In putting these plans in place, Gail had acted to assure her own peace of mind that should anything happen to her, she and her loved ones would be taken care of.

Whilst most other participants had firm wishes about the end of their life, only Gail
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and Ruth had put in place an Enduring Guardianship. While each of the participants acknowledged the importance of advanced care planning, most saw their DNR order as sufficient planning or simply ‘hadn’t gotten around’ (Mae) to putting more detailed plans in place, despite ongoing encouragement from their health care team.

Summary

The experience of being the adult child of an ageing/dying parent shaped the way participants perceived what it was to be a burden on their loved ones, thinking particularly of their own adult children. In striving to maintain their identity, within the family unit, as a parent and protector, they tended to withhold information and their increasing needs from their children, in an attempt to shelter them from the full emotional and physical brunt of living with COPD. Their identity, as a both a parent and a care-giver, shaped the way they looked at the future, both living and dying. While Ruth and Laurel refused to live with their children, in order to allow them the lives they wished, Mae preferred to refuse treatment, at the time of her next exacerbation, to protect her daughter from experiencing the same turmoil as she still did in her father’s death. Thus, the relationship between parent and child shaped the experience of living with, and dying, from COPD decades before the onset of symptoms.

Chapter Summary

This theme discussed the core relationships that influenced participants’ experiences of COPD. From their parents to their grandchildren, it was family, be it biological or constructed, that served as a motivating force to maintain independence, ensure identity, respond to change and facilitate quality of life. It was through the discussion of those relationships that the concept of quality of life emerged most strongly. The
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emotional implications of actual and perceived burden of care, within these relationships, shaped the participants’ responses to COPD, their approach to end-of-life as well as their identity and role within the family unit. It is not until now, when we understand the nature of the individual and their core relationships that we can begin to understand how quality of life is conceptualised, for older people with COPD. In the following chapter the dichotomy between the intrinsically focused definitions of quality of life, provided by the participants, is explored in light of the narratives of their lives, particularly their identity, independence and relationships.
Chapter 8

‘Quality over Quantity’

The three previous chapters provided insight into how the participants saw themselves as individuals, within their core relationships, and then how their identity shaped the way they responded to change, both in general, and related to COPD. To understand the participants’ interpretations of quality of life is to understand how they balance different aspects of their identity, including their sense of self, their relationships and their health. In describing the quality of life specifically, however, their responses were highly intrinsic, focusing on functional capacity and ability. Their wider narratives would suggest that being able to achieve more, they would be better able to retain their identity and core relationships.

Quality of life, as a comparison of what is and what was

As the largest node coded from the data, ‘Quality of Life’, could have been broken down into many, many smaller nodes. Instead, the existing project nodes will be allowed to speak for themselves. Of the original 109 references in the node, only about 40 were coded into child nodes, ‘definitions of quality of life’ and ‘value statements’, discussed here, prefaced by Geordie’s interpretation.

Quality. Ah, being able to do things without straining yourself. It’s hard to explain, ah, ah, how would I put it? Ah, I’d rather the quality than the quantity. Do you get what I mean? (Yep). I’d rather have, I’d rather stay like I am, than get worse and sort of have no functions at all, you know, like being able to talk…. I’d like to improve a little bit, but maybe I won’t, I don’t know, although the last couple of days I’ve felt an lot better because the weather sort of settled down a lot, and that sort of made me ah, you get on an even
sort of a keel; haven’t been waking up... that you can do different things that
normally I wouldn’t like to be confined to ah, not being able to get around,
you know, walk around or go to the toilet, or have a shower or dress meself,
or cook a feed or you know, them sort of things. Geordie

Here, Geordie manages to encompass many of the core factors that participants
described as quality of life, from personal independence to symptom control, and
balancing of good and bad days. Geordie also described his quality of life at the level
of the individual, bound in ‘I’ statements, as did many other participants, Gail
included.

I think my quality of life is being able to get out of bed myself, go and shower
myself, dress myself, without having to have help to do that. Gail

More than just performing tasks, as Gail implied, there was a general wish for
physical independence, to be free of tubing and mobility barriers. In speaking of
quality of life this way, there was a tendency to compare what was once possible to
what was currently possible, thus defining it as an ableism or deficit paradigm.
‘Quality’ seemed to stem from the capacity to do whatever, whenever, however;
more aptly, what I want, when I want, and the way I used to.

It means, quality of life to me would mean being able to do what you wanted
to do, when you wanted to do it and there not being any hindrance in you
being able to do it. Evan

As well as defining quality of life, participants were asked to rate their quality of life,
according to their definition, or their health status. These questions remained open to
interpretation by participants, several of whom responded with statements that
suggested the importance of the construct, rather than providing a value for what
their quality of life was. Gail’s understanding of the value of quality of her life was
that it ‘means a lot more than it used to.’ For some participants, the value ascribed to
their quality of life was so variable it changed between sentences, providing
conflicted definitions and value statements, and highlighting how confusing the
language surrounding the construct can be. Mae stated openly that she didn’t have a
quality of life, followed directly by ‘what I’ve got, I’m quite happy with. It’s not
bothering me.’

One interesting comparison was how people rated their health, rather than their
quality of life. Whilst John rated his health as poor, his understanding of health and
quality of life were vastly different, so rating his quality of life as ‘good’. This is
compared to Evan, who noted the inverse relationship - fair health and poor quality
of life. One interpretation of this disparity is that quality of life was a choice,
influenced by frame of mind and frame of reference. For John, who chose to look at
quality of life, as the quality of his whole life, he could see a good life; for Evan who
look from the perspective of loss and immediacy, quality of life was even more
diminished than his health.

It is important to note there were no direct references to mental health, emotional
wellbeing or spirituality when participants were asked to discuss quality of life
directly. Instead, when asked, most participants responded with highly pragmatic,
functional definitions of quality of life. As discussed previously, however, managing
the difference between functional needs of the individual to maintain physical
independence, was balanced with a more holistic need to be seen and treated as a
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person of value. This balance was reflective of their identity, as a person who was ‘not sick’ but instead one who was and is, and will overcome.

No story brought together the influence of identity, acceptance and management of change, and the influence of relationship on the perception of quality of life, more than John’s story. In reflecting on how COPD had changed his life, and his own transition from independence and interdependence to dependence, his sense of self remained grounded in his identity and worth, as a member of his family. Whilst change was never easy for him, he submitted himself to the routine of therapy and the care of his wife, as an act of love and reciprocity - to submit to care was to appreciate the act. Toward the end of the interview, John’s reflections on quality of life voiced the balancing act that emerged through each of the stories, that COPD was one aspect of a whole life, well lived. John’s story reflected the idea that Quality of Life was a fusion of intrinsic needs and desires with a holistic view, of time and others.

The Quality of a Life – John

As the final participant, John’s story became the taste left in my mouth after months of devouring story after story. John’s story settled a little deeper, for me, than others; his sense of duty and familial concern mirroring those I had experienced from the men of my childhood.

Of course, I was worried about my wife and 5 kids, because they’re the ones carrying the load... I've gradually lost the ability to do things, the garden, I don’t touch the garden now... I often say, my wife and my daughter, they look after me like a bit of crystal, they’re very careful of me, you know, always watching, sometimes that’s a bit of a burden, you know, they want to, you feel
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as though you’re, you’re a bit of a load on them, and you want to be left alone, you know, to sort things out yourself and not to be, not to be watched so much… at the same time, you know you’re going downhill and you become a bit more of a burden on them.

John’s instinct to protect his family was strong, and so too, his appreciation of the weight of burden he had become. In the discussion of his early medical retirement, he broke down several times, particularly at the points where he perceived that he had let people down. He went on to discuss how his declining health has continued to impact the life of his family, especially his wife. There was a life-long legacy of sacrificial love between the spouses, as well as a duty, possibly a reflection of the generation, the religious upbringing and their culture, that was being upset. This burden weighed incredibly heavily on him, to the point where he could not control his emotions.

My wife’s 84, you know, and I’m preparing for the fact that ah, I, I’d pass away first, but it might be that she’ll pass away, and it often happens, doesn’t it, the carer goes first, so ah, you can’t avoid these worries, and ah, so you’ve got them, but still you try to soldier on. John

John’s reflections of being cared for acknowledged that in a married couple, spouses bear the brunt of the care but also in the statement ‘but that’s what wives are for, isn’t it?’, that caring unto death is considered part and parcel of being married. This expectation and acceptance was metered, with the considerable fear for, or maybe because of, her age and health. In receiving this care, John also painted an interesting picture of reciprocity, in his life and its impact on his quality of life; that a life’s work
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allows you to sit back and receive care without the sense of burden that was seemingly felt more acutely by younger participants.

...we’re very involved with our community, [my wife] is... very interested in the refugees at present, but she’s always, when we were younger, our younger married life, we always took part in School activities; if things were going on at the Church, we’d join in, so ah, I’m quite happy about that, the, you know, we’ve done as much as we can. John

John’s idea that 'we've done as much as we can', differs from the currently pervasive worldview that ‘we can never do enough’. What I experienced in our time together was a man who had lived ‘a good life’, worked hard, loved his family and participated in the life of his community. He was now able to sit back, a little, and accept the care being provided by those people; his family and his community, knowing that everything had its time. This wider perspective of giving back, and a life well lived, shaped his perception of quality of life, that was so much more than this current experience.

Quality of life is being happy with those around you, quality of life is... if they’re happy with you. If they’re not happy with you, you’re making them miserable, and there’s no quality in that. My quality is with my family and my wife particularly (pause, emotional), yeah, I’ve been lucky. We’ve both been lucky; we had great parents, that’s where it starts.

The capacity to look back on his life and see it as a whole, did not protect John from the psychological or physical implications of the disease but did allow him to frame his suffering in a wider context. His quality of life was okay despite his declining health, because it reflected the breadth of his life. At the same time, COPD was
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never relegated to one aspect of his being, but as much a part of him as his family and culture.

_There are a lot of things that affect you, you know, your religion, and your family finances... the people around you, where you live, but ah, all these things are bound up a bit with your upbringing, you know, and where you worked, and your background, and all things; it’s not a sort of a solitary thing where you can, you can say ‘this thing is just COPD’, it’s not - it’s your whole life._

In setting the scene for a discussion of quality of life, John reminds us that COPD acts as a core dimension of the individual’s identity, making salient the dimensions of their lives that it tries to take away, both independence and relationship, which sit at the very heart of quality of life.

**Chapter Summary**

The participants described quality of life in pragmatic and functional language that reflected an internalisation of the concept, typical in the chronic disease lived experience. These descriptions however sat in contrast to much of the rest of their narratives, on what it was to live with COPD. Taking their functional representation of quality of life in the context of the previous themes, we see their definitions and descriptions of quality of life as the desire to do what they want, when and how they used to do it. This as a mechanism or measure to maintain physical independence, and through that independence sustain interdependent relationships in the face of mounting dependence. The implications of this deepened understanding of quality of life and its implication on decision-making, coping and engagement with the health community will be discussed in the next chapter.
Chapter 9

A Discussion on the Conceptualisation of Quality of Life

Introduction

This chapter builds on the themes of the previous chapters, linking the concepts and ideas established by the participants to each other and the established literature. At the level of the individual, the discussion focuses on how the participants’ identities inform the way they respond to functional decline, in line with the successful ageing psychological theory of Selection, Optimisation and Compensation (SOC) (Baltes & Baltes, 1990; Young et al., 2009). Looking relationally, the discussion will explore the nature of communication within care-dyads, families and with health professionals. Communication barriers, including self-perceived burden and ambiguous loss, will be discussed to establish context for both the nature of coping with advanced COPD, within those partnerships, and the wider description of the often paradoxical conceptualisation of quality of life for older people with advanced COPD. The chapter will conclude with a discussion of the issues faced by health professionals, generally and in the rural context, in overcoming barriers to improving quality of life, toward the end of life for those with COPD.

Thematic overview

Chapter 4, Context of the Research Findings, introduced the voices of the participants, to allow them to articulate their understanding of what it is to live with COPD, through their own narratives. Four major themes emerged from their stories that inform the following discussion of the conceptualisation of health-related quality of life, for older people with advanced COPD.
The theme ‘Accepting Change’, reflected how the participants constructed their identity and sense of independence as people whose lives were impacted, but not defined, by their COPD. It was from the participants’ understanding of themselves and their priorities that they were able to accept the changes occurring in their bodies and respond to those changes through self-regulation. The specific response described in the second theme, ‘Mind over Matter’, suggested that participants worked to create an equilibrium in their daily life, where symptom management, change and uncertainty, were controlled using a range of psychosocial strategies, supported by more traditional medical interventions. Critical to the success of interventions, and this coping style, was the manner in which change was communicated with the individual, allowing them to perceive interventions as part of the process of adaption, rather than yet another source of change.

The coping strategies used by the participants reflected their priorities, which in turn reflected their desire to maintain their own sense of identity and physical independence. One impetus for maintaining independence was explored in the third theme ‘Being in the World Together’. By maintaining physical independence, the participants were able to shelter their family from the full burden of their care. Additionally, they were able to reduce the emotional impact of the perception of burden for their adult children. This played back into their identity as an active and valued member of the family. Whilst this perceived burden encouraged many to engage with coping strategies that removed burden from their care-givers, it also affected their decision making regarding end of life care and planning.

The participants’ pragmatic discussion of quality of life was balanced between their desire for physical independence, identity and meaningful relationships in the final
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theme, ‘Quality over Quantity’. The desire for independence, which stemmed from their sense of identity and role within the family, underpinned their conceptualisation of quality of life, as not just their own quality of life, but the quality of the lives of those they loved. It is from this understanding the following chapter will discuss the themes, in relation to the established literature and each other.

Accepting Change

A Cycle of Acceptance

Participants wove their historical context throughout their narrative, detailing how their past experiences shaped who they had become. Their historical situatedness became the lens through which they discussed their current circumstance and described their present horizon. In accepting the changes that were occurring to them physically, they entered a seemingly cyclical process of change and adaptation that had the capacity to reinforce their ability to accept more change, together with uncertainty of change, into the future (Figure 9.1).

New change was perceived in light of past experiences, and accepted well when the manner in which the change was communicated to them was successful, especially in the case of externally mediated change including therapeutic and adaptive technology interventions. As change was initiated, participants entered into a cycle of adaptation, where the success of navigating change bred greater confidence that further change was also able to be managed well. Evidence of this positive feedback was seen time and time again, narrated throughout the participants’ stories. In addition to past successes of smoking cessation, other examples included Laurel successfully navigating leaving the house, and overcoming her anxiety, by using suitable medication, Valerie continuing to take holidays because of successes
travelling with her oxygen concentrator. Mae described feelings of connectedness and safety, as she successfully used her walker and portable oxygen cylinder when visiting her local club.

**Figure 9.1** Successful adaption to change. Past experiences of navigating change, self-regulatory behaviours and effective communication of change rationale and possible mechanisms, can all facilitate adaption, which in time become additional examples of past experiences that allow the individual to perceive and accept new change with a positive attitude.

These positive experiences honed resilience, for many participants, even when change was more difficult to implement or to adopt (Figure 9.2). This resilience was seen in Ruth’s story of changing diuretic medications. Ruth was willing to persist in the trial of new medications, largely due to her trust in Bernadette, despite her experiences with her mother’s COPD when medications were much more limited and less effective than in the present day.

With time, and the build-up of less positive experiences, resilience to poorly executed change implementation without adaption, tended to shift acceptance toward
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the negative (Figure 9.2). In these situations, participants’ repeated exposure to, and experiences of failing to adapt to change, eroded confidence and triggered anxiety. This was evident in Mae’s not being willing to quit smoking, and the attitude she held towards people who encouraged it. The same is true of Camilla’s retirement from community engagement, due to multiple instances of public breathlessness, which she deemed embarrassing and distressing for herself and others.

Figure 9.2 Successful and unsuccessful adaption to change over time. Past experience of successfully navigating change created resilience for the participants so when adaption was unsuccessful, they were able to learn from the experience and move back into the cycle of adaption, as their identity was unaffected. With repeated failure to adapt, however, feelings of fear and frustration emerged, affecting the way they engaged with change into the future, altering their identity, to reflect their resignation at not being able to cope with ongoing change.

It was Vida’s story, however, where the movement between the cycles of change and adaption and the impact of COPD over time, became most salient. Early in her story, Vida spoke of walking down the street to the shops. Over time, that walk changed routes and included window shopping, breaks and rest periods, to accommodate increasing impact from symptoms and fatigue. At the time of the interview, years
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after she had ceased walking to the shops, Vida still identified leaving the house as a trigger for breathlessness and panic attacks. Years of steady adaption had been worn down by increasing symptoms, anxiety and fear of oxygen therapy; paradoxically the fear of having oxygen and a fear of being without it. The net result was that she would not leave the house, willingly. Whilst her husband had taken the lead in managing her anxiety, having experienced so few successful transitions from house to car, transition between oxygen systems (fixed and portable) and the logistics of preparing to leave the house (dressing, gathering required personal items) in the recent past, meant she still resisted the idea. Vida clearly demonstrated self-regulation and resilience earlier in her COPD story, but many years of poor experiences and functional decline had worn down her confidence and her joy at being out in the world.

Understanding the cyclical nature of acceptance of change, as well as how it is shaped by past experiences and symptoms, is critical to an understanding of quality of life, in advanced COPD. Through slow and constant adaption to both change and uncertainty, each participant learned to live with their COPD without being defined by it. Using a blend of self-regulatory and therapeutic mechanisms and strategies, each maintained roles, ritual and activities that facilitated their sense of identity within themselves, their families and to a diminishing extent, their communities.

An Identity of Change

Using past experiences to contextualise present experiences sits close to the heart of Gadamer’s philosophy of hermeneutics. The idea relates not only to historical situatedness and personal horizons, but to his discussion of ‘sameness and otherness’, which is a way to come to understanding by comparing ‘the new’ to our
present understanding and assumptions, and seeing what is different (Simms, 2015). The participants used their stories to argue that they were the same people as always, despite their COPD. In essence, they had maintained a sufficient ‘sameness’ in their identity, particularly in the face of mounting ‘otherness’ (i.e. physical change and functional decline), so as to still be who they thought themselves to be; spouse, friend, parent, valued by others, able, or simply being someone worthy of love and care.

It was in cases where identity was precious and protected, that transcendence was more likely to be displayed. This transcendent behaviour was one attribute that allowed them to accept the changes that were happening in their body, to conceptualise, as part of their identity, being a person who was subject, and able, to change. In addition to a history of change, their daily experience of symptoms, and symptom variability, served to remind them of their mortality and increase the ambiguity surrounding their situation.

When exploring the relationship between self-transcendence and acceptance, within chronic disease literature, these constructs were linked with the idea of spirituality (McCarthy & Bockweg, 2013; Reed, 2008). This connection ran, partly true, within this study where spirituality and religiosity were central to a number of the participants’ perceptions of suffering and change, but the link was certainly not universal. Within the Australian context, where religion and spirituality are often considered ‘private matters’, Unantenne, Warren, Canaway, and Manderson (2013) described the power of spirituality to assist in transcendence, as was demonstrated in Laurel’s story. She used her growing spirituality to facilitate acceptance and change, not just in her own life but that of her family.
More commonly, the participants’ transcendence was seen in the way the participants were able to live with paradox; hope and hopelessness, or the unwillingness to plan for death despite its inevitability. The participants’ stories tended to align more closely with the Davis and Magilvy (2000) interpretation of transcendence, a ‘shift towards the older adult’s acceptance of the chronic illness’ (p.387). The participants’ stories clearly demonstrated transcendental attributes, however, these were not related to their illness directly, but rather, the changes that COPD triggered in them, as opposed to spirituality. As such, the findings of Davis and Magilvy (2000) and this research aligned to the work of Benner (1994) and Charmaz (1991) who described the impact of transcendence as ‘coming to terms with the reality of illness and its demands, despite feelings of anger and hopelessness’. Davis and Magilvy (2000) noted the absence of resignation or passivity, in the participant group, which was incongruent with the stories of some of the experiences recorded in this project.

Salience of the daily experience of symptom burden, and variability for the participants, was not evident within the existing literature. Despite this, the findings of the current research would suggest that it was an awareness of change, from hour to hour, day to day and month by month, that became the litmus by which larger change was measured. It was through the recognition of the volatility of their condition that the participants sought meaning in their life, and shifted their sense of self to reflect their ability to understand, interpret and manage change. To this end, COPD-related change was accepted more freely than the diagnosis of COPD, and in doing so, shifted this dimension of their identity to focus on their ability to adapt and respond to ongoing change rather than focusing on their identity as a person who ‘is sick’, another hallmark of transcendence (Reed, 2013). The blend of transcendence
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and acceptance allowed participants to maintain identity and hope, as well as manage COPD-related change, without accepting the ‘label’ of COPD.

Duggleby et al. (2012) explored transcendence, in the context of hope, in older people with chronic illness. The authors noted that the participants’ ability to rise above their current difficulties came from using inner strength derived from their beliefs, memories and past experiences. As well, others contributed including connectedness to family, friends, health professionals, the natural world and the divine. It was from this position that older people filtered their perspective on current suffering and condition; described in Laurel’s experience of spiritual transcendence and John’s holistic description of quality of life wherein quality of life was about much more than the present moment.

Bound up in the participants’ hope for the future, was a desire to maintain physical independence. Pinnock et al. (2014) and Falter, Gignac, and Cott (2003) both discussed the tendency of people with COPD to prioritise tasks in order to maintain a sense of independence. The value of maintaining physical independence lay, primarily, in a desire to retain dignity and privacy. In particular, personal care, but also sheltering, or protecting, primary carers and family from the full physical and psychological impact of the ever increasing burden of their care.

Prioritisation of tasks, to preserve independence, manifested pragmatically for the participants. The preservation of independent self-care, or refinement of valued activities, congruent with the self-imposed limitations, that participants employed, assisted in decreasing risks of potential exacerbation. Critically, the desire to maintain a sense of independence became a powerful force in the motivation required to prevent deterioration, and manage change. In maintaining tasks and
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activities, participants asserted their roles and identity, facilitating resilience. For Laurel, the ability to provide for her family reflected her need to be needed, and loved. In creating a sustainable environment, that drew her family into her home, she bolstered the aspects of her identity that met her existential and emotional needs, whilst compensating for the aspects of her personality and abilities that were lost, through the death of her husband and her own declining functional capacity.

As the participants’ priorities reflected their desire for independence, and identity as a person who was more than just the disease, so too were the ways that they responded to those changes. Each used personal resources to maintain physical independence; a ‘mind over matter’ approach to manage symptoms and change. Integral to the success of those coping strategies was the influence of the health professionals, who worked to embed effective interventions into the participants’ lives.

Mind over Matter

Successful Ageing in COPD

Living with COPD becomes a balancing act of the mind and body, not engendering equity between them but for the mind to compensate, mitigate and overpower the ongoing changes of the body. In exploring how this balance is established and maintained over time, the strategies used, linked closely to the established healthy ageing theory of Selection, Optimisation and Compensation (SOC) (Baltes & Baltes, 1990). Baltes and Baltes (1990) outlined the mechanisms by which older people adapt to ageing, in the presence of functional decline. The theory suggests that as people age, they are able to transform dimensions of their life, to maintain independence and purpose, through the reshaping of goals, expectations and
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activities. This is achieved through the three mechanisms of SOC; Selection (of goals for which resources are focused), Optimisation (maximisation of gains) and Compensation (for losses in ability) (Baltes & Baltes, 1990). Whilst SOC has traditionally been explored in the context of healthy ageing, research in the area of Osteoarthritis (Gignac, Cott, & Badley, 2002), Macular Degeneration (Bouchard Ryan, Anas, Beamer, & Bajorek, 2003), Alzheimer’s Disease (Rapp, Krampe, & Baltes, 2006), and advanced Dementia (Volicer & Simard, 2006) have noted the presence of SOC behaviours within their cohorts. Additionally, from a care provision perspective, research into acquired brain injury rehabilitation suggested that SOC theory was an effective framework for a person-centred approach to goal setting (Donnellan & O’Neill, 2014).

SOC theory involves the orchestration of selective, compensatory and optimisation-based self-regulatory behaviours in response to functional loss(es). SOC theory can be viewed as a holistic integration of adaptation in which the individual masters higher levels of functioning. Simultaneously, it can be separated out into the three discreet processes of development, which play into a wider experience of adaption, as outlined here (Donnellan, 2015).

Selection was demonstrated throughout the participants’ narratives in the way they prioritised tasks, particularly self-care and valued activities, over other activities of daily living, home care and community mobility. This reflected the desire of the individual to maintain dignity and privacy above all else, with a secondary priority for tasks that maintained engagement with core relationships, and activities that provided both joy and identity. When tasks were de-selected, they were often done so for both physical/pragmatic reasons, as well as to avoid negative emotional responses. This was seen in the way the participants imposed restrictions on when
they could leave the house, being guided by the weather and time of day to prevent health deterioration (i.e. exacerbations).

There were quite specific ways in which participants optimised their function to achieve personal tasks and goals, predominantly slowing down the pace of activity performance. Initial optimisation techniques tended to be subconscious, although deliberate planning of activities, lowering of expectations, taking breaks and establishing routine, all became conscious decisions over time. Vida described the nature of this change directly, as she recounted her experiences of walking down the street, where increasingly she chose easier routes or take short, opportunistic breaks. Goal-setting was also critical to the optimisation of tasks. Participants noted that one way to slow things down was simply to expect less of themselves, accepting that they wouldn’t achieve what they used to. By resetting goals, there seemed to be a reduction in the level of frustration. Importantly, these participants were not removing goals completely, or handing over all responsibility to others, instead they were being more gracious in accepting how much they could achieve in the day.

Of all the optimising strategies used, it was the participants’ capacity to manage emotions and symptoms when they are at their worst, through an internal dialogue, that resonated across each of the stories. This strategy was often instigated to prevent, or reduce, anxiety, panic attacks and breathlessness, as was recounted by Ruth, Vida and Laurel, throughout their stories. Each of the women depended heavily on their primary care-giver, medication and oxygen in those situations. It was self-talk, however, that allowed them to internally mediate their thinking, and make and execute plans while distressed.

Participants used a wide range of interventions and aids to compensate for their symptoms, and functional decline in their daily living. Interestingly, there was no
one aid that all participants used, suggesting that interventional approaches need to be viewed as individual rather than generalised. Medication and oxygen were the dominant interventions, although mobility aids and paid care providers were well utilised, in specific situations. Donnellan (2015) postulated from the literature that SOC could have two distinct trajectories for older people. Firstly, as people age, their accumulated life experience would facilitate greater implementation and integration of SOC strategies. Alternately, SOC could be seen as resource dependent, thus as functional capacity declined, so did the individual’s ability to initiate and facilitate adaption this way. The findings from this research suggest that the participants in this study used past experiences of coping with change to support the self-regulatory behaviours that minimised loss and maximised gain. This appeared to happen not in direct response to functional decline, but was rather, governed by where in the process of adaption (Figure 9.2) they were for that specific goal.

This is not the first study that has linked coping and adaption, in COPD, to SOC Theory. Building on the work of Falter et al. (2003), it is suggested here that not only do participants engage with the principles of SOC, as they adapt to physical and psychosocial change associated with their condition, but because of the nature of accelerated ageing in COPD, they are forced to adapt at an accelerated pace. This, then, contributes to the wider debate on the nature of successful ageing highlighted by Young, Frick, and Phelan (2009), disagreeing with the notion that to have a chronic condition is to automatically be precluded from the categorisation of ‘ageing successfully’. By assuming that one cannot age well, in the presence of a chronic condition, it may be easy to fall into the historical trap wherein one assumes that poor health leads to a poor quality of life, or that poor health precludes living well, which according to the findings of this project, is not necessarily true. This is not to
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claim that to have COPD is to be able to age successfully, and would not be considered correct for several participants of this study. Instead, it is demonstrated that, for some people with COPD, they are able to manage changes associated with ageing and also the unpredictable, often rapid, and significant changes associated with COPD. By using those mechanisms, associated with a more traditional theory of adaptation to ageing (SOC Theory), many participants have been able to transform their way of living, to maintain independence, identity and purpose, that is, to age successfully.

Equilibrium

In exploring coping with COPD, through the lens of SOC Theory, the ability to accept change facilitated a range of pragmatic responses. These strategies became more conscious and deliberate over time. That is, participants recognised the increasing impact of functional decline, but developed a largely self-honed resilience against COPD’s insidious nature. Participants drew upon their personal resources, belief systems, motivations, and an array of past individual and shared experiences, to facilitate well-being and quality of life. Using these resources enabled them to balance their current state with the experiences over a life time. In seeing themselves as part of something bigger, COPD was internalised, as an aspect of their identity; it was not seen as the addition of something new but rather, the loss of a part of themselves. These strategies were complemented by a variety of compensatory interventions, such as medication, oxygen therapy and assistive and adaptive technologies.

Critical to establishing the balance of mind over matter, was management of the ‘body’; the place of health intervention. Medications regimes, oxygen therapy and
assistive technology were generally extrinsically driven and facilitated by health professionals. Standard interventions were routinely implemented generally without the individual challenging questionable efficacy, and used despite frustration. The appearance of passivity in their acceptance, of these interventions, contrasted heavily with the self-regulatory coping strategies they had developed over time. Whether actively or passively initiated, it was when these strategies were used together, that the participants spoke with a sense of future, hope and defiance; intimating that the mind was in control of the body. What is presently missing, from current literature, is discussion of the efficacy of resilience-based interventions and the effect of psychological support, that may facilitate increased optimisation and resilience, which may assist in the process of adaption and improved mental health in older people with COPD (Keil, Vaske, Kenn, Rief, & Stenzel, 2016; Kong & Lee, 2015).

**Being in the World Together**

**Barriers to Family Communication**

Whilst care-giver fatigue, and burden, has been widely explored in the context of chronic disease and palliative care literature, care-givers make up only half of the care dyad; the voice of the care recipient has only recently been explored from the perspective of ‘being a burden’. The seminal work of Cousineau, McDowell, Hotz, and Hébert (2003), then McPherson, Wilson, and Murray (2007b) articulated the idea of ‘self-perceived burden’ (SPB), through their research, into the experience of people with chronic disease at the end of their life, respectively. This phenomena has been described only once in COPD before, but never through qualitative research, nor is the research currently available in the English language. This quantitative research in older people confirmed high rates (75%) of some degree
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self-perceived burden in older people with COPD, which was influenced by disease knowledge and severity as well as the health of their care-giver, although little additional detail is available (Xu, Liu, Xian, Huang, & Yu, 2011).

In their explorations of SPB, at the end of life, McPherson, Wilson, et al. (2007b) defined it as “empathic concern engendered from the impact on others, of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self” (p.425). McPherson, Wilson, Lobchuk, and Brajtman (2007) suggested that care-receivers were fairly accurate in articulating how much of a burden they were to their care-givers, while recognition of SPB by care-givers was considerably lower. How heavily SPB weighed on the care-receiver was more likely to be associated with their affective state rather than the degree of physical impairment they experienced. In dyads where one person had terminal cancer, McPherson, Wilson, Lobchuk, et al. (2007) demonstrated a clear association between SPB and care-giver burden. It could be seen that the care-giver often underestimated SPB, in the partner, suggesting two things; that care-givers have a stronger sense of the physical rather than psychological needs, of their partner, and may also infer the care recipient is not communicating need effectively. This is considered to be more commonly associated with ‘protective care receiving’, where physical and psychosocial needs are concealed to protect and prevent an overwhelming burden on the care-giver. The lack of communication seemed to be an adaptive choice rather than ‘just’ poor communication (McPherson, Wilson, Lobchuk, et al., 2007).

What became apparent, through the research, was that actual and perceived burdens were not placed on the same individuals, but rather, actual burden was generally placed on a single primary care-giver, where perceived burden was more commonly (McPherson, Wilson, Chyurlia, & Leclerc, 2010) associated with adult children. This
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actual burden was well understood, and the care provided was well tolerated, which may reflect the impact of reciprocity on the coping of that care dyad. SPB is commonly associated with Equity Theory, that suggests that individuals will work to maintain a balance of benefit and contribution, to a relationship. In the situation where a member of the dyad considers themselves to either over, or under-benefit, in the relationship, the individual will act to regain equity of reciprocity; as inequity can lead to negative impacts on both members of the dyad (McPherson, Wilson, & Murray, 2007a).

There are two primary mechanisms of regaining balance, in the presence of inequity described within the literature; balance restoration and altered relationship perception (McPherson, Wilson, et al., 2007b). Evidence of balance restoration, or lack thereof, was seen in both Mae and Evan’s stories. In dyads, as described between Mae and her son, there was a balance of reciprocity between the physical care provided by her son and the financial security provided by Mae, as the homeowner. This was different to Evan’s experience, where he did not feel he was able to adequately reciprocate with his wife’s role as breadwinner, care-giver and home-maker, this becoming a trigger for negative emotional responses. In dyads where a wife was being cared for by her husband (Ruth, Vida, Camilla), the coping strategy tended to lean more towards an altered relationship perception, that was, care-giving being seen as an act of love from the spouse, and well accepted as an extension of the marital role. Thus, these wives tended not describe their spouse as a lover, or rarely even as a companion, but rather a care-giver. This reconceptualisation of roles, indicated a strategy to cope with over-benefitting that did not result in a weakening in the relationship, as these relationships generally remained or even increased in intimacy, with that conceptual shift.
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As a result of over-benefitting from care, most participants acknowledged the actual burden they were becoming for their primary care-giver. The weight of self-perceived burden, however, surfaced within discussions involving adult children and their role in current and future care. Whilst only two of the participants were being directly cared for by an adult child, much of the emotional turmoil for participants, and response to SPB, was triggered by the risk that they could become a future burden on their children. It was within this context that the participants responded to SPB, or the risk of SPB, by increasing their uptake of coping strategies and implementing Advanced Care Planning.

The perception of what it was to be a burden, was grounded in the participants’ past experiences of having been burdened. These experiences projected forward, influencing the way participants planned for the future. The links made between past, present and future were distinctly overt when compared to other cause-effect descriptions, such as smoking history and pathogenesis, which was discussed with a sense of denial. Rather, discussion of burden and its implications were remarkably direct and self-initiated, that was, rarely stemming from direct questioning.

Feelings of self-perceived burden became a primary warning signal for the need for behavioural change. The motivation to protect family and support people from the full emotional and physical impact of their condition, and care, triggered several adaptive responses. Evidence of this was seen in the way the participants used SOC strategies to cope with COPD, adapted their wishes for Advanced Care Planning to alleviate burden, or past experiences to build resilience to change. Less positively, changes in communication were also noted in response to SPB, particularly under-communication and purposeful restriction of information, evident in both the data and literature, as a coping mechanism (Northouse & Northouse, 1988).
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In addition to SPB, and to add to the complexity of intra-family communication, there is a level of uncertainty experienced in COPD, seen in few other disease states (Boss & Yeats, 2014). Vida broached the idea of this uncertainty in her discussion of when she would die, while Geordie linked uncertainty to the variability of symptoms and day to day capability. These uncertainties are known sources of ambiguity that affect the individual and the family (Boss & Couden, 2002).

Within the literature, breakdowns in family communication may also be associated with the theory of Ambiguous Loss (AL), in which there is ambiguity surrounding the certainty of the loss, which creates a paradox of presence and absence of the individual (Boss, 2007). Specific to COPD, ambiguity associated with lack of progression, and the variability of symptoms, may trigger the immobilisation of family roles, rituals and responsibilities that can lead to poor communication, conflict and relational collapse. In an environment where there is a distinct lack of certainty, discussions regarding change may be considered pre-emptory (Boss & Couden, 2002).

The idea of immobilisation resonated with the fear-avoidance previously discussed in the management of panic attacks and dyspnoea. Both strategies are known to be as, or more, disabling than the symptoms, and the outcomes, trying to be avoided (Boss & Couden, 2002; Northouse & Northouse, 1988). This combination may speak to the low actualisation of Advanced Care Planning in the group, where only two of the eleven (Ruth and Gail) had anything more than a ‘Do Not Resuscitate’ order at the time of the interview. From the perspective of health care provision, the combination of immobilisation, and fear-avoidance, are likely to complicate discussions surrounding advanced care, and transitions from curative to comfort based approaches and palliative care services.
The Paralysis of Politeness

Common barriers to communication, in the care triad, were outlined in Chapter 2. In relating these barriers to the findings of this project, there was a strong overlap in the themes (Figure 9.3). What the data added to this framework was an understanding of the motivating force behind these barriers, not fear, stress or disease, but love. In light of the positive intent of this motivator, the framework is termed here The Paralysis of Politeness; the communication barriers of good intentions.

Figure 9.3. The Paralysis of Politeness: Barriers to effective communication within the Care Triad.

In alignment with the established literature, the perception of the participants as ‘not being sick’, sat as a core barrier to communication, whilst the desire to maintain independence served as a barrier between the participants and their informal care-giver. Looking at the motivation behind this sense for independence, it was largely the participant’s own desire to protect their loved ones that motivated behavioural change, which facilitated independence. Here, seeking independence was an act of love and protectivism.
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In addition to the established literature, both Ambiguous Loss and Self-Perceived Burden factored into all participants’ ability and willingness to communicate with their primary informal care-giver. As the individuals regulated feelings of self-perceived burden, this tended to manifest as withholding or under-communicating stress, due to the need to protect their loved ones and care-givers from the full physical and emotional impact of their illness. Additionally, increased ambiguity can create both confusion and conflict, regarding when and how to initiate difficult conversations and implement change (Boss & Couden, 2002).

The wider implication, of the Paralysis of Politeness, is that in this state, no member of the triad is unilaterally aware, willing or equipped to challenge the equilibrium the individual has established to maintain independence. The flow-on effect is that opportunities to improve quality of life through changes in coping strategies, or to be more honest and emotionally intimate, are missed. Alternately, if and when change is instigated, by any member of the triad, it is highly reactive to a crisis situation such as an acute exacerbation, and so potentially occurring without the input of the individual or their informal care-giver (Kaasalainen et al., 2011).

Importantly, there is a strong risk that opportunities to work with the individual and their family, to put measures in place that will assist in a ‘good death’, will also be missed. These measures include but are not restricted to transition from curative to comfort-based management and effective Advanced Care Planning, both of which are known to increase quality of life, at the end of life, for all parties (Mousing, Timm, Kirkevold, & Lomborg, 2014).

The participants shared stories which indicated, that when health professionals intervened in their care with authentic and relationship-based encouragement and
options, it served to increase the quality of their life. Further, most participants gave permission for relationships to be built within the care triad, as well as permission for the sharing of information. To facilitate this, Health Professional/care-giver communication must become normalised, but not at the exclusion or undervaluing of the Health Professional/care-receiver relationship. Family, directly or indirectly, have a strong influence on care planning and ACP decision making (Silveira, Kim, & Langa, 2010). If this influence is grounded in mis-information or poor communication, health professionals may lose what limited opportunities they have to promote quality of life for every member of the team, over the entire journey of COPD, particularly at the end of life.

‘Quality over Quantity’

The Idiosyncratic Nature of Quality of Life

How do older people with COPD conceptualise health-related quality of life? In essence, they don’t. The critique of HRQL measures, by Moons, Budts, and De Geest (2006), suggested that assessment of the HRQL construct requires the individual to differentiate between the dimensions of their life, their health effects, and those dimension that remain unaffected. When the findings of the present study were viewed, in light of Moons et al.’s work, it became clear that asking a person, with COPD, to separate their health from the rest of their life, could play into the creation of a disability paradox, in this group.

Central to the complication of this differentiation, for the participants, was their perception of identity. It was rare for a participant to identify as ‘being sick’ (n = 2/11) unless acutely unwell i.e. having an exacerbation. Perceiving themselves as unfit (Evan), simply getting older (Valerie, Camilla) or prioritising other health
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cconcerns (Clem), seemed to prevent those participants from fully comprehending the impact of COPD, specifically, on their lives. Alternately, the three participants who described their health in relation to an acquired physical disability, specifically, the loss of a limb through amputation, highlighted the intrinsic yet far-reaching implication of disability, rather than disease state, on quality of life. Even John, who did identify as being ‘unwell’, spoke about COPD as something that affected all aspects of his life.

Overwhelmingly, through the participants’ narratives, COPD was seen not as a ‘diagnosis’ or even a disease state, but more as a source of change that had insidiously woven itself into their being. COPD was seen as an entity central to their personhood, which rather than being added to them was a natural progression of who they were, that changed them in both positive and negative ways, chipping away at their functional capacity; an inseparable dimension of who they were, as inevitable and constant as ageing.

What older people, with advanced COPD, do conceptualise, is the ‘quality of their whole life’ and the quality of the lives of the people they love/care about. In taking a more longitudinal view, they seemed to meter their current situation with past experiences, both positive and negative, playing into their cycle of adaption to change (Figure 9.1). A positive outcome, of the balance of past, present and future, was for some a transcendent attitude to suffering and death, whilst the emotional impact for others, who struggled with this balance, tended to manifest as resignation to a downward trajectory of health, towards disability and death, as described in Figure 9.2.
Additionally, the inclusion of others’ quality of life, into the participant’s conceptualisation of quality of life, must be considered. This inclusion was seen most prominently in the discussion of self-perceived burden, ambiguous loss and the care-receiver/care-giver dimensions of the Paralysis of Politeness. Factoring the welfare and happiness of others, in their own quality of life, became a motivating force behind the implementation and/or uptake of many adaptive and coping strategies (Chapter 6), as well as a primary motivator for the articulation of Advanced Care Planning; that was, to protect their support network from a negative experience of their death.

In examining these findings, from the perspective of Gadamer’s constructs of tradition and horizon, each participant came to their understanding from a different horizon, willing to engage with other perspectives and truths, and open to the shaping of ideas and opinions. They also came with their own tradition, history and understanding of quality of life, that informed the way they selected stories, crafted their narrative and underpinned their interpretation of the questions asked. Across the breadth of their stories, the participants spoke of physical and psychosocial well-being, of course, but also of spirituality, emotions, social and civic engagement.

What became salient in this exploration of quality of life, rather than the conceptualisation of the construct itself, was an all too common misuse of terminology, particularly quality of life and HRQL. A limitation of this study was the interchangeable use of the terminology, outlined in Chapter 1, associated here and in the wider literature with limited conceptual or theoretical knowledge of the constructs, and complicated by the lack of consensus regarding their definitions (Post, 2014). Moons et al. (2006) made a strong argument for health professionals to
Quality of Life in COPD

increase their awareness of the impact of interchanging terms that are not synonymous. Whilst it is the finding of this research, that HRQL is not conceptualised by the research participants, it is not a call to say it has no clinical utility. Rather, the use of measures of quality of life and HQRL should be grounded in the knowledge of the strengths and limitations of the construct, and the appropriate selection of tools, should be a priori in research and longitudinal client assessment. This research adds detail contextualisation to these discussions for the specific population studied. Specifically, older people may consider the quality of their whole life, despite the fact we wish only to assess quality of life related to their current health. Secondly, that people with COPD may not compartmentalise the domains of their health, and well-being, influenced by their condition traditionally measured by HRQL, as they see their COPD, and COPD-related change, as affecting the whole self. Thirdly, that a lack of knowledge of the condition can complicate assessment and differentiation for the individual, so the use of medical language, or even the term ‘COPD’, may affect responses to assessment questions. Finally, greater understanding, by health professionals, regarding technical language is warranted; understanding that both quality of life, and HRQL, will be understood and interpreted at the level of the individual, based on their assumptions and horizon. As words, ideas and constructs will all mean different things to different people, those differences will also extend across the life course and disease state. This presents a challenge, and opportunity, to engage with clients, as assumptions and meaning barriers are broken down, and so achieve the goal of better quality and more impactful communication, together.

This last reflection on language and assumption links directly to the work of Moons et al. (2006) who noted the tendency, with health literature, to use quality of life,
Quality of Life in COPD

HRQL, Health Status and Perception of health measures, as indicators of each other. Furthermore, there was an unconscious bias toward the measurement of ‘global’ quality of life in the ‘normal’ populace, as opposed to HRQL in groups with a diagnosis, and in so doing creating a disability paradox for people who stray from normalcy (Moons et al., 2006). On personal reflection, these comparisons of unequal assessment, assist in the maintenance of the pervasive and ableist narrative that poor health equates to poor quality of life, as well as the facilitation of the disability paradox.

Critically, to change the narrative around COPD, away from stigma, disability and uncertainty, health professionals need to be empowered, and equipped, to engage with tough issues and create an environment where complex conversations can take place at times of calm, rather than times of crisis. In establishing a culture of open and empathetic communication, in regards to quality of life, many of the complexities surrounding the management of coping strategies, end of life and palliation, as well as the prognostic paralysis, could be circumvented.

Responding to a New Understanding of Quality of Life

Whilst a description of how the participants coped with change is central to this exploration of quality of life, the wider discussion of how health practitioners engaged with the process, of change management, is critical. Further, a new understanding of quality of life, for older people with Stage IV COPD, can help inform how health professionals engage with these clients. The participants described both positive and negative exchanges, with their health care team. At the heart of the positive experiences were descriptions of empathy, timely guidance and
recognition and facilitation of the goals of the individual, namely the facilitation of independence and the protection of loved ones.

In the case of this research, the impact of rurality, and access to services, cannot be overlooked. At the time of data collection, in the Regional city where the study was conducted, there was no local access to a Specialist Respiratory Physician or advanced pulmonary function testing. The RCCP employed one Respiratory CNC who had access to multi-disciplinary support, and consultation-based Palliative Care service, with little or no access to hospice or community-based palliative care. This situation is highly representative of many regional and rural communities throughout Australia (Agency for Clinical Innovation, 2014; Rosenwax, Spilsbury, McNamara, & Semmens, 2016), placing the care of people at the end of their lives in the hands of generalist, community nurses, General Practitioners and specialist Respiratory Nurses (Agency for Clinical Innovation, 2014). As such, each participant’s primary health care providers were their GP and the Respiratory CNC.

From the Australian perspective of chronic disease management in non-metropolitan areas, it is unlikely that rural health services will access sufficient specialist psychological or palliative care support for patients in the near future (Agency for Clinical Innovation, 2014). Additionally, the participants seemed not only comfortable with their existing health support, but comments, made by Clem and Gail, would suggest that the fragmentation of care to alternate services would be seen as potentially deleterious. Rather than focusing on prognostication for transfer into alternate services, such as Palliative Care, I would suggest that the focus of improved service delivery, focuses on how Health Professionals can take the best of those services and embed those practices into the existing structures. By way of example, as access to specialist palliation was not readily available for these
participants, there are palliative processes that may be readily applied to the end of life, in COPD, through the upskilling and support of health professionals working in this space, in rural Australia. At the heart of the participants’ requirements, from their health care team, was empathy, timely guidance and facilitation of the goals of the individual.

Empathy, defined by Theodor Lipps, is the ability to ‘internally resonate with and mirror another person’s mental state, when we observe their activities or their bodily gestures’ (Stueber, 2013, p. 724). Gadamer, however, refuted the idea of empathy as ‘epistemologically naïve’, as the construct negated the importance of interpretation, tradition and prejudice, in the way we understand the emotions and actions of others. In exploring each participant’s experience of therapeutic relationships, the nature of effective communication included proactive, informed and empathic dialogue, which reconciled their past experiences (particularly of sub-optimal care) with the proposed change or information. What the participants asked of their health professionals, and received from Bernadette, was not ‘walking a mile in another man’s shoes’ empathy, but more a fusion of horizons; deeper understanding of their experience by another whose own horizon was grounded in clinical knowledge, wisdom and experience.

The request for timely guidance covers two core ideas from the data. Firstly, that there is a sense of responsiveness from the health professional, and secondly, that information provided is exactly that, information. It was important to the cycle of adaption to change, that decision making was left to the individual and their support network, but was grounded in the knowledge of their health-care team. Camilla’s experiences with her GP highlighted the impact of unresponsive health professionals. It was the lack of communication, from her GP and lack of trust in the GP practice staff more widely, that made her feel dismissed. In not trusting that her GP would be
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available in times of crisis, Camilla had shifted all her trust to Bernadette, who acted as a conduit for information between Camilla and her GP, who she considered a friend, in the past. Alternately, Clem’s experience of a thorough and patient GP, meant he felt comfortable to ask questions and seek information directly, as he trusted and appreciated the GP’s thoroughness and attention to detail. In this case, Bernadette functioned as an additional support person, and source of information, rather than the link between the two parties. Whilst Clem was resigned to health decline, he and his wife both felt most comfortable in the care of their GP, and Bernadette.

The other dimension, of timely guidance, was the provision of information and the permission for the individual to make decisions based on the combination of that information and their knowledge of self, and their support network and/or family. Ruth’s story reflected the power of open communication and self-determination, in the way she led the process to establish her Advanced Care Directives with her family. She was able to learn to advocate for herself, in health settings, when experiencing anxiety and/or care that was inappropriate for the condition. The flow-on effect, of increasing her self-determination, was her willingness to engage in the discussion of medication change. She developed the confidence to ask for, consider and make informed decisions about her medication, with the support of her health team. In so doing, this particular change, the alteration of her diuretic medication, was seen as a positive step forward, rather than the rectification of error or mismanagement. Ruth’s expressed wish was to be heard, as well as be provided with the kind of information that would help her decide how best to proceed in the management of her conditions. She did not mind being given things to think about, in fact the distraction was welcomed. This information sharing, however, was most
effective between Ruth and Bernadette; a relationship built on trust, over time, through relatively un-fragmented care and authentic engagement.

Ruth’s story further demonstrated the impact of health professionals supporting the priorities and goals of the individual, to both maintain independence and protect their loved ones. This was seen particularly in the participants’ discussions on Advanced Care Planning, where planning focused heavily on protecting the needs and quality of lives of adult children, as opposed to prolonging the life of the participant. These decisions reflected the desires of the participant to act autonomously, and as an expert, of both themselves and their own family. In creating the kind of environment where these two goals (independence and protectionism) are prioritised, a person’s autonomy should be safe-guarded. Whilst decision making that emphasised the quality of life of another, could be seen as a loss of autonomy for the participant, it can also be seen as the ultimate act of autonomy, going against the wishes of family, who may focus on the quantity of life, as opposed to the individual’s conceptualisation of quality of life. Alignment with the priorities of the individual may also allow for the discussion of critical and sensitive topics, which have the potential to improve the overall experience of death and the individual’s ability to self-advocate in those situations. This is particularly important in light of the implications of immobilisation, from Ambiguous Loss and the Paralysis of Politeness, on the ability of a family to engage in distressing and seemingly premature conversations.

In creating an environment where the individual is considered an expert of themselves, the individual and their family are encouraged to assist in decision making based on their relationship with each other. Here, health professionals may have an opportunity to break through the mutual protection that is influencing stress
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communication and dyadic coping. To do this, researchers and health professionals alike, can use the participants’ insights into quality of life, to guide the provision of care within existing services. Additionally, health professionals can look to, and learn from, both psychological and palliative care philosophies that can respond directly to the participants’ requests for empathy, timely guidance and the facilitation of personal goals.

Recommendations for Further Research and Transferability

There are a wide range of recommendations that emanate from the findings of this enquiry. They predominantly relate to the assessment and validation of findings, but also recommend the expansion of these findings into other progressive chronic disease states, especially those with unknown trajectory. The goal of this work has always been to challenge preconceived notions of disease, disability and death through an understanding of the experiences of the participants. As such, I am to continue this dialogue through the following recommendations.

- The research was conducted in older people with advanced COPD. The sample population was relatively homogenous in socio-economic, ethnic, work status and geographical background. As such, further research is warranted to account for each of these variables. Stemming from the findings of the two youngest participants, both of whom were medically retired because of their COPD, there is significant scope for exploration of quality of life and adaption to change in relation to gender, younger age (40 – 65 years), and change in work status. These ideas were identified within the data, but did not recur sufficiently to be discussed as a theme. The intersection of identity and adaption, the effect of gender on actual and perceived
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reciprocity and adaption to the shift of societal gendered roles are also avenues for further research within COPD and other chronic conditions.

- Further research is warranted in combined used of psychotherapy and/or Cognitive Behavioural Therapy with standard pharmacotherapy for anxiety/depression in people with COPD. Of particular relevance to this work is how early psychological intervention could potentially influence the development of the self-regulatory strategies used sub-consciously by people with COPD to manage constant, incremental change.

- Understanding the cyclical nature of acceptance of change (Figure 9.2), as well as how it is shaped by past experiences and symptoms, is critical to an understanding of quality of life in advanced COPD. There is no reason why this cycle could not be explored in to context of healthy ageing or other chronic disease states. Additionally, the cycle creates pathways for both physical and psychological interventions that can promote successful adaption and/or prevent unsuccessful adaption. In exploring the cyclical adaption to change, other factors became salient, that may influence the nature of this cycle:
  - Self-transcendence emerged as a critical personal resource in adapting to change and retaining hope in paradoxical situations. The findings of this research were not entirely congruent with the established literature and did not specifically relate to the Australian context. As such, opportunities exist to explore the ideas of transcendence, hope and acceptance of change within the broader Australian context.
  - What is presently missing from current literature, is discussion of the efficacy of resilience-based interventions and the effect of
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psychological support, that may facilitate increased optimisation and resilience, which may assist in the process of adaption and improved mental health in older people with COPD (Keil, Vaske, Kenn, Rief, & Stenzel, 2016; Kong & Lee, 2015).

- In contextualising SOC Theory to the COPD experience, future research could explore the idea of both successful ageing and specifically, the use of SOC for older people with a range of progressive chronic conditions. With increased breadth of evidence for SOC in different ageing populations, theorists may need to consider the very definition of successful ageing in the current day and age.

- From the perspective of health care provision, the combination of immobilisation, and fear-avoidance, are likely to complicate discussions surrounding advanced care, and transitions from curative to comfort based approaches and palliative care services. Further investigations into the presence, quantification, and impact of self-perceived burden and ambiguous loss in COPD are warranted. Further, the implications of immobilisation and SPB on the development of ACP should be explored from the perspectives of psychological/emotional effect on the individual as well as the capacity for Health Professionals to more effectively engage in planning and ACP discussions when working through the lenses of SPB and/or AL.

- The Paralysis of Politeness model developed here was informed by the voices of the participants and the established literature. To validate this model it would need to be tested from the perspective of the Care-giver and Health Professionals. This is exciting work that has the potential to inform Health professionals from a wide range of services and clinical scenarios on how to
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recognise and breakdown the silence that impedes proper planning and care implementation.

**Conclusion and Final Remarks**

As the heart of this work was my desire to support ruraly-based health professionals in the delivery high quality care to older people with COPD, toward the end of their lives. This project reflected that goal, through coming to a greater understanding of the lived experiences of some of their clients, and the communication of those experiences back to their care providers; to inform and encourage. The goal was never to pinpoint the ‘four steps to quality care’, but rather, to open a dialogue that bridges science and practice, to further develop evidence-based practice that meets the needs of people with COPD, and their families. In the light of the limitations of access to palliative services, in rural areas of Australia, one area of focus must include asking how existing health services can enable these skills, and support sustainable practice, within the current model of health provision.

A question may also be asked regarding health professionals access to non-medical services for clients. With the participants’ heavy emphasis on psychosocial adaption and coping strategies, throughout their stories, how could health professionals utilise psychological support services, earlier in the COPD journey, to better facilitate the journey of adaption and acceptance? COPD management cannot just be about managing physical and mental health, but rather, prophylactically facilitating healthier responses to change, grounded in the recognition that every individual and care dyad have their own identity, resilience and coping strategies, that can be harnessed, encouraged and optimised.
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The eleven people, who told their stories, did so in the good faith and understanding that in doing so, the telling would improve the lives of others, with COPD. It is in this spirit that those tasked with their care should move forward, seeking relationship and connection. As truth is only ever a perception of itself, so too, is an understanding of the quality of a life. Opening research and praxis to the global and fluid nature of quality of life, one shaped over time and by experience, allows health professionals to meet their clients where they are; as people whose understanding and management, of themselves, is defined by much more than their diagnosis or disability.

>You know, quality of life doesn’t just stand there,

>but quality of life is what your whole life’s been,

>and I think I’ve had a very good life,

>yeah, happy, despite the troubles I’ve had. John
Epilogue

The Chair

In my office, there is an armchair.
It was my grandfather’s, and now it is mine.
It smells of stale smoke with a hint of salt air as he smelt of fresh smoke and the ocean breeze.

I call my reading chair.
Others call it ‘the crying chair’.
They send me their students when the student might cry, because I have a place for crying.
I am young and I am woman, so I am strong enough for crying.
Or so they think.

Some don’t cry.
They are in a rush for change
And there is no time for tears during the frustration of lost ambition.
But I have learned with time the chair provides more comfort for a lost soul than I can.
So I listen and the chair cradles.

In the chair you can be lost.
In the chair you can be scared.
And in the chair you can be angry.
We will talk of greater things while you are there.
We will talk of the future, of family, of obligation and of hurt.

You can make plans in the chair, including plans to make no plan at all.
You can ask questions and so can I.
You can smell the faint smell of my childhood and I can be affirmed by the presence of my past - the chair supports me as much as it supports you.

The chair is heavy, hard to move.
It is oak, upholstered in chintz; strength veiled with tenderness.
You will sink deep into its seat, but the broken spring at your back will remind you that you can’t stay forever.

Every now and then I sit on the chair myself, and I am with family again.
And family is comfort
Comfort is connection
Connection is language
Language is understanding
And understanding is why you sat in the chair in the first place.
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Appendix A

Reflective Strategies
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| Critical Friend | SH and I met monthly from before data collection through to the conclusion of the project. Knowing me as a colleague, co-researcher and friend, SH was able to engage with me at a personal level about more sensitive issues- and was able to not just ask for my interpretation, but feed her understanding of me back into the discussion. | SH: What are your prejudices, Pip? Belonging to a tradition - what tradition do you belong to, at the moment? You’ve said you’re a scientist a couple of times now.  
Pip: I am, and I like to fix things and this is where this becomes a battle for me, because I can't fix, I can't stop this [COPD progression]. I think part of my tradition is my faith, which means I put an emphasis on caring and dignity and respecting people where they're at.  
SH: People without religious beliefs will do that too - how do you think your beliefs make that different to others who don’t believe?  
P: I see this as an act of worship. I see the time that I take to engage with people as one way that I demonstrate my faith and for me, I believe that curiosity into how that is happening, has stemmed from how I relate to God...  
SH: How do you bracket that out?  
P: Well, you can’t - but I can acknowledge that I do believe that everybody has their own perception of what Truth is. February 6th, 2015 |
| Recorded Reflections | The recorded reflections were used to capture thoughts immediately post-interview as well as discussions with supervisors and mentors about the project. They revolved heavily around challenging assumptions and preconceptions. | DB (supervisor): What are you going to get out of these interview - would you say, what sort of thing does the health system do to work out where these people are at?  
P: Right, there's two parts to that. The quantitative person in me says 'what am I going to do with this' and the qualitative person in me says 'my job is to explore the area' and I have to keep resting in the fact that this is exploratory and if I had a mixed method protocol; yesterday was the first time I went, gee, I wish I had the time to do the mixed method study, because I know what I'd go and do... 24th April 2015 |
| Written Reflections | The written reflections were used as part of the process in identifying and questioning my assumptions; documenting critical incidents that have                                                                 | I think my perspective going into the data collection is grounded in my experience with the Cystic Fibrosis patients. They were full of hope and I have assumed that |
made clear the path to this particular project. As the data collection continued however, the writing moved from more formal journaling to a stream of consciousness, annotating the transcription, coding and analysis processes.

COPDers will be the same. I think I might be wrong though. Hope I don't cry in public.

I have memories of seeing people on the worst day of their life - the day their kid was diagnosed with cancer. I didn't see them before, and I seldom saw them after. I saw parents mourning the life they thought their child would have, their old life. The kids though (if they weren't in pain, and sometimes they were), generally seemed oblivious. They were the light in a dark room, oblivious, doing what they were told, bouncing from test to test because they were good kids trying to please their parents. Maybe COPDers are oblivious?

I think my identity is grounded in:

- Family, especially Rich (husband) and Ben (son). Increasingly, I am realising how much of my world is bound up in my Yabsley-ness [the family I grew up in]. Much more than I perceived at the time of writing this reflection. Mind you, I've had a lot of therapy about that since I originally wrote this.
- Church and faith - which are totally different things
- being a doer, being reliable, being the guy 'the guy' counts on
- coffee, good coffee with or without another person

I have assumed that spirituality and sociality will override physical health - because for me it does. Not necessarily true though. Written reflection, January 7th, 2015, annotated (italics) 6th April, 2016

'Give the pain to me, give it to me, it doesn’t matter how old they are, you’re still there mum.' (Laurel).

Here's the thing about QL and getting older - maybe they don't mind taking the burden if it means someone else doesn't have to have it. They talk about lung transplants etc. and refer to themselves as getting older, so save it for the young ones. These aren't just people, they are parents, and if they refusing treatment, going into a home, becoming a recluse allows their children to live, well, they'll do it, a hundred times over. Despite the fact that these are

Reflective Annotations

The reflective annotations were often written as quickly as they were thought to not lose the flow of the idea. They served as question and analysis prompts, reminders of what the big picture looked like (at the time) and how the participant voices had contributed to my understanding of that big picture - a dialogue demonstrating the constant movement between the parts and the whole.
potentially negative influences on QL, their capacity to parent their (adult) children actually improves quality of life. Ties in with Geordie, Valerie's quotes about transplants and a couple of quotes about living in a home (Laurel, Ruth). Ties into burden. What a great quote. Reflective Annotation, November 17th 2015
Appendix B

Ethical Approvals and Amendments

Includes:

Letter of Approval, Charles Sturt University Human Ethics Research Council

Letter of Approval, Greater Western Area Health Service Human Ethics Research Council

Letter of Approval, Bathurst Health Service Site Specific Application
11 July 2013

Mrs Phillipa Southwell
Cl- School of Biomedical Sciences
Charles Sturt University
Leeds Parade
ORANGE NSW 2800

Dear Mrs Southwell,

Thank you for the additional information forwarded in response to a request from the Human Research Ethics Committee (HREC).

The CSU HREC reviews projects in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans.

I am pleased to advise that your project entitled “Health-Related Quality Of Life In Chronic Disease (Phase I)” meets the requirements of the National Statement, and ethical approval for this research is granted for a twelve-month period from 11 July 2013.

The protocol number issued with respect to this project is 2013/129. Please be sure to quote this number when responding to any request made by the Committee.

Please note the following conditions of approval:

- all Consent Forms and Information Sheets are to be printed on Charles Sturt University letterhead. Stadems should liaise with their Supervisor to arrange to have these documents printed;
- you must notify the Committee immediately in writing should your research differ in any way from that proposed. Forms are available at: http://www.csu.edu.au/__data/assets/word_doc/0010/176833/ehr_aurep.doc (please copy and paste the address into your browser);
- you must notify the Committee immediately if any serious and or unexpected adverse events or outcomes occur associated with your research, that might affect the participants and therefore ethical acceptability of the project. An Adverse Incident form is available from the website as above;
- amendments to the research design must be reviewed and approved by the Human Research Ethics Committee before commencement. Forms are available at the website above;
if an extension of the approval period is required, a request must be submitted to the Human Research Ethics Committee. Forms are available at the website above; you are required to complete a Progress Report form, which can be downloaded as above, by 16 May 2014 if your research has not been completed by that date; you are required to submit a final report, the form is available from the website above.

YOU ARE REMINDED THAT AN APPROVAL LETTER FROM THE CSU HREC CONSTITUTES ETHICAL APPROVAL ONLY.

If your research involves the use of radiation, biological materials, chemicals or animals a separate approval is required from the appropriate University Committee.

The Committee wishes you well in your research and please do not hesitate to contact the Executive Officer on telephone (02) 6338 4628 or email ethics@csu.edu.au if you have any enquiries.

Yours sincerely:

Julie Hicks
Executive Officer
Human Research Ethics Committee
Direct Telephone: (02) 6338 4628
Email: ethics@csu.edu.au

Cc: Dr Judith Crockett Associate Professor Deborah Butter
Quality of Life in COPD

23 July 2014

Mrs Phillipa Southwell
School of Biomedical Sciences
Charles Sturt University
Leeds Pde
ORANGE NSW 2800

Dear Mrs Southwell,

Greater Western Human Research Ethics Committee (HREC)
Project No. HREC/13/GWAHS/61

Health-Related Quality of Life in End-Stage Chronic Obstructive Pulmonary Disease (COPD)

Application for Ethical Review

Thank you for responding to the HREC’s request for clarification and further information for the above project. The HREC reviewed your responses at its meeting held on 22 July 2014.

The Greater Western HREC has been accredited by the NSW Ministry of Health as a lead committee to provide the single ethical and scientific review of proposals, to conduct research within the NSW public health system. Further, this committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research and the CPMP/ICH Note for Guidance on Good Clinical Practice.

I am pleased to advise that the HREC has granted ethical approval of this research project. The following documentation has been reviewed and approved by the HREC:

- NEAF (AU/1/0359117) dated 02/07/2014
- Research Protocol including appendices Version 4 dated 02/07/2014
- Researcher Response Template dated 17/06/2014, 28/05/2014, and 25/10/2013.
- NSW Health Privacy Questions dated 02/07/2014

The project is approved to be conducted at the following NSW Public Health sites:

- Bathurst Health Service Respiratory Coordinated Care Program
Quality of Life in COPD

Please note the following conditions of approval:

1. The coordinating investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including any unforeseen events that might affect continued ethical acceptability of the project.

2. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review in the specified format.

3. The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.

4. The coordinating investigator will provide an annual report to the HREC and at completion of the study in the specified format.

HREC approval is valid for 2 years from the date of this letter.

This HREC approval letter constitutes ethical approval only. You are required to submit a site specific assessment application for each site at which you wish to conduct this project. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained. A copy of this letter must be forwarded to all Principal Investigators at every site for submission to the relevant Research Governance Officer as part of the site specific assessment process.

Should you have any queries about your project please do not hesitate to contact the Greater Western HREC Executive Officer on (02) 6339 5601 or via email ethics.committee@gwahs.health.nsw.gov.au.

Please quote HREC Reference No. HREC/13/GWAHS/61 in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely

[Signature]

Suzanne Degiorgio
Ethics & Research Governance Officer
Western NSW & Far West Local Health Districts
19 February 2015

Mrs Philippa Southwell
Lecturer
School of Biomedical Sciences
Charles Sturt University
Leeds Parade
ORANGE NSW 2800

Dear Mrs Southwell,

Western NSW & Far West Local Health Districts
HREC Project No. HREC/13/GWAHS/61
SSA Application No. SSA/14/GWAHS/132

Health-Related Quality of Life in End-Stage Chronic Obstructive Pulmonary Disease (COPD)

Site Specific Assessment Application

Thank you for submitting a site specific assessment application to conduct research within the Western NSW & Far West Local Health Districts.

I am pleased to inform you that authorisation has been granted for this study to take place at the following sites within the Western NSW & Far West Local Health Districts:

- Western NSW LHD
  - Bathurst Health Service

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

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the Research Governance Officer; and
2 Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the Research Governance Officer.

Should you have any queries regarding your project, please do not hesitate to contact the Western NSW & Far West Local Health Districts Research Governance Officer on (02) 6330 5941 or via email WNSW.HD-EthicsCommittee@health.nsw.gov.au.

Please quote SSA Reference No. SSA/14/GWAHS/132 in all correspondence.

The Western NSW & Far West Local Health Districts wish you every success in your research.

Yours sincerely

[Signature]

Suzanne Degiorgio
Ethics & Research Governance Officer
Western NSW & Far West Local Health Districts
Quality of Life in COPD

Appendix C

Research Visit Documentation

Includes:

Participant Information Pack: Participant Invitation, Participant Information Form & Participant Reply Card

Consent Form

Demographic Questions

Participant Contact List
Dear Sir/Madam,

My name is Pip Southwell, I am a qualified respiratory scientist, lecturer and PhD candidate at Charles Sturt University. I would like to invite you to participate in a research project exploring Health-related Quality of Life in Chronic Obstructive Pulmonary Disease (COPD) through the discussion of people’s experiences of living with COPD. The project will involve the completion of a questionnaire, a one-on-one interview discussing what it’s like to live with COPD and what ‘quality of life’ means to you.

We value your time and your story, so this interview may take between 1-3 hours over one or more sessions, depending on your preference.

There is an information sheet attached describing the project in more detail and answering some of the questions you may have. If you are interested in participating or have any more questions, please contact me on (02) 6365 XXXX or by returning the reply card in the reply paid envelope provided.

Yours Sincerely,

Pip Southwell
Lecturer in Anatomy & Physiology | School of Biomedical Sciences
Charles Sturt University
Orange, NSW 2800
Tel: (02) 6365 XXXX
PARTICIPANT INFORMATION SHEET: Health-Related Quality of Life in COPD

You are invited to participate in a research study into quality of life for people with a Chronic Obstructive Pulmonary Disease (COPD). The study is being conducted by:

Ms Phillipa (Pip) Southwell, PhD Candidate, Charles Sturt University, Orange Campus

Under the supervision of:

Dr Judith Crockett, Lecturer in Health and Rehabilitation, Charles Sturt University, Orange Campus

Assoc. Prof. Deborah Burton, Adjunct Associate Professor, Charles Sturt University, Orange Campus

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done, what it will involve and which outcomes it is intended to achieve. Please take the time to read the following information carefully and discuss it with others if you wish. This information sheet is for you to keep.

What is the purpose of this study?

There are a wide range of tests that can be used to measure a person’s satisfaction or happiness and how it affects or is affected by their health. The purpose is not just to measure your quality of life, but discuss with you what influences your quality of life and find out more about what people mean when they talk about their quality of life.

Why have I been invited to participate in this study?

This study is exploring the quality of life of people aged 65 years and above who live with COPD in the Central West region of NSW. We would like to invite you to discuss your experience of living with Chronic Obstructive Pulmonary Disease (COPD) and how that influences your quality of life. We are inviting a wide range of people with severe COPD from around the region aged 65 years and above to participate, of which you have been identified as one through your participation in the Respiratory Coordinated Care Program at Bathurst Health Service.

What does this study involve?

If you agree to participate in this study, you will be asked to sign a Consent Form. You will then be asked to participate in a recorded interview about your health and quality of life. The interview will take at least one hour, possible more, but can be split over one or more visits if you wish. With your permission, the interview will be video or audio-recorded and transcribed by Ms Southwell into a written document that will be provided to you to review and keep. There will be opportunities to participate in later stages of this project. These opportunities are entirely voluntary and do not affect your participation in this stage of the study.

Are there risks to me in taking part in this study?

There are no tests or procedures involved in this study. As part of the interview we may discuss some personal or sensitive topics that may be upsetting. You are able stop the interview at any time to allow you to compose yourself and seek some assistance, if needed. If you decide to stop the interview or withdraw from the project, it will not affect the treatment you receive then or in the future. Whatever your decision, it will not affect your relationship with the staff.
Quality of Life in COPD

caring for you. Should you wish to continue the interview at another time, arrangements will be made with you for another visit at your convenience.

**Will I benefit from the study?**

This study aims to further our understanding of quality of life and care of people with severe COPD. Through a deeper understanding of what provides and prevents good quality of life, we hope to be able to provide more appropriate and holistic care for all people with COPD and their families and friends. This project may not be of any direct benefit to you personally.

**How is this study being paid for?**

The study is being supported by the Faculty of Science, Charles Sturt University.

**Will taking part in this study cost me anything, and will I be paid?**

Participation in this study will not cost you anything, nor will you be paid.

**What if I don’t want to take part in this study?**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the health staff caring for you.

**What if I participate and would like to withdraw later?**

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. If you decide to withdraw, it will not affect the treatment you receive then or in the future. Whatever your decision, it will not affect your relationship with the health staff caring for you.

**How will my confidentiality be protected?**

Of the people involved in this project or your health care, only Ms Southwell from the University and the nursing staff from the Respiratory Coordinated Care Program will know whether or not you are participating in this study. The nursing staff will only be notified of your involvement should you consent to participate for the purpose of contacting you within two days of the interview, providing an opportunity for you to talk or ask questions that may have arisen from the interview. Should you decide not to participate, they will not be notified. Whatever your decision, it will not affect your relationship with the health staff caring for you.

Any identifiable information that is collected about you in connection with this study will remain confidential and be disclosed only with your permission, or except as required by law. Your interview transcript will be de-identified (including name changes). Any recordings or footage of your interview that you permit to be used to present the findings of the study will be used respectfully. It is your choice whether or not we are allowed to use your image, voice or both. Only the researchers named above will have access to your details and results that will be held securely at Charles Sturt University.

**How will the interview be recorded and data used?**

You may select whether your interview is audio recorded using a Dictaphone or video recorded. You may also select how we use your recording, whether your image, your voice or the transcribed interview can be used to present the research findings. The researcher will discuss your options with you at length on the day of the interview to ensure that you are aware of all your choices and comfortable with any consent decision you make.

**What happens if I do not want my interview recorded?**

We wish to convey the findings of the research as accurately as possible. Due to the style of interviews being conducted and the amount of information that may be collected over the
duration of the study, we feel that it is inappropriate to only take notes of your story during the interview, thus all interviews will be recorded. Should you decide that you do not want to record your interview we will welcome you to participate in the later, unrecorded phases of the study. Whatever your decision, it will not affect your relationship with the health staff caring for you.

**What happens with the results?**

If you give us your permission by signing the attached consent form, the results of the study will be published in the form of a PhD Thesis. The study results may also be presented at a conference or in a scientific publication. Results of the study will be provided to you and we will invite you to feedback on these findings upon their completion if you wish.

**What should I do if I want to discuss this study further before I decide?**

When you have read this information, Ms Southwell, the primary researcher will happily discuss any queries you may have with you. If you would like to know more at any stage, please do not hesitate to contact her on (02) 6365 7583 or using the mail slip and reply-paid envelope that have been provided for you.

**Who should I contact if I have concerns about the conduct of this study?**

<table>
<thead>
<tr>
<th>Charles Sturt University’s Human Research Ethics Committee (HREC) has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee via:</th>
</tr>
</thead>
</table>
| The Executive Officer,  
HREC Office of Academic Governance,  
Charles Sturt University,  
Panorama Avenue, Bathurst,  
NSW, 2795  
Telephone: (02)63384628  
Fax: (02)63384194  
Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome. |
| The ethical aspects of the project have been approved by the Greater Western Human Research Ethics Committee (HREC) of the Western NSW & Far West Local Health Districts. If you have any concerns or complaints please contact: |
| The Executive Officer,  
Greater Western Human Research Ethics Committee,  
Western NSW Local Health District,  
PO Box 143 Bathurst NSW 2795  
or telephone (02) 6339 5601 |

Thank you for taking the time to consider this study,

Pip Southwell  
Lecturer in Anatomy & Physiology | School of Biomedical Sciences  
Charles Sturt University, Orange, NSW 2800  
Tel: (02) 6365 XXXX
PARTICIPANT REPLY CARD:
Health-Related Quality of Life in COPD

Name: ___________________________________________________________________

Phone Number: ___________________________________________________________________

Best contact time: ___________________________________________________________________

☐ I would like to be contacted regarding the project ‘Health-related Quality of Life in COPD’

Signature: ___________________________ Date: ______

Please return this slip using the reply paid envelope provided. You will be contacted by phone in the near future. Alternately, you are welcome to contact the Mrs Southwell directly on (02) 6365 XXXX.

Sincerely,

Pip Southwell
Lecturer in Anatomy & Physiology | School of Biomedical Sciences
Charles Sturt University
Orange, NSW 2800
PARTICIPANT CONSENT FORM: Health-Related Quality of Life in COPD

- I have read the attached Participant Information Sheet on the above named research study, and understand that I will be asked to complete a quality of life questionnaire and participate in a recorded interview about my health and quality of life.
- I have been made aware of any known or expected inconvenience, risk, discomfort or potential side effect as currently known by the researchers.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I freely agree to participate in this study and understand that I can withdraw at any time.
- I understand that I will be given a signed copy of this document to keep.
- I consent to the Respiratory Coordinated Care Program Coordinator being made aware of my participation for the purpose of providing a follow up visit or phone call within 2 days of my interview.

Please select from the following options how you wish your interview to be recorded:

☐ I consent to having my interview audio-recorded for transcription only.
☐ I consent to having my interview video-recorded for transcription only.
☐ I consent to having my voice or image used in the presentation of the findings of the study. I understand that as much identifying information as can be reasonably altered will be to maintain my confidentiality.

We will send a printed copy of your interview transcript to you in the mail for your comment. Further to this, you may also wish to receive a copy of the recording we have made. Please select any relevant options from the following list.

☐ I would like to receive a copy of the recording of my interview.
☐ I would prefer not to receive a copy of the recording of my interview.
☐ I would like my family to be able to access a copy of the recording of my interview at any time in the next 5 years.

Participant's name (please print): .................................................................
## Participant Demographic Record

| Code: | 
| --- | --- | 

<table>
<thead>
<tr>
<th>Date of Visit:</th>
<th>Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td>Height (recalled):</td>
</tr>
<tr>
<td>Year of diagnosis:</td>
<td>Weight (recalled):</td>
</tr>
<tr>
<td>Time in RCCP:</td>
<td>BMI (calculated):</td>
</tr>
</tbody>
</table>

### Smoking history:

### Current Therapy:

### Living Arrangements:

### Work History:

### Co-morbidities:
Participant Emergency Contact List

In case of an emergency, please call 000 for an ambulance.

Respiratory Clinical Nurse Consultant (Bathurst Health Service)
Work hours: (02) 6330 XXXX
Out of hours: (0409) 605 XXX

Bathurst Health Service
All hours: (02) 6330 XXXX

Lifeline
All hours: 13 11 14

Beyond Blue
All hours: 1300 22 4636

Pip Southwell (Charles Sturt University)
Work hours: (02) 6365 XXXX
Appendix D

Evidence of Intra- and Inter-Interview Saturation
### Quality of Life in COPD

<table>
<thead>
<tr>
<th>Rationale for Statement of Saturation</th>
<th>Evidence</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intra-interview</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant Fatigue</td>
<td>Pip: <em>I don’t have too many more questions for you.</em></td>
<td>It was not just researcher-perceived saturation that had to be accounted for. In several interviews, participant fatigue led to the interview being brought to a close. Whilst Clem was able to make a joke, his posture and restlessness indicated he was significantly fatigued, but not willing to bring the interview to a close. Despite trying to end the interview a number of times with Camilla, instead, William would distract me to allow her to regain her composure.</td>
</tr>
<tr>
<td></td>
<td>Clem: That’s good, because I’m running out of puff (laughs).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Camilla: I just kept telling myself that they can’t tell you, the Tobacco companies won’t tell you the ingredients ion the cigarettes, there’s known to be a combination of up to 400 ingredients that they use… (Significant coughing)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>William (husband): <em>The thing about it that originally when we started smoking, the cigarettes were pure tobacco, and eventually as time went on, they started to add all these additive</em> C: Chemicals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>W: <em>That’s what does all the harm.</em></td>
<td></td>
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<tr>
<td></td>
<td>(Removes nasal prongs to blow nose; has shakes)</td>
<td></td>
</tr>
<tr>
<td>Open-ended questioning without response</td>
<td><em>I’m just about out of questions.</em> Good heavens. <em>I know, you’d never think it of me, but if you think there’s anything else...</em> Not that I think, I think we’ve covered most things. Gail</td>
<td>In creating space for participants to raise any other issues, for # interviews, there were additional comments that allowed the interview to continue, but often the participants felt they had expressed all they thought they needed or wanted to.</td>
</tr>
<tr>
<td></td>
<td>Is there anything else? (Pauses) I’m just trying to think, ah, no, I</td>
<td></td>
</tr>
</tbody>
</table>
Quality of Life in COPD

Is there anything you think I should hear about living with COPD? Anything we haven’t touched on?

I can’t think of anything that I could tell you that you probably don’t know already or anything, I think I covered everything, to be honest, I can’t think of anything that I could possibly tell you any different. Valerie

Reviewing core ideas at second interview

Valerie: I think because, you don’t class yourself as sick because there’s an alternative with the oxygen. Now, if I were to take that off for 5 or 6 hours and start (laboured breathing), well I would be sick, but seeing I have an alternative, with the oxygen, I think that’s more of a cure than, than, than, than a sickness. (Yeah). Does that sound? (Yeah). It seems like I’m curable, not that I’m every going to be able to get rid of the oxygen, but I think it’s more of a cure for my condition.

Pip: If I replace the word ‘cure’ with ‘manage’...

V: Yeah, probably, more of a ‘manage it’, yes, yes, definitely, most definitely.

Overall Saturation

Transition from Purposeful to theoretical sampling

With the sample size, the literature says between 8 and 15. I got to 8 and could say, I know what I’m seeing here - I’ve got my head around the story now and when back to Bernadette

Individualistic variation aside, the initial 8 interviews provided a strong conceptual basis for the ‘typical’ experience of COPD. From this point cases with atypical or
and ask for people who weren't coping etc., so the next four were theoretical sampling, although one declined and three agreed... I felt like I hit saturation at 8, but I wasn't comfortable with 8. Recorded Reflection, July 21\textsuperscript{st}, 2015

I think they weren't that different. There were things about them that were different - the general story was very familiar, but they tended to have one core difference, such as still smoking... Recorded Reflection, July 13\textsuperscript{th} 2015

Consistency of ideas: Disability vs. Invalidity

\textit{Pip: Do you think of yourself as somebody who's sick?}

Clem: Not really, no I don’t. It’s just an acceptance of the way things are. Like if you had one arm, you've only got one arm - or you've got one arm missing.

Laurel: It’s like an amputation, like a person has their leg off, they’ve got to learn to adjust; I haven’t got any good lungs, so I’ll have to lean to adjust to that and work it accordingly, you know, I’ve just got to realise, the fact that I can’t go like a bat out of hell!

Valerie...if somebody had lost a leg, would you ask them if it was hard to stand up? A person with lung disease, they’re asking if it’s hard to breathe. It’s just... of course it is.

From reading Drum et al 2008: that we should reject the idea that disability is equitable to ill-health. I was trying to use the Disability Paradox in relation to QL, but it's bigger than that - I've always heard that people...
with COPD don't think they are sick - and the data confirms that. They compare themselves to people with a disability instead. The premise of this all was to explore the DP for COPD, but what I'm seeing instead is that because they don't identify as sick, but disabled conventional discussions about chronic disease management 'don't apply' - we should be talking about disability models of care instead, where people can achieve life satisfaction etc. by 'secondary gain' associated with adaption to the new normal (my word). Reflective Annotation, January 29th, 2016

Researcher fatigue
I got into the second last interview and said my head can't take any more of this. Recorded Reflection, 21st July, 2015

Possibly the most important aspect of the data collection and representation is to allow the stories of the participants be at the forefront of every dimension of the project. Towards the end of the project two critical signals of saturation occurred - I could not help but compare one story to another due to the commonality of the experiences and because of this, I no longer felt that I was giving each participant’s story the respect it deserved.

The last few interviews haven't been great, I haven't felt in control of the interview - I've turned around and gone 'I missed basic follow up question', my head is too full of everything to not be leading in the way I'm asking questions… I felt less interested in the story and more interested in comparisons… Recorded Reflection, 17th June 2015

Study constraints
I thought to myself, if I could go back in September and do the analysis and have another go, I could probably get a few more. I don't feel I need it... I need to move on in a different way - I'm ready for the next bit. Recorded Reflection, 17th, 2015

The data collection period was limited to a three month period in Autumn/early winter 2015, ending June 30th, to avoid exposing the participants to risk of cross-infection through the flu season. The final interviews were conducted two weeks prior to this cut-off date. Despite the capacity to
I was limited by the fact that it was almost winter and I couldn't collect over that period - so the window was narrow.

Recorded Reflection, 21st July, 2015

continue recruitment, I chose not to, but left open the option to apply for an extension of the data collection period that Spring should the preliminary data set be insufficient after the preliminary analysis. This was not the case, and no further data was collected.
Appendix E

Table of Node Summaries
<table>
<thead>
<tr>
<th>Parent Node</th>
<th>Child Node or Core Ideas</th>
<th># References</th>
<th># Sources</th>
<th>Node Definition</th>
<th>Exemplar Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td>Journey stories</td>
<td>40</td>
<td>11</td>
<td>Of the diagnosis, the symptoms, the changes that have happened. As opposed to denial, includes stoicism and acceptance of futility</td>
<td>I mean you just make the best of it, I don’t get angry, I get more annoyed than anything, but I don’t get angry. I’ve got it; I’ve got it. Winnie says, oh mum, what would you really like and I say ‘new lungs’, you can have a heart and lung operation, I believe, but I don’t think I’d bother, let it get the young ones have it. Laurel</td>
</tr>
<tr>
<td></td>
<td>Hope vs. resignation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accepting Assistance</td>
<td>Breadth of care required</td>
<td>52</td>
<td>11</td>
<td>Receiving assistance for ADLs that were not previously required.</td>
<td>I’ve got my son here. I do all the cooking and he does most of the washing up, the cleaning, we have a lady come in twice a day, a week, for three hours, she does, just mops the floor and does the toilet and the bathroom and the kitchen, so yeah, otherwise it’s alright. Mae</td>
</tr>
<tr>
<td></td>
<td>Strategies that help</td>
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</tr>
<tr>
<td></td>
<td>Strategies that hinder</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Adaption and Change Stories</td>
<td>Communicating Change</td>
<td>58</td>
<td>11</td>
<td>Stories and monologues that show a change or adaption to living with COPD or poor-health, generally over time.</td>
<td>And up until 18 months ago I used to drive but that was, I could probably still drive, but it was a bit scary. Because different coloured cars I could not see. So I decided to sell the car, which I did and became a passenger. Then, I used to get around, from walking to walking sticks, from the bone deterioration, or the joints, and not I’m on this wheelie-walker thing, but the effort to do things, takes the wind out of you, but before that, I could do most anything... Clem</td>
</tr>
<tr>
<td></td>
<td>History Repeating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities of Daily Living (ADLs)</td>
<td>Valued activities Roles and responsibilities Energy preservation</td>
<td>86</td>
<td>5</td>
<td>Managing ADLs, what is/isn't getting done anymore</td>
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<td>We had a property out, a 10 acre lot just outside Bathurst and I was doing the gardening, you know, keeping good order and interested in all the kid’s activities and ah, sort of gradually I’ve had to give away all those things one by one, go, and I barely dry up now. John</td>
<td></td>
</tr>
<tr>
<td>Assistive Technology</td>
<td>Strategies and devices used Technology to reduce physical engagement</td>
<td>35</td>
<td>11</td>
<td>Use of technology to facilitate coping and adaption</td>
<td></td>
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<td></td>
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<td>I have an electric wheelchair that fits in the car when Jenny goes shopping, I go with her and drive around, but like I said I used to walk, once. Clem</td>
<td></td>
</tr>
<tr>
<td>Being Cared For</td>
<td>Handing over traditional care role Handing over traditional family role Frustration, guilt</td>
<td>21</td>
<td>10</td>
<td>Comments about the act of being cared for by anyone</td>
<td></td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td>I often say, my wife and my daughter, they look after me like a bit of crystal, they’re very careful of me, you know, always watching, sometimes that’s a bit of a burden, you know, they want to, you feel as though you’re, you’re a bit of a load on them, and you want to be left alone, you know, to sort things out yourself and not to be, not to be watched so much... John</td>
<td></td>
</tr>
<tr>
<td>Being Sick</td>
<td>Functional Decline</td>
<td>Not actually being sick</td>
<td>30</td>
<td>11</td>
<td>Discussion about being sick, invalidity and disability</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
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<tr>
<td>I don’t feel sick, it’s not a ‘sick’ thing, it’s just you can’t breathe (yeah, okay) it the part of not being able to breathe really is the hard part, that’s the getting the grip of not being able to breathe when you do something normal, which a normal person would do, to go to, as I said, from point A to point B, and then come back and go (pants heavily). You know, it’s just not on, and to me, that’s not being sick, if you can understand that. Laurel</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Building and Maintaining Relationships</th>
<th>People coming through the door</th>
<th>20</th>
<th>9</th>
<th>Engaging with people other than family and care staff, can include activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>I haven’t been able to go out lately and I’ve had appointments and that, that I can’t fill, I can’t go and do them, but I’m happy just staying here and lucky I’ve got some very good friends, even to this day have kept calling, you know, every now and again, even though it must be tedious for them, but I think I’ve got about 4 so, so they’ve been wonderful, they just keep on popping in or occasionally giving me a phone call and what have you. Vida</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Co-morbidities</th>
<th>Prioritising one over the other</th>
<th>COPD exacerbating others</th>
<th>Adapting to co-morbidities before COPD</th>
<th>42</th>
<th>11</th>
<th>References to other conditions that affect their health and quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’ve had breast cancer; a mastectomy. I had a car accident, which is this (holds right hand up, fingers clenched); a year and a half physiotherapy and I can straighten them now, but they were absolutely rigid every day for a year and a half to get to that position (flexion); can’t turn my wrist over. Other than a couple of other smaller things, you know, Osteoporosis, I take a tablet once a month for that. All the other niggly things, I suppose you have when you get to 78 (laughs). Valerie</td>
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</tr>
</tbody>
</table>
### Confusion or Uncertainty in Dialogue

<table>
<thead>
<tr>
<th>Statement</th>
<th>Frequency</th>
<th>Topic</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statements that come out muddled, convoluted (and therefore hard to follow) or contradictory in itself (as opposed to larger themes that are contradictory). This also includes statements like 'I haven’t thought of that before' - for the time being. This node excludes statements that state their uncertainty about a topic i.e. I don't know what will happen etc. but includes situations where the topic is deflected.</td>
<td>22</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>What would be the main emotions that would dominate your day? Probably your feelings and that, you know. Yeah, which feelings? Just sort of, I get constipated... Ruth</td>
<td></td>
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</tbody>
</table>

### Contributing Factors (Pathogenesis)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Frequency</th>
<th>Topic</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long running health issues</td>
<td>19</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Exposure to irritants (smoking not coded here)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other factors that may have participated in the development of COPD</td>
<td>102</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Painter by trade - not a good trade. Old days, no safety equipment, no gloves, no masks, no anything it was just full on. And lead based paints, all the real bad stuff and mostly enamels and a lot of that kind of stuff before these modern things came out. Clem</td>
<td></td>
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</tbody>
</table>

### Coping Strategies

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Frequency</th>
<th>Topic</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domains of CS</td>
<td>102</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Mechanisms of coping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strategies that help in coping physically, emotionally, spiritually, psychologically or socially</td>
<td></td>
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<tr>
<td>I’ve learnt to handle it, you know, like, you start getting anxious and I just, I sit down and ah, either put on a good record or pick up a good book and just sit down and read for 10 minutes, ah, I had anxiety and stress when I was working, the latter years that I was working but I think my doctor took me off one of my tablets the other day that was for stress, he said 'you don’t need it anymore’, so that’s good. Evan</td>
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</tr>
<tr>
<td>Topic</td>
<td>Description</td>
<td>Page</td>
<td>Column 1</td>
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</tr>
<tr>
<td>Death</td>
<td>Loss of loved ones</td>
<td>42</td>
<td>11</td>
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<tr>
<td></td>
<td>Being close to death</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>The afterlife</td>
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<td></td>
<td>I couldn’t go through the future just getting worse and worse, I don’t think, but the, I suppose I’ll have to. You know, in other words, I have thought of suicide, but not, only lightly, this stage and really ruling it out because it’s a sin anyway, to take your own life, so you know, that’s that side of it, but I just hope God will be kind... Vida</td>
<td></td>
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<tr>
<td></td>
<td>Advanced Care Planning</td>
<td>29</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>I’ve got a do not resuscitate, yeah, that’s all done. My funereal has been planned, I don’t want any service, I don’t want nothing. Valerie</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Defying COPD</td>
<td>Maintaining ADLs</td>
<td>26</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Maintaining family roles</td>
<td></td>
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<tr>
<td></td>
<td>Hope</td>
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<td></td>
<td>I think your quality of life is what you make it to be yourself, to be honest, If you’re happy just to sit around and that’s it for the rest of your life, you know that’s your choice. But I choose not to do that, I do everything in my power to do something every day, but sometime it gets the better of me and I can’t do it. Gail</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denial</td>
<td>Hope</td>
<td>33</td>
<td>10</td>
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<tr>
<td></td>
<td>Ignorance</td>
<td></td>
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<tr>
<td></td>
<td>Impact on others</td>
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<td></td>
<td>Is there anything else you think I need to know to understand what it’s like to live with COPD? Ah, I don’t think it’s as hard as a lot of people think it is. Evan</td>
<td></td>
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<tr>
<td>Exacerbations</td>
<td>Avoiding hospital, avoiding death Effects of Exacerbations</td>
<td>68</td>
<td>11</td>
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<td>---------------</td>
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</tr>
<tr>
<td>Experiences with Health Professionals/System</td>
<td>Conflict with HPs Being supported, strategies that work</td>
<td>119</td>
<td>11</td>
</tr>
<tr>
<td>Family</td>
<td>Family as an affordance to QL</td>
<td>119</td>
<td>11</td>
</tr>
</tbody>
</table>

Well, like I said, it was flu like and three trips to a doctor over possibly a month who kept saying you've only got the flu and went from just about passing out, I don't remember anything... I know they carted me off to hospital and that's where I woke up in ICU a few days later. Clem

Now I make sure I sit there and explain to them, or get them to explain to me what is going to happen. That's what I did when I went to the dentist; and I said, because they could see that I was on that (walker) and I just sort of sat down and said, look, you know, if this is going to happen, well, tell me what's going to happen. Ruth

I suppose the fact that I know who I am and I know where I'm going stems from the fact that when I was a child my mother would not make decisions for me. For instance, subjects I wanted to study at school, she would say, you think about it and make your own decision, because whatever it is, once you've taken it, you're stuck with it. Camilla
<table>
<thead>
<tr>
<th>Family as a barrier to QL</th>
<th>There were three distinct ways in which family acted as a barrier to good quality life, interestingly, none of them seem to prohibit QL through a direct action.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on Family</td>
<td>Broken down into how they participated in and with the family socially and the burden placed on the family</td>
</tr>
<tr>
<td>Neutral family statements</td>
<td>Descriptions of family involvement without valued-ladened language</td>
</tr>
<tr>
<td>Getting Older</td>
<td>Comments about getting older, but also perspective that age provides, which are likely to be more abstract references.</td>
</tr>
<tr>
<td>The creeping dread</td>
<td>To have somebody shower you is, you know, especially if they were younger, you know. I know it’s an old fuddy-duddy thing, but it’s just that it’s... I’m no prude or anything... Laurel</td>
</tr>
<tr>
<td>Fighting the fight</td>
<td>‘...I’m not going to L’s 21st which I’d love to, you know, so, we decided that would be too hard... So that would be my next wish, to do that; but everyone understands that I can’t, a bit too readily actually (chuckles)... I say I can’t and they say, ‘oh we understand’ sort of thing which probably, I’d prefer if they talked me into it (chuckles), but anyway, that’s the way it is, you know, I mean, they probably think that they’re doing the right thing.’ Vida</td>
</tr>
<tr>
<td></td>
<td>I don’t get out with the family as much because when they were going out I was always included, but now it’s, it’s impossible for me to do the things that they do. Valerie</td>
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<td></td>
<td>I remember, this lady doctor I had, she was the one who found out I had something wrong with my bones and she sent for all these test and she said ‘I was right’. She said Osteoporosis, I thought, hang on a minute, my mother died of that, and she had it at the end of her life... Clem</td>
</tr>
<tr>
<td>Important Quotes</td>
<td>124</td>
</tr>
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<td>------------------</td>
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</tr>
<tr>
<td><strong>Independence</strong></td>
<td>66</td>
</tr>
<tr>
<td>Losing Independence, Dependence on others</td>
<td>It’s a good day, when you can do things like that you can sort of ah, please yourself. You don’t have to say, ‘oh I can’t do that, I can’t do that’. You can get up and do your washing up straight away… Geordie</td>
</tr>
<tr>
<td>The independent spirit, being needed</td>
<td></td>
</tr>
<tr>
<td>ADLs &amp; Valued Activities</td>
<td></td>
</tr>
<tr>
<td><strong>Isolation</strong></td>
<td>35</td>
</tr>
<tr>
<td>Withdrawing from community</td>
<td>Well no one really sort of comes around now, you know, yeah, even from the Church; they did say they’d come every month, or every three months, but they haven’t. You know, even the minister came out in January and he had another lady with him and she said that she would visit me and that, and the only way I keep in touch is through a bulletin they have on the computer every week, you know, yeah, so you’re still keeping in touch and knowing a bit what’s going on. Ruth</td>
</tr>
<tr>
<td>Feeling alone</td>
<td></td>
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<tr>
<td>People bridging the gap</td>
<td></td>
</tr>
<tr>
<td>Keeping or Changing the Pace</td>
<td>Prioritising self-care</td>
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<td>-----------------------------</td>
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<tr>
<td>Knowing Yourself</td>
<td>A person of value</td>
</tr>
<tr>
<td>Locus of Control</td>
<td>Internal LOC</td>
</tr>
<tr>
<td>Maintaining Health</td>
<td>Avoiding illness</td>
</tr>
<tr>
<td>Managing Symptoms</td>
<td>Medication and Oxygen</td>
</tr>
<tr>
<td></td>
<td>Anxiety/Panic</td>
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<tr>
<td>Medication Effects and Side Effects</td>
<td>Relationship with HPs</td>
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<tr>
<td>-----------------------------------</td>
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<tr>
<td></td>
<td>Discussion about medication types, doses, effects, side-effects, impact, limitations and anything else. Excludes oxygen therapy, but is not restricted to respiratory medications.</td>
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<tr>
<td></td>
<td>Wha<strong>t</strong> are you taking for your breathing? I take ah, prednisone. Every day? 5mg, I’ve never been able to get off it, but I tried and tried, but I always went back on it, but I’ve been taking that since 1965 so that’s 50 years, ah, but you know people tell you that you’d get a balloon face but I’ve never got that. I’ll tell you a naughty thing here, the old doctor told me it’ll make you fat or it’ll make you fart (chuckles); I’m not fat. (Laughs). John</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mental Health</th>
<th>Coping Strategies</th>
<th>Panic attacks and anxiety</th>
<th>Social isolation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>References to mental health, depression, anxiety and panic attacks. Sometimes indirect statements about mood, emotional regulation or comments that hint to underlying mental health issues or management.</td>
<td></td>
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<tr>
<td></td>
<td>They’re [panic attacks] the worst things that I think I’ve ever experienced. People say, oh, you know, breathe in through your nose, out through your mouth. You’re not worried about that when you’re having one. You’re just trying to get that breath into you, another breath into you, so you can get back to normal and the more you do it, the worse it gets, and then you fight it and you start to freeze up. You can feel yourself doing it and usual I can get the brain to take over the body and take another breath, but oh it’s hard. It is one of the worst things I think... it’s so close to death it’s not funny. Laurel</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Negative Emotions</th>
<th>Fear and frustration</th>
<th>Anxiety and panic</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Fear, frustration, anger etc.</td>
<td></td>
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<tr>
<td></td>
<td>Oh, oh, I get frustrated sometimes because ah, of the things I can’t do, like, that I should be able to do. Evan</td>
<td></td>
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<tr>
<td>Orientation</td>
<td>Grieving the lost future</td>
<td>30</td>
<td>10</td>
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<tr>
<td></td>
<td>Hope</td>
<td></td>
<td></td>
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<tr>
<td>Oxygen Therapy</td>
<td>Oxygen is health</td>
<td>45</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Relieving symptoms, including anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participating in the World</td>
<td>Valued Activities</td>
<td>87</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Perceptions of others</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Symptoms</td>
<td></td>
<td></td>
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<tr>
<td>Passing the Time</td>
<td>Passive and active activities</td>
<td>26</td>
<td>10</td>
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<td></td>
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</tbody>
</table>
| Past experiences with COPD or Chronic Disease | Caring for parents  
*History of respiratory disease* | 18 | 8 | Linking their own journey to those of family members and friends - positive or negative. | She had emphysema too, we come up one school holidays to paint her kitchen and the doctor says, oh your mum’s going to die, die very soon. He didn’t say anything to her and thought she’d tell me. She didn’t. I went home and she was gone the next morning at 4.30. Mae |
| Perspectives on COPD | ‘Not sick’  
*The unknowable enemy* | 63 | 11 | Health education, opinions, lived experience specific to the disease | COPD is not a painful thing; it’s just a damn nuisance! I mean, there’s no pain attached, unless you get a cold or a cough, or you break your ribs, well, then there’s pain, but there’s no pain attached to it. Yeah, so, I think looking after all those people who were very, very ill people, yeah, to me it’s not an illness. Laurel |
| Physical Environment | Ruth – anxiety  
& outdoors  
*Time of day and bad weather* | 26 | 10 | References to weather, day/night not living arrangements | once it starts to get colder, I will not go out at night, so, but I’ll still go out in the days, so and stay rugged up and that, because I feel if I don’t, well, what and I going to if I don’t? I’ll have to accept the consequences if I get a chill. You know, I’ve got plenty of good people looking after me, so. Valerie |
| Positive Emotions | Keeping perspective  
*The self and others affecting +ve emo* | 41 | 11 | Includes stories about pride (in themselves and of others) | I think so, we laugh a lot about it, the old bugger, he’s around, he is. And the kids are feeling the same, you know, and it’s a good feeling, it’s not a scary; you know, before, you wouldn’t talk, people wouldn’t talk about things because it’s too scary, but the children are even talking, they’re not frightened of death. Laurel |
<table>
<thead>
<tr>
<th>Previous Setbacks</th>
<th>Long running health issues Building resilience</th>
<th>34</th>
<th>10</th>
<th>The kind of recollections that have shaped who they have become.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td>Well the fact of the matter is, since I was born, I’ve been sick and nearly dying of something (okay). Initially, I nearly died because I was allergic to the milk and then I nearly died from Scarlet Fever… Ruth</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Definitions and quantification</td>
<td>107</td>
<td>11</td>
<td>Unregulated comments on QL</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Does it affect me quality of life? It does if you want to, if you want to let it get to you, ah, I think you’ve got to learn to do things yourself, you’ve got to learn to do things differently, ah, I find that I get very, oh, how would I put it? Ah frustrated with myself because I can’t do the things I know I should be able to do. I get really, really annoyed. Then I get cranky, you know, sort of do the chocolate, like completely. I’ll rant and rave and swear. It’s only me and the bird here, so, yeah, it may sound silly but does sort of get that out of your system. Geordie</td>
</tr>
<tr>
<td>Religiosity</td>
<td>Cultural religiosity Unable to connect/attend</td>
<td>18</td>
<td>10</td>
<td>Attitudes, commitment and belief in religion, can include faith and spirituality but they are not limited to religiosity</td>
</tr>
<tr>
<td></td>
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<td>We’re both Catholics, brought up in Catholic Schools and ah, we were taught things at School which we adhered to and ah, one of the things is that, I don’t know if you’re Catholic or not, but Mass is a big thing as far as we’re concerned and ah, I can’t always go to Mass now. John</td>
</tr>
<tr>
<td>Resilience and Perseverance Stories</td>
<td>Autonomy as a result of setback Coping strategies</td>
<td>37</td>
<td>6</td>
<td>Stories that demonstrate the building of resilience over time or perseverance through trial</td>
</tr>
<tr>
<td>Rurality</td>
<td>Aetiology associated with limited work choices Don’t care about spec. care, just the calibre of the people in front of them</td>
<td>11</td>
<td>6</td>
<td>Impact of living in a non-metropolitan centre</td>
</tr>
<tr>
<td>Sense of Burden</td>
<td>Perceptions of burden Factors mediating degree of actual burden</td>
<td>44</td>
<td>10</td>
<td>Being a burden on others, strategies to avoid being a burden, avoiding help to not burden others, the emotional weight of being a burden</td>
</tr>
<tr>
<td>Category</td>
<td>Theme</td>
<td>Instances</td>
<td>Sentiment</td>
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<tr>
<td>Shared Understanding</td>
<td>Instances where there is a two and fro that is linking concepts, stories and ideas that demonstrate a fusion of horizons</td>
<td>...it seems like I’m curable, not that I’m every going to be able to get rid of the oxygen, but I think it’s more of a cure for my condition. If I replace the word ‘cure’ with ‘manage’... Yeah, probably, more of a, manage it, yes, yes, definitely, most definitely. It’s all manageable with having the oxygen here... Valerie</td>
<td></td>
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<tr>
<td>Spirituality</td>
<td>Non-religious comments about the bigger picture and their relationship to it</td>
<td>God’s always there, God’s always there, every night and you know, God is in my life. I believe in God, put it that way and I think in a way, that’s one of the reasons I don’t get down, you know, that I’m not sure, sort of thing, because you’ve got something to hold onto, or whatever, you know. You know your mother and father are there, sort of. Ruth</td>
<td></td>
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</tr>
<tr>
<td>The Difference a Day Makes</td>
<td>Explaining what constitutes a good or a bad day</td>
<td>A good day would be ah, if I was able to ah, help in the house a little bit and ah, at the same time, breathe in between the three hourly stints, for instance, one of the things I can’t do is to go out and get the mail and pick up the paper. John</td>
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<tr>
<td>The Inner Dialogue</td>
<td>mind over matter, talking to myself, managing emotions and mental health, or anything else by 'talking to myself'</td>
<td>I find myself standing in one place, telling myself I’ve got to go and do such and such, you know, and I haven’t moved yet, yeah, then all of a sudden, I’ll do it. Vida</td>
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<tr>
<td>Restricted Nodes</td>
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<tr>
<td>Things that get you Down</td>
<td>Being dependent</td>
<td>Giving up/being given up on</td>
<td>67</td>
<td>11</td>
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<tr>
<td></td>
<td>Diagnosis Story</td>
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<td>7</td>
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<td></td>
<td>Where it started</td>
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<td>14</td>
<td>11</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Smoking stories</td>
<td>31</td>
<td>11</td>
<td>Each participant's recollection of their smoking journey from start to finish.</td>
<td><em>I was born smoking - because my parent's smoked, my grandparents smoked - everybody smoked. I probably started smoking when I was 17 and of course when I joined the AF, if you didn't smoke, you were quite weird. And I gave up smoking, probably 30 years ago. Gail</em></td>
</tr>
</tbody>
</table>

**# References:** The number of quotes that were coded into the Node

**# Sources:** The number of participants that had a quote coded into the Node
Theoretical Frameworks and Existing Theories:

- Dignani’s Conceptual Model of COPD
- Successful Aging
- Successful Aging Disability Paradox
- Palliative Care Holding Space
- SPB Theory

Reference Nodes:

- Quality of Life
- Building and Maintaining Relationships
- The Difference a Day makes
- Perceptions of COPD
- Family
- Coping Strategies
- Medications
- Spirituality
- Religiosity
- The Difference a Day makes
- Passing the time
- Physical Environment
- Mental Health
- Assistive Technology
- Accepting Assistance
- Family
- Being Sick
- Perceptions of COPD
- Past experiences with COPD/CD
- Pathogenesis
- Orientation
- Exacerbations
- Death & Advanced Care Planning
- Defying COPD
- Previous Setbacks
- Family
- Sense of Burden
- Family
- Being Care For
- Past experiences with COPD/CD
- Orientation
- Death & Advanced Care Planning
- Family
- Death & Advanced Care Planning
- Experiences with Health Professionals
- Mental Health
- Exacerbations
- Rurality
- Sense of Burden
- Family