



THE UNIVERSITY
of ADELAIDE

Developing a model of care for people with end stage chronic obstructive pulmonary disease (COPD) and their carers

Report on NHMRC funded study 519359

March 2011

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Study Three: Service availability and accessibility for people with end stage COPD and their carers

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List of Abbreviations

ACAT	Aged Care Assessment Team
ACP	advance care planning
ADL	activities of daily living
AKPS	Australia-modified Karnofsky Performance Status Scale (Appendix 9)
BMI	body mass index
BODE	The BODE index is a prognostic tool to determine COPD mortality risk that assesses BMI, airflow obstruction, dyspnoea, and exercise capacity (ie. six-minute walk distance [6MWD]) using a score ranging from 0 to 10
CCM	chronic care model
CDM	chronic disease management
COPD	chronic obstructive pulmonary disease
CPR	cardio-pulmonary resuscitation
Dom Care	now Domiciliary Care SA (DCSA)
DNR	do not resuscitate
DCSA	Domiciliary Care SA
GOLD	The Global Initiative for Chronic Obstructive Pulmonary Disease was established jointly between the WHO, the National Heart, Lung and Blood Institute and the National Institutes of Health (USA) (Appendix 1)
GP	general practitioner
ICU	intensive care unit
MHL	Metro Home Link
MMRC	Modified Medical Research Council Dyspnoea Scale
NHMRC	National Health and Medical and Research Council
PATS	patient assistance transport scheme
QOL	quality of life
RDNS	Royal District Nursing Service of SA
WHO	World Health Organisation

Recommendations

This project demonstrated that the needs of people with COPD are not being met. Care for people with advanced COPD has been focused in the acute care setting, with some community support but this has been shown to be inadequate in meeting the day to day and palliative care needs of people with COPD. Application of the chronic disease management model to include people with COPD, with a new level of integration of a palliative approach at all phases of the illness, should be reflected in health policy.

1. COPD guidelines and health professional education should emphasise the vulnerability of people with advanced COPD, the symptom burden (in particular dyspnoea and fatigue), the many losses including changes in role, the impact on relationships experienced by people with this chronic illness and the need for sensitivity and compassion.
2. The care for people with advanced COPD should be provided according to the 'patient-centred care' principles outlined by the *Australian Commission on Safety and Quality in Health Care*, so that care is dictated by needs and symptoms rather than age or prognosis.
3. The focus of service provision should be on enabling people with advanced COPD to live at home. This would include revision of eligibility criteria (e.g. age limitation and performance status), to reflect the principle of 'patient-centred care'.
4. Increased recognition of the need for, and importance of, support for activities of daily living for people with advanced COPD including cleaning, shopping, personal care, transport and parking is required. Access to relevant services should be improved and streamlined.
5. Care co-ordination is pivotal to any new model of care. Care co-ordination should be flexible and able to occur across hospital, community and home. The role should be pro-active, supporting as much independence as possible through education and assistance with problem solving, but also have the skills and capacity to intervene with more specific assistance when needed. The role would combine the skills of a palliative approach, with those specific to COPD, e.g. oxygen therapy.
6. There needs to be a strong focus on psychological assessment and where necessary, improved access to psychological support.
7. The model of care needs to incorporate access to 24 hour advice.
8. The model of care must have a palliative approach (see Section 1.1) as a core principle. This must include timely and accurate communication with people with advanced COPD and between all care providers (respiratory physicians, hospital staff, GPs, specialist nurses, allied health practitioners, pharmacists and palliative care clinicians) to achieve quality care in a multidisciplinary environment. Health professionals in all areas of chronic disease management require education in palliative care principles and practice.

9. The model of care will work towards a clearer definition of the interface between specialist palliative care services and generalist providers.
10. Advance care planning, which includes conversations about substitute decision-makers, legal advance directives, the focus of care and end of life, should be introduced to all people. For people with chronic diseases such as COPD this should occur as soon as possible after diagnosis by a well informed, trained professional who understands the complexity of this disease and the current documents in the state. A system of advance care planning should be available and advance care planning should be recognized as an ongoing conversation which is part of the treatment plan and recorded appropriately. A system must be developed so that the patient's wishes are available for all clinical interactions and particularly emergency episodes. If the conversation is documented appropriately, it does not need to be revisited at every consultation but should be reviewed when clinically relevant.
11. Bereavement support is part of a palliative approach and a bereavement risk assessment should be incorporated in the model of care and intervention provided as required.
12. The importance of the role of informal care givers in the model of care should be recognized and supported. Awareness of, and access to, respite services for carers, should be strengthened.
13. Pulmonary rehabilitation should be an integral part of the model of care and be available early in the course of the disease. Programs need to be sensitive to issues of access, the timing of sessions, taking into account the difficulty for people with COPD in getting to early appointments, and the needs of smokers and non-smokers. Alternatives to group based pulmonary rehabilitation should be available including programs that can be delivered in the home.
14. There should be ongoing support for smoking prevention and cessation programs.
15. In caring for people with COPD, interventions to increase the level of health literacy at an early stage of the disease should be a priority. Strategies to increase health literacy include clear advice on the recognition of exacerbations, participation in pulmonary rehabilitation at an early stage, education at all stages of the disease and access to resourced support groups.

1. Introduction

1.1 Background

In Australia today, cancer patients can expect significant levels of care as they approach the end of their life, however patients dying of non-malignant disease often do not receive such care and indeed, may not even realise that they are approaching the end of their life. Chronic obstructive pulmonary disease (COPD) is a common chronic illness that falls into the non-malignant life-limiting category. COPD has been identified as a major (and increasing) cause of mortality both in Australia and internationally (1, 2). There is growing evidence that current end of life care provision for COPD is inadequate, at least when compared with the care provided for lung cancer patients (3-6) is a major burden on the community, and often requires repeated hospitalisations (5-7). Edmonds et al (8) (p293) note that 'patients dying of CLD [chronic lung disease] experience physical symptoms and psychosocial distress at least as severe as patients with LC [lung cancer]'. Elkington et al (9) demonstrated that care in the last year of life of COPD did not meet the needs of patients or their families, but the expertise in symptom control that is part of palliative care would have been very beneficial for these patients. Yohannes (4) identified that COPD patients in the US do not receive palliative care and suggested that such care could provide a way of meeting many of their unmet care needs.

Because of the growing prevalence of diseases such as COPD, the issue of end of life care for patients dying of non-cancer disease is increasing in importance both nationally and internationally (10, 11). There is growing evidence pointing to sub-optimal care for patients at advanced stages of chronic illness, with many experiencing repeated hospitalisations, poor communication between the hospital/community interface and problems accessing care that may be available through community services (12). Although some people with COPD may receive palliative care, there has been little examination of whether current provision meets their needs.

Current models of palliative care have developed almost exclusively around the needs of people with cancer (8),(13-15) and internationally, few service models have been explored with no consensus (or clear guidance) in the literature about the aspects of palliative care that could or should be adopted to best meet the needs of *non*-cancer patients. The need for a palliative approach to be an integral part of health care provision, and available to all who need it is being increasingly recognized (16, 17). The WHO defines palliative care as:

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of

suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (18).

Kristjanson et al (19) have argued that 'the palliative care approach', rather than 'specialist palliative care services' may offer the most benefit for people in the advanced stages of neurodegenerative disease, and this is also the case for other chronic illnesses such as COPD. Gott et al (20) suggest that a palliative approach is central to best practice end of life care, defining this as the introduction of palliative care at the time a life limiting disease is diagnosed, beginning with minimal palliative care and increasing input as required.

Gardiner, Gott and colleagues, in a series of articles on the needs of people with COPD, highlight the significant symptom burden experienced by people with COPD and their families, as well as specific needs around education and access to specialist and palliative services (20-22). They note that, although the UK has developed a national *Strategy for End of Life Care* aimed at all people who are dying (11), for those people not dying of cancer, care is likely to be inadequate (20). Their literature review highlights the need for further research around the most appropriate ways of delivering care for people with COPD (21).

The current research project was initiated because of an increasing recognition by the collaborating researchers (representing both hospital and community health services) that, in Australia, the needs of people with COPD and their families are not being consistently and effectively met. We proposed that service delivery models based on the principle of integration of hospital and primary care potentially provide the most appropriate and feasible framework for the development of models of end of life care for people with non-malignant disease. Closer linkages between hospital, general practice and community services should result in improved quality of life at the end stages of the disease for both people with COPD and their carers and may result in significant savings in the cost of care for these patients (12, 23, 24).

Australia currently has a major opportunity to develop a model/models of care for people with end stage COPD with a number of health system reforms currently underway and a growing recognition of the importance of end of life care for both malignant and non-malignant disease. In particular, health reforms are underway to improve the ways in which hospital, specialist palliative care units and primary care services (including general practice) can interface to meet identified patient and carer needs. Our study set out to identify the most effective ways to address the types of care required by people with advanced COPD. It examined (from the perspective of people with COPD and carers) what end of life care needs are (and are not) being met under current conditions and what type of services would most effectively and efficiently address these needs. Because respiratory care, palliative care, general practice and community services were represented in the project, recommendations for a model/models of care have been considered from each of these viewpoints,

but most importantly, recommendations arising from the project reflect the needs, experiences and suggestions of people with COPD and those people that care for them most closely.

1.2 Project aim and objectives

The aim of the project was:

To explore the unmet care needs of people with end stage chronic obstructive pulmonary disease (COPD) and develop recommendations for a model of care.

The objectives of the project were:

1. To describe the care services available to, and accessed by, people with end stage COPD in South Australia.
2. To determine whether the care provided met the patients' self-perceived and reported needs.
3. To ascertain the views of the patients' carers about the adequacy of care provided.
4. To inform the development of a distinct model (s) of care that addresses the needs of people with end stage COPD.

1.3 Chronic obstructive pulmonary disease (COPD)

The care of people with COPD is becoming an increasing burden on both the hospital and community, but more importantly, many of these people are not receiving the optimal care that would ensure that their end of life care meets the needs of both themselves and their carers (4-6, 21). Internationally, few service models have been explored, whilst the needs of people with COPD and their carers are increasingly being documented (21, 24, 25).

Pearson et al (26) identified that COPD differs from other chronic diseases in its responsiveness to the systematic care processes employed in other chronic diseases – indeed home based interventions such as self-management are not as effective for COPD as for other chronic diseases such as diabetes. They suggest that 'programs of care that place an emphasis on palliative support and treatments will prove more successful' (26), (p649). Seamark et al (27) suggest that care for COPD should be provided by both primary and secondary care and a multidisciplinary approach is required. Gardiner et al (21) and Spathis and Booth (24) further emphasise the need to develop a model of care for COPD which integrates care across the hospital/palliative/community spectrum to meet the needs of both carers and patients.

1.3.1 Defining COPD

COPD has had many names in the past 50 years including: *Chronic Obstructive Airways Disease* (COAD); *Chronic Obstructive Lung Disease* (COLD); *Chronic Airflow Limitation* (CAL or CAFL); and *Chronic Airflow Obstruction*. COPD as we currently understand it comprises two related diseases, *chronic bronchitis* and *emphysema*, one rarely occurring without a degree of the other. Therefore, COPD is seen to be a collective term for chronic bronchitis and emphysema. The definition of COPD that is currently accepted internationally is that COPD is a chronic disease characterized by progressive airflow obstruction, chronic cough, and dyspnoea in advanced stages, caused by smoking, environmental, and hereditary factors. The Global Initiative for Chronic Obstructive Lung Disease has expanded to define COPD as a disease state characterised by airflow limitation that is not fully reversible. The airflow limitation is usually both progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases (28).

Smoking is the main cause of COPD (29), however the above definition highlights the more recent evidence that there appear to be genetically determined factors that result in between one in five to one in two people being susceptible to the harmful effects of tobacco smoke (30).

The problem of classification and definition of the syndromes that lead to chronic airflow limitation (CAL) that is associated with COPD is made complex by many factors because it is a physiological term and therefore requires a measurement of airway function, usually spirometry, for diagnosis. Hogg (31) (p709) suggests the following definition:

airflow limitation that defines COPD is the result of a prolonged time constant for lung emptying, caused by increased resistance of the small conducting airways and increased compliance of the lung as a result of emphysematous destruction.

The end stage of COPD generally results in repeated episodes of respiratory failure often related to acute exacerbations of the underlying disease, acute respiratory infection or exposure to pollution. Respiratory failure is defined as hypoxaemia ($\text{PaO}_2 < 60 \text{ mm Hg}$) and in some cases combined with hypercarbia ($\text{PaCO}_2 > 50 \text{ mm Hg}$). Hypoxaemia is often present continuously in chronic respiratory failure due to end stage COPD. Corrections of hypoxaemic episodes underpin the treatment of this condition (32).

1.3.2 The economic burden of COPD

Chronic obstructive pulmonary disease (COPD) is recognized as being one of the major global public health problems with substantial morbidity and economic burdens. It is one of the few chronic diseases that is an increasing cause of mortality and morbidity worldwide (33). The international Global Burden of Disease Study has estimated that from 1990 to 2020, COPD will increase worldwide

from the sixth to the third leading cause of death and from the twelfth to the fifth leading cause of disability adjusted life years lost (34).

The prediction that COPD will rise to be the third leading cause of death worldwide by the year 2020 has enormous implications for economic management of health care. Current prevalence estimates are likely to be underestimates, as the disease is often not diagnosed until late in its course when lifestyle is significantly impaired. In 2008 the estimated financial cost of COPD in Australia was \$8.8 billion. It was also estimated that a further \$89 billion was lost due to disability and premature death (35).

COPD is a major cause of mortality and morbidity in Australia. Chronic airflow limitation that is associated with COPD and allied diseases was associated with 3.7% of all deaths in Australia in 2005 (1). Access Economics, Australia's premier economic consulting organisation providing expert economic advice for business, government, industry groups and not-for-profit organisations, recently reported that COPD increases the person's risk of death 3.2 times that of the general population and that approximately 16,000 deaths from this disease occurred in Australia in 2008 (35). Approximately 2.1 million Australians have some form of COPD and by 2050, this figure is expected to more than double to 4.5 million Australians (35). Of those with COPD, 1.2 million Australians have COPD (Stages II – IV), a stage at which symptoms are already affecting their daily lives (2, 35). Chronic lung disease is also a major cause of mortality and morbidity in Indigenous Australians. Indigenous Australians die from COPD at a rate 10 times greater than non-Indigenous Australians (36).

1.3.3 COPD symptoms

The cardinal symptom of COPD is dyspnoea, which is of differing intensity in those people who have varying airways obstruction, but which is progressive and unvarying in those with advanced emphysema. Kinsman and colleagues (37) asked patients with chronic bronchitis and emphysema to report and rate the frequency of all their symptoms. In decreasing order of frequency these were dyspnoea, fatigue, sleep disturbances, congestion, irritability, anxiety, loss of interest, poor appetite, helplessness/hopelessness, poor memory and feelings of alienation. Solano et al (38) identified breathlessness, fatigue, anxiety, pain and depression as the most prevalent symptoms of advanced COPD. Many of these symptoms may be caused by hypoxia, particularly loss of memory, sexual dysfunction and weight loss (39). However, there have been no studies as yet demonstrating a close relationship between the symptoms and the arterial PaO₂. The greater the degree of emphysema the more severe were the symptoms relating to loss of interest in life (40).

Typically the person living with COPD is confronted with long term limitations with many intermittent serious episodes, each of which may lead to death. However, people often survive these episodes but with a further deterioration in functional status and health (22, 41). The pattern of the illness and

the uncertainty of when death is approaching make it very difficult to define a period that can be called 'end of life'. This uncertainty and the lack of knowledge amongst people with COPD about their disease (22, 42) may help to explain a reluctance to initiate discussion of end-of life issues and some of the barriers to delivering palliative care for people with end stage COPD (5).

1.3.4 Measuring the severity of COPD

The importance of the need to manage and prevent COPD was recognized internationally in 1997 with the establishment of the Global Initiative for Chronic Obstructive Pulmonary Disease (GOLD) which was established jointly between the WHO, the National Heart, Lung and Blood Institute and the National Institutes of Health. GOLD established a spirometric classification for the severity for COPD based on FEV₁/FVC and predicted FEV₁, with rankings from Stage 1 (mild) to Stage IV (very severe) (43). In 2004, Celli et al (44) suggested a more comprehensive measure of severity – the BODE index, using BMI, degree of airflow obstruction, dyspnoea (as measured by the Modified Medical Research Council [MMRC]) and exercise capacity (as measured by the 6 minute walk test). The Modified Medical Research Council (MMRC) Dyspnoea Scale has been shown to be a simple and valid measure of dyspnoea when assessing severity in COPD (45).

In 2008, Huijsmans et al reported that whilst the GOLD classification is useful to discern groups of COPD patients, it is not specific enough to use for individual management plans, and whilst the BODE index is more discriminating, it also has major shortcomings in planning individual pulmonary rehabilitation programs (46). Funk et al (47) also found the BODE index score more discriminating than GOLD for explaining anxiety and depression in people with COPD.

1.3.5 Stigma and COPD

There is a growing recognition that many people with COPD feel a stigma associated with having the disease, both because of the distressing symptoms (and requirement for the use of oxygen in public) and because it is often perceived as a 'self-inflicted' disease caused by smoking (48, 49). Halting et al (49), (p1) reported that participants in their study felt:

...exiled in the world of the healthy, because of self-blame and society's stigmatisation of COPD as a self-inflicted disease. The participants experienced feelings of disgrace through subtle blame and a lack of support from their social network, health care encounters and larger society.

Berger (48), (p15) reported that 'the personal experience of stigma for the individual with COPD includes elements of self-blame, not wanting to burden others, and not wanting to appear sick'. The issue has relevance for people with COPD in two areas in particular:

1. It is vital for health professionals working with people with COPD to do so with a non-judgemental approach as effective communication is key to best practice care in advanced

COPD (most particularly in the areas of encouraging smoking cessation and developing discussions around end of life care) (49).

2. Social isolation is a key factor in reduced quality of life and in the development of anxiety and depression and perceptions of stigma can contribute significantly to increased social isolation (48).

1.4 The clinical management of COPD

Both internationally and nationally there are a number of guidelines for the clinical management of COPD, using measures of severity to determine specific treatment modalities. GOLD regularly publishes guideline documents with the most recent update being in 2009 (43). The UK National Institute for Health and Clinical Excellence (NICE) first developed COPD Guidelines in 2004, updated in 2010 (50). The American Thoracic Society (ATS), with the European Respiratory Society (ERS) released COPD Guidelines in 2004 (51) and in Australia, national guidelines were developed by the COPD-X working group in 2003, based on GOLD reports and Cochrane reviews (52). These are updated annually, with the most recent update in 2010 (53).

The consideration of the care needs of people with COPD at the end of their life varies markedly in these guidelines. The GOLD guidelines include little discussion of end of life care for people with advanced COPD, no discussion on the use of palliative care or a palliative approach, and only mention end of life in the context of patient education, noting that, 'Prospective end of life discussions can lead to understanding of advance directives and effective therapeutic decisions at the end of life' (43)(p48). The UK NICE Guidelines include palliative care as a key section in their algorithm for the management of stable COPD (50) and the American Thoracic Society (ATS) Guidelines contain a chapter on Ethical and Palliative Care Issues (51). Australia's 2003 COPD-X guidelines initially contained only a short reference to end of life needs, focussing on diagnosis and treatment with little mention of palliative care, but the 2010 revision contains a longer section focussing on palliative care (53) (p55).

There has been a growing recognition both nationally and internationally of the need to develop appropriate guidelines and models of care for people with advanced COPD, particularly as increasingly severe symptoms lead to a decreasing quality of life, greater dependence on assistance with activities of daily living (ADLs), increasing levels of social isolation, anxiety and depression and more frequent hospital admissions (21, 24, 54). This has meant that, since 2008, a number of Health Departments, professional colleges and organisations have released specific guidelines/statements and recommendations for COPD care at the end of life (summarised in Table 1.1).

Table 1.1 – Statements/Recommendations for end of life care in COPD

<p>The American Thoracic Society 2008</p>	<p>Palliative Care for Patients with Respiratory Diseases and Critical Illnesses The statement strongly endorses the concept that palliative care should be available to all patients at all stages of illness and should be individualised based on the needs and preferences of the patient and the patient’s family.</p>
<p>The Canadian Thoracic Society 2008</p>	<p>Canadian Thoracic Society recommendations for management of chronic obstructive pulmonary disease - 2008 update - highlights for primary care COPD is a progressive, disabling condition that may ultimately result in respiratory failure and death. Physicians have a responsibility to help patients with COPD and their families to plan for end of life and to make sure the necessary support is in place to assist them through the critical terminal phase.</p>
<p>Department of Health (UK)</p>	<p>Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) At this phase of the disease, palliative rather than disease-modifying approaches are required that reflect the person’s practical, social, psychological and spiritual needs. The needs of family and carer(s) should also be assessed, and support given by suitably trained and competent health and social care professionals throughout the last phase of the person’s life, and afterwards into bereavement.</p>
<p>The International Primary Care Respiratory Group 2008</p>	<p>Palliative Care for People with COPD The aim is then to help patients with COPD plan for, hope for and expect a good death: a death where they wish, with the people they want and with minimal physical, psychological and spiritual distress.</p>
<p>The Australian Lung Foundation / The Thoracic Society of Australia and New Zealand 2010</p>	<p>The COPD-X Plan Despite appropriate treatment, the trajectory of COPD is one of increasing disability and morbidity with time. As the severity of the disease increases quality of life is reduced, more frequent complications require treatment and increasing dependency impacts on carers. Unlike the cancer trajectory, the intermittent and potentially reversible acute exacerbations of COPD make palliative referral and discussion about end of life care difficult to initiate.</p>

1.4.1 Identifying ‘end of life’ in COPD

As advanced COPD develops, there is a progressive functional decline, poor quality of life and social isolation (55), with increasing dependency on both formal and informal caregivers and on the health system (56). There has been considerable discussion in the literature regarding a definition of when people with COPD can be said to be approaching ‘end of life’ or the ‘terminal phase’. One reason for this emphasis is that the ‘end of life’ phase has been seen as the trigger for referral to palliative care services (11, 41, 57). Increasingly however, it is being recognized that there is no clear delineation between advanced disease and when a person can be considered to be approaching the end of their life. Rather, COPD follows an ‘organ system failure’ trajectory described by Lynn and Adamson (58) who nominate three different trajectories of decline towards death:

1. Cancer – where death follows a short period of evident and severe decline.
2. Organ system failure – which follows a longer trajectory and has long term limitations with intermittent serious episodes.

3. Prolonged dwindling – typical of dementia, stroke and frailty.

Lynn and Adamson (58) argue that, whilst the timing of death may not be predictable in the latter two, the care that will be required to ensure quality of life should be triggered by symptoms rather than impending death. Murray et al (59) argue that these trajectories allow practical planning for a 'good death', and that understanding trajectories can be empowering for the patient and carer and suggest different models of care will be appropriate for people with different illness trajectories.

Building on this concept that end of life is part of a continuum of care, a palliative approach introduced sooner rather than later is increasingly being recommended as best practice care (60). In COPD, this is particularly recommended as there is no clearly definable point where active supportive treatment is replaced by palliative care (27). Therefore a palliative approach combined with ongoing management of the disease, is appropriate for COPD as the symptom burden and associated disability increases (5, 20, 24, 61, 62).

1.4.2 Measures to assess function and clinical outcomes at end of life

The AKPS

Abernethy et al (63) developed and validated the Australia-modified Karnofsky Performance Status Scale (AKPS) particularly for use in the palliative and other clinical settings and they note that changes in performance status can indicate a likely change in need for services. In a recent clinical trial on breathlessness in advanced disease Farquhar et al (64) noted that the AKPS is a more relevant and specific tool to measure function than the WHO Performance Scale.

The Modified Medical Research Council Dyspnoea Scale (MMRC)

The Modified Medical Research Council Dyspnoea Scale (MMRC) has been identified as a simple and valid method of categorising patients with COPD in terms of their disability that could be used to complement FEV₁ in the classification of COPD severity' (48)(p581). The MMRC was identified as a useful tool for this study as it both measures disability and is used to help calculate BODE Index, which was used as a key recruitment tool (47). Any changes in levels of disability were measured using the MMRC across the project.

Quality of Life (QOL)

Poor quality of life is consistently reported for people with COPD (21, 24) and the research team wanted to identify a simple, easy to understand measure of QOL to complement the interviews, MMRC and AKPS data. A five point visual analogue scale using pictorial representation of happy-sad faces and written descriptors was developed, based on the GOLD Standards Framework QOL measure used in the GSF Toolkit (65).

1.5 Models of care for advanced COPD

Any model of care for advanced COPD must have at its core, the ability to meet the needs of the people with the disease that it is meant to address. Thus, identifying the needs of people with advanced COPD is the first step in developing any model of care. The first systematic study of palliative care needs of COPD patients was reported by Gore et al (15), with further studies undertaken including Yohannes (4), Seamark et al (66), Curtis et al (67), and Elkington et al (9). The most recent comprehensive review of these studies was published in 2010 by Gardiner et al (21), and all of these reviews highlight the high symptom burden of people with COPD, the impact of the disease on carers and families and most particularly, the lack of effective and appropriate models of care to meet their needs as they approach the end of life. There continues to be little data on the most appropriate models of care for end of life for this group of people in the Australian context.

1.5.1 Access to palliative care

There has been significant discussion in the literature of the need for people with advanced COPD to access palliative care (4, 61, 62). However Spathis and Booth (68) (p23) note that:

the traditional model of care of patients with advanced disease, including COPD, is based on a dichotomy involving an abrupt transition from active, life sustaining care to palliative care. This does not work for patients with COPD.

They suggest that, because of the long trajectory of the illness, the heavy burden of often uncontrolled symptoms and the fact that people with advanced disease should not be denied active interventions, a mixed management model which combines active treatment with the principles of good end of life care is more appropriate.

As noted previously, a palliative approach (rather than referral to a palliative care service) is being increasingly seen as core to any model of care. A major implication of the use of a 'palliative approach' as part of the continuum of care is that health professionals in all areas of chronic disease management require education in palliative care principles and practice. Spathis and Booth (68)(p11) note that:

Care for those approaching end of life therefore cannot be, and indeed should not be, simply the domain of palliative specialists. All health care professionals should be able to provide good quality generalist palliative care for their patients.

1.5.2 The Chronic Care Model (CCM)

One model of care which accommodates care along a trajectory of slow decline and which can incorporate a palliative approach is the Chronic Care Model (CCM) (69). Simpson and Rocker (70) note that current models of care for COPD focus on the disease process rather than the symptoms and needs of the patient and Tiep and Carter (71) note that COPD management has a significant

acute care component, with management by specialists both in hospital and when patients are discharged. Both articles suggest that a chronic disease management (CDM) approach using the CCM may be the most appropriate model for addressing both care and patient needs in COPD. Adams et al (72) note that whilst further research is required on the effectiveness of the CCM in COPD, it has been shown to lower hospitalisation rates, lower presentations at emergency departments and decrease length of hospital stay.

Bodenheimer et al (69) report that CDM has six dimensions including delivery system redesign; health care organization; community resources; clinical information systems; decision support; and self-management support. They note that co-ordinated, multidisciplinary care is a key element of the model, as is the integration of care between the acute and primary care sectors. Gardiner et al (21) note that the new National Service Framework for COPD in the UK is likely to recommend a CCM (21), and the COPD-X Guidelines note that the CCM encompasses many of the areas which need to be addressed in best practice COPD care (53).

1.5.3 Health literacy/self-management

Health literacy has been identified as a key requirement for effective health communication and as vital in ensuring that people are able to effectively participate in decisions affecting their health (73). Roberts et al (74) define health literacy as ‘the ability to read, understand and act on health care information’ whilst Kickbusch et al (75), (p8) define it as:

...the ability to make sound health decisions in the context of everyday life at home, in the community, at the workplace, in the health care system, the market place and the political arena. It is a critical empowerment strategy to increase people’s control over their health, their ability to seek out information and their ability to take responsibility.

The National Health and Hospitals Reform Commission (76) has identified improving health literacy as a key element of health reform in Australia and Kickbusch et al (75) suggest that health literacy is vital if people are to navigate complex and confusing health systems. Both Adams et al (73) and Roberts et al (74) note that reduced health literacy is associated with poor health outcomes and Adams et al (73) (p530) also note that it is associated with ‘premature mortality, higher health care costs, adverse health outcomes, lower health status, less frequent preventive health behaviour and less active self-management of chronic conditions’.

Roberts et al (74) note that being aware of the level of health literacy of patients allows health professionals to tailor information so that it can be more effectively understood and acted upon, thus increasing compliance with health interventions. Because many COPD health interventions involve education (for example, stop smoking programs, pulmonary rehabilitation, self-monitoring), the ability for health professionals to communicate effectively with both people with COPD and their carers is vital.

Effective communication is essential for health professionals to be able to help allay the many fears that people with COPD and their carers live with, especially around dyspnoea (21). Health literacy is also vital for health professionals to be able to effectively discuss issues surrounding the progression and prognosis of COPD (22).

Chronic disease self-management is increasingly being proposed as a key strategy of chronic disease management generally, however there is no clear evidence currently that it is effective in advanced COPD (77). The concept of health literacy (a key element of chronic disease self-management) is particularly important for people with COPD and their carers to assist in allaying their fears, improving their knowledge of their disease and their ability to work with health professionals to manage their symptoms and improve their quality of life (78).

1.5.4 Advance care planning

The other key element of any model of care must be the incorporation of a formal process for end of life care planning. The Inaugural International Advance Care Planning conference held in Melbourne in April 2010 discussed the importance of population based advance care planning and this was seen as an important all-of-society responsibility (79, 80). There was agreement that responsibility for end of life planning should become part of the routine discussion for the entire population with the general practitioner, at a minimum from the age of 55 years. When chronic or progressive illness occurs, then more detailed discussion about actual end of life plans should be initiated and as age or illness advance then conversations should occur about where one might want to be when death occurs. Deficiencies in the United States end of life guidelines were identified with inclusion of clinical signs and symptoms but nothing about quality of life (QOL) or supports (81, 82). In the United Kingdom there has been some planning for end of life care in the Gold Standards Framework for optimising the care of patients nearing the end of life (83, 84). *The Respecting Patient Choices Program* (www.respectingpatientchoices.org.au) has been implemented in a number of hospitals throughout Australia.

Gardiner et al (21), Gardiner et al (22), Gott et al (20) and Spathis and Booth (24) all emphasise the importance of advance care planning conversations with people with advanced COPD and the introduction of advance care planning conversations is core in any model of care for advanced COPD.

1.5.5 The role of carers

Another key consideration for any model of care is the role of, and support for, carers of people with advanced COPD. Caress et al (85) undertook a systematic review aimed at identifying the information and support needs of family carers of people with COPD and found that there was a dearth of literature in this area, despite the core role that carers play in this disease. They report that:

while the contribution of family carers of patients with COPD is acknowledged in some guidelines (e.g. National Institute for Clinical Excellence [NICE] 2004), there is little understanding of the needs of family carers or what interventions provided by health care providers to carers are seen as appropriate or helpful. Providing effective help to carers is important if family carers are to be supported in their role. A supportive caregiver to community living patients is considered one of the most important factors in delaying and preventing institutionalisation of a chronically ill person (85) (p480).

1.6 The policy context

Australia is currently undergoing a significant period of health reform, which has the potential to impact greatly on the development of any model of care for COPD. The following outlines key policy documents/strategies and their relevance for a COPD model of care.

1.6.1 Australian Government

National Health and Hospitals Reform Commission (NHHRC). 2009

A Healthier Future for All Australians – Final Report (76)

This is the key Australian health reform document which sets out a way forward for the Australian health care system. A core element of this is a strengthened and expanded primary health care system, facilitating integrated and co-ordinated care, particularly for chronic disease. The report has a specific focus on caring for people at the end of life, recommending expansion of access to palliative care services, support for implementing advance care planning and workforce education in this area. A number of other strategies have been developed, based on NHHRC recommendations, including the National Preventative Health Strategy, the First National Primary Health Care Strategy, the establishment of 'Medicare Locals' and the strengthening of the Australian Commission on Safety and Quality in Health Care (ACSQHC) – all of which have implications for the future management of COPD in Australia.

National Preventative Health Taskforce (NPHT). 2009

Australia: The Healthiest Country by 2020. National Preventative Health Strategy – the roadmap for action (86)

Smoking is one of the four targets of activity for the National Preventative Health Strategy (NPHS) with the aim to have one million fewer people smoking in Australia by 2020. The measures they propose to reduce smoking rates have the potential to impact significantly on community rates of COPD.

Australian Government Department of Health and Ageing. 2010

Building a 21st Century Primary Health Care System. Australia's First National Primary Health Care Strategy (23)

This strategy outlines four key priority areas for change:

1. Improving access and reducing inequity: Primary health care services are matched to peoples' needs and delivered through mainstream and targeted programs across an integrated system.
2. Better management of chronic conditions: Continuity and co-ordination of care is improved for those with chronic disease through better targeted chronic disease management programs linked to voluntary enrolment and local integration.
3. Increasing the focus on prevention: Strengthened, integrated and more systematic approaches to preventive care with regular risk assessments are supported by data and best use of the workforce. People know how to manage their own health and self-care.
4. Improving quality, safety, performance and accountability: Framework for quality and safety in primary health care with improved mechanisms for measurement and feedback driving transparency and quality improvement.

Australian Government Department of Health and Ageing. 2010

Medicare Locals. Discussion Paper on Governance and Functions (87)

Medicare Locals will be responsible for providing better integrated care, making it easier for people to navigate the local health care system. The roles of these organisations could include:

1. Facilitating allied health care and other support for people with chronic conditions.
2. Working with local health care professionals to ensure services are integrated and people can easily access the services they need.
3. Planning to ensure the availability of face-to-face after hours services for their region.
4. Identifying groups of people missing out on GP and primary health care, or services that a local area needs, and responding to those gaps by targeting services better.
5. Working with Local Hospital Networks to assist with patients' transition out of hospital, and if required, into aged care.
6. Delivering health promotion and preventative health programs to communities with identified risk factors (in cooperation with the Australian National Preventative Health Agency, once it is established).

Australian Commission on Safety and Quality in Health Care (ACSQHC), 2010

Patient-centred care: Improving quality and safety by focusing care on patients and consumers (88)

In September 2010, the ACSQHC released a discussion paper which proposed 'patient-focused care' as the first of three dimensions required for a safe and high quality health system in Australia

(88)(p11). This paper makes a series of recommendations about how to incorporate a patient-centred focus into health care systems and practice. Patient-centred care is defined as:

...health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. The widely accepted dimensions of patient-centred care are respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care (88)(p7).

If patient need, rather than the system or the service, was the focus of care, need would dictate access to services for people with COPD, rather than the current prognosis or age based access criteria, and this would address many of the issues raised in the literature around gaps in care and barriers to access.

1.6.2 Palliative care

Palliative Care Australia (PCA) 2010

Health system reform at the end of life: A Guidance Document (10)

In 2010, PCA released a comprehensive document to inform health system reform in the area of end of life care, regardless of diagnosis. It outlines three major areas around which care should be organised:

1. Care that is person and carer focused (with the four domains of: patients empowered to make fully informed decisions; needs based care; involved and supported carers; and culturally competent, safe and appropriate care).
2. Care that is driven by information (with the four domains of: informed and empowered community; data collected and used to support quality improvement; knowledge led continuous improvement; and supported research, knowledge translation and exchange).
3. Care that is organised for quality and safety (with the three domains of: seamless, well coordinated care; flexible, optimised and effective workforce and appropriately resourced).

National Health and Medical Research Council (NHMRC) 2009

Ethical issues involved in the transitions to palliation and end of life care for people with chronic conditions (89)

In 2009, the NHMRC released a document recognising the need to address end of life care issues for people with chronic disease, noting that 'ethical issues about health care of chronic illnesses or conditions as the end of life approaches are a pressing societal concern' (89)(p9). In 2006, in their examination of the ethical issues surrounding lung disease, Neerkin and Reilly (90) noted that almost equal numbers of people in the UK died from cancer and COPD, and that equal numbers could

therefore be expected to receive equal amounts of care. However this is not so and thus ethically 'palliative care should be available to all on the basis of need, not diagnosis' (90) (p96).

Whilst this NHMRC paper focuses on the transition period between intervention and a move to palliative care, and there is growing evidence that this is not clear cut – rather an ongoing palliative approach is likely to best meet patients' needs – many issues raised in this paper are of direct relevance to the development of new models of care. These include the development of strategies and processes to enhance communication between health care facilities; ways of ensuring continuity of care and team approaches to care; use of Integrated Health Care Plans that emphasise hope and living well; the use of advance care planning; and the development of an approach to dispel any perceptions that palliative care equates with imminent death.

SA Health 2009

SA Palliative Care Services Plan 2009 – 2016 (91)

In 2009, the SA Health Department released their palliative care plan for South Australia (SA), which incorporates recognition of the importance of end of life care for all people who die in SA. This plan uses 'palliative care' to refer to specialist clinical practice and service delivery, whilst 'end of life care' refers to care more generally that is planned for, negotiated with or provided to a person as they approach end of life. This differentiation is aimed at clarifying specialist and generalist provider roles. The Plan goes on to outline how palliative care services can be expanded and reshaped in SA, noting that the key challenges facing service provision in SA are the ageing population and the ageing workforce.

1.7 Summary

There is a growing body of evidence around the care needs of people with COPD and recent literature reviews highlight key needs as symptom management; quality of life, functioning and autonomy; patient-provider education and patient-family education; support for the burden on families and appropriate use of resources, provider skill and family-patient satisfaction (21, 24, 92).

The literature also clearly outlines the barriers for people with COPD and their families in accessing the care they need, particularly in the areas of advance care planning (20), lack of understanding of the disease and lack of knowledge of interventions to relieve symptoms (22). A major issue highlighted in the literature is the 'inherent difficulties in determining prognosis' (24), (p11) and, as many end of life care services are triggered by prognosis rather than need, people with COPD consistently miss out on these services. Communication is another major barrier, and Curtis et al (93) note that this is one of the major barriers for provision of good quality end of life care, particularly in the area of end of life discussions and advance care planning.

Recommendations for a palliative approach to care for people with advanced COPD (rather than transfer of care to a palliative care service) are becoming more common, with the recognition of the difficulties associated with the trajectory of care (where ongoing intervention is required with palliative symptom control) and that the number of people with COPD would overwhelm palliative care services (21, 24). As noted in Table 1.1, there is a growing body of guidelines and recommendations regarding best practice end of life care for people with COPD, however this is not yet reflected in the development of appropriate models of care.

In Australia today, the current health reforms at a national level present an excellent opportunity to develop the co-ordinated, integrated services which link acute, primary and community care services that would meet the needs of people with COPD and help to overcome the clearly documented barriers to care. There are currently few models of care reported in the literature for people with COPD as they approach the end of their life, and it is increasingly being recognized that people with advanced chronic disease (be it COPD or any other chronic disease) have a right to good quality care at the end of their life and that health services have an ethical responsibility to provide that best practice care.

1.8 Methodology

This study combines the voices of people with COPD and their carers with interviews with key service providers in the areas of respiratory health, palliative care, primary care and community based services, to determine the needs of people as they reach end stage COPD. Kendall et al (94), (p1) have suggested that multi-perspective, qualitative interviews are useful in understanding the individual needs of patients, carers and professionals and note that 'linked interviews conducted with patients and their informal and professional carers can generate a richer understanding of needs and experiences than the single perspective most commonly used in qualitative studies'. Project findings from these interviews have been linked to an examination of currently available services and barriers to accessing these services (see Sections 2-4).

In order to address our project aim and objectives, three separate but related studies were undertaken:

Study One (See Section Two)

People living with COPD and their carers: Exploring their needs

Study Two (See Section Three)

Issues and challenges associated with end stage COPD: The views of specialist health professionals

Study Three (See Section Four)

Service availability and accessibility for people with end stage COPD and their carers

A Project Team which combined Research Team members with additional representatives from general practice and the Palliative Care Council of SA, was established to guide each of the three studies (see page vi). Findings from the three studies will be summarised and presented for review to key stakeholders including people with COPD and their carers, service providers, policy makers, members of the community and clinicians. These key stakeholders will be then brought together with a wider representation at a roundtable meeting to discuss the policy and practice implications of the project findings and to make final recommendations for an appropriate model of care.

1.9 Ethical considerations

Ethics approval for the project was obtained through the Research Ethics Committee at the Royal Adelaide Hospital (RAH) in December 2008 (RAH Protocol number 081203). An amendment to the Ethics Approval was requested in February 2009, when the methodology for Study Three was revised to include focus groups or interviews with service providers and COPD consumer groups regarding service availability and their perceptions of how services were or could be accessed and where there were gaps and barriers to access. Approval for this revision was obtained in March 2009 (RAH Protocol number 081203a).

Major ethical considerations included:

1. Protection of privacy: This was particularly important as patient records were accessed in Study One. All participants were given a unique identifier, and this was used wherever possible rather than any names. All case notes were accessed in the RAH only by the COPD respiratory nurse or in Whyalla only by the respiratory nurse, following written permission from participants.
2. Protection of confidentiality: All participant and service provider data was de-identified before publication and only de-identified data will be used in any publications or reports. These confidentiality measures were noted in the 'Informed Consent' information supplied to all participants before they signed any consent forms.
3. Informed Consent: Participant information sheets were provided to all participants before obtaining signed informed consent. All participants in Study One had the project explained to them by the COPD respiratory nurse in the RAH, or the respiratory nurse in Whyalla, before being provided with written information regarding the study and a Project Consent Form.
4. It was emphasised to all participants that they could withdraw from the project at any time, and this would have no effect on their treatment /employment in any way.

5. At all times, all members of the Project Team were aware that they were working with participants at a particularly vulnerable time, and so only undertook research activities if they caused no distress to any of the participants.

Additionally Study One was designed to be sensitive to the vulnerability of participants with end stage COPD and to cause as little stress as possible. This included the selection criteria which were designed to minimize the burden of additional lung function and exercise tolerance testing on potential participants.

Study Two and Study Three focus group participants consented to participating in the discussions and to the audio recording. Participants were assured that they could request the digital recorder to be turned off at any time, and that as individuals they would not be identifiable in the final report. Group norms were also discussed at the commencement of the focus groups and included issues such as confidentiality, respect for the perspectives of others and one person talking at a time.

1.10 Strengths and limitations

This research gives voice to the participants with COPD and their carers, the key service providers and a wide range of health professionals. It provides a depth of insight into the needs and experiences of people with COPD, along with an examination of the services that were and were not provided. A particular strength of this study is that the different sources of data combined together to provide a rich, textured exploration of the issues. The contribution from respiratory, palliative care, primary care and community based services strengthens the authenticity of the findings. The participants with COPD were from metropolitan, rural and regional settings and the two in-depth interviews of each participant, at an interval of six months, provide a broad perspective to this research. Another important strength was the multidisciplinary composition of the research team, bringing their different perspectives which strengthened the design and research process.

The researchers acknowledge the difficulties in determining the selection criteria for the participants with COPD. The original design was to use the Gold Stage IV and the BODE index as ways to identify people with very severe COPD who may be approaching the end of their life. However, the six minute walk test component of the BODE index was distressing for some of the potential participants and had been discontinued as a clinical measure for many. Weight loss was also not a consistent finding in potential recruits and was removed as a selection criterion. The removal of these selection criteria could be seen as a limitation in our ability to identify participants with end stage COPD. Although participants were recruited from metropolitan and rural areas, they were all known to one respiratory service and the researchers acknowledge that people accessing care through other respiratory services, including care in the private health system, may have had different experiences.

However, given that the identified issues strongly reflect those identified in the international literature, it seems likely that they would be transferable to the broader group of people with COPD and their carers. The researchers also acknowledge that time and resource limitations meant that a sample size of 15 participants and their carers were recruited in Study One, and a larger group of people with COPD, recruited across a number of services may have provided a broader picture of their experiences.

2. Study One – People living with COPD and their carers: Exploring their needs

2.1 Introduction

The aim of this study was to explore the experience of people living with chronic obstructive pulmonary disease (COPD) and their carers, and to identify their care needs, what services they were accessing and to examine whether their needs were being met.

Currently there is no specific model of care for people with end stage COPD, despite growing evidence of the specific symptoms and issues of living with this disease for this patient group. There is still little data available and no data in the Australian context. Identifying appropriate services and facilitating access to services are essential for a new model of care.

Study One was undertaken to ensure that the experiences of people with COPD and their carers informed the development of a distinct model of care for people living with COPD in the community. The care needs of 15 participants were explored in two semi-structured interviews, six months apart, carried out at home by one researcher experienced in qualitative research.

2.2 Method

2.2.1 Selection and recruitment of participants

2.2.1.1 Selection criteria

Selection criteria included participants who were 18 years or older, able to speak adequate English, and not suffering any significant cognitive impairment, or with a diagnosis of dementia.

Participants were required to be living in the community, not in residential care. As an index of the severity of their COPD, they were required to have been hospitalised at least twice in the past 12 months. All participants had lung function tests demonstrating that they met the requirements for GOLD Stage IV classification (Appendix 1). Participants were not asked to repeat lung function tests specifically for the study if they had been completed within the previous year and if on other clinical indications, they were thought to be at 'end stage' COPD. Having a prescription for long term oxygen therapy was not included as a criterion.

Exclusion criteria included active treatment for lung cancer in the last five years or for any other cancer in the last 12 months and/or evidence of metastatic disease. Lung transplantation was also an exclusion criterion.

Determining the prognosis of people with COPD has been identified as a major issue in a number of studies looking at end of life care for this group. The BODE Index measurement which measures body mass index, airflow obstruction, dyspnoea and exercise capacity and has been shown to be an accurate predictor of mortality (44), was initially considered as a way to identify those people with very severe COPD who may be approaching the end of their life. A six minute walk test is a component of the BODE index, and without it the calculation cannot be made. However as recruitment progressed for this study, it became apparent that the exercise test could cause unnecessary stress for the participants and was not indicated clinically, so it was decided to omit the BODE index measurement from the selection criteria. Weight loss was not a consistent finding among potential participants and it was felt not to be an essential selection criterion (Appendix 2).

2.2.1.2 Recruitment of participants

Fifteen participants who had been diagnosed with end stage COPD and who met the selection criteria were invited to participate in this study. Several potential participants in the metropolitan area were admitted to residential aged care facilities, making them ineligible, and three people declined the invitation to participate. Before the start of the formal data collection, one male was interviewed during a hospital admission as a pilot interview in order to refine the questions and prompts used in the semi-structured interview.

Participants were recruited by two senior respiratory nurses. Eight participants were from the Adelaide metropolitan area, one was from an inner rural area, and six were from a regional country centre. The nine Adelaide participants were approached by the COPD respiratory nurse at one public hospital during an admission for an exacerbation of their lung disease. The six country participants were at home when they were invited to participate by the respiratory nurse based at the regional hospital. The respiratory nurses explained the research project and provided the Information Sheet, Consent Form and a reply paid envelope if the participant chose to return the forms by mail (Appendices 3, 4, 5). After this initial approach, the respiratory nurses then contacted the carer, if there was one, to explain the project and to see if they would also be willing to participate.

Key to participant details

P	metropolitan participant
R	regional participant
CP	metropolitan carer
CR	regional carer
CP2a	second metropolitan carer

2.3 Interviews

The first round of interviews was carried out over a three month period between June and August, 2009. All interviews except one were carried out in the participants' homes by an experienced qualitative researcher. One participant and carer were seen in a hospital outpatient department. The nature of the research was explained again to all participants and the information which the participants had already received was clarified. Consent Forms were signed.

Between the time when the participant was first approached and the time of the first interview, delays were encountered when several participants were unwell or were readmitted to hospital. In one case one participant was receiving geriatric rehabilitation as an inpatient and the interview was delayed until she was discharged home.

The second round of interviews took place between December 2009 and March 2010, as close as possible to six months after the first interview. This interval was designed to provide the opportunity to examine whether care needs had changed as a participant's condition deteriorated. One participant died prior to the second interview, but his wife agreed to a follow up interview. This took place four months after his death. Some participants delayed the second interview because of fatigue, ill health or extreme heat. No one refused; all were willing to contribute to the research.

The semi-structured interviews, using prompts, focused on the participants' well-being, their understanding and knowledge of the disease, and how they were coping at home. Issues related to oxygen use were also explored. Their activities of daily living, including showering, dressing, cooking, cleaning, gardening, and shopping, were discussed and how they managed with or without a carer and other supports. Information was sought about services involved and perceptions of those services. Access to medical services such as general practitioners and specialists, including transport and other issues in getting to appointments, and the use of emergency departments and ambulance services were explored (Appendix 6).

The two South Australian legal advance directives documents under the *Consent to Medical Treatment and Palliative Care Act (1995)*, the Medical Power of Attorney and Anticipatory Directive,

were introduced and issues associated with the participants' future wishes and treatments were sensitively explored. Participants were asked what they perceived to be their biggest problem, and what might be helpful for other people with the same disease. Towards the end of the first interview, they were asked 'What sort of services do you see yourself needing in six months' time?'

Finally two instruments were introduced, a dyspnoea scale and a measure of the impact of the illness on quality of life. First the Modified Medical Research Council Dyspnoea Scale (MMRC) (Appendix 7) was referred to by the interviewer and the level identified as closely as possible. The purpose of this was to make objective the degree of dyspnoea and allow comparison at each time point (45). (See also the Pulmonary Rehabilitation Toolkit: An Initiative of the Australian Lung Foundation and Australian Physiotherapy Association <http://www.pulmonaryrehab.com.au/index.asp?page=62>)

A Quality of Life Measure (QOL), describing the impact of the illness on quality of life was shown to participants who then selected the level that best described their feelings about their quality of life on a five point visual analogue scale using pictorial representation of happy-sad faces and written descriptors (65). They were asked the question, 'Taking into account all that we have discussed how much is your quality of life being affected by your illness?' (Appendix 8).

Following each interview the ability of each participant to carry out personal care, and household tasks was assessed using the Australia-modified Karnofsky Performance Status Scale (AKPS) (63) (Appendix 9). This also allowed comparison at each interview and correlation with need for services.

2.3.1 Carer interviews

The seven carers who were either a spouse or long term partner, and who lived with the participant, all chose to be interviewed together with the participant for the first and second interviews. One son-carer and two daughter-carers (one a sole carer, the other who shared care with her mother) were present only for the second interview. In this latter case both the wife and daughter spoke separately to the interviewer.

Questions directed to the carer included how the participant's illness had affected their life, whether they had adequate information about COPD, and if there were adequate supports for both of them (Appendix 10).

2.4 Data analysis

All interviews were recorded and a full or summary transcription was combined with the field notes. Thematic analysis was undertaken separately by two of the researchers both of whom listened to all the interviews to ensure validity. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (95). The process used reflects the six phases suggested by

Braun and Clark (2006): 1) Familiarisation with the data; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes; 5) Defining and naming themes; and 6) Producing the report (95). A thematic analysis approach was chosen to allow flexibility in examining the dense data produced from the interviews with participants and their carers and Braun and Clark (95) also note that thematic analysis is particularly useful for analysis aimed at informing policy development.

2.4.1 Selection bias

Although participants were recruited from metropolitan and rural areas, all were recruited through one large metropolitan public hospital and one regional public clinic. The metropolitan hospital had recently redesigned clinical processes to streamline the patient journey for patients with COPD within the hospital and to implement evidence based management of COPD under the oversight of the hospital COPD Steering Committee, 2005. The researchers acknowledge the potential bias resulting from this source of referrals which meant that no privately insured participants were recruited.

2.5 Findings

2.5.1 Participant demographics

Following the interviews of the 15 participants with COPD and their carers, relevant demographic information was collated (see Table 2.1).

Table 2.1 – Summary of participant demographics

	Metro	Regional	Total
Number of participants	9 (including one inner-rural)	6	15
Male	5	4	9
Female	4	2	6
Age range	54-79 years	53-75 years	53-79 years Median 66
Participant living alone	6 3 male 3 female	1 male	7
Participant living with full-time carer	3 3 spouse or partner – 1 later replaced by a son	5 4 spouse or partner 1 daughter	8
Adult children assisting with care	3 female	0	3
Friend support at first visit	3	0	3
Friend support at second visit	1	0	1
No carer identified at first visit	0	1	1
No carer identified at second visit	2	1	3

2.5.1.1 Income

All participants were on a pension; 10 were on the Age Pension and five were on a Disability Support Pension. The participants who were on a Disability Support Pension ranged in age from 53 to 61 years. Five of the participants now on an Age Pension had previously been receiving Disability Support. All eight live-in partner/carers were receiving carer financial support.

One participant reported particular financial difficulties with a range of debts, and a traffic fine being paid off automatically through deductions from his Centrelink payments (P7).

2.5.1.2 Home ownership

Eight participants owned their own home; seven were in Housing Trust properties.

2.5.2.3 Private health

No participants had private health insurance.

2.5.2.4 Home oxygen

Eleven participants were using home oxygen.

2.6 Assessment tools

The findings of the two more objective assessment tools (MMRC and AKPS) are reported here. The subjective, QOL findings are discussed in Section 2.12. A table of the combined scores of all three assessment tools, linked with the use of services is in Appendix 11.

2.6.1 Modified Medical Research Council Dyspnoea Scale (MMRC)

The MMRC Scale for dyspnoea assigns a numerical category to the degree of breathlessness which ranges from Category 0 'I only get breathless with strenuous exercise' to Category 4 'I am too breathless to leave the house' or 'I am breathless when dressing'. The higher the number assigned, the worse the degree of breathlessness.

The distinction between the numbered categories was not always clear in terms of the things that participants could or could not do. There was considerable overlap between the descriptions of activities that resulted in breathlessness.

Of the 28 scores recorded, only three scores were less than 3. Two participants only gave a score at the first interview; one had died before being re-interviewed and the other was interrupted by family before the end of the interview. Five participants indicated deterioration in function between interviews, and recorded a higher MMRC score (Table 2.2).

2.6.2 Australia-modified Karnofsky Performance Status Scale (AKPS)

The AKPS was developed and validated particularly for use in the palliative setting by Abernethy et al (2005) (63). The scale ranges from 100%, which is defined as normal, no complaints, no evidence of disease, to zero (equalling death). The intervals are units of 10 which are grouped into three separate categories, with descriptions of the range of activities and need for assistance at each level. The authors noted that changes in performance status can indicate a likely change in need for services.

Most participants fell in the range of 50-70 on the AKPS. Between the first and the second interviews, six participants had deteriorated and eight had remained at the same level. Most of those who deteriorated were rated 10 percentage points lower at the second interview, although one had dropped from 60% to 40%. This change was due to other factors as well as COPD (Table 2.2).

The participant with a 20 point decrease was admitted to residential aged care and another with a 10 point decrease was referred to a specialist palliative care service. For the other four participants with a decreased AKPS, there was no change in services except in one case where services were

subsequently increased as a result of intervention by the interviewer. Of the two participants who were referred to specialist palliative care services, only one had a decrease in AKPS. This participant who died between interviews had rated at 50% initially, and his death followed a short acute illness rather than a longer period of further decline.

Table 2.2 – MMRC and AKPS results

	P1	P2	P3	P4	P5	P6	P7	P8	P9	R1	R2	R3	R4	R5	R6
MMRC1	1	3	3	3	3	4	3	4	4	4	3	3	2	3	3
MMRC2	1	3	3	N/A	4	4	4	D	4	4	3	3	3	4	3
AKPS1	70	50	70	70	50	50	60	60	60	50	60	60	70	60	60
AKPS2	70	50	60	50	50	40	50	D	40	50	60	60	60	60	60

P: metropolitan participant; **R:** regional participant; **D:** deceased

2.7 Interview themes

This section describes the themes and sub-themes which were identified from the data.

2.7.1 Knowledge and understanding of COPD, co-morbidities and smoking

2.7.1.1 Diagnosis of COPD

All participants were aware that they had a disease involving their lungs, or at least breathing difficulties. The commonest name given to their condition by participants was *'emphysema'* (6). Several appeared to have only a basic understanding of their condition, *'Just bad lungs'* (P2), *'they're not in real good nick'* (P1). One participant used the analogy to pieces of plastic *'mine go pop pop pop...nothing of them left at all, they reckon'* (P5).

Five participants recognized or were aware of the term COPD, and another thought he might have recognized the term from a friend. *'Well a friend of mine, he's got the same thing, he did say, he went into detail about it, but I've forgotten, but there are some things I can't remember'* (P1).

Emphysema appeared to be recognized by most as a serious condition. One participant who had been treated for asthma for many years noticed increasing shortness of breath seven years ago:

I think that was the first time I actually challenged a doctor and said is this emphysema, and he didn't say yes, but he just nodded his head, I don't think he wanted to say it, to verbalise it you know, but since I've been down here [from interstate] it got progressively worse (R4).

The perception of the time of diagnosis was quite variable ranging from 'all my life' (P2) to over 20 years based on a history of chronic cough or asthma (P6). For others the time of diagnosis was linked to specific events in the preceding three to eight years, either hospital admission for complications of their lung disease or another specific medical event, for example hip replacement (P5).

One participant was diagnosed with COPD at the time of a partial pneumonectomy for a tumour six years earlier. He was told the tumour had asbestos fibres in it, but it was not mesothelioma (R1).

2.7.1.2 Aetiology of disease

All participants recognized the role of smoking in their lung disease:

They're rotting... and that is through smoking (P2).

Basically that they're worn out, there ain't much left, I cooked them (P6).

Probably too many cigarettes, might be a bit of industrial stuff, what do you call it, pollutions and stuff, I did work in foundries and stuff, but basically I'd say it was the cigarettes (R6).

Two others also cited industrial exposure as a possible factor, specifically bitumen (P7) and a period of time at Maralinga (P8).

One participant who was aware of the diagnosis of COPD and who described himself as having emphysema, blamed his illness on a car accident and punctured lung 32 years earlier although he acknowledged, 'it could be smoking' (R3).

For one participant, her recent deterioration was linked in her mind to complications of an angiogram, although she now realised she should have taken the advice to give up smoking given by her doctor seven years earlier after an attack of breathlessness:

I stopped smoking at the end of last year, about seven months. I think if I'd stopped smoking in 2001 I wouldn't have had any of this problem. That is what I feel and it makes me cross when I think about [it] (P2).

2.7.1.3 Understanding of prognosis

Few participants were able to articulate the progressive and terminal nature of their illness:

Putting it bluntly, I s'pose my lungs are stuffed and they say they're not going to get any better, they will get worser and when they get worser I get tireder, until one day I won't wake up, that's my understanding anyway, so I understand it to happen progressively, unless there's another way I don't know about (R6).

...what the doctor said to me in intensive care is like a petrol tank. When your lungs are good they're on full (pause) mine's on empty but they've gone over, when I've gone over there's not much you can do about it (P5).

...told I probably won't last much longer, but we don't dwell on it (P2).

Towards the end of the first interview, when participants were asked what services they saw themselves possibly needing in six months' time, a few answers indicated an awareness of their poor prognosis:

Well that's a fair while (P1).

I can't think that far ahead... Honestly, to be quite honest, I know this sounds terrible, but I can't see myself being here in six months' time (P3).

Might not even be here in six months' time... (R4).

A coffin box, that's about the only thing I'll really need (P5).

In response to the interview prompt, 'If there was one thing you'd like to change what would it be?' another participant also showed awareness of his prognosis:

What would it be, my lungs. I'm not ready to go yet but the way things are going it's not going to be long (P7).

One carer, who understood her husband's poor prognosis, argued with his general practitioner that he should have ticked the 'terminal' box on a Centrelink form rather than just 'long term', both in terms of accepting the reality of the prognosis and gaining access to appropriate financial supports (CP6).

2.7.1.4 Co-morbidities in participants

Participants suffered a wide range of co-morbidities, which impacted to varying degrees on their overall function and quality of life.

Five participants had evidence of cardiovascular or peripheral vascular disease. One participant suffered with severe scoliosis and rheumatoid arthritis, and her chronic pain and disability compounded both her breathing problems and ability to cope. Another had a history of severe Systemic Lupus Erythematosus (SLE) requiring ongoing steroid medication which complicated the management of any infective exacerbation of his COPD. Another participant suffered frequent and very severe migraines which impeded him attending medical appointments and pulmonary rehabilitation.

In one case, the co-morbidities of diabetes and previous stroke meant the participant was already receiving good home support services from DCSA (see Section 2.10.1). Another also received regular home support visits on the basis of a mental health diagnosis.

2.7.2 Role of smoking

All participants had smoked during their lives and recognized the role of smoking in the aetiology of their lung disease. Ten participants were self-identified as lifelong smokers. Two participants still smoked regularly. One described the sense of calm he gained when smoking:

...if you can give them up, hopefully you'll last a bit longer. But I do find if I can go two or three days, I feel a lot better, but every now and then if something is bothering you, then you can light one up and it calms me down and I can figure things out a lot better (P1).

At the time of the second interview he had resumed smoking 20-25 cigarettes per day after 'problems hit'.

In the other case both participant and carer smoked, with the participant having reduced her smoking from 'heavy' to 10 cigarettes a day, while her partner smoked a pipe. 'I guess it's an enjoyable habit but it knocks us about a bit' (R5).

One further participant who had been a smoker for 50 years had stopped 18 months ago but described in the first interview how he could have an occasional cigarette now without returning to regular smoking.

I will occasionally have one if I'm out and people are smoking, but it's strange, originally the few times prior that I tried to stop, if I had one cigarette that was enough to trigger me again, but now I seem to be able to have one and not want another one (R4).

At the time of the second interview he had resumed regular smoking.

In one case, a carer continued to smoke when her husband had stopped smoking. She explained it in this way:

The reason he gave up smoking was because he wasn't 100% well, cos I'm very biased because I am a smoker, and I know all the hoo-haa. But it is so addictive, so so addictive. But whenever anyone gives up smoking they seem to be sicker afterwards, when their immune system's adjusting, and also smoking affects your good health but it suppresses bad health to a degree, as soon as you give up smoking you go into quite a turmoil (CP6).

This view was echoed by a participant who was only recently diagnosed with 'emphysema' after presenting with increasing breathing difficulty, '...although the doctors say it doesn't gel with them, but as soon as I gave up smoking this got progressively worse, definitely' (P9).

2.7.2.1 Stopping smoking

Twelve participants had stopped smoking either at the time of diagnosis or once they realised the severity of the illness. One participant who described herself as a heavy smoker particularly when drinking, stopped smoking as soon as she was told the diagnosis 'COPD' and although she was offered support by her GP said that she 'didn't need stickers or anything'(nicotine replacement patches) (R2).

One participant described the time of first diagnosis about eight to 10 years ago when he presented to his doctor with breathlessness:

The doctor said you better give up smoking because you've got chronic destruction of the airways. I said what's that, emphysema? Yeah he said, you've got the makings of it, you better give up smoking. I said, no it's just a cold, I'll give up smoking when I die. [laughs] Well that was about the right choice of words wasn't it? (R6).

He then continued to smoke but gave up smoking six years ago following several admissions to hospital with respiratory infections.

2.7.2.2 Influence of smoking on attitudes of doctors

One participant and one carer described the influence of being a smoker on the attitudes of doctors in their interactions:

P6: Well basically any doctor that knows you smoked for a while will tell you, you have emphysema...when you smoke people stop looking anyway.

CP6: They do which is very frustrating and annoying 'cos smoking, doctors just put the brakes on, don't look any further.

P6: Well it accounts for many problems.

CP6: It does, but it also can mask off other illness. I am very anti doctors and emphysema in that respect, you can see they just put the brakes on, they do not carry down the track.

This theme was repeated by another participant, a diesel mechanic/fitter who had worked extensively with bitumen, and also asbestos. He described the constant fumes, then *'...but doctors won't agree with it, straight out tobacco's done it, burns a lot more than bitumen does.'* He acknowledged the significant role of smoking in his disease but also reflected on the difficulty in getting doctors to listen to a smoker.

Like I said to you I blame a lot of it to smoking, but a lot of it's probably got to do with my work and once people start believing, doctors look more into it, instead of pushing you off – smoked, that's it (P7).

2.7.2.3 Advice to others about smoking

Towards the end of the interview, when participants were asked if there was 'anything you would like to tell us that might be helpful for you, or other people with a similar illness?' five participants specifically wanted to give advice to others to not smoke (P7, 8, 9 R1,5).

Don't smoke! (P9)

Don't smoke, yeah, that's what they put mine down to (R1).

Some of these also recognized the futility of giving this advice to some people.

Don't smoke at all, but that's a waste of time saying that because the amount of people you still see smoking, my daughter smokes, my youngest son smokes and even though they know that I'm crook it hasn't stopped them you know. Like any young one, you try and tell them and they've got their own ideas, think they know more than what we do (P7).

The participant who died during the study was very emphatic about the effect of smoking:

I talk to so many people already, no smoke, no smoke. They only stop for a few weeks. No smoke at all, I say, no more and they listen, stop smoking. You use what happened to me, I cripple, I can't do nothing, that happen to you if you smoke, stop smoking. Some stop smoking, smoking not good, destroy your life (P8).

In response to the prompt of what they would wish to change in their life:

Change in my life - I wished I have never smoked (P3).

2.8 Impact of COPD on participants

2.8.1 Managing with COPD

The general prompt, 'What's it like managing with this disease?' elicited a wide range of responses.

Although a few participants had been encouraged by what they saw as recent improvements in their condition, or felt they were managing quite well overall:

Well I'm doing pretty good (P1).

Just going on regardless (P2).

the response of many expressed how difficult it was for them:

I hate it (P3).

Not easy! I thought it was going to be bad but not as bad as this. Now I know. To tell you the truth I've never been scared of things but this has frightened hell out of me. This is real! This is not just mucking about, this is my life. Doctors at the hospital said you've got about 12 months. Dr... said the same thing and it's going to get worse (P5).

Ah terrible, not easy. Not just the breathing, you know even just walking around takes a lot out of you (P7).

Bad, bad, bad, bad, I wish...everything work bad, wouldn't wish a dog to get it (P8).

It's very hard (R5).

It's easy now, but in the beginning it was 'hell on earth', knowing what to do ... wouldn't go on the nebulizer in front of people. Bought a walker from dom care... rests on that. Took a long time to work it all out (CR3).

This participant had been on oxygen since 1997.

2.8.2 Impact of the symptom of breathlessness

The symptom common to all participants was that of breathlessness, which had a profound impact on their physical functioning, as well as causing great emotional and psychological distress and severely limiting social functioning. The physical, emotional and social aspects were clearly linked much of the time.

Yes and when you go and you can't breathe its terrible, you've got no idea what it's really like, nobody really knows what it's like, just feels like you're like Ned Kelly, someone's hanging you and its shocking, the most shocking feeling... (R1).

Oh yeah, when the level starts to drop it gets you in here, you can feel it closing up or it will get you in the legs, it's like letting air out of a balloon, as it goes down you can feel yourself starting to go, that's when I got on the mobile and called an ambulance (P1).

...very unpleasant feeling, gasping for air (P2).

2.8.2.1 Physical limitations – general mobility

Physical limitations were described by most of the participants. Walking any distance presented difficulties for most, expressed in a variety of ways:

I would like to walk properly [without the frame] (P2).

It's very hard to struggle to breathe, it's alright when I'm lying down or sitting down like this. As soon as I get up and move around that's when I start to struggle for wind. It's like this all the time now. I've got to be on this oxygen concentrator 24 hours a day, never comes off now (P5).

He's just gradually got worse, now he's been on oxygen about three years fulltime, he can't do anything physical at all. He can sit and talk and not really struggle speaking (CR1).

I can't do anything, I can't go anywhere, if I get up I'll get exhausted (R5).

And later:

Well when I walk I can't breathe, therefore it takes the oxygen out of my body and my lungs don't function properly and all sorts of things happen, and I have to get on a nebulizer machine and then I go on the oxygen (R5).

2.8.2.2 Personal care – showering, dressing

At the first interview six participants were managing to shower themselves, four were assisted by their live in carer and five were assisted by a visiting service. At the second interview one male living alone now had an outside service assisting with showering (P7), one participant had died and one female had been admitted to a residential facility. For most participants showering and dressing were significant challenges:

R1: *Getting dressed, things like that, and showering...big effort.*

CR1: *He starts to hyperventilate and he panics yeah, and really gasps for breath, I have to be here...*

Drying off after a shower presented particular difficulties:

She's got to dress me and wipe me off when I get out, it's terrible, puts so much pressure on her (R1).

One participant described the difficulty for him:

I can get in the shower by myself, it's getting out and drying, lifting my arms, moving my arms knocked the wind out of me. It does. Even trying to get dressed, that's why I stay in my pyjamas (P5).

One carer had devised techniques to assist with the showering process in a way that maintained the participant's independence, for example using a towelling dressing gown instead of a towel to dry off, and a padded stick to dry toes.

Even those who managed unaided had worked out a system that allowed them to time their tasks in relation to medication, with pauses to catch their breath in between:

I do, I puff out and I might puff out while I dry myself after showering, but I take that minute, catch my breath and when I get up I catch my breath, sit on the bed, have a little ventolin if I need it, just plod on from there, it's not a rush job (R6).

Organising the day and maintaining routines was important. A pragmatic solution was to simply reduce showering to a minimum. One participant reported that his biggest problem was simply 'getting dressed, getting in the shower, and going to bed' (R1).

The time it took for showering and dressing and the inability to hurry, had important implications for early morning doctor's appointments, tests or rehabilitation appointments (see Section 2.11.3.1).

2.8.2.3 Household chores and maintenance- Cooking, washing up, washing, cleaning, gardening

Living independently in the community without help was extremely difficult. Cleaning (and gardening) was beyond all participants except one male who claimed he did some cleaning. Some managed their washing, but lifting their arms to hang out washing was identified as a specific problem.

Three participants prepared some meals, two others relied on frozen meals. For those living alone, maintaining adequate nutrition and a healthy diet was difficult. Four participants had significant weight loss, three of whom lived alone. One of these described how he used to cook for himself but now was unable to stand to cook, so only bought things that could go straight in the oven or microwave (P7).

2.8.2.4 Shopping

By the time of the second interview, only two participants were doing their own shopping, but for one of these, transport presented problems. Problems in going out to do shopping had impacts at the social as well as practical level:

It is very hard, like I can't go shopping, [partner] has to do all the shopping. I'm absolutely hopeless at shopping and I can't go out anywhere without making a fool of myself, I end up having to sit in the gutter because I can't breathe, and there's nowhere to sit. The council with their do-gooders take all the benches away because smokers sit there and smoke, but

they forget the people with lung trouble need to sit down, and I've got nowhere to sit and I have to sit in the gutter which is very embarrassing (R5).

And one male living alone:

So I park the car in the disabled thing as close to the entrance as I can get. Then take the trolley to the car, but then unloading the bags - I say to the girls only put about four tins in a bag, so that I can lift them. But putting them into the car, by the time I've finished or before I've finished, I am totally out of breath. So much so that I've had people stop and say, are you all right, can we help you, is there anything we can do, are you sure you're all right? I'll be puffing and puffing and panting. But I find getting into the car, turning it on, putting the air conditioner on, getting the cold air and having a puffer (ventolin) with me, is often enough just to settle it down (R4).

2.8.2.5 Driving and transport issues

Four participants were still driving when they were well enough, and none of these were on oxygen. Another man on full-time oxygen had a scooter, although he had difficulty managing it with his cylinder in the basket. The others were dependent on carers or other family members or friends for driving.

One regional participant whose partner did not drive, had Access Cab vouchers for herself, but her partner was unable to use them when he shopped for her. A metropolitan participant had Access Cab vouchers but was nervous about using them.

One participant was now paying off a traffic fine because he drove an unregistered car believing this to be the only way to get his medications from the local chemist.

In one case, DCSA workers were available to assist with shopping but in a Catch 22 situation, they were unable to take the participant in his car or their car, and without access to money he felt unable to use a taxi. In the second interview he described this difficulty with shopping and his deterioration on exertion.

When asked if DCSA could help him with shopping he replied:

We've got a problem with that, with dom care, they're prepared to do my shopping but I've got to have the money here. If I'm really bad with migraine and this, I can't get down to get money out. They are not allowed to take me in their car, they're not allowed to come in my car. Catch 22. You run round and round in circles...

We could get a cab. But once again, I haven't got the money. So how do I pay for a cab to take them and me down to do the shopping? I have to ask the cab to pull up next to one of the auto tellers ...I'd have to get the taxi to park next to the Redi teller, so that I could go and get money out to pay the cab and probably get money out to do the shopping which I have to estimate because they won't accept my card to pay the shopping because I'd have to give them my PIN, again you run around in circles. There's got to be a way out of it, because I see other nurses down there with people, I don't know how they take them - they must go in cabs, that's the only thing I can think. I don't know where they're from and I haven't thought to ask them where they're from.

...I know what it is, it's insurance problems (R4).

A carer reported that she was able to get taxi vouchers for transporting her husband to outpatient appointments, but she had to ring the 'government' to organise these (CP8).

2.8.3 Emotional and psychological impact

2.8.3.1 Anxiety and depression

There was considerable evidence of anxiety about coping with breathlessness amongst the participants and carers, extending to panic in many cases, and also anxiety about coping with practical issues.

The diagnosis of depression has often been linked with COPD but was not obvious in this study. One participant who lived alone exhibited a depressed mood during the interviews (P7). One carer was on anti-depressants by the time of the second interview (RC1) and the bereaved carer appeared depressed prior to the death of her husband and was very tearful during the second interview (CP8).

2.8.3.2 Panic due to breathlessness

The sense of panic when unable to breathe was a strong theme from participants and carers:

The minute I take this off [full time oxygen], all hell breaks loose, I can't breathe... (P5).

If I rush it, I start to panic a bit (P5).

'Cos once or twice [P6] has needed the little oxygen bottle and his concentrator wasn't getting through good enough. He has wanted the little bottle, but he's in panic mode and he can't even turn the dial in the little bottle, and I can't understand that. And that's happened two or three times and that's difficult (CP6).

Panic was reported after an activity such as showering:

He starts to hyperventilate and he panics, yeah and he really gasps for breath, I have to be there (CR1).

If he can't breathe, he sits up, but panics, doesn't breathe like he's supposed to... (CR3).

Participants were aware of techniques to use when breathless, but panic sometimes took over:

R5: *Yes but sometimes I panic, sometimes when I really catch my breath, I can't breathe at all, I really do panic, I think this is it 'I'm dying'. I panic and he [partner] rings an ambulance. By the time the ambulance gets here it's all over.*

Interviewer: *And what do you think pulls you out of this, what stops it?*

R5: *Well [partner] kind of pats me on the back, gets the oxygen out. I think mainly just reassurance that I'm going to be alright, but it's awful when you catch your breath and you can't breathe.*

This participant wanted to give this advice to others:

Don't panic because the more you panic and stress about it the worse the lungs get. I mean if you can relax, take deep breaths if you can. Learn to relax with the condition, you'll find that you breathe easier.

Several participants described the difficulty in calling for help when very breathless and panicking:

It can be a very panicky situation, because sometimes when I catch my breath I might be in the next room and [partner] is in the next room and I have to bang on the wall, I can't yell out to him. I have to bang on the wall, and let him know I'm in trouble and then I panic because he's not hearing me. And if I had a bell maybe I could let him know, it's just that he's partly deaf... and he doesn't mean to ignore anybody but sometimes he doesn't hear me in the shower. I'll sing out for him and he doesn't hear me. I sang out to him this morning and he didn't hear me (R5).

...but you didn't understand what I was trying to say, the communication when you can't talk is very difficult and you can't think clearly enough to write it down (P6).

This participant was describing his panic when his oxygen was not working properly.

2.8.3.3 Social isolation

The theme of feeling housebound or socially isolated was expressed by a number of participants.

... I don't really go anywhere so I'm stuck here all the time (P7).

I used to catch a bus all the time before I had oxygen. There is a little community bus that stops just out the front, if I got bored I'd hop on that and go down to [shopping centre] and look around. I miss that! I miss doing things like that. But I haven't caught a bus since being on oxygen (P3).

Outings, if they occurred, were often limited to doctors' appointments, church and close family or friends (R5). One participant (R5) who now only went out to church and occasionally to visit friends and her brother-in-law identified being housebound as her biggest problem:

Just getting out, getting out, because when I do go out so much has to go with me, the nebuliser, the oxygen machine. I haven't been to [shopping centre] shopping for a long time, I'd like to go and look around, but I can't you know (R5).

One couple who had previously enjoyed dancing each described the lack of the participant's mobility as the biggest problem for them.

[We] used to enjoy going out (CR2).

I miss walking around. If I walk to the car, I'm puffing but it goes away when I sit down (R2).

The need to take oxygen was a very significant factor here. For example, 'I don't go out'. The rigmarole involved in embarking on a trip to Adelaide was then described, including the participant's frustration in being unable to help lift his oxygen cylinders into the car (R1) while his wife was now having to do all the tasks her husband previously did. 'So by the time I go to leave I'm exhausted and I have to do all the driving' (CR1).

Another participant described how his life had been affected:

Before all this got worse, which is only this year, I was doing things I normally do. [Friend] and I used to go to the pub have a few drinks whatever, go and listen to band, 'cos I was a cowboy dance before, but I can't even do that any more 'cos I've got to cart my bottle around with me. And carting that especially in crowded places is a bit hard, so that cuts things down (P7).

This loss of role was a common thread for the participants who lived with a spouse or partner. The physical limitations not only meant that carers were having to provide more of the support but they also had an impact on the shared social activities in the partnership.

A few years ago we used to walk two hours every night (CR3).

2.8.3.3.1 *Impact of the weather on COPD and social isolation*

Cold weather was an additional factor in social isolation:

The colder it is the harder to breathe (R1).

One participant commented that he couldn't go out to a park in cold weather:

In this weather I can't unless I'm really rugged up (P7).

This man, who lived alone, reported anxiety about paying electricity bills in the winter when he knew he would need the heater to be on. He also reacted to the heat during a heat wave when his unit became over heated (see Section 2.11.5.2).

2.9 Issues relating to the use of home oxygen

Nine participants were on oxygen 23-24 hours daily; one participant had progressed from part time to full time at the second interview, four participants were not using home oxygen at all (one had previously used it for three months after a severe exacerbation). One female used oxygen for 15 hours a day and another used oxygen cylinders very part time as she still smoked. It was her understanding that she could not have a concentrator in the house because of the risk of explosion.

Although home oxygen meant that these participants could continue to live in the community, there were difficulties reported about how being on oxygen contributed to their sense of being housebound. Accepting oxygen at home involved a realisation that one's health is deteriorating and life would become increasingly restricted:

You have to be pretty damn crook to get it (P6).

No, I haven't gone out by myself since I've been on the oxygen, not again (P3).

2.9.1 Physical and social restrictions of home oxygen equipment

The physical and social restrictions of home oxygen equipment were an issue for several participants including the burden of lifting and transporting the equipment.

One participant described it as a big adjustment to live with oxygen:

It's a damned nuisance - I just hate it - it's a damned nuisance, driving me absolutely mad at the moment. I have an hour a day with the oxygen off, it's a real nuisance to go out because I have to have a back pack, which lasts three hours and that's a nuisance so I prefer not to go out... (P3).

Yes I keep thinking of what it was like before when I could just dash out and catch the bus and take my bin out, and go to the letterbox and different things. But now I've got to take the oxygen off, lay it down, go to the letterbox and make sure I've got it back on when I come in, silly little things that you take for granted (P3).

She had also recently had a heavy fall, tripping over the oxygen tubing.

Many participants identified the burden of having to take oxygen with them as one of the factors limiting their social interactions. One couple who lived in the regional town wanted to visit their children and grandchildren in Adelaide as often as they could as this was the wife's (carer) only respite:

CRC3: *We've just been to Adelaide. Came back last week. While we're there, just going to visit my daughter and then going back to where we were staying and like, that is just getting to be all too much.*

R3: *It's just getting to be a real problem.*

CR3: *I take the oxygen.*

R3: *She's got to lift that in the back of the car. That's the trouble. It's so heavy.*

CR3: *I strap a pillow around the front of it, in the seatbelt. So that's safely in.*

R3: *She's got to lift that.*

CR3: *I lift that up, and it's so heavy. The back door doesn't open as far as the front, so you've got to lift it up like that and then get it in. I'm going constantly to the chiropractor, and I don't have private health, so that's costing me a fortune. All from lugging that machine around. I have asked dom care. There is one out now that's smaller.*

Because my two children live in Adelaide and I like to go – that's my sanity. Probably every six, eight weeks, we'll go, for five days or a week – and so I have to lug that. So I said to dom care – the girl that came last time – about it, and I said, can you just make a note and ask them at dom care, if they ever get one, whether I could have one, because I do go to Adelaide. My family's all down there. I'm isolated from them, and – so...

Another female participant commented on the weight of the portable cylinders inhibiting her from going out. Also she was unable to always change cylinders herself and relied on her partner, and this meant that he was unable to go away and visit his family (R5).

Of the nine participants who had concentrators at home, only one in the regional country town had the newer, lighter version which was half the weight and easier to transport. This participant had been on oxygen for many years and with the couple's involvement in the local support groups they had the knowledge to understand the possible dilemmas that living with home oxygen can present:

He'd give anything if he wasn't on it. But up here, - we get that for nothing and we get four bottles a month for nothing (CR3).

This couple had found DCSA very helpful in checking the equipment and also providing this more suitable equipment for travelling on the bus when they visited their family in Adelaide.

The new ones are light, they're only 14kg (and not as noisy) ... I can put that on the bus, whereas the other one we couldn't put on the bus because it was 24kg ... So I can lift that quite easy and you don't need two people to try and lift it (CR3).

This same couple also had access to two light weight portable cylinders (fibre glass) as well as two of the heavier (steel) cylinders:

It is so much easier and now we have two lightweights and two heavyweights. ...We're only allowed two ... the ambulances get first option.

These lightweight cylinders made travelling on the bus to Adelaide much easier:

We bought a bigger suitcase for [R3] and he lays two bottles of oxygen in that suitcase and then packs all his clothes right around the oxygen bottles so they can't move, then stands them up (CR3).

This participant also used a pulsator which extends the supply time of the oxygen cylinder from five hours to 12 hours.

CP3: *It only works when he breathes in.*

P3: *If I don't take a breath in every so many seconds, it pushes, forces it through to me.*

2.9.2.1 Fear of running out of oxygen

The fear of running out of oxygen, either at home or particularly when out using cylinders was a persistent theme, described as 'terror' by some.

One country participant described running out of oxygen while waiting in her doctor's surgery and having to go home unseen (R2). Another was concerned about cylinders running out at the public hospital outpatient department, but had lost the phone number to call (P9).

Another participant described the restriction on going out on a bus because of her fear:

But I haven't caught a bus since being on oxygen. I just don't feel right about it, I don't feel safe... the backpacks that you take out last three hours and I think to myself 'what if you got held up or caught up somewhere' ... I have got taxi vouchers which you can use, half price taxis, but I only used that once (P3).

In the second interview this same participant was worried about going to her daughter's for Christmas dinner as she was frightened that her cylinder would not last the time. She felt her family could not manage to move the concentrator for the day:

P3: *But she [daughter] wanted to know for sure if I was coming down there Christmas day and what I'd have to do. I'd only be able to be out for six hours anyway at the most, because I'd have two three-hour backpack oxygen cylinders.*

Interviewer: Can't you get a bigger one?

P3: *I have got a bigger one but I've got nothing to wheel it on or anything.*
That's a seven-hour one but that's not really much help because six and seven hours is only an extra hour anyway. I wouldn't be able to stay overnight. That's what I miss too, 'cause I used to spend a lot of time over there.

They won't give me extra. If I said, can I have a couple of extra backpack cylinders, they wouldn't give them to me. They want the empty ones back and they'll only give me the new one for what's empty. 'Cause I said to them before I'd like to go away; I would like to go out and stay out for a while, can I have an extra one? They said no, we can only give you what you empty.

Interviewer: Do you want me to talk to the respiratory nurse?

P3: *Well you could, but I don't think it'll get you anywhere. You know what they're like. ... Give me a Christmas present.*

Problems were compounded for the participant who lived in an inner-rural environment:

P6: *One of the issues was the machine stopped working the other night. Well I didn't take it all that calmly as you would know. In the end they (maintenance mechanic) came out and replaced it and that was the biggest problem I've had with it.*

CP6: *That was scary, yes we did have little bottles on standby, yes we could have got an ambulance and yes we could have gone to [local] Hospital, there was no way we would have sat there overnight with this faulty machine.*

This couple also described an initial problem with cylinders running out while travelling, needing at least two to get to the doctor and back and difficulty getting the right number of cylinders based on actual flow rate.

2.9.2.2 Supply of oxygen equipment and maintenance

One female participant who lived alone described the first delivery of equipment before she was discharged from hospital:

They rang my son to be here while they delivered it all, then I came home to it and he had to explain it all to me (P3).

There did not appear to be any consistent pattern with maintenance of the equipment:

Oxygen? The bloke just comes here and drops four bottles off and that is it. Nobody comes to see me apart from that, they don't even check the bloody machine. They don't! That's how the machine blew up before (P5).

or in obtaining the accessories such as the nasal canulas:

If X (husband) goes up there (Domiciliary Care) to get these new things, they say, oh you don't get them here; you get them where you get the gas - the oxygen. When he goes to get the oxygen, they say, you don't get it here; you get it where you get the Domiciliary. It's like getting hens' teeth.

...yeah, they're 'canolas' that join on, and they get very grotty even though you soak them, and they get stiff and you've got to have them changed because you can feel the oxygen coming out of them. I put some water up there and you can hear it going into the water. They'll give him one at a time, and then it's like getting blood out of a stone, isn't it? (R2)

There was no consistent pattern for checking on flow rates and participant well-being either. Participants reported some nurse visits, but also that the country nurses were over-worked and running behind schedules for checking.

2.9.2.3 Rebate for electricity bills with oxygen concentrator

There were a number of complaints about not receiving the rebate for the electricity bill:

It must be 12 months since I've had one, but I've got 200-and-something odd dollars to come from mine, because he – before we were only on 16 hours, but now he's 24/7 on it. Dr (X) said just to leave it on all the time. He just needs it if he's more comfortable, because what happens – he goes off it for eight hours, and then all his nose goes purple. He hasn't got enough oxygen in his blood. So he said, just leave it on.

Anyway, I've got 200-and-something odd dollars, and then they said they missed us before Christmas, and they came weeks ago to get me to sign this new paper, but they're still – the people that organised the oxygen said that, two weeks after the rep's been to service the machine, you should get your refund. But no refund (CR1).

We get money back from our power bills. We don't get the whole lot back but you get a percentage of how much you've used. Then if we go to Adelaide and we run out of oxygen, we ring up BOC Gas (CR3).

2.9.2.4 Sleep disturbance

One participant described how his difficulty sleeping had led to him and his wife sleeping in separate bedrooms for the previous four years:

I'm a very bad sleeper, just about every hour I could tell you during the night. I wake up and turn over, I can't sleep (R1).

Another participant reported poor sleep with her new home oxygen, partly related to nasal irritation, with her nose dripping. She commented that she had been given sleeping tablets in hospital but since discharge had not been given anything to help her sleep (P9).

One carer with her own health problems, slept in the same room as her husband but lack of sleep was a problem:

(crying) ...all I want is, I want to sleep in the night, the whole night to rest... but sometimes before I sleep I have to wait for him to sleep before I go to bed, make sure he is alright. But then I can't, every time he calling me do this but do that (CP8).

A further participant described a very disturbed sleep pattern to the interviewer who made the suggestion that his doctor may be able to help. The reply came:

I did ask her for a bullet once and she said 'we're all out' (R6).

Rather than a simple request for sleeping tablets, this appears to raise the question of euthanasia or physician assisted suicide.

2.10 Support for living at home

2.10.1 Community services

Participants' reports of support received from community services covered a wide range of services including home modifications, mobility aids, 'hands on' care and nursing services. There was no clear pattern or pathway to services for the group overall, and participants at times expressed uncertainty about their entitlement to services.

In summary, two male participants did not receive any outside help; one lived alone, one lived with his daughter. Three regional couples were not receiving any outside services other than some gardening assistance from the Council and mobility aids from DCSA.

Four participants were receiving DCSA 'hands on' assistance with showering as well as cleaning services. Two participants were on a waiting list for DCSA services. Three people were receiving cleaning help from local councils, while one person received cleaning help from another community organisation.

The participant with an indwelling urinary catheter also received services from RDNS (P8), although his wife reported there was a division between who provided catheter bags (DCSA) and who dealt with the catheter (RDNS).

For the two participants who were referred to a specialist palliative care service, there was a dramatic increase in services, including links to DCSA, nursing support and counselling. In the case of

the inner rural participant it was unclear to him and his wife where the services actually came from but they were co-ordinated under the palliative care banner.

Participants who needed services, and had been able to access the services they needed, were generally satisfied with the help they received. *'Yeah – everybody's doing a pretty good job. Can't expect too much – fair slice of the cake'* (CP2). In this case, the participant had been receiving services for many years, initially to support her because of multiple co-morbidities rather than just her COPD. Another participant also received regular visits at home from a mental health worker because of a mental health diagnosis.

One couple reported good experiences with the Housing Trust in facilitating alterations to their bathroom, and felt they could rely on DCSA services to respond if they needed more help (R3, CR3).

One participant who had only been home from inpatient rehabilitation for a week, and was receiving daily visits from a care worker, responded to the prompt whether there would be any other things that would be helpful, *'I don't think so, I'm getting so much help now of which I'm grateful, but I don't think I could think of anything else'* (P9). This participant was admitted to a nursing home for respite during the course of the study.

The importance of discharge planning and co-ordination was clear and not all experiences were positive. One carer, initially referring to problems with the delivery of the appropriate size of oxygen cylinders, generalised her comments about services in this way:

No, our confidence went down quickly. As a matter of [fact] I've known it through my own experience, you don't know what people need until they have gone through the drama. No matter how much you've explained or offered to, people on the other side think, 'no she'll be right'. And if something happens and you both start to realise it's not right then let's change it. People have asked us is this OK, is that OK and we don't know what we are entitled to and that sort of thing (CP6).

The transition between Metro Home Link (MHL) services (which are put in place for approximately a week following hospital discharge to facilitate as early as possible discharge) and regular services, was not always smooth.

One participant described how MHL staff had referred her on to the local Council, but:

...she [council worker] feels that at this stage, they can't offer me the help that I should be getting, so she has referred me on to the [Aged Care] Village, down the road here. I haven't heard any more about that as yet (P4).

This experience highlighted the lack of co-ordination and fragmentation of community care which will be discussed further in Section 2.11.8.

Another participant (P5) commented on the change of staff for personal care:

I haven't seen this one before either. That's why I go crook on them half the time, you know, 'cos you get used to one person and then all of a sudden they start bringing these other girls.

However he went on to acknowledge how well the carer dealt with possible embarrassment with humour.

One regional participant who had applied for a walking frame, found the assessment so perfunctory and the person who performed it so rude that she ordered him off the property! (R5)

The cost of services was not raised often. One participant commented about possible payment, '*I don't mind if I do... I probably have to pay the cleaning lady*' (she had paid the Council cleaner previously) (P9).

2.10.2 Age as a barrier to accessing services

Several participants, who were aged less than 65 years, were having difficulty in getting help from domiciliary services, whose funding is generally linked to the aged population:

I said to her [respiratory nurse] what do you have to be 90-100 before you get something done? I've got to sit in that bloody bed and I got nobody to make the bed for me. I can't do much myself and when I ask for help I get nothing (P5, aged 60).

One 60 year old participant was told by a social worker during a hospital admission that it would be difficult to get help, '*She saw me while I was in hospital, but said there is not a lot they can do because of my age*' (P7). Subsequently, when services were able to be organised:

...normally there is a long waiting list for people getting in but somehow they've squeezed me in as quick as they have. They warned me it could be a while before they could put me in all because of my age.

Another participant commented in relation to the age barrier, '*Their problems are just as real as anybody else's*' (P4, aged 64).

2.10.3 Palliative care service involvement – roles and effects

During the course of the study, only two participants were referred to a specialist palliative care service. One had just been referred to the hospital palliative care consultation service by a public hospital respiratory specialist prior to the first study interview and was very relieved with the support he was now receiving:

... like that switch turns it on (P6).

You're entitled to absolutely nothing one day, and the next everyone is being super helpful (CP6).

His wife (CP6) also reported that, *'Different ones [palliative care nurses] come each week but they listen to your moans and groans and they offer advice and they don't pat you on the head which is lovely'*.

Another participant who had reported great difficulty in managing at home alone at the first interview was referred to a specialist palliative care service between interviews.

At the first interview, he commented:

All this stuff they advertise on TV I'd like to know where is it. It's around like I said, but you've got to have one foot in the grave... I won't get any better – no way, I'll get worse. I've already got one foot in the grave (P5).

At the second interview he was much more content with his life overall, and with his care, and the feeling that he was able to be true to his nature as a fighter, *'No I won't give up. I am a fighter and I've been a fighter all my life. I keep fighting this damn thing'*. The introduction of liquid morphine for symptomatic relief of his breathlessness had added to his comfort despite the fact that it, *'tastes bloody shocking, I'll tell you, believe me'*. He made the point very clearly that although he was aware he looked better, he was still extremely limited by breathlessness:

I really want to do something, but I can't do it. Now I do look good, right, but when I get up and I want to do something, bang. Hits me like a ton of bricks. I can't breathe (P5).

2.11 Health system and medical care

2.11.1 General practitioners

All participants identified a general practitioner (GP) who was involved in their care, but there were a number of issues impacting on the participants' access to their GP.

Three participants whose GP visited them at home were very grateful for this service (P4, P5, P8). For one this has only started recently (P4), another reported, *'He comes here, always comes here'* (P8). Another participant had been visited at home by their doctor once; at subsequent visits to the GP surgery however, she reported the GP did not seem interested in her situation (P2).

Two metropolitan participants who had a good relationship with their GP, now found that there were geographical constraints on being able to visit them easily. For one participant, this was because he had moved away from his previous home (P1), while the other who had previously been able to attend the surgery now relied on family for transport (P9).

For another participant (P6), continuing with their current GP meant they did not have access to the local hospital. The GP refused to refer to another GP who could have made this possible and the couple felt, *'It's the ego that is blocking us now'*. In addition, with medical care moving away from the

main Respiratory Clinic to be focussed nearer to home, there was a sense of uncertainty and even abandonment, *'No one wants to look after him'*.

Several participants repeated the theme of difficulty in attending morning appointments as they were unable to get ready in time. One participant who had had a good relationship with his part-time GP, found it impossible to see her as she now only had morning sessions (P7).

Generally it appeared to be up to participants to initiate contact with their GP:

I only go when I need to (R6).

All regional participants reported that their GP did not visit at home. Several reported increasing difficulty in walking to the GP surgery from the nearest car access point (R1). Three GP receptionists helped facilitate access, both in urgency of appointments and bringing the participant in through a back door or via staff access (R2, R3 – surgery or hospital, R4). Waiting a long time to be seen was a problem for a couple of participants (R5, R2). One participant, who reported having to return home because her oxygen cylinder was running low during a long wait, had worked out a system whereby the practice nurses would ring with an updated appointment time to shorten the waiting time (R2).

For the regional participants, if they were very unwell, GPs usually recommended they attend the local hospital where they were usually assessed promptly, either by the GP or a deputy.

2.11.1.1 Communicating with a general practitioner

Several metropolitan participants reported good communication with their GP (P1, P3 (DNR letter), P8).

I feel as though I could say anything to him (P3).

Reports were more mixed in the regional centre, with one participant actively seeking to change her GP.

There were some concerns expressing lack of confidence in the way GPs and medical specialists communicated. One regional participant reported his concern that during a recent episode of severe respiratory infection, his GP had failed to liaise with the metropolitan respiratory specialist.

One participant and his carer described a very unfortunate episode where, in the absence of his own GP, the GP in charge was not prepared to act over the weekend, with the delay leading to a very severe untreated pneumonia being diagnosed two days later (R1, CR1). The severity of the pathology was reinforced in his mind by his respiratory specialist later requesting his X-rays to teach students.

2.11.2 Medical specialists and hospital outpatient visits

Most medical specialist appointments took place in hospital outpatient clinics, or in some cases in the adjacent Chest Clinic, so these two topics will be considered together.

2.11.2.1 Timing and access issues

There were a number of points made about medical specialist appointments. Participants with multiple co-morbidities were faced with multiple medical specialist appointments in a short period of time.

One participant reported '*about half a dozen*' hospital outpatient appointments in the last month. She and her husband reported that it '*falls down*' when appointment times are difficult to keep, '*awkward times, for example 9 am*' (P2, CP2).

Attendance at appointments was difficult when appointments were made in the early part of the day. Participants reported being unable to shower and dress in a hurry. Hot weather, and for one participant severe migraines, were also cited as reasons why participants were unable to attend appointments.

Several participants reported difficulty in getting to appointments because of the distance they needed to walk. One metropolitan participant reported being unable to walk too far, and parking was an issue for her daughter with two small children, one being breast fed (P4).

One participant commented on the difficulty of walking through a long hospital corridor without oxygen or anywhere to sit down:

...and that hospital has got such a long corridor from one end of the hospital to the other and by the time I reach the lifts I'm really puffing and hanging on for dear breath. I haven't got oxygen and I haven't got a walker. If I had a walker I could sit down half way and have a rest, because they take the chairs away (R5).

2.11.2.2 Continuity of care

One problem for participants was the lack of access to or continuity with the clinician who they perceived as co-ordinating their care.

It all depends who is on duty. For a while there I was seeing the same doctor every time I went in, probably about four times. He was pretty well high up, can't remember his name, but that was his specialty (P7).

2.11.3 Access to medications at home

2.11.3.1 Routine medications

A few participants had a good system of accessing medications. For one, the GP would fax a prescription to the local pharmacy who would then deliver the medications to the participant at

home (P5). Another commented on it being helpful when a family member was able to collect routine scripts from their GP's surgery (P2).

In contrast, one carer was unable to pick up scripts for her husband without making a specific appointment with the GP (CR1). However, one participant who needed medication drove his unregistered car to the chemist:

I couldn't walk and I needed my medication, nobody was around to get it for me. So I drove up there to get it and I was just unlucky that a cop car went past at the wrong time (P7).

He was already in financial difficulties and was now faced with a traffic fine. This participant also mentioned the cost of hospital discharge medications as a problem.

One other carer highlighted the cost of medication as her husband was on a medication that was not subsidised by the government Pharmaceutical Benefits Scheme. She also reported that the hospital was cutting back on the previous seven day supply on discharge (CP8).

2.11.3.2 Emergency medications

A few participants had been provided with a prescription for 'emergency' medications to start when they felt they were becoming unwell. One participant described how he could tell when an infection was developing and how he used the antibiotic prescription, always keeping in mind whether he needed to see his doctor or go to the hospital:

You can tell when you're getting sick and with me, pardon the expression, my spit changes flavour... when I'm getting really sick my spit tastes like bucket loads of salt. And when it gets really really salty I know if I'm not going to the doctor in the next day or two I better be prepared because I'm going to drop like a bag of bearings. ... So I have a prescription already prepared and I just take it and get it filled. Unless I think it is something else, I go to the doctor, and take that prescription and it gets me back on track.

I've had a couple of antibiotic refills at home, so if I don't think it's necessary to go I get it filled, but if I don't know what's wrong with me and I'm feeling horrible and need oxygen I'll go to the hospital, and if anything drastically happens (R6).

2.11.4 Medical emergencies

2.11.4.1 Calling for help

One of the problems that participants described was how rapidly their symptoms could deteriorate.

One participant who lived alone but had an emergency connection to the ambulance service described how rapidly he could deteriorate, *'I just managed to press this button in time'* (P5). He described how rapid the ambulance response had been, and how he had apparently died but was successfully resuscitated in Intensive Care.

In one case, when a regional participant was unwell, his foster son in NSW phoned for the local South Australian ambulance who responded promptly to his call. The participant was actually transported to another town 70 kilometres away for urgent medical review.

Another carer who showered and dressed preparing to take her husband to the hospital in the middle of the night found he had become so unwell in this short time, she dialled 000 for urgent help (R1).

One participant (P1) reported that a friend had called an ambulance for him when he felt his oxygen levels were dropping. Another participant described his GP calling the ambulance for him.

Mobile phones were mentioned by a couple of participants as a useful way of keeping in touch with family and carers and if necessary calling the ambulance when breathless.

2.11.4.2 SA Ambulance Service

In most interviews, there was praise for the Ambulance Service.

All but one participant was a subscriber to the SA Ambulance Service and she commented, *'but I think we should'* (R2). Another reported a *'couple of trips'* to hospital by ambulance before joining the scheme (P7).

All metropolitan participants had used the Ambulance Service for emergency admission to hospital. In fact ambulance support was usually required for hospital transfer, and each time the participant was usually admitted.

I don't know what I'd do without that, used it six or seven times (P3).

Well, what starts happening is I have trouble breathing slightly, then it gradually gets worse until I'm [panting] like that. Then I think no, I can't breathe properly, I've got to call the ambulance. So they come and then they put this mask on and give me more oxygen and then they see if I need to go, and I always end up going with them anyway (P3).

Another with multiple co-morbidities said she had *'lost count of the times'* she had used the ambulance and they did a *'great job'*. But her husband also commented that on a recent occasion they did not have the right equipment (P2, CP2).

For regional participants, although two reported using the ambulance in an emergency, participants were often driven the short distance to the local hospital by a family member for assessment when unwell.

One metropolitan participant who lived alone, described a particular episode when the ambulance service gave him great support. He had attended a hospital emergency department on a very hot day when his breathing was *'playing up'* and he had chest pain and a cough. He was only in the

emergency department during the day, and was sent home because *'it's not our problem'*. When he was transferred home by ambulance, the officer opened up the house for him, turned on his air conditioner and then stayed for 15 minutes to check he was alright. He was also very grateful when the officer phoned back at 11 pm to check on his well-being (P7).

One carer described her distress when she judged it was necessary and wanted to call for the ambulance, but her husband refused to let her call if he did not feel ready to go to hospital (P8, CP8).

The question of resuscitation (or non-resuscitation) by the ambulance crew was only discussed in one interview where the participant had noticed, and read, a letter being prepared for the ambulance officers at the time of her discharge:

P3: *Yes and I've noticed now, when I leave the hospital, they give a letter like that to the ambulance man.*

Interviewer: Is that about resuscitation too?

P3: *Yes. It's just got on it - I had opened it and looked at it one day - it's got - they just say to me give this to the ambulance and I opened it and looked at it and it just says do not resuscitate. I've made up my mind about that because, I mean, I'm 76 now and I wouldn't be able to stand going on that BiPAP again. I absolutely hate it, so I just don't want it. They said would you accept BiPAP, if nothing else and I said yes, I would, but I hate it just the same.*

2.11.4.3 Emergency department

Overall, when participants attended a hospital emergency department they were usually admitted as an inpatient. One negative experience of discussions about cardiopulmonary resuscitation in the emergency department is reported in Section 2.14.4. One rural participant who was driven to Adelaide by his wife and delivered straight to the public hospital emergency department reported her dismay at seeing how full of people the department was, but then the fantastic response of staff to her husband's needs (CR1).

In the regional centre, the hospital emergency department was frequently used for assessment in the absence of any home visiting by GPs or any locum service.

2.11.5 Hospital admission

All participants had been admitted to hospital more than once in the last 12 months. Some participants were aware of the risk of hospital-acquired infections and the value of avoiding hospital admission if they could.

One participant highlighted the problem of seeing many people in the public system:

I ended up going to hospital and with the public hospital system you get to see who you see – which gets to be a bit of a problem after a while because you have to talk to so many doctors. You end up with that many different people trying to organise things for you and trying to

sort you out and you end up on so many different medications. It's started to do funny things to my brain (P6).

Another participant also felt that the public system did not encourage caring behaviours in some nurses:

You ring the buzzer and they take half an hour to get there, because it's a public hospital they don't care. But if you're paying money they would be right there alongside you (P5).

Another described his various admissions to hospital:

February was only for the day, they wouldn't keep me in but they didn't want me catching anything else. I didn't feel up to going home, but they weren't going to keep me in so there wasn't much I could do about it (P7).

This participant went on to describe another admission where he felt, 'they sent me home too early' and how he was readmitted a day later for several more days.

Two carers reported the difficulty in keeping track of who they were speaking to, and what their roles were. They developed a strategy of recording all conversations in a notebook (see Section 2.11.8).

In a second interview one carer reported at length difficulties with a recent hospital admission, including medication transcribing errors despite taking an updated medication list with her and not being listened to about her husband's medical history. She described staff as patronising her. She also felt medication delivery decisions were being made on the basis of budget constraints, not in her husband's best interests.

2.11.5.1 Intensive Care Unit (ICU)

Seven of the nine metropolitan participants reported ICU admissions, while only one country participant reported experience of ICU six years earlier. This near death experience, where he attributed his unexpected survival to the power of prayer, had a significant impact on his life since (R6). Two participants recalled waking with a tube down their throat:

I get that bad that I pass out, I don't remember. Once I woke up and was in [the public hospital] ... I was in ICU with a tube down my throat and a tube up my nose... just waking up when they were taking the tubes out. That was the worst, I didn't like that (P3).

Overall, however, there was little memory of these admissions.

2.11.5.2 Issues of discharge planning

Several participants were aware of pressure for early discharge and difficulties with discharge planning.

One carer was extremely distressed when the ward doctor suggested to her that she should organise the services that would be needed when her husband was discharged:

I said no, no, no, you have to get your team together and sort it out and then come back to me... I had to put my foot down (CP6).

2.11.6 Rural and regional issues in health care

For the participant who lived in the inner rural area, the distance to travel for health care was a problem in many ways. This has been mentioned already in the question of oxygen supply (Section 2.9.2.1). A further problem was the lack of access to the PATS scheme, which supports travel costs for rural patients and family who live outside a specific radius from the city.

The carer described it in this way:

... yeah we're in the middle of no-man's land and the same goes for services and district council, we're on a grey area on the border of a lot of things (CP6).

Rural participants all described the absence of home visiting by the GPs in their regional centre. One participant contrasted this situation with the access to a locum service in the city (R2).

One participant was concerned that remoteness had an impact on the standard of care delivered (R1).

2.11.7 Navigating the system – difficulties in co-ordination of care

Although there were some examples where care was co-ordinated across hospital and community, there were many examples where participants were unsure of who they were dealing with, whom to contact about problems they were facing and where help could be found. Participants also reported a lack of co-ordination and communication between professionals involved in their care.

Very few participants could identify key staff such as the hospital specialist respiratory nurse.

In many cases, the interviewer was perceived as part of the health care team because the two visits had occurred as she had originally outlined, and the interviews provided the opportunity to talk about their symptoms and problems with someone who was prepared to listen. This was of great benefit to them, and the interviewer also co-ordinated a response to some practical issues.

P2: [to interviewer] *No-one ever talked to me like you.*

Some examples of lack of co-ordination and uncertainty of roles and people involved in their care included:

One participant was aware he was due for a lung function test appointment, but had lost the card and had no idea who to ring. During the interview he searched for, and finally found the card of his old GP (P1). (The interviewer undertook to follow up the appointment for him with the respiratory nurse.)

One participant was unsure who the respiratory nurse actually was, thinking that she was a social worker:

I wasn't sure where she fitted. It was confusing at times – who was what and where they fit in (P4).

One participant was distressed that his specialist at the Chest Clinic had been unaware of a recent ICU and public hospital admission and no notes were available for these events:

The co-ordination down there at the hospital stinks (P5).

One participant was distressed when she couldn't locate the phone numbers to use if her oxygen was running low:

It's here somewhere, but where, I know it's obviously something, and the telephone number's on that... (P9).

Regarding care at home and oxygen supplies:

... so I don't think both sides were communicating, co-ordinating, but it is now being sorted out (CP6).

This carer also reported difficulties obtaining information about Centrelink entitlements, for example carer allowance. There was confusion and also delay when her daughter was told by a social worker that she was the one who should apply for the carer allowance.

This same carer described her strategy to keep track of information in hospital and the response of staff to this technique:

I think one of the best pieces of advice I was given from someone at the [public hospital] was to have a notebook and write date and person and information down. And very much said, 'as of yesterday start doing it'. Your name, your phone number, date, you said this... Also I've found if you do it in front of people (writing), they get their backs right up (CP6).

Another carer had developed a similar strategy:

We've seen that many people from the [public hospital] this time, I write down their names, who deals with what and what areas on what days, it is very, very confusing (CP7).

In another example a carer reported that she and her husband had been promised input from a social worker during a medical outpatient appointment, but this had not occurred.

2.11.7.1 Fragmentation of care

Several participants described significant fragmentation in their medical care. One participant (P2) described how she had received medical care in four of the five major metropolitan hospitals, so that key medical notes and recordings of discussions were not accessible at each site. There was an

additional perception of fragmentation in her care when she was transferred between hospitals during episodes of severe illness.

Another participant receives her emergency and inpatient care in one hospital, while her outpatient specialist respiratory physician and nurse are located in another health region (P4). She also has other co-morbidities and commented poignantly, *'No one doctor looks after all of me'*.

2.11.7.2 Communication difficulties with health professionals

There were several reports of poor communication, particularly with doctors who did not appear to listen to the participant, either simply not listening at all or not listening to the messages the participants were trying to convey. Doctors also failed to identify themselves adequately.

They *'waffle on or talk to each other at the bedside ... can't hear or they talk double Dutch'*. The same participant complained that many doctors talked too quickly and she could not get their names. She also described her frustration in always being asked how she felt when she was admitted to hospital when unwell, *'How do you think I feel?'* (P2).

One participant described a hospital admission for elevated blood pressure which he attributed to panic:

I tried to tell them but these doctors don't listen. Too many chiefs and not enough Indians, and then another doctor comes along and you say who the hell are you? And then another one – you don't even know who your doctor is. You don't even know who your doctor is, that's what I said to them: who the hell is...what and what is what...nobody want[s] to know and nobody is telling you nothing. Whispering to them bloody selves...the only one that told me anything was the doctor from intensive care and Dr (Chest Clinic), he said you've got roughly 12 months (P5).

He came back to the problems with communication again:

Yes they want to communicate with people a little better instead of brushing them aside. They're not even talking to people, you want something done and you have to scream blue murder to try to get something done, and they don't listen to you, they turn their head and look at the other people. You don't know what is going on, they don't tell you nothing, they just whisper among themselves, that's where I reckon that's wrong.

He also reported that several doctors had said to him, *'There's nothing more we can do for you. Nothing we can do for you'*.

One participant (CP6) described a very distressing visit in hospital from a palliative care nurse and an inappropriate discussion about withdrawing medications, *'it would cause him [to go] into a coma and in 48 hours he will pass away.'* This conversation took place in a corridor, without family support and she did not receive an apology when he realised he was misinformed about the nature of the referral. She also commented about 'tactless' DNR discussions in the emergency department (see Section 2.11.5.3).

Two other participants felt doctors did not listen to them; one was in relation to the dosing of a long term steroid medication (prednisolone) which also needed adjusting with exacerbations of COPD (P6), the other related to the participant's concerns about the role of bitumen and asbestos as well as smoking in the aetiology of his COPD which he did not feel were adequately addressed (P7).

2.11.7.3 Access to information

When prompted in relation to whether participants had enough information about their condition, one carer replied that she now understood the condition because she accompanied her husband to the doctor on every visit (CR3).

All participants with one exception did not make use of computers to access information, nor had any computer literacy.

2.11.8 Lung function tests

Lung function testing was raised with participants. Many reported difficulties when undergoing testing and for some, formal testing had been suspended.

As soon as they say breathe out, I start coughing and I just can't, I can't do it. It's alright for them to say breathe in, breathe out, but you can't do it...and I get a bit cranky, because I can't do it, I get cranky at myself. They seem to think I get cranky at them, but I'm not, I'm cranky at myself, I get frustrated (R5).

Later regarding a recent test:

I don't know how the results are of that. But I don't think they'd be too crash hot. I can't breathe in and breathe out just to suit them, even with ventolin after, and then wait 20 minutes and do it again, it's no good (R5).

[Dr -] was going to give me the breathing test to see how I was going but I couldn't do it...[Dr -] said I don't think we'll worry about them anymore... Puts you under too much stress, they are very hard to do those things ... I used to have them early on and I went in there and they had this guy in there ... He used to yell and scream at you, 'You're not trying, you're not trying.' So anyhow, they got rid of him, and the girls in there now are brilliant, yeah they are lovely, really lovely girls (R1).

His wife commented:

He came out of the last lot of breathing tests and he had tears streaming down his face, he never does that ...he went all blue in his face (RC1).

One participant when considering her physical ability on the MMRC scale said:

I did a respiratory test at the [hospital]. I had to walk for six minutes, it was a struggle. When I saw Dr [-] after, she thought it was quite good. I thought it was awful (P4).

One participant who was on a three month trial of home oxygen was due to go back to the Chest Clinic soon:

Because I argued with them, they put me through this test, the lung function area where I had to go off the oxygen for a while and then do a 20 minute walk. I'd be lucky if I saw bloody two minutes before I was bugged, and they got me, and ran down and put me in the wheel chair and put my oxygen on. And my blood tests, the oxygen was low but still they reckon not low enough and I thought I'm struggling now, how am I going to get on when I go home. 'Don't fret' they said, 'we'll talk it over', and they come back and said, 'we're going to put you on a three month trial' (P7).

One participant described being at the public hospital for five hours for a 'stress test' whilst an inpatient at another rehabilitation hospital. She found the whole experience exhausting but, 'it was the waiting around' rather than the test itself (P9).

One carer confused lung function testing with pulmonary rehabilitation and described it as:

Yes we have been down there in the hospital, you know you blow and then after they send us across the road (CP8).

2.11.9 Pulmonary rehabilitation

Only three participants had completed a formal pulmonary rehabilitation course.

One participant attended pulmonary rehabilitation in the period between interviews, even though he had been diagnosed with COPD some years ago. He found the course helpful:

I reckon that talking to them and the physio guy and that, you talk to them and they tell you different ways and things like that. I think it really helped, if you know what I mean (R1).

He was keen to continue with the weekly exercise class but the 9 am starting time was too early for him and his carer. His wife felt that the exercise had helped him cope with his sense of panic and breathlessness.

Attending courses or classes required a considerable effort from these participants, and again timing of the class too early in the day was a barrier for some. Travelling to the course was also an issue for some, attendance could be interrupted by illness, and the effort of attending was assessed as not being worthwhile. The issue of continuing smokers and non-smokers attending together was also raised, suggesting the possible need to separate smokers and non-smokers in pulmonary rehabilitation.

I've been to that and I found it quite boring actually. I went about five times, the people there were not responsive and not very good and there was a hassle getting there and getting home... I breathed easier staying at home (R5).

No, they wanted to put me on some course but I couldn't see the point. I couldn't do it here, why go somewhere else (P7).

He did actually try one day of the course:

Yeah, I did once, that was the first day, I can't remember how long ago it was now. But I parked my car, 'cos I was driving then, parked my car out the front, walked to the building, buggered when I got there. Then I had to sit through an hour's theory and then be told on what we were going to do in the course. Then walked back to the car, then somebody was smoking and I was dying for a smoke and I thought, what's the point of me going if people are still smoking? I've given it up and they're still smoking, because it wore me out. I thought what's the point? (P7)

One participant reported at the first interview that pulmonary rehabilitation was planned, but it was then put off, and she reported at the second interview not having heard anything since (P2).

One carer who felt it had been worthwhile for her husband, commented on the timing of the process in relation to disease progression:

As good as it was, that should have happened years ago, in my opinion, it might have got us in touch with services as well as education (CP6).

One participant who had been unable to attend pulmonary rehabilitation largely because of his frequent and severe migraine headaches, described the diaphragm control he had developed during swimming training when he was pushed to do 12 strokes per breath and later when playing wind instruments, and his additional use of meditational breathing techniques. He reported having learnt pursed-lips breathing in hospital and was a strong advocate of the combined benefits of these techniques as early as possible in the course of the illness. He also felt these skills accounted for his ability to manage without oxygen (R4).

Another participant, aged 79 years, was able to receive inpatient rehabilitation in the geriatric system following an acute hospital admission as it was recognized that she was too de-conditioned to enter pulmonary rehabilitation as an outpatient.

2.12 Quality of life measure (QOL)

In assessing the impact of the illness on their quality of life, participants studied the happy-sad face scale and the verbal descriptions carefully before assigning a numerical value. Participants identified a range of values from 0 (two participants) where there was no impact on their quality of life at all, to 4 (six participants) where their quality of life was totally affected. Two participants only gave a score at the first interview; one had died before being re-interviewed and the other was interrupted by family before the end of the interview (Table 2.3).

Eight participants recorded the same numerical value at the first and the second interviews. Three felt their quality of life was more affected by their illness at the second interview. Two male participants (P7, R6) recorded that their quality of life was less affected by their illness at the second interview, although in one case, a male living alone, he appeared worse in that he was more debilitated and his relationship with a friend who had been an informal carer had become more

distant. In the second case, even though the participant had lost quite a lot of weight, he declared himself to be *'fit as a mallee bull'*.

Another responded in this way:

Well [breathless from getting up to find glasses, unable to speak for two minutes] without going overboard I'd say a lot, simply because I can't do anywhere near as much as I could. Say if I wanted to change the battery on the car, I'd get it all unstrapped, and then I'd have to have a breather before I lifted it all out. To sweep the floor, I might sweep half this floor and then have a breather. It's affected me a reasonable amount, even though what I've told you today might be improving or getting better, doing things is a lot more difficult now than it was seven years ago, you know. It's easier but it's hard, if you understand what I mean, so I'd have to say a lot. I'd like to say not at all 'cos that's a nice colour, but I have to be honest, between a lot and a great deal, I'd say a lot (R6).

None of the participants were reminded of or appeared to remember their initial score.

Table 2.3 – Quality of life (QOL)

	P1	P2	P3	P4	P5	P6	P7	P8	P9	R1	R2	R3	R4	R5	R6
QOL1	1	3	2	4	4	3	4	4	3	4	2	2	1	4	2
QOL2	1	3	2	N/A	4	4	3	D	3	4	2	3	2	4	1

One participant (P1) described how quality of life can vary from day to day:

One day you can get up and can take on the world, the next day you couldn't knock a feather off a fence.

When asked what was the biggest problem being faced one participant summed it up in this way:

Life itself at the moment, the way I am it's so hard to get used to because I was always on the move (pointing to many sports awards) always busy. But now because I'm stuck home all the time there's, I miss it...yes, just life I 'spose, just life (P7).

At the second interview, the same participant reported:

I 'spose everything, it's getting a lot harder, managing, moving around, the whole lot.

Another had difficulty relating to the faces on the QOL scale and simply repeated:

My life have finish...my life buggered...my life buggered, I got no life any more (P8).

These words were echoed by a rural participant:

I've got no life anymore.

2.12.1 Attitudes to the future

However, the attitudes many participants expressed about their life and the future were remarkably positive. The question about the services they might need in six months' time was often a useful way to elicit how they saw their future.

I think I do pretty well for 73 (P1).

I'll be training for the marathon in six months (P4).

Hope I'm still alive (P5).

Even those who were fully aware of their poor prognosis didn't 'dwell' on it. One participant reported that her GP described her as a fighter, and she re-affirmed that she was not going to give in, wanting to stay with her husband and son (P2).

I live from one day to the next day. I live for the day. Yesterday was gone; tomorrow never comes. So today I'll wake up in the morning; when I wake up in the morning I say to my cat Sooty, there's another day mate. Right, so we go through that day until it's night time, 'til it's dark and say, well mate we've made it through another day. Then I sleep... (P5).

2.12.2 Advice to others

Most participants appeared to appreciate the opportunity to offer advice to others with similar problems:

...battle on, we've got to battle on. Don't let it get you down if you can help it (P1).

Yeah, well just tell them to just do what I do. Don't think about it, just live from one day to the next day. Try not to worry about what goes on. Keep a smile on your face and keep your chin up. Just plod along with life like as nothing happens. That's the only way you're going to do it. Because if you start playing on it and thinking about things it's just going to make you worse, which it does (P5, second interview).

Don't smoke in the first place, keep on your medication, try to exercise as much as you can [and] make sure you have someone in your life to go through it with you (P7).

At both interviews one participant advised, 'Don't give up, don't sit down, keep going. Make sure the right foot's following the left foot, that's what I tell everybody' (R3).

2.13 Carers

Of the eight full-time carers, seven were a long term spouse or partner. One carer was an adult daughter with her own two children. At the time of the second interview, one spouse had been diagnosed with dementia and an adult son had taken on carer responsibilities for both his parents. In another case, also at the time of the second interview, a daughter had withdrawn from her university studies to spend time at home, both to assist her carer parent and spend time with her parent with COPD.

2.13.1 Physical and emotional burdens

While carers were all committed to their caring role, and some would not acknowledge it as a burden, most acknowledged the enormous task and both the physical and emotional burden of caring for their loved one:

The job is huge (CR5).

On a bad day, I've had it (CP2).

One carer described herself as at 'breaking point' (CP8).

Another carer clearly articulated the impact on her own health, her anxiety about her husband and the impact of the change in roles:

Yes he's good, but he's not very well this morning. I can see that he won't tell you, he won't tell me. He's always been like that, his pride, he thinks he worries me, which it is starting to tell the tale on me, yeah healthwise. It's just so constant and you're just worrying all the time, having to do these things day in and day out, with all the other jobs that you have to do. I'm used to him having done all the manly things because he has all our life, but now like I'm out there, cos to go [to Adelaide], I've got to go out and prune those trees, out on the ladder and things like that (CR1).

CR2 and R2 commented on the restrictions on their social life imposed by the illness.

Participants frequently acknowledged the wonderful support they received from their carer as well as their concern for their welfare, 'She copes, she does a wonderful job' (R1).

2.13.2 Unwillingness to access services

For some carers there was a dilemma between wanting to provide all the care for their loved one and accepting help from outside services.

At this stage, look I'm coping, and I just, you know I just, the personal things that I have to do... I don't think he would appreciate it if I let someone else do that, but if I get to the stage where I can't cope, well he'll just have to have someone else help to... (CR1).

In the absence of any ongoing review, there appeared to be no mechanism for introducing services gradually, rather than waiting until the carer reached crisis point.

Another dilemma was raised by a carer whose husband did not want more people in the house:

I have a problem, he doesn't want people always coming here, that's why I not agree. I want help but he says too much people running around (CP8).

2.13.3 Respite

The need for respite for carers was a strongly recurring theme.

In the first interview, the carer who did not want help responded to the possibility of help in this way:

No not really, we like to do it, I can do it. I'm a fairly fit person like I'm capable of doing it. It's only on an odd occasion I would love to go and stay with my daughter for a couple of days and just go, just so that I can relax. ...But there is no way I would send him to respite, that is out of the question (CR1).

In the second interview, when speaking to the interviewer on her own, she responded to the question 'How are you?' in this way:

Oh yeah. Have a look at me. I'm bathed in perspiration. Are you watching me? I'm struggling. I'd love to have a break, but I've got nowhere. I don't want to put him into respite. He's too bright. I'm fine. I'm happy to do it. I struggle sometimes...It's ok. I get a bit down and out sometimes but I try not to let him know (CR1).

Another country participant cited the lack of options for respite as preventing him from visiting his own family in Perth (CR5).

After the introduction of palliative care services, one carer commented on the value of having an afternoon off each week. But because of the need to administer her husband's medications an ordinary respite worker would not be able to provide care so she was only able to have a nurse for respite for four hours a week.

One participant who was having great difficulty with the burden of her caring role, described her 'rescue' afternoon each week:

I go to the city for four hours. But sometimes if I miss my bus I have to wait, and only for two hours I can go out and only for that time I have to come back (CP8).

Later in the interview, crying:

It's hard, I can't breathe any more, looking after him, I said I want to give up but I can't, he's my husband. He [GP] said why not put him in nursing home but if the patient not agree then I cannot do nothing.

Yes but I can't give him up, he's my husband. All I need is somebody to help me look after him then I can go out, I get crazy, before I could manage but now they getting worse because I have a problem with my health. I have high sugar, high cholesterol, high blood pressure, all I want is, I want to sleep in the night, the whole night to rest.

This carer was under the impression that her outpatient doctor was arranging for a social work visit but this did not take place.

2.14 Future wishes: Advance care planning (ACP)

2.14.1 Knowledge of advance directive documents

In the first interview, 14 participants and six carers were asked the question, 'Has the specialist, nurse or anyone at the hospital had a conversation with you (and your carer) about your future wishes and what types of treatment you may or may not want?'. They were then shown the two advance directive legal documents under the South Australian *Consent to Medical Treatment and Palliative Care Act, 1995*: the Medical Power of Attorney and the Anticipatory Direction.

Eleven participants and five carers had not seen these documents before, although six of these had heard of them or thought they had heard of them. One carer stated, '*I think this one is about when they don't want to be revived, if you got so bad ...it is for him to give permission for me to make his decisions on his behalf knowing what he wants?*' (CR1).

The six who were aware that such documents existed had given some thought to who they might ask to make their decisions but had not completed any documents. For those with a spouse or partner, this seemed a relatively straightforward choice. However, one man who could easily nominate a friend (carer at the time) or cousin as a potential agent (decision-maker) then stated, '*If it comes to that (meaning decisions about turning off life support) I don't want to ask [them]*' (P1).

One participant had been shown some papers in hospital he thought might have been an advance directive, by someone he identified as a nurse and had signed something but he had no record of this, '*...if anything happens and we can't get to you in time what [do] you want to do, instead of being stuck on a machine, you want us to turn you off? And I said you might as well turn it off*'. When asked if he would like to talk to someone again he answered vehemently, '*No! No!*' (P5).

Only one participant had completed the Anticipatory Direction and appointed a Medical Agent (his wife). They were in a second relationship and both had children from previous marriages, '*[We] talked to children; son doesn't want to go there. Not fair to put anyone through it, so we've decided...*' (R3). They appointed each other as decision-makers. This couple was very active in the local COPD support group and was well informed of issues surrounding future decision-making. Their advance care planning had been assisted by the local palliative care bereavement counsellor who also happened to be a Justice of the Peace.

There was some confusion amongst several participants about the Enduring Power of Attorney (for financial matters), several mentioned their Will in the discussion and one raised the topic of a funeral plan (R5).

2.14.2 Conversations about wishes and 'Do Not Resuscitate' (DNR) directions

One participant (76 years) who lived alone had had a conversation with someone, although she was not sure who, and had completed some papers but did not know where they were:

I did have a conversation with someone and I did have one of these (documents) but I don't know where it is now, (laughed), I didn't fill it out ... but I was showing it to the children and I remember... one was this way and one was that way and one was the other way, so I probably left it (P3).

This participant had witnessed her sister's death after attempts at resuscitation and was clear she did not wish this for herself. She described the situation:

Palliative care came around and I said to them 'let her go'. She had had enough, she was 84, she was paralysed down one side, she couldn't speak, and I just said to them 'let her go'.

When asked if she thought her children would feel comfortable in making that decision for her, she replied:

I don't think they would feel comfortable making that decision, I really don't... I can't imagine them saying 'let her go'.

She described one daughter's ongoing guilt about her father's death:

She didn't even like her father and she still says 'oh I think I killed Dad'. And I say 'no you didn't, he had to go and he just went' (P3).

Because of the reluctance of her adult children to discuss her possible death, she had discussed the issue with her long-standing GP and he had provided a letter recording her wish not to undergo cardio-pulmonary resuscitation, which she kept in her handbag. The letter was dated 2007, *'that was before all this started. When I had my first bout I asked him to write me a letter'* (P3). Despite this, she had been resuscitated earlier in the year by two ambulance crews in her daughter's home following a *'heart attack'*.

At the second interview she repeated her view that, *'I don't want to put it on somebody that they have to decide for me'*. She still carried the letter about resuscitation from her GP in her handbag, and although she had a SA Ambulance fridge folder, it only contained her medications, not a record of her wishes. This participant described how the hospital now provided a letter directing the ambulance service not to use cardio pulmonary resuscitation (CPR), having opened and read the letter on discharge:

And I've noticed now, when I leave the hospital, they give a letter like that to the ambulance man they just say to me give this to the ambulance and I opened it and looked at it and it just says do not resuscitate.

Her family had also been taken aside during a hospital admission by one of the doctors and the question of resuscitation had been discussed with them. Following this the participant had more confidence that they understood her wishes, but no other steps had been taken, 'We sort of left it at the moment and see what happens'.

She also said:

They [the hospital doctors] have spoken to me about it. Dr X (consultant, aged 55) says to me, well, you're only young yet. I said, 'No, I'm not, I'm 76 years old'. To me that's not young anymore. But he thought I was - he's probably - I don't know- he's a fair age.

One participant who had been admitted to several different hospitals thought her wishes were recorded at the public hospital. At the second interview she said:

I think you've (referring to interviewer) got that on record, and at the [public hospital] as well. I'm not sure. I know at the [public hospital] they've got a plan there (P2).

When this was explored in more depth she stated, 'Yeah, I have got that written down officially.'

Her adult child carer agreed:

I'm pretty sure they have at the [public hospital], they put it into their computer. Because they wanted to know about Mum's wishes there and, yeah, I'm sure they've included that (CP2).

It was not clear what this record included. The participant was also adamant that she did not want her daughter making any decisions for her, 'I think I've told you and you've made a note of it, that on no condition do I want any interference from my daughter about me'. The researcher then asked more directly about resuscitation or if it was on the record of her wishes. The participant was unclear about the actual term 'resuscitation'.

P2: *Yes, yeah. What actually is that now?*

Interviewer: *It's when they, if you stop breathing ...*

P2: *Yes, I'm not to be brought back - if they think I'm brain dead, that's it, I just want to be left. ... Let go peacefully, I don't want to linger on because of the family. If I'm brain dead - because what's the use of living if you can't recognize your family and that? It's only putting hardship on them. .. I don't want that.*

Interviewer: *Is that written down somewhere?*

P2: *Yes, that's definitely another one that I had made, that I am not to be brought back if they think I'm brain dead. Isn't it, [son]?*

CP2a: *Yes.*

P2: *You know my wishes on that.*

CP2a: *Yes, we already have that. Yeah, that was one of the things that they wanted to know about last time you went to hospital.*

- P2: *[Husband] promised me. ... [son], is that recorded somewhere?*
- CP2a: *Yes, yes. Well, it's only on the database at the hospital. They got us to - actually, I think we had to fill out a form while we were actually there about it. They've probably got that on record.*
- P2: *[Her husband] promised that he wouldn't let that happen - if I'm brain dead, to let me go.*
- CP2a: *But by the same token, too, we've stated that they're not to turn it off unless they've exhausted all possibilities. ... That's what the main thing was, that was the main question that they asked us that time.*

This woman was frequently admitted to the local public hospital, not the major metropolitan hospital in an emergency. Her spouse-carer had been diagnosed with dementia by the time of the second interview, and their adult son had taken over all his responsibilities, including understanding his mother's wishes and the advance care planning documents about which he seemed quite well informed.

2.14.3 Who to appoint as decision-maker - Medical Agent

At the first interview, 12 participants identified spouse or partner (7), children (4) including one live-in carer, and a friend (1) as carers. In the case of married or partnered participants, each partner expressed willingness to take on the role of decision-maker, but for those participants relying on the support of adult children the situation was not always as clear cut.

One woman whose children lived in other states reflected on the possibility of her son making decisions for her:

- R5: *He can't make a decision if he's way over there and I'm over here, and if life support, if that happened well I wouldn't want to stay on it, I'd rather just go peacefully.*
- Interviewer: Would you like to talk to someone about it?
- R5: *Yeah it would be good. It's going to happen sooner or later.*

Calls her partner in from the clothes line to ask him:

Like if they wanted to keep me on life support and you knew that I didn't want that, I'd rather go peacefully than keep me alive on a life support machine. Something like that, it may never happen, but you know.

- CR5: *No worries, I could do that.*

At the second interview, this participant indicated that she had spoken to her son about her wishes. It was unclear whether this was only related to financial matters or included her health care decisions.

Of the four participants who relied on adult children, two felt that the children knew and understood their wishes. One participant's experience has been described above (P3), and a further participant (R6, 53 years) whose daughter was his live-in carer felt it would be difficult to ask her to make decisions for him:

Yeah, I don't know. I suppose I could get off my whatever, and discuss it with her. Emotionally I don't know – she's quite an emotional girl. Sometimes when the chips are down or when I'm down, one of the two, I don't know whether she could just say alright, turn the button off or whatever. I mean that's a bit much to ask. She's looked after me all this time, on and off when I've been sick. I don't know, I'd just simply say to the doctor, if you don't think I'm going to come out of it, turn it off, be done with it. After all, I get the last say don't I? [Prompt from interviewer re not being able to or being unconscious] Oh right, I never thought of it that way (R6).

At the second interview, when his daughter was present, he was surprised to discover that his two daughters had already raised the issue with his brother, their uncle, who had agreed to take on a decision-making role if necessary.

R6: *I thought he was just doing the Will part of it?*

CR6: *No, and this stuff. It's just easier for us I suppose if anything bad was to happen. I don't think us girls would be capable of doing anything like that. So that's why we spoke to our uncle and he's quite happy to do it all.*

For participants without family carers, the question was a difficult one. They all seemed to focus on the appointing of an agent as a decision-maker, rather than making an advance directive to express their wishes, and this made the task almost impossible in their mind. Two male participants (living alone) who had identified at least some support from a friend, reported that this relationship in both cases had failed by the time of the second interview, but in each case there was increased contact with family; in one case with a cousin who had agreed to act as agent, and in the other, more tentative contact with a previously estranged daughter.

Another single male participant was still agonizing over the possible role of an inter-state, and not very reliable 'foster son', 'I think with me, it's a matter of trust' (R4). This participant had been most enthusiastic about the documents at the first interview, 'That's wonderful, that's the kind of thing that I would like to have.' But he had not taken any action by the second interview (R4).

2.14.4 Negative experiences in hospital

Two carers reported extremely traumatic and insensitive discussions in hospital about resuscitation. The wife of one participant described how she was approached in the corridor of the hospital about resuscitation for her husband:

It wasn't just the corridor factor, it's right in your face. And when P. was admitted and in the emergency when we got there this time I think we were actually in there five minutes or

something - and one of the doctors right in your face - saying 'do you want resus?' and all these sorts of things but more blunter.

But I'm thinking hey, put it into three sentences at least, not just in front of this distraught relative of a sick person about I don't think we should resus him. ...Come back in an hour or two or give me a few sentences, ... then when I saw her a few days later, 'Oh you didn't want to discuss it, we better discuss it,' that sort of thing. The [public hospital] does not, just did not, does not have any tact dealing with relatives. ... P. said they've done that to me before, so I'm sorry I'm complaining but it was that bad, I know P. was ill, but they could have been more tasteful. Two or three sentences to get to this point, in front of the daughter, granted she's eighteen and a half, but she didn't need, ... in ways she is my backbone when she sees me start crying she's the strong one, they should do things and then talk (CP6).

She then described a second situation:

P. had been in hospital two - three days, I had an appointment in Adelaide so I was going to come in and see him and my daughter was on the train coming in to meet us.

P. had had a bad turn and it sounded like he was dying right there and then the way the doctor was going on (my interpretation, that is debatable). I'm nearly having four or five car crashes and as you're going along it escalates. What I did say to the doctor was my daughter's coming along separately, if you can you please stop her from going in until I get there. Granted it is not their business but I asked.

I eventually get in there as quick as I could and the daughter - they've given her the right royal on how ill he is and not for resus and everything and of course she's sitting there bawling her eyes out. Granted it's not their problem not their business but I did ask them to hold her and straight away they'd blurted it all out to her. They knew I was coming, why couldn't they have waited?

So yes a lot of emotion, I'm angry, I'm upset, I'd really like to take some of them and shake them (CP6).

The negative experience of one participant (P5) in hospital has been described already. It is worth noting that at the time of the second interview he was receiving support from a palliative care service and had also found a very generous friend-of-a-friend carer who was providing considerable practical and emotional support. He was now talking in such terms as, *'I like to get prepared a little bit, just in case something does happen'* (P5).

2.14.5 Reactions to the conversation, advance care planning

In the first interview all participants and their carers appeared comfortable in discussing advance care planning and future decision-making:

Nobody has ever given us ... like I've thought about these, but never ever asked, but I think they are very important (CR1).

Nobody has talked to me the way you do (P2).

While most participants saw advance care planning as a way to avoid unwanted, invasive treatment at the end of life, one participant in the interviews suggested a possible impact on survival and hope:

I'd sort of thought about it, and you think if I fill that out now, that could be the end of me (R6).

However, despite the initial enthusiasm, only one further participant had completed advance directives (with the help of a lawyer) by the time of the second interview six months later, and this was largely in response to their difficult experiences during several hospital presentations, described above. This participant was one of only two who were referred to palliative care services during the course of the study.

CP6: *Yes, yes, we did go to a lawyer before Christmas sometime and did new wills, ... a Medical Power of Attorney form - appointing me and he's also got an Anticipatory Direction, which we carry a copy with us everywhere.*

The carer produced a large file of papers and the advance directive documents.

CP6: *That supersedes that ambulance folder.*

Interviewer: It doesn't quite fit on the fridge!

P6: *(Joking) Not quite on the fridge!*

CP6: *We all know it's there and I have told the carer who comes.*

P6: *Every hospital gets a copy of it every time you walk in the door.*

CP6: *It goes with the ambulance people.*

CP6a: *It's one of the first things we hand them.*

P6: *Because they immediately screw it up and throw it in the bin. They claim they've never seen one, but they're supposed to get one every time you go.*

CP6: *Every time, yeah. ... There is one or two things that could have been done better we were told, but it does cover.*

Interviewer: Did the lawyer give you those? (Forms)

CP6: *No, with that type of form, we talked it over with palliative care nurses who come out and also with a coronary care nurse in the [hospital] who went over a few things with me. ... And there is an Anticipatory Direction form and it does have a few examples.*

P6: *We did add a few bits and pieces to it on advice of the lawyer and whoever else we spoke to.*

CP6: *Plus the palliative care nurse, plus the coronary care nurse from [hospital] all gave input - I wrote something out and got their input and changed it. ... The lawyer actually picked a fault in that, saying if P. got into hospital in a certain state I couldn't override - these directions. But there was a grey area and he did tell me. I said, we'll do this, it's 99% okay and he said 'yeah'. I said, we'll do this and we'll worry about it later.*

- P6: *You can't cover everything I don't think, no matter how much you write down.*
- CP6: *...there's a very good example in that brochure, but to the layperson, if you put a: Please do this. Please don't do this list, and then combine it. ... That was a very good guide.*

The Anticipatory Direction form provided a good guide for this couple given the participant's complex health problems. The participant had recorded his wishes on this legal form rather than in the Medical Power of Attorney document which appointed his wife as his Medical Agent.

They had established a plan of action for ensuring the document was with the participant whenever he was admitted to hospital. His wife explained:

- CP6: *Yes! He has a bag full of drugs, like one of those normal shopping bags and in there is a copy of his drug chart and normally a copy of his Anticipatory Direction. That goes with him in the ambulance and then I come with this folder.*
- P6: *She's got multiple copies of everything. Doctors are very good at denying that they've ever seen anything.*
- CP6: *Gosh yes, and also, when something's happening, I do my own progress notes, so like when that drug changed, I had my own progress notes, which I presented to the doctor and which they go pfft! And I'll photocopy it.*
- Well they should just say, do you have one? Then again it takes them time. The last one we've got is dated when you came in on so and so, is that still valid? I can see it can take time on their part, which they don't need to have to deal with, but someone did say every time you go you need to present a fresh copy - which I can understand.*

Although seven other participants had given it more thought, none of the others had completed any of the documents or had follow up conversations about their future wishes at the second interview. 'Too much to think about' (P7). Several had misplaced the forms left at the first interview, including some who had previously been enthusiastic about the idea of advance care planning:

No, I don't know what I did with them (CR1).

It's something you keep shoving aside all the time. It's too hard. I don't feel like doing that (R1).

I'm a real bugger for forms. I hate them. The worst thing you can do is give me a form to fill in because I'm likely to say, yeah, and have every intention to fill it in, then I'll take one look at the form, blow that (P2).

Several participants expressed willingness to follow up with someone who could help talk them through the forms such as the palliative care bereavement counsellor who was known personally or by reputation by several participants in the regional centre. However there was no specific person identified for metropolitan people to be referred to.

2.14.6 Role of GP or other medical staff

No one reported that their GP had raised any discussion of advance care planning. The one participant who had discussed it in detail with her GP had a DNR letter but there was no other discussion of it or completion of the legal documents.

2.15 Discussion

This qualitative data has provided richly textured evidence about the difficulties faced by people living with severe COPD. There were two major themes to emerge from this data, with many sub-themes. Firstly, the profound impact of the illness on the life of each participant and those who cared for them. Within this theme the subthemes included knowledge and understanding of the disease and its relationship to smoking; the impact of the disease, physically (including activities of daily living) and the emotional and psychological impacts on participants' lives, such as social isolation; and the issues associated with the use of oxygen.

The second major theme related to how the participants' lives intersected and interacted with health professionals and the health system. This theme incorporated subthemes such as accessing and relating to doctors and hospitals, and calling for help in emergencies. Navigating the system, together with communication were significant subthemes. The lack of conversations about the participants' wishes for future care and advance care planning was woven into the communication theme.

These two major themes were themselves inextricably connected in many ways.

2.15.1 Impact of COPD on participants and carers

'Biggest problem – life itself' (P7).

The participants in this study were selected because of the severity of their COPD. For each of them the symptom of breathlessness had a devastating impact on their lives, in terms of their physical functioning, the emotional effects and their social roles. For all, the severity of the disease meant they were no longer able to work, and for many, the physical limitations meant dependence on others, either their spouse or another carer for all the basic activities of living. For many, the simplest things outside the home such as driving, getting on a bus, or shopping were no longer possible, and social isolation was a consistent subtheme.

There was a contrast between those who lived alone and those who lived with a spouse, partner or other family carer. For those who lived alone, without a strong support network, the challenges of managing day to day, and the isolation were even greater. For participants with a permanent carer, there was a tension around trying to maintain independence as individuals and as a couple. No participant wanted to be seen as a burden, but each recognized how much their carer did for them.

For carers it appeared difficult to get to the point where they could acknowledge how much help they needed, wanting to do all they could alone for their loved one. Once outside support from community services was put in place, it was obvious how heavily burdened they had been. The lack of respite options for carers was also an important subtheme here.

All participants had smoked and recognized that smoking had contributed to their illness. This created a sense of ambivalence knowing that they had played a part in causing the condition with which they struggled. Some described a sense of abandonment as they perceived that doctors lost interest in their condition because of the smoking factor. Two males believed that their occupation had contributed to their lung disease but this was not acknowledged by the medical profession.

In this study participants were recruited from within a public hospital, and regional centre participants were all pensioners, either on Age or Disability pensions, and none of them had private health insurance. Thus they represented a more vulnerable (disadvantaged) section of the community, and in several conversations the sense of powerlessness was reflected in the language used. The struggle to cope with daily living left little energy to follow up on practical problems, such as making a phone call. The role of advocate was one that several carers took on, as well as the other emotional and practical support they provided.

Home oxygen appeared in the study as a 'two-edged sword'. On the one hand it enabled participants to remain at home and provided some relief from breathlessness, but on the other hand it became the focus of much anxiety about maintaining supplies and the equipment itself contributed to participants' sense of being housebound.

Despite the profound changes the disease had wrought in their lives, there was a strong sense among participants of 'battling on' for as long as they could, getting on with their lives despite the limitations. Although some described their life as being over, they still remained engaged in this day-to-day battle.

2.15.2 Interactions with health professionals and the health system

Life for participants with end stage COPD was inextricably linked with various aspects of the health system.

The fact that COPD falls into the category of a long term chronic illness (condition) and is not considered to be a terminal illness (even though the person may be dead tomorrow) excluded some of these participants from accessing community services, in particular palliative care. It was apparent from the data that the lack of a 'case manager' or co-ordinator meant that getting information about services, oxygen supplies, or even who to contact to get the information was a problem for participants.

The most obvious theme from all the data about interactions with the health system was the absence of a clear co-ordinated pathway to obtaining support and advice, and the fragmentation of services. For some, a GP filled this role, but for most the GP role was simply to provide medications. Although all participants understood that the interviews were part of a research project, they keenly awaited the second interview to assist with some of their unresolved problems.

Response to medical emergencies was seen as generally satisfactory, with the SA Ambulance Service providing prompt and reliable support. Other aspects of the system were more variable with several negative experiences and examples of poor communication. There were examples of fragmentation of care, and a lack of continuity, even in the simplest aspects such as ward care, discharge planning and outpatient appointments at times that were impossible to get to.

There was an overall lack of co-ordination and planning, and even in the face of advanced disease with poor prognosis, there was an absence of conversations about future wishes. Generally there seemed to be a lack of imagination to appreciate the difficulties faced by participants, and a lack of sensitivity in discussions.

There was a clear absence of anyone who could act as a point of first contact for participants and their carers, and who had the knowledge and capacity to give appropriate advice, and co-ordinate a response either in the community or by accessing hospital services. Although the specialist palliative care service appeared to take up this role in the two cases they became involved with, the uncertain prognosis in COPD, as well as the size of the population affected, means that another model may be more appropriate. Providing a co-ordinator and surveillance earlier in the course of the illness, could mean that support could be introduced gradually, rather than when a breaking point is reached. This may result in avoiding some of the acute hospital admissions.

The role of the interviewer filled this gap of co-ordinator for some of the participants as they awaited the second interview with enthusiasm. Some had practical issues which they did not know how to deal with, others were relieved to have someone to talk to and express their concerns. One carer had been waiting for the second interview to unburden her sense of exhaustion and need for respite. One man living alone, whose condition had deteriorated did not know how to, or did not have the energy to initiate extra support. He was clearly in need of additional services. Another woman was so distressed and tearful in the second interview, that it was almost impossible to continue with an unbiased interview as she needed urgent support.

Being a witness to the needs and suffering of these participants was an ethical challenge for the interviewer. As a trained health professional, the decision to act out of a duty of care became paramount. This involved phone calls to the respiratory nurses to request follow up interventions or advice. We, the researchers, acknowledge this as a potential bias in this study.

The skills learnt at pulmonary rehabilitation were valued by the few who were able to complete the course, and went some way in assisting with the otherwise overwhelming panic when breathing became more difficult. It was apparent that the timing should have been earlier in the illness, as the pulmonary rehabilitation course provided useful education/information. Of all the couples interviewed, the regional pair who were most involved with COPD support, were the most knowledgeable and appeared best equipped, literally and figuratively, to cope with the disease.

2.15.2.1 Communication

Communication emerged as one of the significant subthemes in this research. Participants described many of their experiences of communicating with health professionals in terms of *'not being listened to'*. The professional discourse focused on different aspects of the illness, the medical results and treatment in language that seemed removed from the participants' world. The participants spoke about their difficulties and coping with everyday life. The gulf between these two worlds, the professional and the participant, created an ambivalence for the participants as all were dependent on the treatments offered to extend their lives.

There was almost no experience among participants of formal advance care planning or even informal discussions about their wishes for future care. All welcomed the opportunity to discuss this when it was raised by the interviewer. There were, however, descriptions of insensitive questioning at inappropriate times about resuscitation. This inability to talk about their dying other than couched in medical rescue terms, *'Do you want to be resuscitated?'* changed for the two participants who were referred to palliative care. The lack of conversations around advance care planning and end of life wishes was stark given that any one of these people could have had an acute episode and *'been dead tomorrow'*.

2.15.3 Assessment of care needs with instruments

This study revealed some limitations with the three instruments used: MMRC, AKPS, QOL.

For the MMRC Dyspnoea Scale measuring breathlessness there was difficulty in allocating one number as the grades did not clearly separate out participants' descriptions of breathlessness. The distinction between the numbered categories was not always clear in terms of the things that participants could or could not do. There was considerable overlap between the descriptions of activities that resulted in breathlessness. Most described difficulty with showering and dressing, and activities that involved lifting hands and arms over their head were identified as being particularly difficult, but this did not limit them all from leaving the house. Only four participants were identified as having an increase in their MMRC score between interviews.

The relationship between AKPS and MMRC in determining performance status and requirement for more intensive services was unclear. In our study, changes in MMRC scores in four participants only correlated with a fall in AKPS in two and in neither case did these scores act as a trigger for additional services. What was apparent in this study was the lack of systematic monitoring of these participants by a health professional. The increasing frailty of participants meant it was difficult for them to ask for help; either in defining the help they needed or whom to ask for this help.

For the three participants who recorded an increase in the impact of the illness on their quality of life (QOL), two had a 10 point decrease in AKPS, while for the third, MMRC and AKPS were unchanged. One participant who had an increase in MMRC and a decrease in AKPS implying a changed physical status (which was also confirmed by observation by the interviewer) actually felt the impact of the illness on QOL had reduced. The other participant, who reported a decrease in the impact of the illness on QOL, had no change in MMRC or AKPS but was observed to have significant weight loss.

The findings of this research question the sensitivity of the instruments in acting as triggers for change in services and the capacity of the current health care system to respond. It could be argued that the use of scales (instruments) could not replace skilled observation.

2.15.4 Conclusion

This study highlighted the symptom burden and day-to-day struggle for people with end stage COPD and their carers, and the additional challenges for those who lived alone.

The health system was often experienced as fragmented and lacking in co-ordination; care was episodic and reactive. In several cases, the interviews were seen as an opportunity to talk in a way that had never been available before.

It was apparent that a pro-active, co-ordinated palliative approach to care would have been relevant more generally and earlier than the timing of the two referrals to specialist palliative care services. This would include advance care planning as an ongoing conversation as part of a treatment plan and recorded appropriately, so the person's wishes were available for all emergency admissions.

Health professionals need to understand the many possible layers of loss experienced by people with advanced COPD: loss of roles at work and at home, loss of financial security, loss of independence, loss of peace of mind. Professionals need to be aware of the vulnerability of these people and bring sensitivity and compassion to all their interactions.

Social isolation is a key factor in reduced quality of life and the perception of stigma can contribute to increased social isolation. This social isolation and disconnection may result in few social supports when the person is dying.

A future model of care for people with COPD needs a professional co-ordinator who could work across hospital and community settings. This role would be charged with supporting as much independence as possible, through education and assistance with problem solving, but would have the skills and capacity to intervene with more specific assistance when needed. This role in many ways would resemble that of the palliative care outreach nurse who works across hospital and community settings, but would be seen to have specific knowledge and skills around COPD, oxygen supply issues, but also advance care planning.

Pulmonary rehabilitation should be an integral part of the model of care, but should be considered at a stage when the burden of attending is not too great. The question of accommodating smokers and non-smokers separately should be addressed and the timing of sessions should take into account the difficulties for people with COPD in getting to early appointments.

Advance care planning discussions should be introduced to all people with COPD, as soon as possible after diagnosis by a well informed, trained professional who understands the complexity of this disease and the current documents in the state. Advance care planning should be recognized as an ongoing conversation which is part of a treatment plan and recorded appropriately so the people's wishes are available for all emergency admissions. This would include discussions about resuscitation.

The findings of this research indicate the need for developing a pro-active, multidisciplinary model of care which is less reliant on tertiary care but places primary care at the centre of the model. Greater collaboration between respiratory, palliative and primary care services could provide an integrated approach which focuses on the needs of the person with COPD and their carer.

3. Study Two – Issues and challenges associated with end stage COPD: The views of specialist health professionals

3.1 Introduction

The purpose of this section is to report the findings of Study Two. The original intention of this study was to convene an Expert Panel of South Australian COPD clinicians in order to identify an agreed method of refining existing COPD mortality/morbidity data for use in policy planning and service development. They would establish agreed definitions for COPD, examine the most effective ways of addressing the current limitations in the existing data, and develop an agreed method based on these determinations. This work would then assist with the development of recommendations for a new model of care.

As the project progressed however, it became evident that identifying prognosis in COPD was less important than treating symptoms as they arise, particularly as the trajectory of COPD is so difficult to predict. This approach has been increasingly identified in the international literature (24, 25). In terms of likely COPD mortality, a recent Australian report from Access Economics (commissioned by the Australian Lung Foundation) has provided a comprehensive picture of COPD in Australia (35) and the Australian Institute of Health and Welfare provides regular statistical updates specifically on lung related disease (29). Thus, the aim of Study Two shifted from the proposed mortality/morbidity data focus to a broader examination of the issues and challenges for professionals dealing with COPD.

There were some difficulties in recruitment related to illness and timetabling issues, however two focus groups were able to be convened over a 10 month period. The data reported here were generated in these two focus groups, although there was overlap in the membership between the first and second groups. The first focus group was held in July 2009 and the second in May 2010.

3.2 Method

3.2.1 Focus group participant recruitment

Recruitment for the focus groups was purposive. Invitations were sent to specialist health professionals working in all the regions of Adelaide. The intent was to have a mix of respiratory and palliative medicine and generalist disciplines and also specialist nurses participating.

The six participants of Focus Group One were three respiratory specialist physicians (RS); one palliative medicine physician (PM); one general practitioner (GP); and one respiratory scientist/academic (RA). One of the respiratory physicians has a particular interest in palliative care and has a significant palliative care focus to his practice (RSPC). The respiratory physicians worked in three different regions of Adelaide and the palliative medicine physician had also worked in three different regions of Adelaide. This focus group was facilitated by a chief investigator and was held at an Adelaide teaching hospital.

The seven participants of Focus Group Two were two respiratory physicians; one palliative medicine physician; two respiratory nurse specialists (RNS); one palliative care nurse specialist (PCN); and one general practitioner. The focus group was facilitated by the palliative care nurse specialist who was the Nurse Unit Manager of Mary Potter Hospice (Calvary Health Care, Adelaide), a specialist palliative care in-patient unit and was held in the same venue as Focus Group One (Table 3.1).

Table 3.1 – Focus group participants

	RS1	RS2	RSPC	GP	RA	PM	PCN	RSN1	RSN2
Focus Group 1	✓	✓	✓	✓	✓	✓	–	–	–
Focus Group 2	✓	✓	–	✓	–	✓	✓	✓	✓

3.2.2 Analysis

The focus group discussions were digitally audio-recorded, and notes were taken of the key issues arising throughout the discussions. Where possible, relevant direct quotes are included in the analysis, however the Project Team felt that it was not necessary to have verbatim transcriptions for each focus group. Digital recordings were listened to a number of times, and notes taken of key themes arising from the discussions.

3.3 Findings from Focus Group One

The initial questions of the Expert Panel were to define end stage COPD and to determine when was the appropriate timing of a referral to specialist palliative care or what were the indicators that the focus of care should be palliative.

Four key themes arose in analysing the responses of participants:

1. Difficulties in defining end of life in COPD.
2. Why should palliative care services be involved at all?
3. The roles of respiratory and palliative medicine physicians, general practitioners and nurses.

4. Changes that might be required in health systems and policy.

3.3.1 Defining end of life

All participants agreed that identifying when people with COPD were approaching the end of life was very difficult, and there were few existing diagnostic criteria which were accurate.

If you, as a clinician, have to say that this person has got less than six months to live now with COPD, that's impossible. You can just look at the BODE scores and you can have the worst possible BODE score and still be alive two to five years later. That [BODE score] doesn't comment on their quality of life but you can still be alive (RS).

I asked respiratory physicians about [defining] end stage respiratory disease. Out of 27 responses, a variety of the respiratory physicians didn't have a clue – a couple said FEV1, a couple said requiring domiciliary oxygen but there was no stand out of what respiratory physicians considered end stage respiratory disease (RSPC).

One participant noted that there were some indicators when considering the broad clinical picture, but that co-morbidities were also often present as well:

It doesn't stop you from being highly suspicious, the frequency of admissions to hospital, the rising blood gases, the 'crumbling', the presence of cancer. With COPD patients, one third of them die from heart disease, one third of them die from cancer and one third of them die from respiratory failure, so again that brings another balance to the whole discussion (RS).

A lack of a predictable trajectory at end of life was considered to be a complicating factor:

...the difference with a non-malignant disease, ...makes it more challenging because there is a less predictable timeline, there are different sorts of symptoms to manage (PM).

Participants proposed that rather than trying to quantify when a person is approaching death, it may be more useful to identify that they are reaching a point where they require specific services to support their care and quality of life. In particular, a reliable indicator may be the actual complexity of need:

I don't think we are going to solve the problems of who can tell whether somebody is going to die within the next six months because we can't. But I would be inclined to say the person is perceived to be dying in six months and is likely to need services which look like this and they [the services] will be to do with mobility and breathlessness (RS).

...what I ended up really deciding was it was a complexity of needs (RS).

When to refer into palliative care is often influenced by social circumstances ...when it all becomes too hard and I need someone to try and coordinate those community services and act as the lynch pin to contact Domiciliary Care and to get help at home 'cause we don't always have these skilled practice nurses to do it – so we might give the services to palliative care (GP).

Another participant suggested using the following checklist to indicate a need for referral, but not necessarily that death is approaching – rather that the complexity of need is increasing:

- Has this patient had three [hospital] admissions in less than 12 months?

- Has there been significant weight loss?
- The six minute walk as a performance indicator.
- BMI under 21 and they have lost a lot of weight.
- They can't walk 100m.

What I am ticking off is the BODE or 3 out of 4 of the BODE score. This person should be referred to a respiratory physician to review all of the above issues with a view to a change of approach, be it palliative approach, community-based, community care so there is a tick box that comes, i.e. COPD admission [means] use the sheet before they go home and that doesn't take a lot of time. That might then capture more of these people, so let's ramp up the community package for this person (RS).

3.3.2 Why involve palliative care?

There was discussion about why specialist palliative care services might be involved in the care of people with COPD. A number of factors were identified such as easier access to community care and equipment, more time and ability to deal with the many issues associated with end of life care, and accessing a different knowledge base and skill set:

The fact is, do we dump on palliative care so that they can manage the community services that are required for these people? ...just seems a rather inefficient way of doing things (RS).

....because when you get involved with a palliative care service you leap frog the [DCSA] waiting list and sometimes we are used and abused for that. They refer to palliative care so they can leap frog to get the equipment for the ADLs [activities of daily living] (GP).

....but managing death is not my core business. Managing a structured approach to that kind of generic question is I presume what the palliative care physician brings to the big table (RS).

I could whip through all my consults as a respiratory registrar or consultant very quickly. They were quick but when you do the palliative care ward rounds they can take a lot longer. And just because you are asking the questions or taking the time, I think that is one of the big differences - we spend more time asking [broader] questions (RSPC).

3.3.3 The roles of respiratory and palliative medicine physicians, general practitioners and nurses

There was general agreement that skills are required from a diverse health workforce to meet the needs of people with COPD as they approach the end of life. There is a place for respiratory and palliative medicine physicians and general practitioners and no one group can provide all the services required:

The role of the respiratory physician is to ensure that all reversible disease has been optimally addressed (RS).

The respiratory physician who takes on end of life management of a patient in its entirety is a fool, he is not going to be able to deliver it, it just can't be done. You can't manage the ADL side of things which is the single most important issue (RS).

I see the respiratory physician as an expert resource. I don't always physically need them to see my patient but I need to be able to access the expertise. So it is a palliative care system and support that your GP needs (GP).

...limit palliative care to some manageable bite, rather than saying palliative care starts as soon as you start to get minor airway obstruction, towards managing people as their fundamentals are failing (GP).

I see that it is general practice that's often coordinating the community services and we are in a better position now than maybe what we were a decade ago to do that with the advent of practice nurses. We rely on our practice nurses (GP).

...So I think the roles of the various service providers need to be redefined or clarified or strengthened. And I think the respiratory physicians have a limited role, the respiratory nurses have an expanding role and the people managing ADLs have the dominant role - they may be GPs but they may also be practice nurses (RS).

There was also general agreement that a care co-ordinator would improve the navigation and utilisation of services and resources for people with COPD, and that being community based and linked to the general practitioner was a useful model. General practice nurses may potentially have a key role:

I think the important thing is about shifting the focus and having enough resources in the community and presumably to involve a mix of expertise and preferably under the umbrella of the GP as the conductor. But in some places it might be the respiratory nurse and others it might be the palliative care nurse that is actually [the primary focus] or the general practice nurse (RSPC).

You could provide the palliative care by the palliative care nurses and maybe the doctors supporting respiratory nurses in the community to be the lynch pin or the practice nurses to be the lynch pin back to their primary health care providers (GP).

General practice has been involved in chronic disease management including end of life and I think that general practice is quite well placed to be able to coordinate that care (GP).

...have a consultative role for significant issues would be the way. The respiratory physician would be still maintaining the direct input of care with the GP as the major conductor of the orchestra (RS).

One participant however stated that there 'are GPs who don't want to have a bar of it' – i.e. taking on the longer term management and care of people with COPD.

It was agreed that, at the point of the diagnosis of COPD, information and a care plan are required. It was considered that currently, people diagnosed with moderate to severe COPD receive an action plan, but possibly not those diagnosed with mild COPD. It was noted that an action plan was not the same as a care plan – an action plan provides people with COPD with a guide for what to do during an acute exacerbation, whereas a care plan addresses the long term management of the condition.

They [patients] have a need to know how they are to be looked after (if they want to know – some don't!) (RS)

Communication issues were highlighted as being paramount in coordinating care.

...Some kind of communication between the hospital and the GP practice which would be via the practice nurse to coordinate that community care because that is what our practice nurses are doing (GP).

A major issue raised by a number of participants was the sheer number of people with COPD and how their services could cope with them. This was particularly so for palliative care services who have limited resources to serve their current clientele who predominantly have cancers. It was considered that palliative care services as currently structured and funded could not cope with a major influx of people with COPD:

None of us would want the avalanche of COPD and I think it points to what does a palliative care doctor add to the management of respiratory failure? (PM)

As a palliative care service, when do we accept patients? Because there are so many patients with COPD, heart failure, renal failure, we see increasingly more non-malignant diagnosis referrals. And we haven't got the staffing, nursing numbers to look after all those people and neither should palliative care look after all those people. So that started me thinking, who do we accept and when do we accept them? (RSPC)

3.3.4 Required changes in health systems and policy

There was agreement that the current system of health and care services does not adequately support the care needs of people with COPD as they approach the end of life, and that there needs to be policy change to support system change. It was also agreed that there was no 'one size fits all' model, and that there was an existing collaborative base on which to build new models.

I think that the fundamentals of COPD management have to be considered in the context of the health system we work in at the moment. And the health system is very much loaded towards the acute end with a fundamental missing out of community services (RS).

I think at the end of the day what you are going to end up with as a policy, is not going to be one model that fits all. I think different people will want different things (RS).

There will be people who have cared for someone with COPD who will see it through whether it is the GP or someone else who will want to see that through without necessarily passing on some of the challenges that we might associate with palliative care. So I think although you can put up a range of models I think you have got to be careful you don't crunch it down into just one service fitting all sizes (RS).

We have an inadequate community based respiratory management system which we need to guide the government to correct and we need to be part of that correction process. This engagement between palliative and the respiratory side is extremely healthy as far as I can see at the moment (RS).

3.4 Findings from Focus Group Two

Given the difficulties at the first focus group in identifying 'end of life' in COPD and the indicators for, and timing of, a referral to specialist palliative care, the project team considered whether the right questions were being asked. There was considerable discussion about whether it was possible or even useful to try to predict prognosis or approaching end of life in COPD. Different ways of considering 'the problem' were explored and there was a general refocussing of health care away from health professionals and systems and back toward the person with COPD.

Because of these definitional difficulties, it was agreed that there was more value focussing on the needs of the person with COPD as the end of life approached and how these might be assessed. The questions were rephrased to consider whether quality of life and functional decline were more relevant. Consideration was also given to what assessment tools might be used and by whom and where these might be undertaken. Rather than focussing on referral to specialist palliative care and trying to determine approaching end of life, it might be better to assess when symptom control becomes the fundamental focus, to quantify the size of the problem and to discuss the organisational changes needed for managing advanced disease.

Four key themes arose in these discussions:

1. What is needed for end of life care in COPD?
2. When should advance directive discussions occur and by whom?
3. The role of chronic disease management and health literacy.
4. Instruments to improve need assessment in COPD.

3.4.1 What is needed for end of life care in COPD?

There was discussion about whether there is a hierarchy of needs for people with COPD, who might best meet these needs, at what point specific end of life discussions should occur and whether there is a role for a co-ordinating nurse/specialist/GP in this process?

It was suggested that a guideline document be developed to assist GPs and respiratory physicians to give end of life care when being consulted by a person with advanced COPD. A framework or checklist that would guide their care, with prompts particularly about quality of life assessments and information about practical services, was considered to be particularly useful. It was felt that currently nobody knows who is supposed to do what and so it is easy to think someone else will take responsibility for aspects of care, resulting in the needs of people with advanced COPD not being met:

This group of patients can easily 'fall through the cracks.' In an ideal world, tasks would be allocated and everyone would know their role (RSN).

We are too focussed on who does what rather than what has to happen (PCN).

3.4.2 Advance care planning (ACP)

Discussion occurred about advance care planning (ACP) and how it can be a difficult subject to initiate with people with COPD and their families. It was noted that there are no respiratory examples in current ACP documents and information sheets in South Australia – for example, how to raise questions and talk about home oxygen administration, cardio-pulmonary resuscitation (CPR), non-invasive and invasive ventilation, and what interventions an individual might wish to consider in a given scenario. There are also no examples provided in the documentation or information sheets about how to raise conversations about preferred site of current and end of life care.

It was thought that probably 95% of discussions about ACP now occur when the person with COPD is critically ill in hospital. This was considered to be unsatisfactory because this situation does not allow for informed conversation between the person and the health professional. Conversations about end of life should occur and be documented before such a situation arose. Another option was that these ACP conversations should be initiated *after* an Intensive Care Unit (ICU) admission at the next review appointment. It was acknowledged that the initiation of ACP discussions depends on many factors, such as the individual's mental state, medical co-morbidities and even loneliness.

It was noted that people with cancers are often '*ahead of clinicians*' in thinking about issues like resuscitation. This is a less common scenario in people with COPD because of the insidious nature of the progressive disease:

That's not me at the moment (patient voice).

End of life discussions should not be dependent only on ICU or palliative care health professionals – they are everybody's business:

If we know what we're doing, we can make these differences very substantial very quickly (RS).

The critical challenges were perceived to be: (a) At what stage do we start these discussions? – many people are not ready to talk about end of life; and (b) Who does the talking – who can do it best? It was agreed that it is important to consider ethnic issues as well. For people from some cultural backgrounds, discussions about death and dying are considered taboo:

How does one respect cultural values but allow choice? (RS)

It was also noted that people with COPD have a strong positive streak of optimism and so this can impact on the discussion.

They perceive that they are ill so they go to hospital, and the hospital makes them better, and this will continue to occur, so people don't understand that they're actually getting worse (RSN).

An important factor was perceived to be the general clinical ethos of the medical profession:

We, as medicos also promote optimism... we don't go out there knocking people down and the issue about when you talk about these things and how you progress it – I guess many of us (and I put myself in the bracket) can do it once but you're not going to do it every visit and watch people wilting in front of you (RS).

...It is a challenge and there's value in optimism (PM).

3.4.3 The role of health literacy and chronic disease self-management

Health literacy was felt by the participants to play an important role in the management of COPD for individuals. It was agreed that it was important to identify attitudes and 'capacity to know' in people with COPD and it was suggested that work by Adams et al in this area on asthma may be useful (73). It was suggested that there were two groups of people – those that want to know more about their illness and take a more active role in its management and those that do not – and that it is vital to manage expectations (of both the person with COPD and provider). A flowchart/map that outlines two different management pathways for people who are able to self-manage and those who are not may prove useful. This is particularly important for moderate disease when function begins to be affected and exacerbations need to be managed. Self-management is important in early recognition of exacerbations. It was agreed that education is important for all stages of the disease. This was seen to be part of chronic disease self-management. Chronic disease self-management is:

...about people being actively involved in and being at the centre of their own health care to maximise their quality of life. Self-management involves the person with a chronic disease... engaging in activities that protect and promote health, monitoring and managing symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes (96) (p1).

Health literacy was also considered to be very important in considering whether to initiate discussions around advance care planning. Health professionals need to know their patients' capacity to understand what is being discussed – if people have minimal levels of health literacy, this will limit how and with whom these discussions occur. The extent to which these potentially difficult conversations occur will also depend on the skill and time taken by the health professional.

3.4.4 Checklists to help identify patient needs

It was agreed that COPD needs a 'Guideline Document' for people's needs, as it is often very difficult to tell when particular responses should be activated. Participants suggested that a 'Patients' Needs' checklist (rather than a clinical checklist) may be of value. It should be focussed on people's needs and wants (for example, initiatives to assist with ADLs) and be consistent across service providers. One participant noted that:

You must talk about depression if you talk about quality of life (RS).

It was suggested that if the needs of people with COPD could be defined, we could then draw on palliative care services as required but that the core business of talking about symptom control and lifestyle modification and connectivity with other services is not really the role of specialist palliative care services. It was agreed that improved computer based services would also assist with this communication.

It was suggested that the UK principles underpinning their End of Life Framework (11) could be used as a basis for a checklist – with a care plan and process to improve the co-ordination of services. This Framework seeks to move the responsibility away from one health clinician. Any such document must be centred on **need**, not what we can provide.

One participant suggested that a short ‘pathfinder document’ incorporating four key considerations could be very useful:

1. Identifying the need for a changing model of care.
2. Defining the role of palliative care services.
3. Recognising that *‘we have to admit we really don’t know when people are going to die ... we can’t predict the length of life, even in severe COPD’* (RS).
4. Acknowledging that there is a difference between symptom management and end of life discussions.

3.5 Key issues for a model of care

The role of primary care in providing COPD management for people with advanced disease was discussed at some length. A number of issues were identified which impact on the ability of primary care to meet these people’s needs adequately:

1. The importance of a central referral system linking acute, primary and community services.
2. The time needed to set up home supports from primary care is currently not resourced.
3. People with COPD find it hard to attend appointments at the GP and at specialist clinics and consulting rooms.
4. Home visits need to be available when appropriate:

We don’t expect ill cancer patients to attend the GP clinic (PCN).

5. If people are treated in the community, a community based respiratory physician who can liaise closely with hospital based physicians is required – again good electronic communication frameworks will be required.

Participants were asked to nominate the key issues to be considered when developing any model of care for people with end stage COPD and suggested the following:

1. Because it is so difficult to recognize the terminal phase of disease, rather than looking to identify when end stage COPD begins, it is more useful to:
 - a. Identify people's needs from diagnosis to death.
 - b. Identify issues that impact on the type of care provided (e.g. can the person manage their own care?)
 - c. Initiate case management depending on severity and capacity.
 - d. Ensure accurate and timely assessment.
 - e. Ensure education of the person with COPD and their family.
 - f. Define the possible role of the palliative care team.

2. One participant queried whether a COPD care team (rather than respiratory and a palliative care team) was required. It was proposed this team could navigate people through the process of moving between the acute sector and back to the community. Currently there are barriers to accessing many supports for activities of daily living:

You shouldn't need a referral to a palliative care physician to access specific services (RSN).

3. It was proposed that palliative care teams will be vital initially to educate COPD teams and gradually there will be more confidence that the respiratory team can handle the required care.

...that's how you keep a skilled workforce (RSN).

4. To stay at home and cope, people with severe COPD need medical treatment, the opportunity for safe, comprehensive end of life discussions and an ADL package which is co-ordinated and integrated.
5. Current access to an ADL package can take up to 18 months, and there is an age restriction to be over 65 years.
6. The focus of guidelines to date has been about the acute and chronic management of COPD but has **not** considered how you live with COPD as a person. It is seen as a grave omission that the current COPD-X Guidelines do not have a statement about ADLs. It is important that there should be an assessment of the physical and psychological functioning of the person with COPD, their attitudes and understanding of the disease and of what the future might hold for them. These are important parts of clinical guidelines.
7. Consideration of psychosocial issues including anxiety, panic and depression is vital.

3.6 Conclusion

The goals of this study were not achieved. An Expert Panel of South Australian COPD clinicians was convened to determine an agreed method of defining criteria for approaching end of life for people with COPD and to explore timing of referral to specialist palliative care services. It was considered

not possible to determine the end of life phase for someone living with COPD. In fact, it was clear that rather than trying to determine the end of life phase and when palliative care services should be employed, it was more appropriate to use a needs-based approach to care. ADL support was seen as vital and missing in many instances. Often a referral to specialist palliative care services was to access ADL support rather than the expertise of palliative care clinicians. This is clearly an inappropriate and inefficient use of 'the system'. It highlights that there is not a properly resourced system to adequately support people with COPD requiring increased ADL and psychological support.

It was agreed that advance care planning was vital for best care. The difficulty of initiating and timing of these conversations was explored. Better communication and action plans with documented responsibility and good communication about such issues would also be of assistance. Advance care planning should be recognized as an ongoing conversation which is part of the treatment plan and recorded appropriately so the person's wishes are available for all clinical interactions and particularly emergency episodes of care or at transitions of site of care. If the conversation is documented appropriately, it does not need to be revisited at every consultation but should be reviewed when clinically relevant.

Key recommendations were for an increased recognition of the need for, and importance of, support for activities of daily living for people with advanced COPD. Access to relevant services should be improved and streamlined.

Care co-ordination was seen as pivotal to any new model of care. Care co-ordination should be flexible and able to occur across hospital, community and home. The role should involve active monitoring of physical and psychological symptoms, and the provision of education to support independence and build problem-solving skills. The role must also include the skills and capacity to intervene with more specific assistance when needed. In short, the role would combine the skills of a palliative approach, including providing psychological support, with those specific to COPD. The role was characterised as being that of 'a navigator'.

4. Study 3 – Service availability and accessibility for people with end stage COPD and their carers

4.1 Introduction

In Australia, it is generally assumed that people with COPD have access to a full range of hospital and community services if required, however some of these services have specific eligibility requirements, and may have significant costs associated with them. There is also little information on the specific care needs of people with advanced COPD in Australia, and on whether existing services are able to meet these needs. To date, there has been no audit of which services are actually available (across the hospital/palliative care/primary care/community continuum of care) in South Australia and of the eligibility requirements for these. It was therefore proposed that an audit would be conducted of services available in South Australia for people with advanced COPD, using existing information databases for services (for example, the SA Human Services Finder) as well as existing hard copy service guides, information available for people with COPD and any other relevant data sources.

Study Three met the following project objective: To describe the care services available to, and accessed by, people with end stage COPD in South Australia.

4.2 Method

A small Steering Group drawn from the Project Team was established to guide Study Three. At the first meeting it was suggested that rather than an audit, the group should undertake a gap analysis of services available for people with COPD, as a database would require ongoing maintenance and regular updating, and it was unlikely there would be continuing infrastructure support for such a process. It was therefore agreed that a table of existing services would be developed as a basis for this gap analysis and this would be drawn from a number of sources:

1. The Royal Adelaide Hospital COPD Pathway (which contains a list of services for people with COPD), with information from the Central Northern Adelaide Health Service (CNAHS) Pathway Group, was used as the basis of the audit table.
2. The SA Royal District Nursing Service (RDNS SA Inc) has extensive community services listings which were added to the initial table.

3. General practice and primary care provide a significant number of services to people with COPD and these were also added to the table.

The initial draft table of services drawn from the above sources was then distributed to the Study Three Steering Group who reviewed the contents and added to it where required. This table can be found in Appendix 12.

In order to identify gaps in services, barriers to access, service restrictions, functioning of services and service co-ordination issues, it was agreed that Study Three would concentrate on collecting data from service providers regarding service availability and their perceptions of how services were or could be accessed, where there were gaps, and barriers to access. It was also agreed that it would be useful to consult with COPD consumer groups on similar questions, as although Study One was interviewing individuals about their own particular experiences in this area, it was felt that consumer groups may also have significant issues to raise more generally.

A revision to the initial Ethics Application was therefore submitted, and approval obtained for a series of focus groups and interviews with key service providers and consumers (Appendix 13). Key service providers were identified by Study Three Steering Group members, comprising the variety of health care services that people with COPD are likely to require or access. A mixture of focus groups, interviews and group sessions were used according to the preference of each group and Table 4.1 provides an overview of the participants and methods. A purposive sampling technique was used to ensure diversity across the groups, and participants were identified through the differing networks of the Project Team. All participants were provided with an Information Sheet about the project (Appendices 14, 15, 16).

A series of interview schedules were developed, aimed at identifying key services and supports, availability, barriers, gaps and suggestions for the future. Slight changes were made to each schedule to ensure they were appropriate for the various groups being interviewed – for example, the consumer focus group questions and Carers SA questions differed slightly from the health service providers' schedules (Appendices 17, 18, 19). Interviews were conducted by members of the Project Team and all sessions were audio recorded and an individual thematic analysis was undertaken to identify key themes. Data from all groups were drawn together to produce a final summary of services, needs and gaps and the issues associated with providing care and support to people with COPD and their carers.

Table 4.1 – Health care service/consumer interviews

	Type of Contact	When	No. of Participants
1. Respiratory nurses (<i>through the Respiratory Nurses Special Interest Group</i>)	Focus Group	16/9/09	6
2. Palliative care service representatives (<i>Social workers/nurses from palliative care services throughout Adelaide</i>)	Focus Group	13/10/09	8
3. GPs	Focus Group	16/12/09	8
4. Respiratory physicians (<i>private practice</i>)	Focus Group	17/12/09	4
5. RDNS SA	Focus Group	14/4/10	8
6. Carers SA	Interview	19/4/10	2
7. Domiciliary Care SA	Interview	10/6/10	3
8. Public hospital respiratory team (<i>including physicians, doctors in training, nurses</i>)	Group Session	20/5/10	Approx. 20
9. Consumer support group	Group Session	20/10/09	Approx. 30 people with COPD and their carers

4.3 Key issues arising

Although discussions were held with a wide variety of service providers across the course of the project, there was significant agreement on the key issues arising around the services required by people with advanced COPD and their carers, as well as a consistent identification of major gaps in services and barriers to access. Four major themes were identified (as well as a variety of lesser, although still significant themes):

1. Access issues.
2. The impacts of the trajectory of the illness.
3. The role of carers.
4. The importance of communication.

Other themes included the use of oxygen, mental health, and spiritual and emotional well-being.

4.3.1 Access issues

A variety of issues associated with accessing services were identified by all participants and there were a number of specific aspects of access identified:

4.3.1.1 Transport (including more access to disabled parking)

Almost all participating groups raised transport as a major issue for their clients with COPD. There were two particular concerns raised in this area:

1. The need to access transport to be able to attend appointments for medical/allied health care, pulmonary rehabilitation and exercise classes and to be able to undertake basic requirements such as going shopping.
2. The ability to maintain independence, contributing to the ability to stay at home.

Respiratory physicians and GPs noted that it was very difficult for people with COPD to access and use taxi vouchers. GPs and consumers commented on the need for more disabled parking, as people with COPD need to be able to park close to where they shop, visit the GP etc. The support group felt there were too many 'pram parks' – i.e. parking provisions for mothers with babies, and far fewer disabled parks available.

Transport is probably a gap in that a lot of them are not suitable for public transport and if they don't drive or if their COPD is not stable or if they don't have someone who can take them, then they do get quite limited in terms of these services (FG4: Respiratory physician).

DCSA identified the importance of having access to scooters, and that these are now no longer available through their services and so people with COPD must purchase these themselves.

The use of oxygen was also cited by a number of groups as an issue associated with transport – if it is a long distance to go (for example, Hampstead for pulmonary rehabilitation), clients can be very concerned about their oxygen and whether it will last.

4.3.1.2 Accessing palliative care

Two focus groups were held with services specifically providing palliative care, three groups were more focussed on COPD care (specialist physicians, the public hospital respiratory team and respiratory nurse specialists), whilst the GPs and DCSA provide more generalist care. All service provider groups recognized the value of a palliative approach in caring for people with COPD, however many also noted that most people required concurrent, ongoing care of their respiratory disease.

It was generally agreed that the course of COPD was more suited to a chronic disease management approach, but with input and support from palliative care services when required. However, the palliative care service providers, DCSA and RDNS noted that there were difficulties in having people with COPD referred to them because often these people only require services for a short period until the exacerbation of the illness passes – but this '*dipping in and out*' cannot be accommodated by the service structure. The palliative care service providers noted that there was no clear definition of the palliative care services required for people with COPD – i.e. episodic vs. ongoing vs. consultancy.

With non cancer patients, often our involvement is in and out at different periods of time – so it's not so much....it's episodicwe're recognising that's becoming more the pattern with palliative care with non cancer patients and COPD patients. We dip in when there's a complex need that we can help with and then we back out again and I think that's what families often want from us as well (FG2: Palliative care providers).

The respiratory physicians noted that referral to a palliative care service provides a quick way of accessing services. However most groups noted that palliative care services are already overloaded and so increasing chronic disease referrals may not be able to be accommodated.

Do I overload palliative care with COPD patients? (Public hospital respiratory team)

4.3.1.3 Access to hospitals

The issue of access to hospitals was identified by a number of groups, particularly GPs, who noted that they frequently have trouble having a person admitted who they believe requires hospitalisation, particularly if exacerbations occur after hours. They also noted that this difficulty in finding a hospital bed often led to people being admitted to hospitals where their histories were unknown resulting in little continuity of care.

GPs also noted that people with COPD were much more likely to be admitted if they were referred by a respiratory specialist rather than a GP.

The respiratory physicians noted that there are few problems getting patients admitted if they have private health cover. A number of provider groups also noted that patients with COPD are much more likely to stay for longer periods in hospital than really required, because there are fewer care options for them on discharge. This lengthened stay contributes further to hospitals being reluctant to admit people with advanced COPD.

The respiratory nurses noted that a key issue was the lack of interface between acute care and chronic disease management and the need to integrate with primary care.

The consumer focus group expressed concern that there were not enough hospital beds in the north of Adelaide, particularly with proposed major new housing developments, and that proposed expansions of GP services (the GP Super Clinic at Munno Parra) will not be able to meet their needs.

GPs noted that a major problem is referring people with exacerbations to hospitals to be admitted through the emergency department where they may have to wait up to 12 hours. This is not appropriate, particularly as the stress of this exacerbates the COPD and there should be some streamlining of this process. This is the same with outpatient appointments, where patients have to arrive at 9 am and perhaps wait for three hours – this doesn't happen if they have private insurance where appointments are made later (as 9 am is very difficult for people with COPD) and people don't have to wait.

Some deteriorations you can see coming - it's more out of exhaustion - and carers as well (FG 3: GP).

4.3.1.4 Age related issues

Many of the participating groups identified being under 65 as a major problem in accessing care and services. DCSA noted that they can only provide services for people under 65 if they have a disability, or if they have been accepted as palliative care patients by the RDNS or a palliative care team.

I fall into a big black hole because I'm under 65 – there's a lot of services not available to me ... people my age aren't supposed to be this sick (Consumer support group participant).

GPs noted that it was very difficult to access care for people under 60 with any chronic disease, especially if they required institutionalised care.

That brings up a huge issue ... a couple of nursing homes that I go to have patients under 60 sitting with elderly demented people – it's a tragedy for those patients (FG 3: GP).

The palliative care service providers group expressed concern that the age limit for accessing care packages was being increased to 70 years of age. Care packages provide the ability to access a variety of different services, and by increasing the age limit, many people would be excluded from access to these.

Respiratory physicians noted that younger people with serious lung disease cannot access care and so they admit them to hospital through respiratory units, and then refer them to palliative care to access services.

4.3.1.5 Continuity of care / care co-ordination

The importance of continuity of care was emphasised by all service provider groups, with a particular emphasis on the need for better co-ordination between acute and primary care services. The public hospital respiratory group noted that one issue was the lack of a shared medical record, and that the proposed e-health record may address this. GPs noted that the difficulty in finding hospital beds for people with exacerbations means that often they are admitted to hospitals/units where there is little knowledge of their past history or treatments, and there is little communication with the GP on discharge. GPs also noted that discharge information from private hospitals is quite inadequate, and that a hospital based GP liaison officer makes a huge difference. GPs emphasised however, that the role of a case manager or care co-ordinator should be as a facilitator of services, not denying services.

Another issue identified by GPs was a lack of a plan for people with COPD to help them deal with an exacerbation and the importance of intervening early to prevent it becoming worse. It was felt that this should be developed by the specialists and hospitals and then an annual GP review could feed into this – greater co-ordination between services is required however to facilitate this.

The big issue I think is just chronic, recurrent crises of shortness of breath, usually on a weekend, usually after hours – whenever – and they just need to know how to handle it (FG 3: GP).

A number of services noted that, because of the variety of care providers that people with COPD often see (such as respiratory specialists, pulmonary rehabilitation, mental health service providers, occupational therapy, DCSA) there is often no-one who actually knows all of the services that the person is using, and a care co-ordinator would be invaluable.

If there were someone – and I particularly think of the Divisions [of General Practice] in that sense – that their job is to keep on top of all the services and be available (FG 3: GP).

RDNS noted that a care co-ordinator could provide advice on the type of care required in hospital and this would also be linked to advance care planning. The respiratory nurses emphasised the need for continuity and interchange of care.

The respiratory physicians suggested that the care co-ordinator did not need to be medical – rather they needed to be someone who understands and can access the health system and this may be a professional or a case manager or a family member.

4.3.1.6 ACATs / Working the system

All service providers identified the importance of access to Aged Care Assessment Team (ACAT) assessments. (An ACAT provides a free assessment service to older Australians with complex needs to work out their eligibility for the many aged care services available around the country. An assessment identifies which services a client is eligible for and the level of assistance required to manage daily living activities. Care is provided at a number of levels.) Without an assessment, access to many services is very restricted and so, as COPD progresses, an ACAT assessment is required to either provide services to support people at home, or to admit them to residential care.

To obtain an ACAT in the community, people must go on a waiting list. Previously, if a person was admitted to hospital, they could be assessed whilst an inpatient for their eligibility for a community package as well as other packages. Therefore, if the health service provider felt a person needed access to an ACAT quickly, they could be admitted to hospital and assessed. This has recently changed and ACATs for community packages can now only be undertaken at home. This means that people with COPD must now be added to significant waiting lists.

The availability of aged care packages varies between locations, which makes care planning and service access difficult for GPs who may work across different areas, and so are able to access care packages for some patients, and not for others, depending on their address.

Availability is certainly a barrier (FG 3: GP).

Respiratory physicians noted that it was often easier to get services in rural areas and that discharge co-ordinators were often very good at knowing how to access services, because the services change so frequently. They also noted that sometimes they would refer patients to palliative care services to allow access to specific services.

Referring patients to palliative care services was noted by a number of respiratory groups as a means of gaining services and supports which would not otherwise be available to patients with chronic disease, particularly access to RDNS and DCSA services. This was particularly so for people under 65 years. The palliative care providers stated however, that many services people believe are available through palliative care (such as social work or counselling) may not be available, and some palliative care services are extremely stretched.

A number of service provider groups noted that community packages could be particularly difficult to obtain for people with COPD as they often did not appear ill – for example, if they are sitting down and answering questions, they do not appear breathless. The RDNS noted that if people are not viewed in their own setting and the effort required to do the simplest things (e.g. go to the toilet) is missed (e.g. as hospital in-patients), the extent of the impact of COPD on activities of daily living (ADLs) is not identified. An in-home assessment from an occupational therapist can therefore make a huge difference.

...they don't look sick (FG 4: Respiratory physician).

Often it comes down to the referrer and them knowing how to spin a story to get them in here. Because if you can say that there's lots of needs the people will probably get a priority one. [Note: Under the Aged Care Assessment protocol (used in an ACAT), a Priority One rating is a person who requires a response within 48 hours]. But if you ring up and say they need showering, they may not get in. But they may need a whole lot of other services that the referrer isn't au fait with, like a home safety assessment, physio, home mods [modifications], equipment, showering, cleaning. If you can give a complex list of needs, then they'll get in as a priority one, and they're seen within a fairly short time. it does depend on how you put your story across. I referred a friend who had really bad COPD. I visited him and I said you need help. He was really, really struggling. So I put in the referral and they rang him. When I checked he'd been given a really low priority... I rang and talked to the girl and she said well, I asked him can he do his shopping and he said yes he could. I said, yes, but did he tell you that he can only go shopping on days when he can breathe, when he's well enough to actually get in the car and go to the shops - and that's not every day, it's every now and then. When he gets home he's totally exhausted (DCSA interview).

Some people with COPD do not wish to have access to community packages. They do not believe that their illness warrants it, and don't understand that whilst they may not require the services at that particular time, their condition can deteriorate fairly rapidly and they will then have to wait a significant period of time for services when they really need them.

It was noted that people who could nominate a specific carer were eligible for extra hours of home support, so the nomination of a neighbour or friend as a carer (even if they were not actually the person's carer) was encouraged to enable access to this extra care.

4.3.1.7 The importance of community services

A number of specific community services were identified as vital for supporting people with COPD: DCSA and outreach services.

Services are out there, but you have to find them out for yourself (Consumer support group participant).

A number of the participating groups identified the need for support for activities of daily living (ADLs) as a major need for people with COPD. Because breathlessness impacts on people's ability to move around, the simplest tasks such as showering or preparing food, can become extremely difficult. Services such as DCSA are able to provide up to five hours per week in home support, equipment and assessments and supports by occupational therapists and physiotherapists where required. Because of the huge demand for these services however, they are quite restricted and there are long waiting lists for equipment at the moment.

Five hours per week. That's the maximum, but the average for people getting personal support services is two - just over two hours a week. That two to three hours might involve a couple of showers, maybe some domestic assistance once a fortnight or once a month and a component of equipment. All of this is done as the result of assessment (DCSA interview).

The palliative care providers noted that people with COPD most often do not need skilled nursing support, as their needs are relatively simple to manage as they are focussed around ADLs. However, they also noted that they do need review regularly by a health professional who understands COPD.

The roles of RDNS and DCSA are sometimes perceived to overlap, however DCSA has a major role in supporting ADLs. This is a problem for people under 65 who have not been referred to or accepted by a palliative care service or who do not have a disability, as they cannot access this care. The RDNS noted that if the COPD is fluctuating, DCSA services might better meet the person's needs – there needs to be flexibility – i.e. the right service at the right time in the right place.

Outreach services were also identified as potentially playing a very important role in supporting people with COPD. The public respiratory team noted that outreach nurses can play a key role, and the private physicians noted that outreach nurses are 'universally positive'.

The respiratory clinic nurses are great. I've found them really, really helpful, but they are located in the hospital (DCSA interview).

I think it would be helpful if there were more outreach nurses from the hospital that could actually visit people in their homes and assist with their oxygen management (DCSA interview).

Respiratory nurses noted that outreach services could provide the care that would allow people with COPD to die at home (currently they do not feel safe there). They also noted that outreach services could greatly assist the development of integrated services between acute and primary health care, which are vital in supporting people with COPD.

DCSA and respiratory physicians noted that outreach nurses were particularly important for people using oxygen.

4.3.2 The impacts of the trajectory of the illness

Almost all participants recognized that the trajectory of COPD, with its acute exacerbations and long periods of relative maintenance and the length of time that people may be seriously ill, has a major impact on the services that people require as the disease progresses, how services can be planned and provided, access to services and how this impacts on the carers and family.

Palliative care providers noted that this issue of the unclear trajectory of COPD, with exacerbations requiring support from RDNS and DCSA and subsequent improvement therefore no longer requiring these supports, has meant that it is very difficult to support people with COPD because of the system requirements in admitting people to specific services. The other major complicating factor for palliative care services is that end stage COPD can go on for a long period of time (even years) and it is very difficult for palliative care services to keep people on their books for prolonged periods (the normal period is 12 months or less). This was a similar issue for the RDNS – i.e. funding structures currently do not support this prolonged period of need.

GPs noted that their current remuneration system also made caring for people with advanced COPD difficult because of the time required to co-ordinate care and address the wide variety of problems and co-morbidities that people with COPD often have.

The last 5% of your income takes up 95% of your stress (FG 3: GPs).

Respiratory nurses noted that the trajectory of the illness and the fact it can go on for so long means that it is very important that there is a continuum of care between acute and primary care and a language needs to be developed to allow integration of these services.

4.3.2.1 Activities of daily living (ADLs)

ADLs are particularly impacted by breathlessness, which make even the simplest tasks almost impossible for some people. The consumer group noted that it is often a lack of ability to access assistance at home that means people with COPD have to be admitted to hospital.

Certainly some of the services are not there for these people when they are becoming unwell, when they need a little bit more help and support and that might actually make them go on and not have that episode (FG 3: GPs).

People with COPD who are regularly readmitted to hospital were referred to by a number of groups (including the consumer group) as being '*frequent flyers*' and all felt that this could be avoided with more community supports.

The RDNS identified supporting ADLs as a '*huge issue*' and the palliative care providers noted that changing the access criteria to need rather than age would solve 80% of problems particularly around ADLs, respite and issues such as cleaning and gardening.

4.3.2.2 Financial implications

The financial impact of COPD on both patients and their families was mentioned by most groups. Because the trajectory of COPD is so long, breathlessness has such a major impact on people's ability to function and patients require carers, both the person with COPD and their carer have to give up paid employment. If they are under 60, this may have significant impact on their superannuation, and the financial support they are able to receive.

The palliative care service providers and the RDNS noted that financial issues are major for people with COPD, because in many instances they are relatively young and have had to retire early due to illness. Many people with COPD are on pensions (either Aged or Disability) and they have to spend their pension on their medical needs and so are often in public housing and their carers (often spouses) have had to leave paid employment to care for them. They therefore may not be able to afford their medication and equipment and oxygen (with associated electricity use/nebulisers/medications) can be a particular problem. It is important to ensure they are covered by the Medicare Safety Net, are aware of oxygen subsidies and are aware of groups such as Breathing Space which support disadvantaged groups and provide a wide range of services. (Note: The Medicare Safety Net provides families and individuals with financial assistance for high out-of-pocket costs for out-of-hospital Medicare Benefits Schedule (MBS) services. See <http://www.medicareaustralia.gov.au/public/services/msn/index.jsp#N1003C>)

Most people with COPD cannot afford private health insurance and this impacts on their ability to access specialists, respite care, private hospital care and home help. They may also not be able to access mental health support in a timely manner. People with private health insurance can be admitted to hospital for respite, do not have to wait in emergency departments and will often be able to see their specialist more quickly than their GP.

4.3.2.3 Advance care directives

All participating groups were asked about advance care planning and advance care directives. There was general agreement that planning would be very useful, but it was not often done, and there was

disagreement about who should be responsible for beginning conversations about end of life care and who should be responsible for talking to people about signing advance care directives.

Respiratory physicians noted that they had no problems starting a discussion about end of life care, however one felt that it was often not appropriate for them to initiate such discussions – it really should be the GP who can discuss it with the whole family. Respiratory physicians suggested that they divided advance care directives into two separate categories: a general directive encompassing broad discussions about care and a ‘respiratory’ directive which is specifically related to a ‘Do Not Resuscitate’ (DNR) order (although no formal ‘respiratory’ advance care directive actually exists). Another noted that they will only make VERY explicit DNR orders in the notes, but will not do the advance care directive paperwork – they are happy to have the discussion, but recommend people do the actual paperwork at home.

I think it's also a difference between a general advance directive and a sort of respiratory one... I ask if they might have thought about what would happen if their lungs got worse and they needed to breathe with a machine and they've said that's not a good idea, but they've still wanted everything else done after that (FG4: Respiratory physician).

A number of participants noted that some people with COPD felt that they were not ready to discuss the issues associated with developing an advance care directive if they were raised, or were resistant to the idea.

With this disease, unless you actually stay positive – I'm thinking will I be here next week – let me be here in the next minute – so it's very hard to associate what sort of plan I should make.

I'm not aware of it – no (Consumer support group participant).

GPs generally felt that it was not difficult to introduce the issue of advance care directives, but they often did not have enough time to, and so would ask the outreach nurse to do this. Respiratory nurses thought that people with COPD and their carers need to plan for end of life care and this rarely happens and that it should be part of the continuum of care. They also noted that people often do not know their options.

The GPs and DCSA participants noted that advance care directives needed to be signed by JPs and so people do not bother, as this can be difficult to do. It was also noted that there was no common wording across available advance care planning documents.

Respiratory physicians mentioned that some people were happy to have the discussion but did not want to sign anything. Most people in the consumer group had not heard of advance care directives but reported interest in them. However one woman reported being asked about a DNR order when she was having a major acute exacerbation. She felt that was very wrong, as she felt so bad she did not want to live, but when she had recovered she felt much better and was very concerned that she

had signed a DNR order and so next time she would not be resuscitated. (Note: This person was reassured that the DNR order would not be considered valid in any subsequent re-admission).

Palliative care providers noted that language was an important issue in this area and using the words 'end stage COPD' and 'palliative' may not be understood. It was also suggested that people still want 'hope' and may not want to hear they could be dying.

Other members of the consumer group were concerned that even if they signed an advance care directive, the hospital may not know this, and respiratory physicians and GPs also expressed similar concerns. Patients being resuscitated by ambulance services when they are called to an acute exacerbation was also discussed, and a new 000 paramedic service was noted. An OACIS flag (*The South Australian Hospital Database system*) was suggested as one option for flagging that people have developed an advance care directive.

A number of service providers raised the issue of ethnicity when thinking about discussing advance care directives which are often not appropriate for some families of certain ethnic origins.

4.3.2.4 Invisibility of the disease/blame issues

A number of focus groups, and the consumer group noted that there was often a highly judgemental attitude towards people with COPD, assuming it is caused by smoking and is therefore a person's own fault.

It's caused by smoking so it's the person's own fault (FG5: RDNS).

Respiratory nurses noted that people with COPD are '*invisible*' – COPD is not '*sexy – like diabetes or cardiac failure*'.

The consumer group noted that people thought the disease was self-inflicted, and so had little sympathy for and did not recognize the impact on individuals and families.

There's a general consensus from people that you see in the street – oh well you've got this disease and it's self-inflicted so it's your problem – where it's not – that's just an ignorance on their behalf where they don't understand the disease. So my main thing is ...everyone has a different level of suffering with it and no-one can really understand how they feel (Consumer support group participant).

4.3.3 The role of carers

4.3.3.1 Lack of recognition

The importance of the role of carers was raised by almost all groups, as well as the recognition that this importance was rarely acknowledged and that there are few services available to support carers.

The palliative care providers group in particular expressed significant concerns for carers, noting that people with COPD are a lot sicker for longer: whereas cancer patients are often sicker for shorter

periods. Services for people with COPD are required for a longer period of time and people with COPD in the community will often expect their family to look after them. Families are often willing to pull out 'all stops' to help someone dying from cancer for a short period, but are not prepared for the financial burden (unemployment, taking time off work), the ongoing care needs of someone who needs hygiene and food shopping support, and the time required over very long periods to care for someone with COPD. Significant burn out often results. People can do it for a short period but the long term is much harder.

Respiratory nurses noted that carers are '*enormously forgotten*' and that palliative care services will follow up and support carers, however respiratory services do not.

The RDNS and respiratory specialists noted that often there was strong family and community support for carers in ethnic communities such as the Italian and Greek communities in SA.

The consumer group noted that the disease completely changes both your own life and the life of your spouse and family, which becomes focussed around the illness. If a carer becomes ill, it causes major problems and people can also become very isolated in trying to reduce the risk of catching infectious respiratory diseases – for example, any family with colds are asked not to visit.

Carers SA noted that there was no real way into services for people with chronic illness and their carers if they do not fall into either the over 65 age group or have a disability. There is a huge gap for carers in the middle aged group and there is little equity in access to services.

Carers SA noted that the medical profession '*was not good at supporting carers*' and there is often no sense that carers are part of the care. Carers SA also emphasised that, particularly in older people, the carer themselves may have multiple medical issues which are put on the backburner to care for their partner who is perceived to be 'sicker'. They also noted that there is an issue around carers often not recognising that they are actually 'carers' and so not realising they are eligible for supports and services.

The consumer support group felt that there were enough supports for carers, however the issue was accessing them and people knowing they were available. They nominated a website for their local area as being very useful.

4.3.3.2 Respite care

The specific issue of respite care for carers was raised by a number of groups. The RDNS noted the importance of carers having access to respite care, but noted that this could be very difficult to find, especially as a number of day respite care services had recently been closed down.

Carers SA noted that they provide short term respite care and a number of other services. However there is an issue about making people aware of these services – there seems to be no easy way of connecting and referring carers to these services.

It was noted that there is a lack of recognition by health services and medical professionals of the need to refer carers to carer support services – many may be willing to hand out brochures, but may not be willing to make specific referrals to carer support services. This means many people miss out. If someone is referred using an electronic referral process, they can get into the system at the beginning and so have many things explained which could prevent many problems. Another systematic way of referring people could be on a proposed new chronic disease needs assessment form.

The family issues are huge.

They expect their families to look after them ...they have refused RDNS and other services like Meals on Wheels and then they reach a crisis point and they ring up and say we want hospice care...such a long disease ... but the expectation on families is just so much and families burn out (FG 2: Palliative care service provider).

It should be noted that a considerable number of people with COPD do not have carers, and this poses significant issues for them with ADLs and often results in increased hospitalisations to help them cope and to provide some respite for them.

I'm very isolated at home with no carer...I spend far too much time in hospital (Consumer group participant).

4.3.4 The importance of communication

4.3.4.1 Communication between health service providers and people with COPD

The consumer group was very critical of the communication between health service providers and people with COPD, noting that they did not explain enough about the disease and what it would mean to people. This often led to acute anxiety and the development of depression. They also felt GPs did not have enough information about the disease and that in general, service providers did not tell them about the services that were available for them, and where they could go for help.

Carers SA also reported that medical professionals rarely referred carers to their services and did not tell them about what was available.

Some consumers also reported significant issues around discussions regarding end of life issues and DNR orders, and also a lack of information (particularly who to talk to) around lung transplantation issues.

Doctors need to learn when they diagnose people with it, just don't tell them they've got it like they've got toothache and send them out the door...

It's my tenth year of emphysema and the biggest problem has been communication with providers (Consumer support group participant).

4.3.4.2 Communication between health services

A number of participants noted that a lack of communication between different service providers, and primary and acute care is a major issue to be addressed for ensuring co-ordination and continuity of care for people with COPD. GPs noted that discharge information in particular is an issue, particularly from private hospitals, although public hospitals have improved in this area. RDNS and DCSA also noted issues with communication with health service providers and discharge information.

I can understand that those doctors are very busy but when they're wanting us to be involved in care that's not usual care, I think that communication ... and if they can't provide a letter then I think they need to provide a phone call, and it does need to be medical to medical (FG 3: GPs).

A number of participants noted that an electronic shared record (or access to medical records on the computerised patient management systems used widely in general practice) would streamline care and allow services to see where patients are in their illness and what care they have received.

It was also noted that each service has different enrolment criteria and so every time a person with COPD enters a new service they are required to complete new paperwork, much of which is the same as they have already done, but as it is not shared they are forced to repeat themselves.

4.3.5 Other

4.3.5.1 Oxygen

The issue of access to, and living with, oxygen was raised by almost all participating groups. Not all people with COPD are eligible for oxygen, and it is easier to obtain through some services, which leads to inequities in access.

Using oxygen concentrators instead of cylinders was also raised, but it was noted that concentrators only suit certain people (for example, people with walking frames cannot use them).

It was also noted that concerns around oxygen are a major factor in isolating people with COPD at home. They worry about their cylinder running out if they have to travel distances and/or wait to be seen by medical services, and transporting oxygen cylinders can be problematic (they are heavy and cumbersome). The cost of oxygen (and associated costs) is also a major issue for some people. Outreach services from hospitals were felt to be a very important component of care for people on oxygen, particularly around education and maintenance.

4.3.5.2 Mental health

The importance of recognising and treating mental health issues for people with COPD (and their carers) was highlighted by a number of groups. The consumer group identified anxiety and

depression as major issues, particularly for newly diagnosed members. They felt this was closely associated with a lack of knowledge and understanding of the disease.

The public hospital respiratory group noted that anxiety and depression are big issues in COPD and are often actually the main reason for hospital re-admissions. They further noted that access to psychological support services in the community is very difficult and further research is required on the best way to manage these issues.

A number of groups noted that isolation was a problem that then could lead to mental health issues such as anxiety. If people cannot get access to someone to check if things are going badly, panic and anxiety can result.

The RDNS noted that a person receiving palliative care will have a mental health review, but often a standard depression screen is not undertaken more generally on people with COPD.

The impact of breathlessness on the mental health of both people with COPD and their carers was emphasised, as it leads to significant anxiety, particularly when it happens on such a regular basis.

4.3.5.3 Spiritual and emotional well-being

The consumer group raised the issue of independence on a number of occasions, noting that the disease had completely changed their lives and that of their families, because they were now so dependent on assistance. One woman noted that this was particularly difficult for women, who were used to organising their own home, playing with their grandchildren etc, and they could no longer do this, whilst men noted they could no longer work, play golf etc.

It's a pain in the butt and it's very scary and debilitating (Consumer support group participants).

It's a horrible disease but we find time to smile in between (Consumer support group participants).

The consumer group noted that one of their key roles was to support members with information and advice on how to manage the disease. In particular they felt that depression and anxiety were often a result of lack of information and support from health providers, particularly doctors, who they felt should be better informed.

The respiratory physicians and hospital respiratory team emphasised the importance of a spiritual mentor to support overall care and spiritual needs – again not necessarily a professional, but someone who goes beyond medical care. They also noted the importance of peer support groups. It was also noted that spiritual needs are often addressed outside the health system.

4.3.5.4 IT potential

Although not all groups mentioned information technology, its potential to support both people with COPD (and their carers) and health care professionals is very important, and so it has been included as a minor theme.

Respiratory physicians noted that a significant number of their patients use computers, particularly if they were previously business people. They suggested that online support groups may be useful. They further noted that IT options such as videophones could be very useful for communication with GPs or in rural areas.

The consumer group reported accessing information, for example, regarding support for carers through the Northern Carers' website.

The respiratory physicians and consumer group suggested that more use could be made of new technologies such as Skype and videophones to support both patients at home, and GPs and other health service providers who may require advice and support from specialist services.

4.3.6 Participants' suggestions for improvement

A recurring suggestion from almost all groups was access for people with COPD to regular review (which could be an annual GP review feeding into a specialist review). A number of participants also noted the role that a care co-coordinator could play in ensuring regular review, and also in ensuring that all service providers were aware of treatment and services in place. A care co-coordinator could also organise required services.

Access to medical care and hospital admission on an acute basis was noted as important, however it was also suggested that a system be developed that allowed people to come into hospital, get treatment and then be discharged very quickly if they only require antibiotics, nursing care, steroid medication or oxygen for three to four days. This is closely linked to the suggestion of developing an appropriate service delivery model to ensure people with COPD exacerbations are seen and treated quickly in emergency departments. 'Hospital in the Home' was mentioned by a number of groups as being a very useful concept for caring for people with COPD, particularly for less acute exacerbations.

Another recurring theme was the need to implement a chronic disease management model across acute and primary care for people with COPD. This would allow integration and co-ordination of care, and sharing of patient information, as well as a palliative approach as the disease progresses.

Increased access to allied health services (including physical therapy) and mental health services was noted to be very important. A number of participants also noted the importance of the presence of a

spiritual and/or social mentor to assist with navigating the system and supporting the mental health of people with COPD and their carers.

4.4 Discussion

COPD is a major and growing health issue in Australia and one which will increase the pressure on a wide range of health services in the coming years (35). This review of acute and community services indicates that health services are not currently meeting the needs of people with advanced COPD who may be approaching the end of their lives, and this situation is likely to become worse as more people are expected to be diagnosed with COPD in the coming decade. It is clear that palliative care services, as they are currently structured, cannot address the needs of people with advanced COPD and primary care and general practice also do not have the resources or structures to properly support them. There is inadequate communication between the acute and community sector and there are not enough services available in any sector for this growing group of people with COPD.

The trajectory of COPD, with its long periods of relative stability interspersed with serious exacerbations (often requiring hospitalisation and ventilation), means services need to be provided in a flexible manner (24, 25). Some level of service provision is required by many people with COPD (particularly if they have no carer) because of their significant breathlessness and associated inability to maintain their ADLs without assistance (21). If this is linked to regular review of the COPD, and a plan for early intervention in exacerbations, it is likely that many hospitalisations can be prevented. However, if deteriorations occur, with associated increased service needs, it should be possible to temporarily increase the number and/or intensity of services until the crisis has passed. It was often reiterated by service providers that, because no-one could predict the trajectory of COPD in any individual, it was difficult to plan or provide services, particularly palliative care services. This points to the need to provide services based on need or symptoms rather than stage of the disease (60).

4.4.1 Chronic disease management / co-ordination of care / care co-ordinators / integration of care

A key message arising from the interviews with the range of health service providers was the need to systematically implement a chronic disease management (CDM) process to ensure optimal care for people with advanced COPD.

The need for clinical information systems that can be shared between health service providers was a specific aspect noted in this study. GPs reported that they would be able to manage the care of people with COPD, however this would require significant system re-organisation and a much higher level of care co-ordination and communication. The concept of a care co-ordinator was raised by a number of project participants. Such a position could address a number of other issues raised by

participants such as GP or acute care liaison (particularly if a person requires emergency department treatment), organising ongoing services and community supports, and early intervention to prevent acute exacerbations.

4.4.2 A palliative approach

Almost all participants recognized the importance of the support that palliative care services can provide for people with COPD. However it was also recognized that, for many people with advanced COPD, referral to a palliative care service may not be the most appropriate option. Palliative care providers noted that many people with COPD needed to ‘dip in and out’ of palliative care services – during acute exacerbations palliative care can provide effective symptom management and supports for ADLs, as well as carer support, and can then withdraw services as they are no longer needed. Respiratory nurses noted the importance of maintaining access to respiratory disease expertise to help manage advanced COPD. They also noted that respiratory services had often been looking after people for a long period of time and were very familiar with their history and family situation, and it was difficult to hand this over to palliative care services.

Respiratory specialists and the respiratory care team noted that what is required is a palliative approach (see Section 1.1). Such an approach, combined with a chronic disease management model across the acute and primary care sectors would mean a much more co-ordinated and integrated approach to care for people with COPD.

4.4.3 Mental and spiritual care

There is an urgent need to recognize the importance of addressing mental health issues (particularly depression and anxiety) in the provision of services for people with advanced COPD. The ongoing anxiety that breathlessness causes for both people with COPD and their families was reported in this study, supporting the findings of Gardiner et al’s 2009 study, where participants reported an overriding fear of dying from breathlessness (22). Gardiner et al go on to report that fear and anxiety make breathlessness worse, so a vicious cycle can result (22), and again, this was reported by GPs in this study. It was further noted that there are a variety of interventions which may significantly improve dyspnoea including oxygen and pharmaceuticals, however relieving fear and anxiety can also significantly improve this symptom (22). The respiratory team interviewed in this study also noted that they felt that many hospitalisations for COPD were associated with mental health issues, rather than exacerbations of COPD. Whilst most services noted the importance of recognising and addressing mental health issues, none reported a process for systematic screening and /or early intervention for mental health problems.

Closely associated with mental health issues, spiritual issues were also mentioned by a number of participants, with the suggestion that a spiritual mentor for people with COPD was important. The

consumer group emphasised the impact of the loss of personal independence on both individuals and their families, and how difficult this is to cope with. The respiratory nurses and palliative care respondents noted the grief issues arising from the variety of losses experienced by people with COPD, and also the importance of having psychological support to cope with recognising approaching death. Again, there are no services or systematic review available for most people with COPD in these areas.

4.4.4 Advance care directives

Two key findings regarding advance care directives arose from this study, many of which were also noted by Gott el (2009) in their UK study on barriers to advance care directives in COPD (20):

1. There is confusion regarding who should initiate the discussions around advance care directives and so often no discussions are held.
2. Whilst all participants believed advance care directives were important and useful, there were a number of caveats around their use, including:
 - a. There is confusion around the issue of DNR orders and advance care directives which needs clarification.
 - b. Some people just weren't ready for the discussion and/or did not want to have the discussion.
 - c. Whilst some people are happy to discuss the issues around end of life and advance care directives, they do not want to actually sign anything.
 - d. There are still concerns about non-recognition that an advance care directive has been signed – for example, the ambulance service or emergency department may not be aware of the ACD.
 - e. Both health professionals and consumers talked about the importance of hope, with the inference that discussing advance care directives was an indication of the loss of hope.

Discussions regarding advance care planning and advance care directives are a responsibility of both specialists and GPs. It was agreed that the earlier these discussions can be held, the greater the understanding of the disease process and, with ongoing review, a realistic approach to crisis intervention can be developed and agreed. The directives can be changed at any time should the person so desire: it is the discussion that the topic prompts that creates better communication and understanding between the person with COPD, their family and health care professionals. Communication was one of the areas identified as a large gap in the model of care for people with COPD and their families.

4.4.5 Carers

Carers are a vital part of the care provided to people with COPD, but there appears to be little recognition of their importance by the majority of health service providers. Carers themselves often do not recognize their caring role, and they are rarely referred to carer support services. It was noted by respondents that often hospitalisations are a result of both the carer and person with COPD needing respite. The long trajectory of COPD and the associated physical and emotional burden means that ongoing access to respite support is imperative for carers to 'recharge' and continue through what can be a very long process.

Closely associated with this are the financial issues associated with COPD, with the person with COPD and their carer no longer being able to work, often leading to a dependence on government assistance and an inability to access extra services which require payment. This project identified the advantages of having private health insurance, including more timely access to specialist respiratory physicians, access to private hospitals for admission and respite, and an ability to purchase extra support for ADLs.

4.5 Conclusion

The current level of services and supports available to people living with COPD is not commensurate with the impact of the illness. The impact of COPD on individuals and families is major, and it affects all aspects of life, including financial, emotional, mental and physical. Because the trajectory of the illness means that it can continue for many years, and the nature of the illness means that ADLs are significantly impacted, making services such as palliative care and home support conditional on prognosis rather than symptoms means that COPD sufferers are considerably disadvantaged.

The research undertaken through this project has demonstrated that there are practical and effective strategies which could significantly improve the quality of life of both people with COPD and their families. Such strategies could reduce the cost of COPD to the community through early interventions and reduced hospitalisations and limit the burden of care for individual health service providers through greater integration and co-ordination of care.

5. Discussion

The overriding message from this research was that current health care systems do not meet the needs of patients with COPD and their carers.

This research was carried out as three separate studies providing a comprehensive insight into the end of life experiences of people with COPD, and the views and experiences of their carers and the health professionals who provide care. The findings of this study reflected international evidence in the recent literature (21, 25, 56). Although there remains a dearth of literature in the Australian context, this study begins to fill this gap. COPD guidelines and health professional education fail to emphasise the vulnerability of people with advanced COPD, the many losses including changes in role, the social isolation and the impact on relationships experienced by patients with this chronic illness, and the need for sensitivity and compassion in their care. Although the health professionals who care for people with advanced COPD recognize the very specific care needs of this population, accessing and providing the care required is often hampered by a lack of available and responsive services, cumbersome and inflexible access rules, difficulties in communication between health service providers and a system centred around the needs of the system rather than the patient. Social withdrawal and isolation for these people and their carers is often very well developed by the time the person with COPD is at the end of their life, meaning that there may be very few social supports when the person is dying.

5.1 COPD and the current health care system

Overall, the research highlighted that the impact of COPD, the lived experience, is underestimated. Our findings emphasized the symptom burden and day-to-day struggle for people with COPD and their carers. Personal care, cooking, cleaning, shopping and transport were significant challenges, particularly for those people who lived alone. Indeed support for activities of daily living (ADLs) was their greatest need, even ahead of services like medication supervision.

The current health system was seen to raise many barriers to accessing necessary services to support living at home with COPD including age criteria, limited resources that generated waiting lists, as well as patients not meeting the restrictive criteria required by specific organisations, for example, level of disability may preclude even an assessment. Assessment tools failed to recognize some of the specific difficulties generated by COPD and there appeared to be little place for skilled observation by professionals. Although many service providers recognized and were frustrated by these deficits,

there was inertia around tackling these issues. Accessing services for these people was seen as too difficult because of these restrictive criteria, waiting lists and age barriers.

Emotional support was also identified as important. The key components of a palliative approach, which address emotional, psychological and spiritual issues, were only apparent when a specialist palliative care service was involved. In the absence of a patient-centred approach, patients perceived strictly medical care as not meeting their needs, for example, GPs were perceived as simply providing prescriptions for medication. Creating the time to deal with emotional issues was also difficult because of inflexibility within the system and simply a lack of resources. Overall, professional psychological and emotional assessment and support was very limited, as was attention to spiritual issues. Bereavement support was lacking for people outside the specialist palliative care system.

There was very limited capacity for monitoring and assessment to occur at home for people with COPD and there was no one person responsible for the provision of follow-up and support. The role of the interviewer in Study One was seen by many of the participants as filling this gap. Attending medical appointments was also difficult for a range of reasons including the timing of appointments in the morning, access to appropriate transport and fears of running out of oxygen. Triggers for an increase in service provision at home often only occurred in response to a crisis hospital admission.

There was limited planning for future crises so care remained episodic and reactive. For many participants and carers, the overall experience of the health system was one of fragmentation and abandonment. For those in this study living in a rural area, where service provision was largely through one organisation, continuity of care was less disrupted in contrast to the metropolitan experience, although absence of any GP home visiting was problematic.

The social stigma of COPD, potentially being seen as a self-inflicted disease caused by smoking, was another burden for participants, both in their social and professional interactions. Participants, with a few exceptions, were strong advocates for their family and other members of the community to stop smoking. This view is reflected by the current National Preventative Health Strategy (86) which will focus on a major reduction in smoking in Australia over the next 10 years.

The use of oxygen was seen as a two-edged sword – the physical burden of moving around or travelling with oxygen and the time limitations on portable oxygen supplies contributed to social isolation in this group. Difficulties with oxygen equipment and the resulting panic, as well as the rapidity of onset of exacerbations or infections, were arguments in favour of 24 hour access to support for people with COPD.

Pulmonary rehabilitation has become increasingly available in South Australia within the last two years, but despite significant evidence of its benefit, ongoing funding is not secure. Most participants

in our research found difficulty accessing rehabilitation because of timing and health issues. Those who did attend commented it would have been helpful earlier in the course of their illness.

5.2 Role of prognosis in access to community services

The three studies in this project were unanimous in identifying that the concept of 'end stage' in COPD was not useful for patients or health professionals, as there was no clear point of transition to end of life within the framework of advanced or severe COPD. Whilst the NHMRC discussion paper, *Ethical issues involved in the transitions to palliation and end of life care for people with chronic conditions* has suggested that there is a clear time of transition between chronic illness and the approach of end of life (89), our study determined that it was not possible to reliably recognize the terminal phase of COPD with any degree of accuracy. It was considered that there was a need to change the focus from trying to assess approaching end of life and determining timing of referral to palliative care, to considering patient needs as the primary determinant of service provision. This absence of a clear transition can lead to what Pinnock et al (25) call 'prognostic paralysis'. Health care delivery should be flexible and symptom driven (58). Prognosis or stage of disease should not be the driver for access to services. The current health system in South Australia does not allow this flexibility. In focus groups, health professionals described the ways in which they have to 'manipulate' the system to access even the most basic care. Palliative care programs are often more flexible and timely but do not offer longer term solutions. This causes uncertainty for respiratory professionals about when to refer for palliative care.

5.3 The role of carers

The very important role of informal care givers and the lack of available support was a recurrent theme in all three studies. A lack of access to respite care was a major issue raised by people with COPD and their carers as well as health professionals and by Carers SA. The long trajectory of COPD, with distressing symptoms such as dyspnoea, use of oxygen and often frequent hospitalisations, places great strain on carers and a lack of respite services means that this is a constant stressor. In many instances, carers are older people and may have a chronic disease or medical co-morbidities themselves, but have little time to care for their own health whilst caring for their partner or family member.

Financial hardship was another major issue. Because of the long trajectory of the illness, many carers were required to leave paid work, and as the person with COPD was also unemployed, the financial burden on these families was reported to grow steadily. This impacted in many ways – worries about paying bills (particularly electricity accounts because oxygen concentrators require power), access to

transport, limited ability to access health services requiring co-payments or private insurance necessitating long periods on waiting lists, and an inability to access extra support for ADLs.

Whilst palliative care services recognize the important role of carers and integrate them into palliative care provision, this does not generally happen for people with COPD, leaving carers unsure of the progress of the disease and what is required of them. They are also very aware of the delicacy of maintaining the balance between providing necessary support and maintaining independence. Any new model of care must recognize and support the key role that carers play in supporting people with advanced COPD.

5.4 Current role of specialist palliative care services

The health professional interviews indicated that timing of referral to a specialist palliative care service was problematic. Although specialist palliative care services do not have restrictive time lines for referral, there is a tacit assumption that end of life or end stage has been identified. This research revealed that referral to a specialist palliative care service, while providing immediate access to services and co-ordinated community support as well as emotional and spiritual support that were otherwise unavailable, was not necessarily appropriate in this illness where the disease trajectory is quite variable and transition into end stage is by no means clear.

It was apparent that referral to specialist palliative care services at times was only for access to those special programmes available from community agencies providing ADL support, for 'palliative care clients'. Specialist palliative care services are being used to 'unlock' access to these services. This is not an effective use of specialist palliative care and highlights an unmet need. Indeed, if people with COPD are currently accepted for community services and then improve temporarily with cessation of home supports, there appear to be difficulties in re-referring for ADL support. There was clear evidence of this in Study Three.

5.5 A model of care

Although COPD is regarded as a major chronic disease in Australia, a chronic disease management approach has not been systematically implemented in caring for people with COPD in South Australia. COPD has largely been managed in the acute hospital setting for exacerbations of the disease or for infections, with support from respiratory specialists or general physicians, and referral back to GPs. There has been little or no co-ordinated community support for people with COPD living at home. A chronic disease management approach would be appropriate in this population as they largely see themselves as 'living with COPD'. Pinnock et al (25) report that people in their study perceived COPD as a 'way of life' whilst Habraken et al (78) (p844) noted that 'patients with end

stage COPD do not actively express a wish for help because they do not consider their limitations to be abnormal and because they do not realise that there are possibilities to improve their situation’.

This research demonstrated that current health care systems in South Australia are inadequate for people with advanced disease, or who are approaching the end of their life. This is also reflected in recent Australian policy, including the NHHRC Report (76) and the National Primary Health Care Strategy (23). There is growing recognition of the importance of a palliative care approach for people with advanced chronic disease (16, 89, 91). Palliative Care Australia, the peak body for palliative care in Australia, has provided a blueprint for a health system change in this area (10).

In Australia there is growing recognition that patient-centred care is the appropriate base on which to build new models of care (88). The ACQSHC note that ‘Patient-centred care is health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers’ (88) (p7). Recommendation 1 in their recent *Discussion Paper on Patient-Centred Care* states that, ‘Policy makers and regulators should include patient-centred care as a dimension of quality in its own right in strategic and other policy documentation’ (88)(p8). If care for people with advanced COPD was patient-centred and based on need, many of the issues identified in the three studies undertaken in this project would be addressed.

A key strategy in the implementation of patient-centred care as part of chronic disease management is the role of a care co-ordinator. Each of the separate studies in this project determined the need for a co-ordinator of care for people with advanced COPD. Needs will clearly change and fluctuate along the illness trajectory. It is important to build a model of timely and accurate assessment which anticipates, navigates and co-ordinates care. This model must be continuous, pro-active rather than episodic, taking into account the changing needs of people with COPD. A professional co-ordinator who can work across hospital and community settings could provide this overarching approach and would facilitate the important issue of communication between patient and health professionals, and between health professionals in different disciplines and settings. Good communication will reduce fragmentation.

The care co-ordination role would be charged with supporting as much independence as possible, through education and assistance with problem solving and navigating the health system, but would have the skills and capacity to intervene with specific assistance when needed. A COPD care co-ordinator would combine the palliative approach, with those skills specific to COPD, for example, pulmonary rehabilitation, oxygen therapy, and access to home help. Because the majority of care for people with advanced COPD occurs in the community the focus of care co-ordination could be from outside the acute hospital sector. Health professionals in this research project agreed that co-

ordinated management might also contribute to the avoidance of unplanned and unnecessary presentations to emergency departments and admissions to hospital.

With the increasing recognition that people with advanced COPD require symptom management concurrently with interventional treatment, and that prognosis and age are not appropriate criteria for access to services, a model of care that places patient need at the centre of care is required. Recent international evidence reflects clearly the need for respiratory, palliative and primary care services to work together to provide co-ordinated and integrated care for people with advanced COPD (24, 25, 97).

5.6 Health literacy

People with COPD and their families and carers have changing and increasing needs as COPD progresses and understanding these changes and accessing support require a significant level of health literacy. In caring for people with COPD, interventions to increase the level of health literacy at an early stage of the disease should be a priority. Roberts et al (74) demonstrated the importance of health literacy for people with COPD in understanding their treatment, being able to recognize the onset of exacerbations and in understanding the course of the disease. In our studies, it was clear that people with advanced COPD and their carers often had little understanding of their disease. Low health literacy also impacts on the ability of people with advanced COPD to define their own needs and goals and to negotiate the system themselves. Strategies to increase health literacy include clear advice on the recognition of exacerbations, participation in pulmonary rehabilitation at an early stage, education at all stages of the disease and access to resourced support groups. These are key strategies for a person-centred model of care for advanced COPD. Rather than being case managers, perhaps the more accurate role for the COPD clinician is to be a navigator of the system; someone who ensures that the patient is at the right place at the right time for the right care. With increasing health literacy and self-determination there will be a need to manage and set realistic patient and provider expectations.

5.7 Advance care planning

The absence of significant and sensitive discussion about the future was evident in this research, as well as limited planning for future events. Advance care planning was rarely addressed. Many health professionals recognized the importance of having discussions about patient future wants and needs and planning for these, however there was uncertainty about whose role this should be and how to time these conversations. There was a strong link in the minds of some health professionals between advance care planning and 'Do Not Resuscitate' orders rather than a broader approach to planning over a period of time. There was a lack of knowledge about the relevant documents to support the

process of advance care planning. Some health professionals also raised the issue of optimism, noting that advance care planning may interfere with the maintenance of a positive outlook, however others were comfortable with their ability to introduce the discussion.

5.8 Future role of specialist palliative care services

Palliative care services have led the way with their broad ranging, multidisciplinary, flexible approach, and will need to continue to lead in embedding a palliative approach in a chronic disease management model. The role of specialist palliative care services will be vital in providing education, consultation, advice and support for respiratory and other clinicians to continue to care for people they may have known for considerable periods of time. Referral to a palliative care service may not be necessary for the majority of people with advanced COPD and the interface between specialist palliative care and other clinicians will continue to be important in the model of care for these people.

The skills to discuss issues such as the desired extent of intervention and to sensitively raise end of life conversations are core skills of palliative care clinicians, however they are not perceived as necessary for many other health professionals. Other members of the treatment team for people with COPD need to be supported to develop confident communication skills in this area and to become familiar with the relevant documents and processes. A clear finding of this research was that advance care planning discussions were often initiated around the time of an acute exacerbation when both people with COPD and their carers were stressed. This was not appropriate as people could not think clearly, did not have the time to consider the issues and it was too late for many of the planning aspects.

5.9 Summary

This project has demonstrated that neither respiratory nor palliative care services alone can adequately support people with COPD. There is little doubt that a new model of care for people with advanced COPD is required in Australia. The findings of this project reflect both the international evidence and the Australian context and demonstrate clearly that the health care system must change for best practice care to be provided for people with advanced COPD and for their carers and families.

There is a need for a model of care that assists these people to navigate the health care and community support systems, that is patient-centred and reflects a palliative approach and which is co-ordinated across the primary, acute and community sectors. The integration of a multidisciplinary palliative approach within a chronic disease management strategy, as well as the recognition that

active disease management and palliation are complimentary, not mutually exclusive, will be central for the best care for people living with advanced COPD.

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Appendices

Appendix 1: GOLD Stage IV classification

GOLD Spirometric Classification of COPD Severity

Stage	Severity	Spirometry
Stage I	Mild	FEV ₁ /FVC < 0.70
		FEV ₁ ≥ 80% predicted
Stage II	Moderate	FEV ₁ /FVC < 0.70
		50% ≤ FEV ₁ < 80% predicted
Stage III	Severe	FEV ₁ /FVC < 0.70
		30% ≤ FEV ₁ < 50% predicted
Stage IV	Very severe	FEV ₁ /FVC < 0.70
		FEV ₁ < 30% predicted or FEV ₁ < 50% predicted plus chronic respiratory failure

COPD = chronic obstructive pulmonary disease; FEV₁ = forced expiratory volume in 1 second; FVC = forced vital capacity

Used with permission from the Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. Global Initiative for Chronic Obstructive Lung Disease, 2006.

www.goldcopd.org.

Appendix 2: Recruitment Criteria Checklist (Study One)

RECRUITMENT CRITERIA CHECKLIST

1. Name of Patient: _____ Pt ID: _____
2. The patient is not living in high or low level residential care
3. The patient is able to speak adequate English
4. The patient is over 18 years
5. The patient has no significant cognitive impairment
6. The patient has received no active treatment for lung cancer in the last 5 years, or any other cancer in the last 12 months and / or does not have metastatic disease
7. The patient has not had / is not listed for a lung transplant
8. The patient has been hospitalised >2 times in the past 12 months
9. One of these hospitalisations was for acute respiratory failure
10. The patient has a GOLD Stage IV Classification
(Please print off and attach Lung function report)
11. The patient has lost weight in the last 6 months or has a BMI <19
12. The patient is on optimal therapy but remains dyspnoeic (ie MMRC of 4)
13. The patient is eligible for the study
14. A *Consent Form* has been signed
15. A *Demographic Details Form* has been completed for the patient

Appendix 3: Participant Consent Form (Study One)



ROYAL ADELAIDE HOSPITAL PARTICIPANT CONSENT FORM - PATIENTS

PROJECT TITLE: Identifying the Care Needs of People with Advanced Chronic Obstructive Pulmonary Disease (COPD)

INVESTIGATORS: Dr Greg Crawford, Ms Margaret Brown, Dr Mary Brooksbank, Associate Professor Alan Crockett, Ms Teresa Burgess, Dr Ral Antic, Dr Michael Briffa, Mrs Mary Young and Dr Debbie Kralik

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not directly benefit from taking part in the project.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
5. I understand there is no payment for taking part in this study,
6. I have been asked for my permission to audio tape any proposed interviews, and I **have given** this permission.
7. I have had the opportunity to discuss taking part in this project with a family member or friend
8. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet

Name of Subject: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____

Dated: _____

(Investigator)

Appendix 4: Carer Consent Form (Study One)



ROYAL ADELAIDE HOSPITAL PARTICIPANT CONSENT FORM - CARERS

PROJECT TITLE: Identifying the Care Needs of People with Advanced Chronic Obstructive Pulmonary Disease (COPD)

INVESTIGATORS: Dr Greg Crawford, Ms Margaret Brown, Dr Mary Brooksbank, Associate Professor Alan Crockett, Ms Teresa Burgess, Dr Ral Antic, Dr Michael Briffa, Mrs Mary Young and Dr Debbie Kralik

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not directly benefit from taking part in the project.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
9. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
10. I understand there is no payment for taking part in this study,
11. I have been asked for my permission to audio tape any proposed interviews, and I **have given** this permission.
12. I have had the opportunity to discuss taking part in this project with a family member or friend
13. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet

Name of Subject: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____

Dated: _____

(Investigator)

Appendix 5: Participant Information Sheet (Study One)



ROYAL ADELAIDE HOSPITAL

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Identifying the Care Needs of People with Advanced Chronic Obstructive Pulmonary Disease (COPD)

As Chronic Obstructive Pulmonary Disease (COPD) progresses, it can have a big effect on the way you live and the services that you might need. The Royal Adelaide Hospital, in partnership with the University of Adelaide, is working on a project looking at the types of care and support that will be most useful for people with COPD and their carers and families. We also want to know if there are any services that would be useful, but that are not currently available.

Our project will follow a group of people with COPD, for a period of about six months to learn more about the care they receive. This is a research project and you do not have to be involved if you do not wish to. If you do not wish to be involved, your medical care will not be affected in any way.

Your participation in this project would involve:

- The COPD Nurse discussing the project with you, and providing information about you to the project team. This information will include your age, details of your illness, contact details, family supports, whether you have health insurance, any benefits you receive, any referrals that are made and specific information about your COPD.
- Both you and your carer (if you have one) having an interview with a project team member now and in 6 months time. These interviews will be audio taped, if we have your permission to do so.
- At these interviews, we will ask you about any problems you are having, any services you are using, any specific needs that are not being addressed and any problems or other issues you are having.
- The interview will take between 40 minutes and one hour and take place in your home (or place of your choice)
- When the Project Team reports on this project, your name or any personal details will never be mentioned, and you will not be identified in any publications that may be written.

Participation in this trial is voluntary, and no payments are being offered for people agreeing to participate.

We hope that you will be able to participate in this very important initiative. If you have any questions about the project, please do not hesitate to contact **Dr Greg Crawford** on (08) 8239 9144, gregory.crawford@adelaide.edu.au or **Margaret Brown** on 0419 183 757, Margaret.Brown@unisa.edu.au

If you wish to discuss any part of the study with someone not directly involved with the project, you may also contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

Appendix 6: Interview prompts – Participants (Study One)

Questions/prompts for semi-structured interview with participants

Introduction Clarification about the project

Care needs of patient.

How are you feeling today?

What is it like managing with this lung disease?

Your primary carer is ***.

Do you have other family members or friends who assist you and your carer?

How are you managing at home - showering, shopping etc?

Are you on oxygen?

Breathlessness 0-4

Self care

Are you still driving?

Does your carer drive?

Tease out transport issues

Are you on a pension?

Services used in the past six months

We have some questions about the services which you are currently using.

Firstly, can you tell me what types of services/ supports you are using?

For example:

GP

Do you have a regular GP?

If not how do you get to see a GP when you need one?

Do you have any problems getting to see your GP when you need to?

Transport?

Making appointments?

How often approx do you go or does the GP come to your home or do you go the surgery?

Specialist

How many specialists have you seen in the past 6 months?

Why did you visit them?

Any problems getting to see specialists when you need to?

Transport?

Making appointments?

Emergency Department

How many times have you visited the Emergency Department in the past 6 months?

What were the reasons for you visits?

Ambulance Service

Have you used the Ambulance Service?

Do you subscribe?

Hospital outpatient departments

Do you attend any hospital outpatient departments?

Nursing

Can you tell me if you have used any nursing or other services at home or elsewhere over the last 6 months?

e.g. respiratory nurse

Royal District Nursing Service (RDNS)

Private nurse

Mental Health nurse

Metro HomeLink
Palliative care team

Allied Health

Dietician

Physiotherapist – massage

Occupational Therapy

Social worker

Psychologist or other counselor?

Pulmonary rehab?

Can you tell me a little about this?

Naturopath

Maybe the internet

Online consult or ordering medicine

Were any of these services helpful for your needs?

How did you find out about the service – were you referred?

Domestic

What about domestic support services at home?

Domiciliary care SA

Local Council

Meals on wheels or other food provision?

Were any of these services helpful for your needs?

How did you find out about the service – were you referred?

Other services

Are there any other services that you have received?

Or any services that you would like to have but unable to access?

Are these services helpful for you - are they meeting your needs?

(Physical, emotional, social needs?)

Are there other supports/services which you can think of that may assist you?

Is there any other care that would really help you with your life at this stage?

Minister of religion?

What sort of services do you see yourself needing in 6 months time?

Advance Care Planning

Explain the term

Has the specialist, nurse or anyone at the hospital had a conversation with you (and your carer) about your future wishes and what types of treatment you may or may not want?

Show brochure (Medical Power of Attorney and Anticipatory Directive)

Do you understand what this is about?

Have you appointed someone to make decision for you in the future?

Can you remember if this was for your health care decisions or finances?

Would you like to talk more with someone about your future wishes?

Quality of Life Scale

What do you think is the biggest problem for you?

Is there anything else you would like to tell us that might be helpful for you, or other people with similar illness?

Appendix 7: Modified Medical Research Council Dyspnoea Scale (MMRC)

The Pulmonary Rehabilitation Toolkit: An Initiative of The Australian Lung Foundation and Australian Physiotherapy Association. <http://www.pulmonaryrehab.com.au/index.asp?page=62>

Grade

- 0 "I only get breathless with strenuous exercise"

- 1 "I get short of breath when hurrying on the level or walking up a slight hill"

- 2 "I walk slower than people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level"

- 3 "I stop for breath after walking about 100 yards or after a few minutes on the level"

- 4 "I am too breathless to leave the house" or "I am breathless when dressing"






Appendix 8: Quality of Life Measure (QOL)

Name: _____

Pt ID: _____

Date: _____

1. Taking into account all that we have discussed, how much is your quality of life being affected by your illness?

0	1	2	3	4
Not at all 	A little 	A lot 	A great deal affected 	Totally affected 

2. If there was one thing you would like to change, what it would be?

3. Any other issues you would like to mention?

Appendix 9: Australia-modified Karnofsky Performance Status Scale (AKPS)

Definitions Rating (%) Criteria

Able to carry on normal activity and to work; no special care needed.	100 (A)	Normal no complaints; no evidence of disease.
	90 (A)	Able to carry on normal activity; minor signs or symptoms of disease.
	80 (A)	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70 (B)	Cares for self; unable to carry on normal activity or to do active work.
	60 (B)	Requires occasional assistance, but is able to care for most of his personal needs.
	50 (B)	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40 (C)	In bed more than 50% of the time.
	30 (C)	Almost completely bedfast.
	20(C)	Totally bedfast and requiring extensive nursing care by professionals and/or family.
	10(C)	Comatose or barely arousable.
	0	Dead.

Appendix 10: Interview prompts – Carers (Study One)

Questions/prompts for semi-structured interview with carers

Introduction

Clarification about the project

Can you tell me a little about what you understand about [*] condition and what it has meant for his/her health?

How has [*] illness affected your life?

Do you feel as though you understand enough about [*] condition/are you satisfied with the information you have been given about his/her condition and the supports that may be available for you both?

What do you think are the biggest problems for [*] at the moment?

What are the biggest problems you are dealing with at the moment?

Do you think the services you are able to access at the moment are meeting [*] and your needs? If not – why not?

Can you tell me a little about the services you are accessing and how well they are meeting your needs?

Have you been able to access any support for yourself as a carer (e.g. groups, funding etc)?

Are there any services that that you think might help either or both yourself and [*] that you have not been able to access?

Are there any other issues you would like to raise with us?

Appendix 11: Table of combined scores of QOL, AKPS and MMRC linked with the use of services (Study One)

		P1	P2	P3	P4	P5	P6	P7	P8	P9	R1	R2	R3	R4	R5	R6	
MMRC1		1	3	3	3	3	4	3	4	4	4	3	3	2	3	3	
MMRC2		1	3	3	N/A	4	4	4	D	4	4	3	3	3	4	3	
AKPS1		70	50	70	70	50	50	60	50	60	50	60	60	70	60	60	
AKPS2		70	50	60	50	50	40	50	D	40	50	60	60	60	60	60	
QOL1		1	3	2	4	4	3	4	4	3	4	2	2	1	4	2	
QOL2		1	3	2	N/A	4	4	3	D	3	4	2	3	2	4	1	
Lives	Alone																
	Partner																
	Sibling																
Age		74	79	75	64	60	54	60	79	79	67	72	65	67	61	53	
Services at Home	None		-								-	-				-	
	On list and awaiting services				-												
	Aged Care assessed for community services						-				-						
	Early Supported Discharge / short term					•											
	Transitional Care Rehab	Personal Care Assistance									•						
		Shopping									•						
	GP Home visits - regular					•	•			•							
	Meal service					•	•				•						
	Council	Personal Care Assistance					•				•						
		Cleaning				•	•	•		•	•						
		Gardening			•									•			
	Metro Domiciliary Care	*Equipment	Mobility aids		+			+	+				+	+			
			Safety		+			+								+	
		Personal Care Assist			•					•	•	•				•	
		Cleaning			•			•		•						•	•
		Gardening															•
		Laundry			•												
	Shopping assistance			•													
	RDNS	Catheter care								•							
	Specialist Palliative Care support						•	•									
	Mental Health Services	Home assessment					•										
		Case Management															•
	Carer Respite							•									
Home supports in place for other family			-														
Services increased over 6 months			-	-		-	-		D								
Total		0	5	1	4	7	2	3	3	6	0	0	1	2	3	0	

*Equipment being utilised, but not included in total count as does not require ongoing interaction with a service provider

Appendix 12: Table of existing services for people with COPD in South Australia (Study Three)

<u>PRIMARY & COMMUNITY CARE</u>	
<p>Basic level of health care that includes programs directed at the promotion of health, early diagnosis of disease or disability & prevention of disease. Primary Health Care is provided in an ambulatory facility to limited numbers of people, often those living in a geographical area. It includes continuing health care. Community services are provided in locations within the community, including client's homes, rather than within hospitals, residential facilities and other institutions.</p>	
Name	Services provided
General Practice Team	<p><i>Management of COPD</i></p> <ul style="list-style-type: none"> ▪ Control risk factors in at risk population ▪ Screening for disease ▪ Confirm Diagnosis & stage of disease ▪ Assess for risk factors which accelerate progression or worsen function ▪ Promote Self Management ▪ Manage complications and co-morbidities ▪ Optimise function / symptom control ▪ Periodic health examinations <ul style="list-style-type: none"> ○ assessment & review ○ - manage stable & unstable state
	<p><i>Lifescrpts</i></p> <ul style="list-style-type: none"> ▪ Management of lifestyle related risk factors i.e. smoking, poor nutrition, risky alcohol use & physical inactivity

	<p><i>Access to Lifestyle Co-ordinators</i></p> <ul style="list-style-type: none"> ▪ based in community health centres and maybe only accessible for certain ‘at risk’ groups e.g. ‘pre-diabetes’ <p>Mental Health Management of anxiety & depression</p> <ol style="list-style-type: none"> a) Psychological Intervention - Focussed Psychological Strategies – FPS) (<i>Some Divisions of General Practice employ their own psychologists and mental health workers or have trained existing staff in FPS</i>) b) Referral to either Psychiatrist via Medicare or Psychologist or other Mental Health Worker via a Mental Health Plan under the Medicare Mental Health initiative <p><i>Vaccination Programs</i></p> <p><i>Disease Specific Education</i></p> <ul style="list-style-type: none"> - Referral to other medical services such as medical specialists (private) and secondary and tertiary care <p><i>Health Assessment via Medicare</i></p> <ul style="list-style-type: none"> - People aged 75 and over - Aboriginal and Torres Strait Islander peoples over the age of 55 <p><i>Chronic Disease Management programs funded through Medicare</i></p> <ul style="list-style-type: none"> ▪ GP Management Plan ▪ Team Care Arrangement with access to Allied Health interventions (e.g. physiotherapist, dietician, exercise physiologist, OT, private pulmonary rehab) ▪ Case conferencing for complex cases ▪ Referral for Home Medicines Review (HMR) <p><i>Referral to Allied Health Professionals via private health funds and DVA</i></p> <p><i>Referral to other CDU programmes such as CDCP (Chronic Disease Community Programme) – SAHS</i></p> <p><i>Referral to Quitline (specific GP referral process)</i></p>
Public Health	<p><i>Health Literacy</i></p> <hr/> <p><i>Education</i></p> <hr/> <p><i>Awareness (state and national health promotion messages)</i></p>

Community Services	<i>COPD Patient Support Groups – (Consumer, not Health Professional driven)</i>
	<i>Mood Disorders Association</i>
	<i>QUIT Line</i>
	<i>Carer's Association</i>
	<ul style="list-style-type: none"> ▪ Information ▪ Home supports including access to respite
	<i>Community Health Centres</i>
	<ul style="list-style-type: none"> ▪ Lifestyle and Self Management Programs
	<i>Non-government organisations such as Helping Hand / Resthaven / Italian Village / Breath Better Centre (Asthma Foundation of SA)</i>
	<ul style="list-style-type: none"> ▪ Lifestyle and Self Management Programs ▪ Disease specific pulmonary rehabilitation ▪ Non-English speaking (Italian) programs
	<i>Home Supports</i>
<ul style="list-style-type: none"> ▪ Council ▪ Private home nursing services ▪ RDNS ▪ Domiciliary Care ▪ Hospital in the Home (post acute) 	
<i>Emergency Services</i>	
<ul style="list-style-type: none"> ▪ Ambulance ▪ Medical Alert 	
<i>Oxygen Companies</i>	
<i>Meals Services</i>	
<i>Dental care</i>	

	<p><i>Spiritual support (both Parish based and Health Chaplaincy)</i></p> <hr/> <p><i>Pharmacy</i></p> <ul style="list-style-type: none"> ▪ Prescriptions ▪ Webster / Dosette packs and delivery <hr/> <p><i>Housing services</i></p> <ul style="list-style-type: none"> ▪ Public – Housing Trust; Shelter, Homeless ▪ Private
	<p>Those provided to people over the age of 65 years; ATSI over the age of 45</p> <ul style="list-style-type: none"> ▪ Aged Care Assessment via Domiciliary Care Services to allow streaming into one of the following <ul style="list-style-type: none"> ○ Transitional Care Package ○ Community Aged Care Package ○ Extended Aged Care Package ○ Placement into Residential Care ○ Access to respite beds
Palliative Care Services	<ul style="list-style-type: none"> ▪ Specialist palliative care services ▪ In home health professional care / information / education / case management ▪ Access to hospice care
Aged Care Services	<ul style="list-style-type: none"> ▪ Legal Services ▪ Pension services i.e. Centrelink / Veterans system ▪ Specialist medical services ▪ Allied & Mental Health services (psychiatry / psychology / crisis care) ▪ Dental care ▪ Private hospital admission ▪ Equipment ▪ Home Care
Public / Private / Health Insurance	<ul style="list-style-type: none"> ▪ Access to private hospitals and private specialists

SECONDARY CARE

An intermediate level of health care that includes diagnosis and treatment, performed in a hospital with specialised equipment & laboratory facilities

Name	Services provided
Rehabilitation	<i>Inpatient rehabilitation</i>
	<i>Step-down rehabilitation</i>
	<i>Disease specific rehabilitation i.e. Pulmonary Rehabilitation</i>
Private Hosp.	<i>Step-down rehabilitation</i>
	<i>Disease specific rehabilitation i.e. Pulmonary Rehabilitation</i>
	<i>Respite / convalescence</i>

TERTIARY CARE

A specialised, highly technical level of health care that includes diagnosis and treatment of disease and disability. Specialised intensive care units, advanced diagnostic support services and highly specialised personnel are usually characteristic of tertiary health care. It offers highly centralised care to the population of a large region and in some cases to the world.

Name	Services provided
Hospital	<i>Emergency & inpatient care</i>
	<i>Diagnostic services</i>
	<i>Hospital in the Home</i>
	<i>Multi-disciplinary care planning</i>
	<i>Specialist assessment & review</i>
	<u>Respiratory</u> <ul style="list-style-type: none"> ▪ Pulmonary rehabilitation ▪ Domiciliary Oxygen therapy ▪ Respiratory Nursing Services – outreach care ▪ Surgical intervention i.e. Lung Transplantation / LVRS ▪ Sleep Services ▪ Clinical Trials
	<u>Aged Care / Palliative Care / Cardiology /Oncology</u>
	<u>Ambulatory Care / Outpatient services</u>
Hospice	Palliative Care

Appendix 13: Ethics Approval (Study Three)



Government of South Australia
SA Health

5 March 2009

Dr Greg Crawford
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Research Ethics Committee

Level 3, Hanson Institute
Tel (08) 8222 4139
Fax (08) 8222 3035
Email:
Heather.O'Dea@health.sa.gov.au

Dear Dr Crawford,

Re: "Informing the development of a model of care for patients with the end stage Chronic Obstructive Pulmonary Disease (COPD): what are their care needs and are they being met?" Protocol Final Version 1 (5 December 2008). Participant Information Sheet & Consent Form, Version 1 (20 November 2008). Carers Consent Form, Version 1 (20 November 2008).

RAH PROTOCOL NO: 081203a.

I am pleased to advise that Research Ethics Committee APPROVAL is granted for the following amendments to the above project:

- **Addendum: Interview or Focus Groups for Study 3.**
- **Participant Information Sheet & Consent Form – Key Service Providers, Version 1 (17 February 2009).**
- **Participant Information Sheet & Consent Form – Consumer/Carer Groups (Support Groups), Version 1 (17 February 2009).**

Please quote the RAH Protocol Number above on all correspondence. Research Ethics Committee deliberations are guided by the NHMRC National Statement on Ethical Conduct in Human Research 2007.

The general conditions of approval follow:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
 - (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
 - (b) changes to the protocol,
 - (c) premature termination of the study,
 - (d) a study completion report within 3 months of the project completion.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is ongoing, subject to satisfactory annual review. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each year using the Annual Review Form available at:
<http://www.rah.sa.gov.au/rec/index.php>

Yours sincerely,

Prof M James
CHAIRMAN
RESEARCH ETHICS COMMITTEE

Appendix 14: Participant Information Sheet – Key service providers (Study Three)



ROYAL ADELAIDE HOSPITAL

PARTICIPANT INFORMATION SHEET – Key Service Providers

Respiratory Nurses / Palliative Care Service Representatives / GPs /
Respiratory Clinicians / RDNS / Public Health Respiratory Physicians

PROJECT TITLE: Identifying the Care Needs of People with Advanced Chronic Obstructive Pulmonary Disease (COPD)

As Chronic Obstructive Pulmonary Disease (COPD) progresses, it can have a major effect on the way people live and the services that they might need. The Royal Adelaide Hospital, in partnership with the University of Adelaide, is working on a project looking at the types of care and support that will be most useful for people with COPD and their carers and families. We also want to know if there are any services that would be useful, but that are not currently available.

Our project is following a group of people with COPD, for a period of about six months to learn more about the care they receive. We also want to identify exactly which services are available to people with COPD as it is often assumed that patients with COPD have access to a full range of hospital and community services if required. However some of these services have specific eligibility requirements, and may have significant costs associated with them. This project will be undertaking an audit of exactly which services are available (across the hospital/palliative care/primary care/community continuum of care) and of the eligibility requirements for these. As part of this audit, we would like to ask you about the services which you are associated with, particularly any barriers to access, gaps in current service and aspects of your services that you think are working particularly well.

Your participation in this project would involve you participating in a small focus group to discuss the services you provide and any suggestions you may for services which may not be readily available. The focus group will take approximately one hour and take place in a convenient venue to be negotiated with focus group participants.

When the Project Team reports on this project, your name or any personal details will never be mentioned, and you will not be identified in any publications that may be written. Participation in this trial is voluntary, and no payments are being offered for people agreeing to participate.

We hope that you will be able to participate in this very important initiative. If you have any questions about the project, please do not hesitate to contact **Dr Greg Crawford** on (08) 8239 9144, gregory.crawford@adelaide.edu.au or **Teresa Burgess** on (08) 8303 3468, teresa.burgess@adelaide.edu.au

If you wish to discuss any part of the study with someone not directly involved with the project, you may also contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.



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Appendix 15: Participant Information Sheet – Service providers (Study Three)



PARTICIPANT INFORMATION SHEET – Key Service Providers

Carers / Domiciliary Care SA

PROJECT TITLE: Identifying the Care Needs of People with Advanced Chronic Obstructive Pulmonary Disease (COPD)

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AUSTRALIA

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As Chronic Obstructive Pulmonary Disease (COPD) progresses, it can have a major effect on the way people live and the services that they might need. The University of Adelaide, in partnership with the Royal Adelaide Hospital, is working on a project looking at the types of care and support that will be most useful for people with COPD and their carers and families. We also want to know if there are any services that would be useful, but that are not currently available.

Our project is following a group of people with COPD, for a period of about six months to learn more about the care they receive. We also want to identify exactly which services are available to people with COPD as it is often assumed that patients with COPD have access to a full range of hospital and community services if required. However some of these services have specific eligibility requirements, and may have significant costs associated with them. This project will be undertaking an audit of exactly which services are available (across the hospital/palliative care/primary care/community continuum of care) and of the eligibility requirements for these. As part of this audit, we would like to ask you about the services which you are associated with, particularly any barriers to access, gaps in current service and aspects of your services that you think are working particularly well.

Your participation in this project would involve a member of the Project Team visiting you to ask questions about the services you provide and any suggestions you may for services which may not be readily available. The interview will take approximately one hour and take place in a convenient venue.

When the Project Team reports on this project, names and any personal details will never be mentioned, and you will not be identified in any publications that may be written. Participation in this project is voluntary, and no payments are being offered for people agreeing to participate.

We hope that you will be able to participate in this very important initiative. If you have any questions about the project, please do not hesitate to contact **Dr Greg Crawford** on (08) 8239 9144, gregory.crawford@adelaide.edu.au or **Teresa Burgess** on (08) 8303 3468, teresa.burgess@adelaide.edu.au

If you wish to discuss any part of the study with someone not directly involved with the project, you may also contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

Appendix 16: Participant Information Sheet – Consumers (Study Three)



ROYAL ADELAIDE HOSPITAL

PARTICIPANT INFORMATION SHEET –

Consumer Groups

PROJECT TITLE: Identifying the Care Needs of People with Advanced Chronic Obstructive Pulmonary Disease (COPD)

As Chronic Obstructive Pulmonary Disease (COPD) progresses, it can have a major effect on the way people live and the services that they might need. The Royal Adelaide Hospital, in partnership with the University of Adelaide, is working on a project looking at the types of care and support that will be most useful for people with COPD and their carers and families. We also want to know if there are any services that would be useful, but that are not currently available.

Our project is following a group of people with COPD, for a period of about six months to learn more about the care they receive. We also want to identify exactly which services are available to people with COPD as it is often assumed that patients with COPD have access to a full range of hospital and community services if required. However some of these services have specific eligibility requirements, and may have significant costs associated with them. This project will be undertaking an audit of exactly which services are available (across the hospital/palliative care/primary care/community continuum of care) and of the eligibility requirements for these. As part of this audit, we would like to ask you about the services which you are associated with, particularly any barriers to access, gaps in current service and aspects of your services that you think are working particularly well.

Your participation in this project would involve a member/s of the Project Team visiting you to ask questions about the services you provide and any suggestions you may for services which may not be readily available. The interview will take between 40 minutes and one hour and take place in a place of your choice.

When the Project Team reports on this project, your name or any personal details will never be mentioned, and you will not be identified in any publications that may be written. Participation in this trial is voluntary, and no payments are being offered for people agreeing to participate.

We hope that you will be able to participate in this very important initiative. If you have any questions about the project, please do not hesitate to contact **Dr Greg Crawford** on (08) 8239 9144, gregory.crawford@adelaide.edu.au or **Teresa Burgess** on (08) 8303 3468, teresa.burgess@adelaide.edu.au

If you wish to discuss any part of the study with someone not directly involved with the project, you may also contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.



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Appendix 17: Interview schedule - Key service providers (Study Three)

Questions/prompts for semi-structured interviews with Key Service Providers re service usage and access

Respiratory Nurses / Palliative Care Service Representatives / GPs / Respiratory Clinicians / RDNS / Public Health Respiratory Physicians / Domiciliary Care SA

Introduction (clarification about the project – aims and objectives)

Purpose of the group: To obtain a broad view of the services available to people with end stage COPD, some of the barriers to accessing these services, whether service needs change over time and what services are missing

- Can you tell us a little about the main services that you found that patients with advanced COPD require and whether these services are easily accessible?
- Do you think the services that people with COPD are able to access at the moment are meeting their needs? / If not – why not?
- What are the main barriers you have identified for patients (or that they have identified to you) when trying to access different services for them?
- What are the major gaps in services that are available to people as their disease progresses?
- Are there any other services that that you think might help people with COPD that they cannot currently access?
- In terms of Advance Care Planning, have you found that the opportunity to discuss the needs and wishes of people with COPD?
- In a perfect world, what services (and access requirements) would you like to see for patients with advanced COPD?
- In what ways do you think the services that patients might require change as their condition deteriorates?
- What are the barriers or facilitators for patients in access to /changing / extending services as their conditions deteriorates?
- In terms of supporting infrastructure for sustaining services and care for patients with advanced COPD, what do you think are the most important elements the health services need to address -
Prompts: Workforce / training / IT

Appendix 18: Interview schedule – Carers (Study Three)

Identifying the care needs of people with advanced COPD

Questions/prompts for semi-structured interviews with Carers SA

Introduction (clarification about the project – aims and objectives)

Purpose of the interview: To obtain a broad view of the needs of people caring for their family/friends with COPD, what types of services would be most useful, any issues accessing services and whether service needs change over time and what services are missing

- Has caring for people with COPD been identified by Carers SA as a particular issue for their clients? If so, what are some of the specific issues identified?
- Can you tell us a little about the main services that you have found that carers of people with advanced COPD require and whether these services are easily accessible?
- Do you think the services that people with COPD and their carers are able to access at the moment are meeting their needs? / If not – why not?
- What are the main barriers you have identified for carers (or that they have identified to you) when trying to access different services?
- What are the major gaps in services that are available to people caring for people with COPD as their disease progresses?
- As COPD progresses and a need for the care associated with end of life increases (e.g. symptom relief, opportunities to discuss approaching death), have you found that this sort of support is available for carers and their families?
- In terms of Advance Care Planning, have you found that the opportunity to discuss the needs and wishes of both carers and people with COPD is being provided?
 - If so, do you know who initiates this discussion (e.g. GPs)?
 - If not, who do you think should initiate this discussion?
- Are there any specific issues around advance care planning that Carers SA has identified?
- Are there any other services that that you think might help people with COPD and their carers, that they cannot currently access?
- In a perfect world, what services (and access requirements) would you like to see for patients with advanced COPD and their carers?
- In terms of supporting infrastructure for sustaining services and care for patients with advanced COPD and their carers, what do you think are the most important elements the health services need to address?

Appendix 19: Interview schedule – Consumer support groups (Study Three)

Questions/prompts for semi-structured interviews with Consumer Groups re service usage and access

Introduction (clarification about the project – aims and objectives)

Purpose of the group: To obtain a broad view of the services available to people with end stage COPD, some of the barriers to accessing these services, whether service needs change over time and what services are missing

- Can you tell us a little about how this illness has affected your life, particularly as it has gotten worse?
- What services have you been able to use that you have found helped you the most with this illness?
- Have you had any problems with any of these services?
 - finding out about them
 - difficulty getting to them
 - not being very useful
- Are there any other services that you think might help you but that you haven't been able to access?
 - Why cannot you use these services?
- At different times, as your illness progresses, have you found that the services you might need have changed much?
- Have you found that having *this* illness has interfered with you being able to access services for any other problems you may have – e.g. going to the dentist?
- What's the **one** thing that you think would make the most difference to you, if it were possible to have it, in dealing with this illness?
- In a perfect world, can you describe for us how treatment for your illness would work so that you felt that you were getting the best care possible?
- We've talked about services that are available or might be useful – do you think there are any services that should be provided specifically for carers?
- Has anyone spoken to you at all about Advance Care Planning (sometimes called a Living Will?) – e.g. GP/specialist/nurse
 - How useful do you think it was/would be to be able to discuss this with someone?
 - Whose responsibility do you think it is to talk to you about these sorts of things?