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## **A patient-centred model of care incorporating a palliative approach: a framework to meet the needs of people with advanced COPD?**

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# **A patient-centred model of care incorporating a palliative approach: a framework to meet the needs of people with advanced COPD?**

## **ABSTRACT**

**Background:** Current models of care for people with advanced chronic obstructive pulmonary disease (COPD) have been demonstrated to be inadequate, particularly in areas such as advance care planning, symptom control and psycho-social and spiritual care.

**Aim:** This paper aims to explore how a model of patient-centred care can incorporate a palliative approach to form a practical and useful framework for care that meets the needs of people with advanced COPD.

**Discussion:** There is increasing recognition of the need to provide active disease management at the same time as supportive care for people with chronic disease. A palliative approach can incorporate these two care imperatives but a number of barriers often make implementation problematic. A patient-centred care approach can help to address these barriers and is increasingly being seen as an appropriate framework for all health care service provision. Significant changes are required to health systems and service provision for this model of care to be implemented; specialist palliative care services can take a leading role in change management.

**Conclusion:** Patient-centred care provides an appropriate framework for the development of a model of care for advanced COPD. It allows for a needs based approach to service provision, rather than the current prognosis based system and brings patient and carer needs and concerns to the forefront of care.

**Key Words:** Advanced COPD; patient-centred / person-centred care; palliative approach; palliative care

## BACKGROUND

Chronic Obstructive Pulmonary Disease (COPD) is a major and growing international public health problem, with the Global Burden of Disease Study estimating that by 2020, COPD will be the third leading cause of mortality worldwide.<sup>(1)</sup> The care of patients with COPD is becoming an increasing burden on both the hospital and community<sup>(2)</sup> but more importantly, many of these patients are not receiving the optimal care that meets the needs of both themselves and their carers as their disease progresses and they approach the end of their life.<sup>(3-6)</sup> A recent study in Australia which examined the care needs of people with end-stage COPD and their carers, identified there was minimal care co-ordination, resulting in episodic, reactive and fragmented care, with poor communication between the acute, primary and community care sectors.<sup>(3)</sup> Access to services such as support for activities of daily living was restricted and the role of carers was poorly recognised. The absence of a clear transition to an end-stage in COPD led to uncertainty about when to initiate palliative care, a finding also reported by Pinnock et al.<sup>(4)</sup> An in-depth understanding of the nature of the palliative care needs of non-cancer patients is emerging from prospective, qualitative studies that take account of patients' and carers' perspectives.<sup>(3-5)</sup> Evidence about the aspects of palliative care that should be adopted to meet the needs of non-cancer (including COPD) patients is also growing.<sup>(4, 7, 8)</sup>

The end-stage of COPD generally results in progressive functional decline, poor quality of life and increasing dependency on caregivers, and the health system.<sup>(9)</sup> Typically, COPD patients are confronted with long term limitations interspersed with acute exacerbations which may lead to death. Patients often survive these episodes, but with further deterioration in functional status and health.<sup>(10)</sup> A number of studies have identified that people with advanced COPD experience physical symptoms (e.g. dyspnoea and fatigue) and psychosocial distress at least as severe as patients with lung cancer,<sup>(11, 12)</sup> often compounded by increasing social isolation.<sup>(13)</sup> Chronic disease management (CDM) frameworks which currently incorporate systematic review, care planning, self management and evidence based interventions<sup>(14)</sup> form the basis of COPD care in the community.<sup>24</sup> However It is clear that neither models for CDM nor palliative care currently meet the particular needs of people with *advanced* COPD.

It is debatable whether the current model of specialist palliative care service delivery is appropriate for people with advanced COPD either. Specialist palliative care developed to meet the needs of people with cancer with a relatively short and predictable disease trajectory and associated functional decline. Increasingly, specialist palliative care services are being directed towards the management of people with non-malignant disease, but

without adequate resourcing and infrastructure. People with COPD need to access support services, based on need rather than prognosis and referral to specialist palliative care services may not be appropriate or required for the majority.<sup>(10, 15)</sup> Often, the person with advanced COPD has multiple health providers, including general practitioners (GPs), hospital outpatient departments, general physicians, respiratory specialists and possibly palliative care services, resulting in uncertainty about who has overall responsibility for care.<sup>(3)</sup> Service models to address the needs of this group of patients are increasingly being discussed.<sup>(16)</sup>

A number of barriers contribute to the absence of supportive/palliative care for people with COPD including its unpredictable trajectory and the reluctance of specialist clinicians to discuss end-of-life issues and incorporate a palliative focus of care.<sup>(17-19)</sup> There is also a lack of knowledge amongst COPD patients about the likely trajectory of their disease.<sup>(20, 21)</sup> Philip et al<sup>(19)</sup> identified that there is limited understanding of palliative care by both patients and health care professionals, noting that health care professionals see palliative care as relevant only for the last days of life and “*exclusive of life prolonging treatments*”.<sup>(19)</sup> Thus, it may be the term “palliative” itself that acts as a barrier to the application of the principles of palliative care in people with advanced COPD.<sup>(22)</sup>

In Australia, the term “a palliative approach” is increasingly being used to describe care which allows continuing active interventions whilst introducing elements of palliative care (Box 1).<sup>(23)</sup> The recognition that active disease management and palliative care are complementary rather than exclusive<sup>(3-7)</sup> and the early integration of a palliative approach with active treatment is now being promoted as an appropriate framework for care.<sup>(4, 16)</sup> However, the use of a “patient-centred” or “person-centred” framework for care may provide a more comprehensive, all encompassing strategy.

The Australian Commission on Quality and Safety in Health Care has defined *patient-centred* [or person-centred] *care 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.*<sup>(24)</sup> Within the context of a progressive illness, these principles are relevant at all stages of the disease. In the UK person-centred care has been linked to advanced disease management through the UK End of Life Care Strategy. Table 1 highlights the key principles of CDM and person-centred end of life care and where they diverge.

**Box 1. Definition of a Palliative Approach<sup>(23)</sup>**

A palliative approach aims to improve the quality of life for people with a progressive life limiting illness and their families. It aims to reduce their suffering through early identification, assessment and holistic treatment of pain, physical, psychological, social, cultural, and spiritual needs.

A palliative approach is not delayed until the end stages of an illness or the ageing process. Instead, a palliative approach provides a focus on active comfort care and a positive approach to reducing an individual's symptoms and distress, which facilitates [patients'] and their families' understanding that they are being actively supported through this process. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying

**Table 1. Key principles of CDM and Person-Centred End of Life Care (PCEoLC)**

<b>Chronic disease management<sup>(14)</sup></b>	<b>Person centred end-of-life care<sup>(25)</sup></b>	<b>Commentary</b>
Active disease management	A focus on active comfort care including symptom control	<i>PCEoLC should include active disease management. CDM should include symptom control.</i>
Multidisciplinary care	Multidisciplinary care	<i>This is a key area of concordance on which to build a framework of care.</i>
Care planning	An individual's choices and priorities are at the centre of care planning and delivery	<i>PCEoLC will include a focus on advance care planning.</i>
Self Management	Individuals, families and friends are well informed about the range of options and resources available to them	<i>Whilst there is some degree of self management possible with advanced disease, the capacity for this may be more limited.</i>
Evidence based care	Care is delivered in a sensitive, person-centred way, taking account of circumstances, wishes and priorities of the individual, family and friends	<i>CDM may be evidence-based for only one specific disease, but PCEoLC will consider best practice in multiple diseases and palliative care and take a holistic approach.</i>
Care co-ordination	Care and support are available to anyone affected by the end of life and death of an individual	<i>Care co-ordination is essential to both.</i>
Communication	Effective, straightforward, sensitive and open communication	<i>In CDM clinicians should proactively address the uncertain prognosis and broach end of life issues. PCEoLC will include end of life discussions</i>
	Addressing physical, psychological, social, cultural, and spiritual needs	<i>These are not core in CDM but are important and form a clear focus in PCEoLC.</i>
	Non palliative care professionals are supported to develop knowledge, skills and attitudes and to take responsibility for, and recognise the importance of, their continuing professional development	<i>Palliative care professionals have an important role to facilitate this education and development.</i>

## **A patient-centred model of care for people with advanced COPD**

Crawford et al.<sup>(3)</sup> made a series of recommendations which provide an overarching framework for developing a patient-centred model of care for advanced COPD (Box 2).

### ***Box2: Recommendations from Crawford et al, 2012<sup>(3)</sup>***

1. COPD guidelines should emphasise the symptom burden of COPD and its devastating impact on patients' lives.
2. Care should be patient-centred, dictated by needs and symptoms.
  - a. A palliative approach should be a core principle of COPD care.
  - b. Access to activities of daily living (ADL) support is central to COPD care.
  - c. Eligibility to access services should not be restricted by age or performance status alone
  - d. A stronger focus on psychological assessment and support is needed.
  - e. Advance care planning should be available to all, together with skilled assistance to make and document these decisions.
  - f. Bereavement risk should be assessed and intervention provided as required
3. Any model of care must incorporate care co-ordination across hospital, community and home.
  - a. The interface between specialist palliative care services, respiratory specialists and general practice needs clearer definition.
  - b. Planning for contingencies and access to 24 hour advice are required.
  - c. Access to pulmonary rehabilitation programmes should be a priority.
  - d. Smoking prevention and cessation programmes need ongoing support.
  - e. Increasing health literacy should be a priority.
4. The importance of informal care givers must be acknowledged, and access to respite increased.

This framework requires an understanding of the multi-dimensional, multi-disciplinary and multi-professional nature of care, as well as recognition that care will be required across several settings during the course of the disease. To date, no chronic disease management models in Australia have delivered this holistic care, although the UK and Canada have begun to develop such models<sup>(16)</sup>. Placing the patient with advanced COPD at the centre of the model of care, as articulated in a palliative approach, can ensure best practice care is provided and patients' needs are more likely to be met in an appropriate and timely manner.



## **1. The burden of COPD**

Any model of care for people with advanced COPD must be built around sensitivity and compassion for the patient's vulnerability. This is related to the symptom burden, in particular dyspnoea and fatigue; the many losses including changes in role; the social stigma of COPD (often seen as a self-inflicted disease caused by smoking) and the impact on relationships experienced by people with this chronic illness.<sup>(3, 26)</sup>

## **2. Care should be patient-centred, dictated by needs and symptoms.**

There are a number of key elements to incorporate into any model to ensure care is patient-centred:

**Incorporation of a palliative approach with active disease management:** COPD care should be based on a CDM framework, allowing active disease management (i.e. risk factor management including smoking cessation and vaccination, standard pharmacotherapy, long term oxygen therapy, pulmonary rehabilitation and management of complications including infection and respiratory failure) at the same time as the supportive care measures described below. The core of a CDM framework is structured care planning involving the patient<sup>(14)</sup> and the practical aspects of a palliative approach can be incorporated into this care planning.

**Patient, carers and families included in care planning as early as possible:** Care planning in Australia occurs mainly in the general practice setting and may involve community nursing services. Care planning for COPD should occur soon after diagnosis, recognising that care requirements will change as the disease progresses. Families and carers need to be involved from the initial care plan and included in a regular review process. Care planning may involve self management, but patients and families/carers should feel supported at all stages of the illness. It should be recognised that COPD care planning is different from advance care planning<sup>(27)</sup> and the signing of "Do-Not-Resuscitate" (DNR) orders.<sup>(27)</sup> The process of care planning should lead to discussion of advance care planning.

**Advance care planning:** Advance care planning requires skilled assistance to discuss and document the person's wishes and decisions about treatment including resuscitation and the focus and site of care. Multiple conversations will be required as the relationship with the patient develops and decisions reviewed as the disease progresses. In COPD, because of the possibility of severe exacerbations requiring ventilation, DNR orders may be seen as the only aspect of advance care planning. However, advance care planning is a much broader process. When an advance care plan is in place, it can assist in decision making about life sustaining treatments in the Emergency Department or Intensive Care Unit minimising

inappropriate discussions at a time when people are most vulnerable.<sup>(28, 29)</sup> ( Box 3: Vignette 1)

**Box 3: Vignette 1: Stories from the Australian NHMRC COPD study<sup>(30)</sup>**

**Lack of clear and open conversations about advance care planning**

Mrs A was a 76 year old woman diagnosed with COPD eight years earlier. She lived alone with adult children in the same city. Her daughters helped with shopping and some household chores, the Local Council provided some assistance with house cleaning but the waiting list for domiciliary care services was approximately six months. She had a history of cardiac disease and acute renal failure following an angiogram in the past twelve months. She was on continuous home oxygen, had recently lost 10kg in weight, and had multiple admissions to hospital for exacerbations of dyspnoea. The GP was supportive but did not routinely visit her at home. She recently had difficulty getting to the early morning hospital outpatient appointments.

At her request, her GP had written a 'do not resuscitate' (DNR) letter which she carried with her in her hand bag. Despite this she had received cardio-pulmonary resuscitation in her daughter's home after a collapse. During a recent hospital admission the question of resuscitation was raised with her family, but not with her knowledge or permission. On a ward round the consultant dismissed the issue saying "you're only young yet". However, she explained

*I've noticed now, when I leave the hospital, they give a letter like that [DNR] 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".*

The responsibility for initiating advance care planning in this model of care is with the multidisciplinary team caring for the patient, *not* the specialist palliative care team. Clinicians will require specific training to gain confidence and competence in this area of practice. Initiatives which mentor clinicians in advance care planning are available and should be widely promoted.<sup>(31)</sup> A major issue in Australia currently is ensuring that all health service providers have access to known advance care plans, particularly as there is no electronic health record universally available. Advance care wishes should be clearly recorded in all health records (hospital, GP, outpatient and community).

**Access to services based on need rather than prognosis:** A number of studies have identified the importance of access to support services, such as personal care, transport and cleaning.<sup>(3, 5)</sup> It is vital then, that there is greater recognition of the importance of these services, with an associated increase in funding. In Australia, referrals to these services often

result in patients being placed on long waiting lists or not being accepted at all, because of restrictive eligibility requirements.<sup>(3)</sup> Access to these services is facilitated if a person is a current patient of a specialist palliative care service.<sup>(3)</sup> Specific needs-based criteria (without a minimum age limit) must be developed to allow the multidisciplinary team to appropriately access the same services that would be available to a specialist palliative care service. (Box 4: Vignette 2)

**Box 4: Vignette 2: Stories from the Australian NHMRC COPD study<sup>(30)</sup>**

**Barriers to access to appropriate support until specialist palliative care involved**

Mr B, a 60 yr old man, living alone, was very frightened of the future after a recent admission to ICU. He was breathless on minimal exertion, barely able to make a cup of tea and had been on continuous home oxygen for two years. He was booked into pulmonary rehabilitation but “*didn’t make it there*”.

*I can get in the shower by myself, it’s getting out and drying, and 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.*

His only support at home was a cleaning service fortnightly and some assistance with deliveries from the local supermarket and pharmacist. His GP did visit him at home.

The respiratory nurse was unable to access other home services for him until he was referred to the Specialist Palliative Care service. At the second interview with the researcher, the domiciliary care services had commenced providing regular help with personal care, and his dyspnoea was better managed with oral morphine. He had enjoyed the contact with palliative care staff and the humour they brought with them.

Embedding a palliative approach to care requires consideration of treatment to relieve symptoms which may not be understood as standard therapy. The integrative review undertaken by Disler et al has identified clear evidence for the use of pharmacological agents such as opioids and or benzodiazepines in relieving dyspnoea.<sup>(8)</sup> Use of opioids does not require referral to a palliative care service but palliative guidelines for the safe introduction and titration of opioid doses should be followed. Whilst oxygen is recommended where hypoxaemia is demonstrated,<sup>(32)</sup> the use of oxygen for symptom control alone does not have strong evidence and for some people, the burdens associated with oxygen therapy may outweigh the benefits.<sup>(8, 10)</sup>

**Psychological, emotional and spiritual support:** This is a core component of a palliative approach, but is often overlooked in people with advanced COPD. Although depression and anxiety have been identified as prevalent, particularly anxiety associated with dyspnoea,<sup>(3, 10)</sup> assessment and treatments are not systematically considered. Social isolation, associated with symptoms such as cough and breathlessness and the use of oxygen therapy, is a frequent phenomenon impacting further on psychological wellbeing. Family relationships can be strained, and spiritual and existential issues can add to the emotional burden.<sup>(8)</sup>

Recognition of these issues should be part of early assessment and management and referral to COPD support groups can be useful. Ongoing review of psychological issues such as depression and anxiety is best undertaken in primary care with ongoing communication with the multidisciplinary team.

**Bereavement support:** Bereavement support has been identified as an important part of care in COPD.<sup>(33)</sup> In many instances, informal bereavement support through the community can help individuals and families deal with their grief, but grief and loss occur throughout the disease, particularly as the symptom burden increases. Bereavement support is part of best practice care.<sup>(34)</sup> Bereavement risk for people with advanced COPD and their families should be assessed and intervention provided as required. All social workers involved in COPD multidisciplinary teams should have some knowledge of, and experience in, bereavement care.

### ***3. Care must incorporate care co-ordination across hospital, community and home***

**Clearer definition of the interface of care:** The multidisciplinary COPD team including the GP should take overall responsibility for end-of-life care for people with advanced COPD. It is important to build a model of timely and accurate assessment which anticipates, navigates and co-ordinates care across the acute, primary and community settings according to patient need.<sup>(3, 8)</sup> This model must be continuous, pro-active rather than episodic, and there should also be access to 24 hour support and information.<sup>(3, 8)</sup> Specialist palliative care can play a key role in supporting the multidisciplinary team in a variety of ways (Box 5).

**Box 5: The role of specialist palliative care in supporting a patient-centred care model for people with advanced COPD**

1. The multidisciplinary COPD team, including respiratory specialists and GPs should have responsibility for the care of people with advanced COPD up to and including the end of their life. Specialist palliative care services should be available for consultation regarding appropriate and timely use of pharmacological and non pharmacological interventions. Consultation can involve discussion and advice (eg attending regular team care meetings) or a one off patient consultation as required.
2. Specialist palliative care services can work with and advise the multidisciplinary COPD team, particularly primary care practitioners, in the development of processes which meaningfully engage both the patients and their family/carer in the care planning process from the initial stages.
3. Specialist palliative care services can work with the multidisciplinary COPD team to provide education and support around advance care planning and the associated conversations
4. Recognising that palliative care services do not have the capacity to provide psychological, spiritual and social support for all patients with COPD, specialist palliative care services can train COPD teams in the systematic monitoring and assessment of these key elements of care.
5. Specialist palliative care services can facilitate access to hospice where required.
6. Specialist palliative care services can support the COPD multidisciplinary team in the use of bereavement risk assessment tools and the development of bereavement support programs.

**Effective Communication:** Clear, timely and accurate communication between health professionals, patients and carers is essential in all good medical practice and particularly for patients with advanced COPD.<sup>(3, 8, 10, 21)</sup> Effective communication involves communication between health professionals and patients and their families as well as communication between health professionals themselves.<sup>(3)</sup> There is currently little discussion between health professionals and people with COPD about their disease, the likely trajectory and end-of-life issues (including advance care planning).<sup>(4, 21)</sup> Also, there is scant communication between acute care, primary care and the community sectors.<sup>(3)</sup> The current Australian health system acts as a barrier to communication as it is often inflexible and compartmentalises care, with few communication pathways developed between the acute, primary and community care sectors.<sup>(3)</sup>

All clinicians must appreciate the impact of communication on health outcomes and ensure they develop and maintain highly-developed skills.<sup>(35)</sup> These health outcomes include increased access to care, greater patient knowledge and shared understanding; higher quality medical decisions, enhanced therapeutic alliances, increased social support, patient agency and empowerment, and better management of emotions.<sup>(35)</sup> It is therefore important that communication training is embedded in all levels of health professional training, particularly continuing professional development.<sup>(36)</sup> Effective communication at an individual clinician and system level should be included as a key performance indicator in all quality improvement programs. New IT connectivity initiatives, such as patient held records, have the potential to support detailed and timely communication across health sectors and to facilitate standardised referral systems.<sup>(37)</sup>

**Health literacy:** People with advanced COPD and their families and carers often have little understanding of their disease.<sup>(3, 21)</sup> The importance of understanding treatment, being able to recognise the onset of exacerbations and understanding the course of the disease has been demonstrated<sup>(34)</sup> and interventions to increase the level of health literacy should be a priority. Strategies include clear advice on the recognition and treatment of exacerbations, participation in pulmonary rehabilitation at an early stage, education at all stages of the disease and access to resourced support groups. These strategies should be included and reviewed within the care planning process.

**Pulmonary rehabilitation:** This is one of the most effective interventions for people with advanced COPD.<sup>(32)</sup> It includes patient assessment, exercise training, education, nutritional intervention and psychosocial support. Programs need to be sensitive to issues of access, the timing of sessions, taking into account the difficulty getting to early appointments, and the needs of smokers and non-smokers.<sup>(3)</sup> Alternatives to group based pulmonary rehabilitation should be available including programs that can be delivered in the home.<sup>(32)</sup>

#### ***4. The importance of informal care givers must be acknowledged, and access to respite increased***

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 with chronic disease or medical co-morbidities themselves and little time to care for their own health.<sup>(38)</sup> Financial hardship is another major issue, as many carers are required to leave paid work. This impacts in many ways including: concerns about paying bills (particularly electricity accounts because oxygen concentrators require power), an inability to access extra support for ADLs<sup>(3)</sup> limited access to transport options and limited ability to access health services requiring co-payments. Increased availability of respite care is crucial if

people with advanced COPD are to remain at home and closer links should be developed between the multidisciplinary care team and carer support organisations. ( Box 6: Vignette 3)

**Box 6: Vignette 3: Stories from the Australian NHMRC COPD study<sup>(30)</sup>**

**The importance of respite for carers**

Mr C was 79 years old and his younger wife was his full time carer. She was having great difficulty with the burden of her caring role including the need to administer his medications. Her only respite was four hours a week provided by a nurse. She described this as 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.*

Mrs C talked about the dilemmas for carers when balancing their own needs against the needs and wishes of a very unwell, dependent partner:

*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.*

She also highlighted the importance of being able to have some respite, to have a break from the constant caring. She spoke of the toll that caring was having on her, especially on her sleep:

*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 its 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.*

## **DISCUSSION**

A patient-centred care approach<sup>(24)</sup>, where the needs of the patient and their families directly inform the care provided, offers a clear framework to address the inadequate care currently being experienced by many people with advanced COPD. Whilst the key elements of such a model of care have been identified, implementation still presents a significant challenge.

The first step in improving care is to bring together policy and systems. Policies need to build in flexibility to allow services to be provided across chronic disease and palliative care

groups as well as across the hospital, primary and community care sectors. Access to services should be based on need rather than prognosis or the referring service, with the development of standardised assessment tools and entry points.

In Australia, there is a growing momentum for a patient-centred approach to care and the Australian Commission on Quality and Safety in Healthcare notes that this approach results in increased patient and provider satisfaction, reduced costs and an improved patient experience.<sup>(39)</sup> The Commission makes a series of recommendations to facilitate a move to a patient-centred health care system; developing a person-centred care process for people with advanced COPD would reflect this broader health system movement. Two other policy facilitators for person-centred care in COPD in Australia are the National Framework for Advance Care Directives,<sup>(40)</sup> which seeks to promote and support the use of advance care directives (and the associated conversations) and the National Carer's Strategy which emphasises the importance of including carers as "partners in care."<sup>(41)</sup>

Whilst policy change and more flexible service provision provide the "top down" tools for reform, it is also important that change is facilitated from the "bottom up". There needs to be a concerted effort to promote the concept that end-of-life care is part of the continuum of care, and is therefore everybody's business. This will require leadership and ongoing education for people working "at the coalface." New skill sets will be required, for both chronic disease and palliative care health professionals. Revision of funding models is a key component of reforming care for people with advanced COPD. In particular, funding would be required for greater access to services and ADL supports and ensuring accessible and sustainable pulmonary rehabilitation services. It is possible that reforming the model of care to a patient-centred model could result in significant cost savings through reduced hospitalisations, more efficient care processes and a reduction in duplication of care.<sup>(42, 43)</sup> Care models in the UK and Canada such as INSPIRED and the Breathlessness Support Model (BSS) are currently being evaluated for the cost and clinical effectiveness of such approaches.<sup>(16)</sup>

## **CONCLUSION**

The current system of care does not meet the needs of people with advanced COPD, particularly as they approach the end of their life. Person-centred care offers a framework which allows the multidisciplinary COPD team to integrate a palliative approach with active disease management with the support of specialist palliative care services.



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## REFERENCES

1. Gulsvik A. The global burden and impact of chronic obstructive pulmonary disease worldwide. *Monaldi Arch Chest Dis*. 2001;56:261 -4.
2. WHO. The Global Burden of Disease. 2004 Update. Geneva: WHO. 2004.
3. Crawford G, Brooksbank M, Brown M, Burgess T, Young M. The unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia. *Internal Medicine Journal*. 2012 (Online first).
4. Pinnock H, Kendall M, Murray S, Worth A, Levack P, Porter M, et al. Living and dying with severe Chronic Obstructive Pulmonary Disease: multiperspective, longitudinal qualitative study. *BMJ*. 2011;342:d142:doi:10.1136/bmj.d142.
5. Gardiner C, Gott M, Small N, Payne S, Seamark D, Barnes S, et al. Living with advanced chronic obstructive pulmonary disease: patients concerns regarding death and dying. *Palliat Med*. 2009;23(8):691-7.
6. Elkington H, White P, Addington-Hall J, Higgs R, Pettinari C. The last year of life of COPD: a qualitative study of symptoms and services. *Respir Med*. 2004;98:439-45.
7. Gardiner C, Gott M, Payne S, Small N, Barnes S, Halpin D, et al. Exploring the care needs of patients with advanced COPD: An overview of the literature. *Respir Med*. 2010;104(2):159-65.
8. Disler RT, Currow DC, Phillips JL, Smith T, Johnson MJ, Davidson PM. Interventions to support a palliative care approach in patients with chronic obstructive pulmonary disease: An integrative review. *Int J Nurs Stud*. 2012.
9. Rocker G, Dodek P, Heyland D. Toward optimal end-of-life care for patients with advanced chronic obstructive pulmonary disease: insights from a multicentre study. *Can Respir J*. 2008;15(5):249-54.
10. Spathis A, Booth S. End of life care in chronic obstructive pulmonary disease: in search of a good death. *Int J Chron Obstruct Pulmon Dis*. 2008;3(1):11-29.
11. Edmonds P, Karisen S, Khan S, Addington Hall J. A Comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliat Med*. 2001;15(4):287 - 95.
12. Gore J, Brophy C, Greenstone M. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax*. 2000;55(12):1000-6.
13. Ek K, Ternstedt B. Living with chronic obstructive pulmonary disease at the end of life: a phenomenological study. *J Adv Nurs*. 2008;62(4):470-8.
14. Wagner E. The Chronic Care Model. Seattle: Group Health Research Institute; 2012 [cited 2012 1st August]; Available from: <http://www.improvingchroniccare.org/>.
15. Dean M. End-of-life care for COPD patients. *Primary Care Respiratory Journal*. 2008;17(1):46 - 50.
16. Booth S, Bausewein C, Rocker G. New models of care for advanced lung disease. *Progress in Palliative Care*. 2011;19(5):254-63.
17. Callahan D. End-of-Life Care: A Philosophical or Management Problem? *The Journal of Law, Medicine & Ethics*. 2011;39(2):114-20.
18. Fitzsimons D, Mullan D, Wilson JS, Conway B, Corcoran B, Dempster M, et al. The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliat Med*. 2007 June 1, 2007;21(4):313-22.
19. Philip J, Gold M, Brand C, Douglass J, Miller B, Sundararajan V. Negotiating hope with chronic obstructive pulmonary disease patients: a qualitative study of patients and healthcare professionals. *Internal Medicine Journal*. 2012;42(7):816-22.

20. Spence A, Hasson F, Waldron M, Kernohan G, McLaughlin D, Cochrane B, et al. Active carers: living with chronic obstructive pulmonary disease. *Int J Palliat Nurs*. 2008;14(8):368-72.
21. Gysels M, Higginson IJ. The Experience of Breathlessness: The Social Course of Chronic Obstructive Pulmonary Disease. *J Pain Symptom Manage*. 2010;39(3):555-63.
22. Reid C, Gibbins J, Forbes K. Palliative Care is not the same as end of life care. *Br Med J*. 2011;342(d2735).
23. Aged Care Australia. Glossary. A Palliative Approach. Canberra: Australian Government Department of Health and Ageing; 2006 [cited 2012 July 6th]; Available from: <http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/Glossary+Index+P>.
24. Australian Commission on Safety and Quality in Health Care. Patient centred care: Improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC. 2011.
25. NHS. Developing end of life care practice: a guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care. Leicester. 2012.
26. Goodridge D. People with chronic obstructive pulmonary disease at the end of life: a review of the literature. *Int J Palliat Nurs*. 2006;12(8):390-6.
27. National End of Life Care Programme. The differences between general care planning and decisions made in advance: NHS. 2012.
28. Jones D, Bagshaw S, Barrett J, Bellomo R, Bhatia G, Bucknall T, et al. The role of the medical emergency team in end-of-life care: A multicenter, prospective, observational study. *Crit Care Med*. 2012;40(1):98-103.
29. Brown M, Brooksbank M, Burgess T, Young M, Crawford G. The experience of patients with chronic obstructive pulmonary disease and advance care planning: A South Australian Perspective. *Journal of Law and Medicine*. 2012;20: 400- 9.
30. Crawford G, Brown M, Crockett A, Burgess T, Brooksbank M, Young M, et al. Developing a model of care for people with end stage chronic obstructive pulmonary disease (COPD) and their carers. Adelaide: University of Adelaide. 2011.
31. Respecting Patient Choices. Respecting Patient Choices. Advance Care Planning. Melbourne: Respecting Patient Choices; 2012 [cited 2012 August 26th]; Available from: <http://www.respectingpatientchoices.org.au/>.
32. McKenzie D, Abramson M, Crockett A, Glasgow N, Jenkins S, McDonald C, et al. The COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease. 2011.
33. Department of Health. An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England. London: Department of Health. 2011.
34. Steinhauser K. Measuring end-of-life care outcomes prospectively. *J Palliat Med* 2005;8(1):S30e41.
35. Street Jr RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician–patient communication to health outcomes. *Patient Educ Couns*. 2009 3//;74(3):295-301.
36. Barnes S, Gardiner C, Gott M, Payne S, Chady B, Small N, et al. Enhancing Patient-Professional Communication About End-of-Life Issues in Life-Limiting Conditions: A Critical Review of the Literature. *J Pain Symptom Manage*. 2012(0).
37. Hysong S, Esquivel A, Sittig D, Paul L, Espadas D, Singh S, et al. Towards successful coordination of electronic health record based-referrals: qualitative analysis. *Implementation Science*. 2011;6(84).

38. Caress A, Luker K, Chalmers K, Salmon M. A review of the information and support needs of family carers of patients with chronic obstructive pulmonary disease. *J Clin Nurs*. 2009;18(4):479-91.
39. Australian Commission on Quality and Safety in Health Care (ACQSHC). Patient-Centred Care: Improving Quality and Safety by Focusing Care on Patients and Consumers. Discussion paper. Sydney: Australian Commission on Quality and Safety in Health Care; 2010.
40. Australian Health Ministers' Advisory Council. A National Framework for Advance Care Directives. Canberra: AHMAC. 2011.
41. Australian Government. National Carer Strategy. Canberra: Australian Government 2011.
42. Charnel PA, Frampton SB. building the business case for patient-centered care. *hfm (Healthcare Financial Management)*. [Article]. 2008;62(3):80-5.
43. Bertakis KD, Azari R. Patient-Centered Care is Associated with Decreased Health Care Utilization. *The Journal of the American Board of Family Medicine*. 2011 May-June 2011;24(3):229-39.

Prof Mellar Davis  
Editor-in-Chief  
Progress in Palliative Care

Dear Sir

**Submission PPC149R1**

Thank you for the opportunity to resubmit our Opinion Piece “A patient-centred model of care incorporating a palliative approach: a framework to meet the needs of people with advanced COPD?”

We have responded to Reviewer 3’s comments and suggestions, some of which were very helpful. However, we do not agree that our manuscript lacks substance in its current iteration as an 'opinion piece'. We have based this work on the literature and the results of our own research, all of which highlight the deficiencies in the current models of care for people with advanced COPD.

Please find our specific response to Reviewer 3.

Nowhere do the authors provide a clear definition of what elements (and why) are being included under "patient-centred care	Thank you. We have now provided the ACQSHC definition. This is the most relevant to the Australian context.
Why not begin by outlining the model (whichever one they choose) and then slotting the various recommendations under each area of that model.	We have discussed at length the format of the paper and decided to use the recommendations from our previously published research as the framework. To change this now would involve a major change to the structure of the paper.
The table that includes the bits of CDM and "person-centred end-of-life care approach" is aimed at this, but does not provide a summary of the theoretical background (or the visual representation) that is out there for each of these models of care. Some parts of this table I think are mismatched (or the connections could be improved).  A comment on Table 1 row 4: Is it not still "evidence-based care" as in best practice standards or standard of care? Clinicians are not obliged to provide care outside best practice, at least as I understand it, regardless of what a patient or family desires.	A discussion of the theoretical background for each of the models was felt to be beyond the scope of this paper.  We thank the reviewer for their suggestions for the table and have clarified the purpose of the table and added a commentary to demonstrate the overlap and divergences in these models.  We have addressed the comment about “evidence-base” in this Commentary column.

Incorporate may be a better term than move to. Move to might imply an 'either/or' situation	We have made this suggested change.
The use of the term "person-centred end-of-life care" may address some of the barriers and perceptions about palliative care and the reluctance to provide supportive as well as active care. I'm not convinced - how does this get at the barriers/uncertainty about the end-of-life stage (when it begins) or getting clinicians to be proactive about addressing this uncertainty with patients	<p>We have rewritten this section and tried to provide a more logical structured argument in the Background. In this process we have removed that sentence.</p> <p>We have included a further reference to the uncertain prognosis in the commentary on Table 1. The body of the paper is directed at encouraging a proactive response to COPD.</p>
<p>Here and there the authors make some profound statements without providing any justification. One example would be (in effective Communication para):</p> <p>All clinicians must appreciate the impact of communication on health outcomes and ensure they develop and maintain highly-developed skills.</p> <p>Is there evidence to support that effective communication impacts "health outcomes" and if so, what sort of outcomes are linked to it?</p>	We have expanded and referenced the statement relating to communication and health outcomes.

Yours faithfully

GB Crawford